Stroke Duties: A Hermeneutic Enquiry into Family Experience Six months Post-Stroke

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Declaration

Name of candidate: Andrew Duthie
This Thesis Project entitled Stroke Duties: A Hermeneutic Enquiry into the Family Experience Six months Post-Stroke is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy

Candidate's declaration

I confirm that:

- This Thesis Project represents my own work;
- Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.
  
  Research Ethics Committee Approval Number: NTX/11/EXP/062

Candidate Signature: .........................................................Date: .....................

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Abstract

Introduction:

Stroke is the third largest cause of death in New Zealand and is a major cause of disability. While a lot is known about the stroke survivor and the primary caregiver, little is known about how stroke affects the survivor’s wider family.

Aims:

This study’s aim is to investigate the lived experience of being a family member of someone who has had a stroke, over the period of six months from the initial stroke. It is part of a larger longitudinal four year project exploring the stroke family lifeworld.

Method:

The method used was hermeneutic phenomenology as guided by Max van Manen (1997).

Results:

The stroke survivor is not the only person who needs care. The overarching theme is duty of care. There are three sub-themes: care is ‘different for different people’; there are care ‘expectations of self and expectations of others’; and care brings ‘strain’. All are significant in the family experience. The family have expectations and obligations of their own duty of care and these are also influenced by sources outside the family. In addition there are considerations of fairness regarding the sometimes competing needs of the survivor and the caregiver.

Conclusion:

Strains on the family change over time. Competing values of mercy and fairness within this family take up time and risk disengagement of the family from the stroke survivor’s progress.

Key words:

Stroke, family, duty, care, experience, New Zealand.
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Preface

For this master in osteopathy thesis I have joined with the Department of Nursing, at Unitec to be part of a longitudinal study into the effect of stroke on family/whānau members of a stroke survivor. The structure of this master’s thesis has been broken down into three sections. Sections one and three provide the background and undertaking of the study, including appendices. These sections show the literature review, methodology and information related to the undertaking of ethics, participants and rigour.

The second section is written as a manuscript, which has been formatted in line with the requirements of Nursing Praxis, a professional nursing journal published in New Zealand, with the aim to submit for publication. The regulations and guidelines for Nursing Praxis are appended in Appendix A.
Section One: Study design and Background

Chapter One: Literature Review
This chapter will outline the study explaining the research and its context within its field. The second part of the chapter will review the current literature on the subject of stroke related effects. There will be a particular focus on the family/whānau.

Outline of this Study. The study investigated the experience of becoming and living as a family of someone who has had a stroke over the first six months from the initial stroke. ‘Family’ was viewed broadly to include people who have a close relationship with the stroke survivor. The research is part of a larger four year longitudinal Parent Project “Improving support for families/whānau of clients post-stroke: A longitudinal study”. The Parent Project is building an in-depth interpretation of what it is to be part of a New Zealand stroke family/whānau. It aims to improve support and outcomes for families/whānau of clients following a stroke and includes multiple members from five families.

This study is one of a number of small studies within the Parent Project and studied one family within the first six months following the stroke. Findings from each smaller stroke study will be used to inform, enrich and give diversity toward the parent project.

Aim of the Study. This study aimed to investigate the phenomenon of becoming and being a family member of someone who has survived a stroke.
Objectives of the Study. The study objectives are as follows:

- To explore the phenomenon of becoming and being a stroke family over the initial six months after the stroke.
- To explore and identify themes specific to a New Zealand stroke family over six months.
- To provide an interpretation giving insight into the experience of stroke on the wider family over six months.
- To contribute to the understanding and interpretation of the phenomenon of becoming and being a stroke family for the Parent Project.


**Literature Review**

*Background.* Stroke survivors are forming a growing population. According to Feigin et al. (2014) in their global stroke epidemiological study, mortality rates of stroke have decreased significantly between 1990-2010. The number of people surviving stroke increased by 23% in high income countries (such as North America, central Europe and Australasia) and 27% in low income countries (including Southeast Asia, Oceania, Latin America and Sub-Saharan Africa) over this period. New Zealand saw a decline of 40% in stroke related fatalities between 1982-2003 (Carter, Anderson, Hackett, Barber, & Bonita, 2007), while during the same period only a 9% decline in the actual stroke rate (Anderson et al., 2005).

While stroke is the third largest cause of death in New Zealand with approximately 2500 deaths annually (Stroke Foundation of New Zealand, 2013), it is also a major cause of disability. An estimated 60,000 people are living with stroke related effects in New Zealand with around 70% dependent on others to help them with their daily activities (Stroke Foundation of New Zealand, 2013; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). Stroke has a huge impact on both the stroke survivor and their families.

This review will look at the known experiences and impact of stroke on the stroke survivor, their primary caregiver (usually spouse) and their families. Themes relating to these impacts will be explored to show where the gaps are in the literature. The themes of isolation, depression and financial difficulties are examined along with other variables that relate to stroke such as age, faith, education and family strength. Other significant themes of strain and duty of care will be explored more thoroughly. Data bases searched were the Ebsco health databases, Google Scholar, Cochrane databases and Science Direct. Key words: Stroke, Family, Experiences, Caregivers, Survivor, Longitudinal, Duty, Affects, Effects, New Zealand, Māori and Impacts. Additionally, relevant articles were identified from reference lists and citations of literature retrieved earlier in the review.

*Stroke prevention.* Stroke is to a large extent preventable. This subsection will describe the known literature on the risk factors and preventable measures that are available to reduce stroke. There are modifiable and non-modifiable risk factors for the possibility of a stroke. Non-modifiable risks are age, gender and genetic inheritance. The modifiable factors include diet, physical activity, smoking, arterial hypertension and diabetes mellitus (Turanjanin, Jovicevic, Bozic, & Zarkov, 2012).
High blood pressure has a strong and direct association with stroke. Lewington, Clarke, Qizilbash, Peto, and Collins (2002) in a meta-analysis study on blood pressure and cause of death by stroke, found that with every increase of 20mm Hg pressure of systolic and 10mm Hg of diastolic pressure above normal ranges was observed a twofold difference in stroke death rate. It is therefore very important to control blood pressure to reduce the risk of stroke.

An epidemiological study by Zhang et al. (2012) on life style factors and antihypertensive treatment established the stroke related risk of lifestyle. Five surveys were completed of 36,686 Finnish participants aged between 25 and 74 over the period of 13.7 years. Healthy lifestyle factors included non-smoking, a low level of alcohol intake (1-209 g/week in men and 1-139g/week in women), normal Body Max Index (BMI <25kg/m²), moderate/high activity three or more times per week as well as three or more times per week of vegetable consumption. They found that a healthy lifestyle significantly reduced the risk of stroke for both males and females.

In a systemic review on dietary impacts on stroke, Sherzai, Heim, Boothby, and Sherzai (2012) found that fruit, vegetables and soy products demonstrated protective effects. The review recommended further research into the effects of animal products, whole grains and vegetarian diets. A DASH diet (Dietary Approaches to Stop Hypertension) or Mediterranean diet were also found to reduce the risk of stroke. Lifestyles including health diets and exercise therefore appear to be important for controlling blood pressure and reducing the risk of stroke.

The Stroke Foundation of New Zealand (2014) promotes stroke awareness and prevention through campaigns such as actions to reduce blood pressure through reduced salt intake and increased exercise. Accepting that smoking increases the risk of stroke, the New Zealand government has a plan to control tobacco use and make New Zealand smoke free by 2025 Ministry of Health (2013). Although more can always be done to prevent stroke and improve general population health, steps are being made to control the major stroke risk factors.

While reducing further strokes is important, research into minimising stroke related effects once they have happened are equally significant. The next subsections will describe the literature on stroke related effects on the stroke survivor, the primary caregiver and the wider family with the aim of highlighting where further research would be useful.
What is known about stroke survivors? As stroke survival rates increase because of medical improvements there are increasing numbers of stroke survivors and their families who are living with the after-effects of a stroke event. Research into the experience of stroke survivorship has been extensive over the past ten years. Vincent et al. (2007) explored the met and unmet rehabilitation needs of stroke survivors in Canada. They stated that because of improvements in stroke event healthcare more people are surviving their initial stroke event, albeit with various impairments.

Kilbride, Allison, and Evans (2011) in a study on stroke survivors opinions of current evidence based care, found that stroke survivors were largely happy with the support and care they received. Contrary to this view Kitson, Dow, Calabrese, Locock, and Muntlin Athlin (2013) reported stroke survivors’ negative experiences in a study on the fundamentals of care such as personal hygiene, toileting and eating. However both Kitson et al. (2013) and two systematic reviews on stroke survivors care (Bridges, Flatley, & Meyer, 2010; Peoples, Satink, & Steultjens, 2010) support the psychosocial importance of the stroke survivor being connected and respected within the communities of their caregivers and family. Respectful empowerment and community are important aspects of the stroke survivor experience and rehabilitation.

Researching social networks such as family and friends could be beneficial for stroke survivors. Vincent et al. (2007) established that getting back into sociable life was the ultimate aim of stroke recovery. This was confirmed by Brunborg and Ytrehus (2013) who interviewed nine stroke survivors 10 years after their initial stroke. The study described how connecting with significant others such as family and friends seemed the most important factor in a adapting to a “good life after a stroke”. Researching the experience of the wider family may broaden our understanding of the stroke survivor social networks.

While it is important to continue improving care for the growing stroke survivor population the emphasis of research can now move beyond the stroke survivor toward wider stroke related effects including those affecting the primary caregivers and the stroke families. The next subsection will look at the literature related to the stroke survivors’ primary caregivers.

What is known about the stroke survivor’s primary caregiver? Themes of strain, isolation, depression and financial difficulties are well known in the stroke literature on the
primary caregiver. Exploring these themes may identify relevant aspects of the wider family experience.

Gillespie and Campbell (2011) described the strain that families of stroke survivors may experience, and also identified factors which may support their wellbeing. These authors claim that while stroke research has mainly focused on the stroke survivor and primary caregiver, stroke also has a significant effect on and creates challenges for the whole family. Their view is supported by a body of research regarding the wellbeing of primary caregivers that also touches on but does not explore other family members’ experiences. It will therefore be helpful to review the research relating to primary caregivers to give an idea of what might be relevant to the wider family.

**Strain.** Strain has been well documented as having a major impact on primary caregivers and their families post stroke for example Bäckström and Sundin (2009); (Gillespie & Campbell, 2011; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Palmer & Glass, 2003; Parag et al., 2008; van Exel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005; Wallengren, Friberg, & Segesten, 2008; Wyller et al., 2003). Strain is defined throughout the literature as negative aspects weighing on primary caregivers such as isolation, depression, guilt, conflict, and physical illness, financial and educational burden.

In a qualitative study Wallengren, Friberg, et al. (2008) aimed to illuminate the experience of relatives (primarily the family members designated were the primary caregivers) in the initial stages after a stroke. They undertook a phenomenological hermeneutic study with sixteen family members of first time stroke survivors, within the first four weeks of the stroke event. They explain that the family’s world is turned upside down, and reported symptoms of physical illness, nausea, restlessness and palpitations. Strain persists until a “turning point” is reached when family members start re-ordering their world to allow for caregiving. Bäckström and Sundin (2009) confirm these findings and they also described how the spouse’s ability to stay working and having a close supportive family, helped them through these challenges.

In a prospective population based study in Auckland, Parag et al. (2008) identified the impact of stroke on unpaid primary caregivers as mainly negative. The authors used a validated 15-item Bakas Caregiving Outcome scale to measure changes in wellbeing in the lives of 167 stroke survivor and primary caregiver pairs at six months, and 62 pairs at 18 months. Although 1/3 of the caregivers said that they had become closer to the stroke
survivor as a result of the stroke, over 50% reported reductions in social activities and emotional wellbeing, while 59% reported that life in general had changed for the worse.

McCullagh et al. (2005) performed a one year randomised controlled trial (RCT) of caregiver-training to delineate determinates of caregiver burden. Two hundred and thirty two stroke survivors with moderate to severe disability and their primary caregivers participated. Fifty percent of caregivers were given a structured training program that provided basic-nursing and personal care skills. A reduction in caregiver burden and improvements in quality of life were achieved with the caregiver training.

A later study by Lutz, Young, Cox, Martz, and Creasy (2011) found, however, that too much quantity and intensity of training can make caregivers feel overwhelmed and exhausted. While primary caregivers are usually eager to get the stroke survivor home, they are often unaware of the skill and commitment needed to care. To reduce caregiver strain the timing of caregiver training is crucial and needs to include the involvement of education on the skill and commitment required.

Wyller et al. (2003) aimed to find variables relating to the wellbeing of stroke family members in a cross-sectional study of 54 stroke survivors and their closest relatives. Their study included 16 male and 38 female participants with a reference group of 419 elderly people who were drawn randomly from a census. The female family members had significantly worse general wellbeing than their male counterparts with a $P=0.002$. Additionally the wellbeing of the wider family was worse off than the reference group, even when they were not the primary caregivers. Interestingly the stroke survivor’s level of disability did not correlate as a variable.

Wyller et al. (2003) argued that the general wellbeing of the families was related more to the families perception of how much burden the stroke survivor was on the primary caregiver, rather than the stroke survivors objective level of disability after the stroke. However in a cross-sectional correlational study of 132 caregivers, Clark et al. (2004) found that family conflict increased with worsening mental health of the stroke survivor. It was also revealed by van Exel et al. (2005) that three out of ten primary caregivers were at risk of impairment and becoming patients themselves as a result of the burden of caregiving. These findings argue that there needs to be more investigation into caregiver support in order to reduce their burden. Isolation. Research by Greenwood, Mackenzie, Cloud, and Wilson (2009) and Grant, Glandon, Elliott, Giger, and Weaver (2004) revealed that a lack of freedom
and a sense of confinement were often felt by the primary caregiver. Similarly Bulley, Shiels, Wilkie, and Salisbury (2010) found that the primary caregiver workload impacts on their ability to be social. Bulley et al. (2010) performed a phenomenological study using semi-structured interviews investigating experiences and life changes of nine primary caregivers between two and five years after the stroke event. Even caregivers with previous caregiving experience can feel overwhelmed and isolated (Lutz et al., 2011).

Berglund and Johansson (2013) identified themes of caregiving and quality of life. Their qualitative study comprised 18 stroke survivor primary caregivers over the age of 65 as well as one caregiver of a person with Parkinson’s disease. They found that the caregivers often found it hard to maintain relationships with family and friends. The caregivers were concerned with the potential burden the stroke survivor might become on family and friends, who were either too afraid to or found it hard to communicate with the stroke survivor and tended to stay away after the stroke. These actions of both the primary caregiver and family members tend to further isolate the primary caregiver and stroke survivor after the stroke.

A qualitative study in Portugal by Pereira and Rebelo-Botelho (2011) investigated the lived experience of one male and thirteen female primary caregivers of patients with impairment-associated conditions including stroke. The other conditions included cancer, motor vehicle accidents or leg amputations and the study was performed in the initial stages no later than six months after the impairing event. These researchers found that primary caregivers can feel isolated and aggrieved that family and friends do not recognise their sacrifice. Examining how this isolation impacts the wider family may help identify recommendations for re-connection.

Depression. High levels of depression among primary caregivers immediately following stroke has been well documented (Dyall, Feigin, & Brown, 2008; Gray et al., 2011; Palmer & Glass, 2003; Saban, Sherwood, DeVon, & Hynes, 2010; Tang, Lau, Mok, Ungvari, & Wong, 2011). McCullagh et al. (2005), however, identified in a randomised trial of caregiver training that depression was significantly reduced three months and 12 months after the stroke event when basic-nursing training was given to caregivers. This finding of reduced depression warrants exploration to see if it relates to the wider family.

Financial difficulty. A systematic review of qualitative studies conducted between 1996-2006 into primary caregivers of stroke survivors was completed by Greenwood, Mackenzie, Cloud, and Wilson (2009). The review highlighted the high financial burden that
stroke can have on the whole family. This is often because the primary caregiver is forced to give up work in order to care for the stroke survivor.

Brunborg and Ytrehus (2013) found that the financial difficulty was worse if the stroke survivor was younger. Bulley et al. (2010) and Lutz et al. (2011) identified a dramatic change in families (spousal) expectations in quality of life if the stroke survivor had to leave work before retirement age. A negative financial impact can also be worse if the primary caregiver is a son or daughter (Dyall et al., 2008). Decisions around care can be difficult when weighed against financial difficulty especially if that conflicts with a strong sense of duty. The next subsection will explore duty of care within stroke care.

**Duty of care of the primary caregiver.** Duty of care is a complicated subject in stroke care. There have been a number of articles discussing the differing views on duty of care in stroke recovery. The below section will outline the salient points.

According to the Oxford dictionary duty of care is “a moral and legal obligation to ensure safety or well-being of others” (Duty of care, 2014). Therefore duty of care is more than just a legal obligation, it is a moral and social one that depends on the context and relationship between the individuals concerned. Where the moral responsibilities towards duty of care start and end depend largely on who is involved, their opinions and the societies views at the time of judgment.

Lutz et al. (2011) performed a grounded theory study into initial phases (6months) of stroke recovery for the stroke survivor and their caregivers. The authors argued that modern society has an expectation that close family members will take on the role of caregiver to the stroke survivors. The study included 19 stroke survivors (11 males, eight females) 15 primary caregivers (14 spouses, one mother) and four adult children; all but three family members took on the duty of care despite some having misgivings and feelings of ill-preparedness.

Lutz et al. (2011) cite National Alliance for Caregiving (2009) in arguing that home care saves the United States of America (USA) billions of dollars in healthcare bills. Lutz et al. (2011) argue that while society believes home care is best, they ignore the burden that family members take on when they choose the duty of care. Goodhead and Macdonald (2007) in a literature review on informal caregivers, suggest that New Zealand has similar cultural expectations that the duty of care should be taken on at home as described.
Furthermore, Lutz et al. (2011) found that having a sense of duty of care can increase strain on some primary caregivers. Alternatively having a strong sense of self advocacy and self-awareness (of own limitations) can help the primary caregiver to reduce their strain. Self-advocacy was not always supported by healthcare professionals or other family members who had an expectation that the primary caregiver, usually the spouse, should be the caregiver.

This high expectation of care can lead to guilt and increased stress for the spouse/potential caregiver. Wallengren, Segesten, and Friberg (2008) found that family members, especially spouses, felt imprisoned, with feelings of frustration at having to be on duty constantly. Their study suggested that all family members struggled for freedom in everyday life.

In a van Manen guided, hermeneutic phenomenological study, Coombs (2007) investigated the experience of eight stroke survivor spouses. She found that the spouses felt an overwhelming sense of responsibility to care for their partners. The spouses described a wide range of feelings from being either forced to care or obliged to care as well as feeling a sense of duty to care. Despite these feelings primary caregivers were determined to do all they could to keep their spouses at home.

Berglund and Johansson (2013) found similarly that caregivers found it difficult to give up the duty of care, even though respite care for the stroke survivor was very important for the health of the caregivers. The physical and mental act of caring could be burdensome for the primary caregivers, although maintaining intellectual communication with the stroke survivor and having professional help and encouragement helped to maintain their quality of life. The caregivers placed high expectations on their own level of care for the stroke survivor and they also felt they were expected by the healthcare professionals to keep up duties such as physical therapy. Satisfaction in daily life for the caregivers depended on the quality of care the stroke survivor had.

In a hermeneutic enquiry Niyomathai, Tonmukayakul, Wonghongkul, Panya, and Chanprasit (2010) found that families with high family strength continually looked to overcome hardships so they could maintain their duty of care. Grant et al. (2004) found that even if there were support solutions in place for primary caregivers often they would be reluctant to take these up. Primary caregivers either felt guilty about giving away the duty of care or they did not want to lose control of the caring situation.
Lutz and Young (2010) argue that the primary caregivers’ needs should be assessed before the stroke survivor is discharged. They describe how caregiver needs before discharge are often overlooked, yet the best outcomes of stroke rehabilitation often depend on the expectation that family and friends will provide the care required by the stroke survivor after discharge. Research investigating how best to assess family needs and expectations appears warranted.

Goodhead and Macdonald (2007) describe how for some spouses becoming the family caregiver is a natural progression, where they believe that they are the best person for the job. For others caregiving has complex motivations such as society and family pressure. Pressure on spouses especially women can sometimes cause them to internalise a sense of duty to care. Goodhead and Macdonald (2007) report that caregiving may undermine a caregiver’s sense of self if they feel they have no alternative but to continue caring. In these cases caring can become filled with repudiation, guilt and disassociation as the caregiver tries to ameliorate their stress and this can be harmful for both caregiver and the stroke survivor.

Duty of care is an important issue to address in a caring situation such as for a stroke survivor. Influences appear to go beyond the caregiver and family to the wider society. What is not known is if and how this duty of care affects the family as a unit. Further research could explore this and may bring some light on family dynamics which may be helpful to stroke survivor and their families care. The next subsection will address the more positive aspects of caregiving that appear in the literature.

**Positive aspects of caregiving.** Not all primary caregiver experiences have proved to be negative. Haley et al. (2009) aimed to explore both the stress and the perceived benefits of caregiving. In their study across the USA they used comprehensive phone interviews with 75 primary caregivers for stroke survivor. They reported that 90% of the caregivers value life and family more because of a heightened sense of awareness of the fragility of life following the stroke.

Green and King (2009) agree, citing caregivers valuing relationships more and no longer worrying about the small things since the stroke. Correspondingly, Greenwood et al. (2009) describe how some primary caregivers felt closer to the stroke survivor. They go on to state that it is important that further research investigates the diversity among caregivers, and should not focus only on negative aspects.
Pereira and Rebelo-Botelho (2011) argue that if you ignore the caregivers “making sense” of the unexpected and challenging activity of caregiving most of the outcomes will appear negative, yet in their view this is often not the case. In contrast a New Zealand study by Parag et al. (2008) researching the impact of stroke on 167 unpaid caregivers at six months and 62 at 18 months, found that while one third of caregivers had an increase in self-esteem, the experience was predominantly negative. In qualitative research it is important to take all aspects into account both positive and negative. The next subsections will examine other aspects of caregiving such as the impacts of age and ethnicity.

**Impact of ethnicity.** Goodhead and Macdonald (2007) state that being part of an ethnic minority accentuates the impacts of caregiving. In New Zealand the average age of stroke in Europeans is 75 years, compared to 62 years for Māori and Pacific Island people, and 64 for Asian New Zealanders (Feigin et al., 2006). Dyall et al. (2008) suggested that the difference in the age results in significantly different financial consequences, with Māori worse off than Europeans. This is because for Māori stroke often occurs before the survivor has reached retirement and the families are often younger, and therefore financially less well established.

Corbett, Francis and Chapman (2006) used a qualitative approach in New Zealand on how stroke affects whānau. Seven focus groups with whānau (numbers and relation to stroke survivor were not defined) and follow-up with interviews with three primary caregivers were undertaken. They found that on the whole Māori whānau see care as part of their responsibility, and have a duty to support the stroke survivor and primary caregiver. Because of that duty they are less likely to accept help from outside the family causing a greater financial impact on the whānau as a whole.

**Age as a variable.** According to Wyller et al. (2003) age and relationship to the stroke survivor whether it be spouse or other family members were not significant variables for family wellbeing. However the study had a small sample size of only 21 people, 39% being someone other than the spouse. This reduces the strength of their claims.

A qualitative study by S. D. Smith, Gignac, Richardson, and Cameron (2008) found that older and younger caregivers had different needs in the rehabilitation stage six months after the stroke event. The authors maintain that younger primary caregivers aged under 55 years have higher social and financial needs and demand more information than older caregivers. Alternatively older caregivers aged over 55 years tended to be overwhelmed by
new information and required encouragement to focus on a positive attitude to cope. Their study interestingly found that both the younger and the older caregivers commented on the importance of support from friends and family. The next subsection will explore the literature on the wider family/whānau beyond the primary caregiver.

**What is known about the wider family/whānau?** According to Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) family and whānau should be part of the stroke recovery team. Gillespie and Campbell (2011) outlined evidence-based interventions that help patients and their families, acknowledging that literature on the wider family is very thin. They go on to show that while strain is high the little literature that was available suggest that interventions such as education about stroke effects, caregiver training, psychotherapy and specialist interventions such as family support workers, all seem to be beneficial.

Kitzmüller, Asplund, and Häggström (2012) explored the long term effects of stroke on family life. Thirty seven narrative interviews were conducted with stroke spouses and their adult children, who reflected back on how their parents’ stroke affected their childhood. The study was performed between three and twenty years after the onset of the stroke. Their findings focus on family roles and communication which will be discussed further later in this subsection.

While the longer term effects of stroke on families were researched by Kitzmüller et al. (2012), the experiences as they happened were not explored except through adult reflection on childhood experience and marital relationships. Stroke effects on the wider family, outside the nuclear family, were not explored. Researching the wider family experience could add understanding of the effects of stroke on the family members other than the primary caregiver.

*Family conflict.* Clark et al. (2004) showed in a cross sectional correlation study of 132 primary caregivers, that 66% of those caregivers reported family conflict. The study indicated that the worse the cognitive and memory impact of the stroke survivor the worse the conflict. These findings show that the level of cognitive burden on the stroke survivor is a pertinent issue for the wider family.

Stroke changes roles within families, which can endanger family identity causing stress and conflict (Palmer & Glass, 2003). Examples of role changes include primary
caregivers giving up work, marital relations changing from equal partners to caregiver, care receiver and children forced to take on grown up responsibilities (Greenwood et al., 2009; Kitzmüller et al., 2012). In a study of eight primary caregiver experiences, Coombs (2007) reported that spouses often suffer a profound sense of loss when their physical and emotional needs can no longer be met by the stroke survivor.

**Family strength.** Family strength or “hardiness” was described in a study by Niyomathai et al. (2010) which sought to explore what the meaning of family strength was when caring for a stroke survivor. They used purposive sampling to investigate families with high and moderate hardiness (measured by using a family hardiness index), in sixteen family members from six families with 36% being primary caregivers. Their findings identified family hardiness (defined as an internal resource of families sharing cognitive, attitudinal and behavioural capabilities) as a positive factor to have.

Niyomathai et al. (2010, p. 17) further reported the “high hardiness” within stroke families can be viewed as families who “continuously strove to overcome caregiving hardships and had hope for the stroke member’s long existence”. Their research established that families with high hardiness shared their caregiver roles and were able to continuously care for the stroke survivor under trying circumstances. In families with moderate hardiness, care was primarily performed by the primary caregiver who was unable to cope over an extended time. Niyomathai et al. (2010) acknowledge that more research into the whole family is important to add other possible perspectives on family strength.

Palmer and Glass (2003) proposed that more research into family empathy, education, problem solving, and emotional cohesion was needed as high levels of these skills seemed to have positive outcomes on stroke recovery. Pierce et al. (2004) agree saying caregiver crises could be overcome by families coming together and identifying a common goal. More research into the needs and experiences of the wider family is important to find out what support needs the families might have so they are able to support the primary caregiver and stroke survivor.

Coombs (2007) expressed that family support was the key to maintaining effective care for the caregiver to the stroke survivor. McCullagh et al. (2005) maintain that the level of family support was an important determinant of caregiver burden, at one year post stroke. Lutz et al. (2011) agreed and also showed that primary caregivers who had family support were less likely to become overwhelmed.
Religion and faith. MacIsaac, Harrison, Buchanan, and Hopman (2011) performed a mixed methods study in Canada exploring the supportive care needs after an acute stroke. They found that only 20% of the participants identified that they needed spiritual support. While only 20% would indicate a relatively low need the study was of low power with only 10 caregiver participants. More research is needed to clarify spiritual support needs.

Coombs (2007) described how religious faith and a trust in God was mentioned as a source of support for eight family caregivers. S. D. Smith et al. (2008) found spirituality was a common theme in four caregivers between the ages of 58-77 years. Niyomathai et al. (2010) also noted that families with high strength believed the stroke had a spiritual component to it. The participants in this study were Buddhists and believed that the stroke was to do with karma and repaying debts; the longer the stroke survivor was alive the more debts could be paid.

Communication/education. A meta-analysis on the effectiveness of information provision by J. Smith, Forster, and Young (2009) found that there is little clinically significant evidence to suggest that educating stroke survivors and their primary caregivers is worthwhile. Education was found to predominantly reduce depression and anxiety of the stroke survivor but not the primary caregiver. The education provided ranged from caregivers being given only information about the patient’s medical history to basic-nursing training and active participation in support groups. It is unknown if education affects the levels of anxiety among the wider family and research in this area may help to improve care for the whole family after a stroke event.

Communication seems to be important for optimal family function (Palmer & Glass, 2003). Kitzmüller et al. (2012) who’s study revisited spousal and childhood experiences, reported that a lack of communication because of aphasia caused emotional problems and feelings of loneliness within couples and their children. They suggested that hiding emotions from children through emotional shielding, is often seen in adults when a family is confronted with illness and that while this may be intended to protect children and other family members, emotional shielding may cause problems such as isolation and a lack of connectedness with the wider family. These researchers found positive consoling relationships within the wider family enhanced long-term rehabilitation outcomes and quality of life for both the stroke survivor and primary caregiver.
Longer term effects of stroke. Scientific literature relating to the long term effects of stroke on families beyond twelve months is remarkably sparse, especially as family support seems to be vital for the stroke survivor (Kitzmüller et al., 2012; Palmer & Glass, 2003). Bulley et al. (2010) found that caregivers’ perception of isolation was worse after twelve months as social networks break down. This suggests that more research beyond the first twelve months is needed regarding the primary caregiver and family wellbeing.

Summary. Stroke is the third largest cause of death in New Zealand and is a major cause of impairment. Research has primarily focused on the wellbeing of stroke survivors and their primary caregivers. Although it is acknowledged in the literature that stroke has a broader effect on other family members, in what way and to what degree is yet unknown.

Strain on primary caregivers has been recognised as having a number of different aspects but education, ability to stay at work and social support can be factors in reducing this strain. Primary caregivers also report some positive outcomes from caring such as a greater appreciation of life. Wider family support may be crucial because three out of ten primary caregivers are at risk of health decline as a result of the burden of caregiving.

In New Zealand stroke often has a greater effect on Māori and Pacific Islanders, due stroke occurring at younger ages in these populations leading to increased financial burden for families. In addition Māori whānau as a whole see care as part of their responsibility, and are less likely to accept help from outside the family to support the stroke survivor and primary caregiver. This is of particular local concern as the effects of stroke increase health disparities between Māori and Caucasian New Zealanders.

Age, family strength and communication are also factors influencing the needs of primary caregivers. Social networks and isolation are important factors in longer term care. There is little research relating to the longer term effects of stroke on the wider family or primary caregivers. The wider family is best placed to support the stroke survivor and caregiver yet little is known about their experience of stroke. This is where this study and the Parent Project can shed some light.
Chapter Two: Study Undertaking, Methodology to Method

This chapter will discuss different qualitative methodologies. It will then explain why the chosen methodology and method were seen to be most appropriate for the aims of the study. Finally it will cover in detail the chosen method and how that method was implemented.

Overview: Methodology. To ensure that any study is worthwhile the methodology and methods used have to be congruent with the aim or aims of the study. This subsection will discuss why hermeneutic phenomenology was used in the study and its appropriateness to the study’s aims. Reflections on other methodologies such as descriptive phenomenology, discourse analysis and grounded theory are also provided.

Starks and Brown-Trinidad (2007) when comparing phenomenology, discourse analysis and grounded theory explain that phenomenology develops a deeper understanding of the lived experience that is otherwise taken for granted in everyday life. The authors clarify that grounded theory has its origins in sociology and seeks to find meaning through social interactions with others in any given environment. In contrast discourse analysis originates from linguistics and aims to see how language shapes our identities. This study aimed to investigate deeply into experience of stroke survivor family members, so the most appropriate methodology, where the greatest meaning can be achieved for the aim was therefore phenomenology.

This study utilised hermeneutic phenomenological research methods consistent with the Parent Project. Hermeneutic refers to the theory of text interpretation and phenomenology being the study of phenomena. Hermeneutic/interpretive and descriptive phenomenology are the two main forms of phenomenological research. Finlay (2009) reports that there is vigorous debate among phenomenological researchers as to which phenomenological methods are more truthful and meaningful. However phenomenological researchers do generally agree that the central concern of phenomenology is to explore and explain experiential meaning.

Phenomenology is essentially the study of lived experience or the life world (van Manen, 1997, p. 9). Finlay (2011) highlights that there are many different and varied ways of focusing on any particular aspect of a phenomenon or life world. Edmund Husserl, known as the father of (descriptive) phenomenology argued that both objects and people were part of experience (Laverty, 2003). Husserl thought by studying ‘phenomenon’, more could be learnt
about human issues than can be understood using natural science methods alone. Husserl viewed reality as a co-constructed dialogue between the person and the world.

Hermeneutic phenomenology as a research method developed from the philosophical writings of Martin Heidegger (Mackey, 2005), and differs from descriptive phenomenology by its focus on interpretation. Heidegger disagreed with Husserl’s view that the person can be separated from the world. Heidegger argued that phenomena or objects are part of consciousness and cannot be separated from it (Laverty, 2003).

Understanding phenomena, therefore, requires researchers to explore/study them in the context in which they occur. According to Mackey (2005) in an article explaining insights into Heidegger’s methodology, hermeneutic phenomenology gives a greater depth of understanding, as opposed to a purely descriptive record of lived experience. Hermeneutic phenomenology was, therefore, considered the most appropriate methodology for achieving the aims of the study; to explore the lived experience of the wider family of stroke survivors over a period of six months after the initial stroke.

**Methods.** The methods used in this study were based on those described by van Manen (1997). Van Manen suggests “hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities” (p. 30). The activities he describes were not followed exactly step by step but were used as van Manen intended, as a guide rather than a formula and are outlined below.

**Turning to a phenomenon which seriously interests us and commits us to the world.** As explained by van Manen (1997) turning to a phenomenon is about ‘going on a quest’ to seek to understand an aspect of everyday living. A researcher first searches for a research question about a phenomenon of interest then narrowing it down and committing to focus on one essential aspect of it. The exploration moves to seeking out what makes that phenomenon separate from the everyday everything of everyday life.

The phenomenon of interest for this study and the Parent Project was first identified in 2009. Clinical staff from a stroke rehabilitation ward in a local hospital expressed a need to have a greater understanding about family experiences over extended time after a stroke event. It was perceived that sometimes some family members “do not move on” at the same pace as the stroke survivor.
The stroke event is normally thought of as something that has happened to someone. What may be forgotten is how the family to which the stroke survivor belongs is also affected. This study focused on the phenomenon of the wider family experience of stroke and the continued effects of living with a stroke survivor. The study committed to focus on the wider family phenomenon and to uncloak and broaden the understanding of their experience of becoming and being a stroke family.

*Investigating experience as we live it rather than as we conceptualise it.* “The lifeworld, the world of lived experience, is both the source and the objective of phenomenological research.” (van Manen, 1997, p. 53). In hermeneutic phenomenology it is important to get as close to the lifeworld (experience as it is lived) as possible. As lived experience is unconscious, reactive, and is happening while you do it, to be conscious of it changes the innate nature of it. Therefore researching it becomes problematic, reflecting on an experience changes or transforms it through the filters of the participant and researcher.

Van Manen (1997) explains that to stay as true as possible to the phenomenon it is important that the researcher suspends all presuppositions (any pre-understandings and assumptions) of the phenomenon. When the researcher does so it allows for a true interpretation of the data gathered, as the phenomenon is all that is left. How encompassing the research is to the actual phenomenon, or how meaningful the interpretation, ultimately depends on the skill and orientation of the researcher. I undertook an audio recorded personal interview to record and examine my presuppositions before the participant interviews were implemented. I also kept a personal journal throughout the entire study to contribute to an audit trail for the purpose of maintaining truthfulness and rigour.

Data were gathered through a series of semi-structured conversational interviews and were focused on the participants’ everyday experiences of becoming and being a stroke family member. Interviews occurred at six weeks, three months and six months post stroke. A research assistant conducted the six week and three month interviews, while I completed the interviews at six months. Weekly email updates, that were written by participant 1 (the stroke survivor’s wife) for family and friends, were also included in the data set. Semi-structured interviews are congruent with hermeneutic phenomenology; the semi-structured conversational style allows the interviewer to delve deeply into the experiences while maintaining a focus to the phenomenon (van Manen, 1997).
Reflecting on the essential themes which characterize the phenomenon. “The purpose of phenomenological reflection is to grasp the essential meaning of something” (van Manen, 1997, p. 77). As explained by van Manen, themes and thematic analysis are tools which give the researcher controls to seek meaning. Ultimately the purpose of this research was to find meaning of the family experience of stroke and how that meaning might change over time. This was done by the researcher continually reflecting on the data and asking ‘what does this tell me about the experience of becoming and being a stroke family?’

In thematic analysis van Manen outlines three ways to extract themes in the participant’s stories. A) The holistic or sententious approach. Where the whole transcript is read and then expressed by the researcher in one phrase which aims at capturing the fundamental meaning of the whole piece. B) Detailed or line-by-line approach where every sentence or group of sentences are gone through with the question asked ‘what does each sentence or group of sentences say about the phenomenon?’ C) Selective or highlighting approach where the data is read or listened to multiple times and the statements phases which seem particularly relevant to the phenomenon are highlighted and reflected on (van Manen, 1997, pp. 92-93). Although all three approaches were used, the latter was primary method of isolating thematic statements for this study.

Describing the phenomenon through the art of writing and rewriting. According to van Manen (1997) “writing is our method” meaning that in hermeneutic phenomenology it is not possible to separate the writing and the method as the process of writing is the method. Writing is not just a way of reporting the research findings as it is in other research. Writing is an integral part of the process of reflecting, refining and illustrating the phenomenon.

I found it was only once I had written, read and reflected on my initial themes, that I could uncover layers and gain greater depth by further rewriting. This process of writing reflecting and rewriting was continued again and again with a committed effort to focus on the phenomenon. Keeping an audit trail of presumptions and transitioning thoughts allowed the researcher to stay true to the family experience.

Maintaining a strong orientation to the phenomenon. Being orientated is staying focused on the lifeworld of the phenomenon and not being distracted by the people’s feelings or thoughts outside the phenomenon (van Manen, 1997, p. 135). For example with this research, it is easy to get caught up in the participant’s discussion about what was happening to the stroke survivor and get distracted from what that means for them in their everyday
lifeworld. Staying oriented to the phenomenon has been practised by the researcher again and again by continually asking of the data, “What is this telling me (researcher) about the family experience?”

**Balancing the research context by considering parts and whole.** Considering parts and whole, van Manen (1997) offers a guideline of how the research may be presented. As discussed earlier, the writing process is indelibly intertwined with the research process, so the final presentation to the reader is just as important and inseparable from the ‘results’ as they are effectively the same thing.

Van Manen (1997, pp. 168-173), gives six general ways of writing/presenting hermeneutic phenomenological research. A) Thematically where the essential aspects of the experience are expressed through themes. B) Analytically where for example the interviews may be reworked to show how the experience may be seen in different ways. C) Exemplification where bullet points are written explaining the essential nature of the phenomenon and those bullet points are then expanded upon. D) Exegetically where further writing is based in finished work on the nature of a phenomenon that has already been worked through in-depth. E) Existential writing is where the experience is based in lived time or lived space, lived relation to others and so on. F) Inventive approach, which uses a new or mixed approach that combines the above five ways of writing and presenting.

This study primarily uses an inventive approach, not new but rather a combination of approaches A and approach E. The experience of becoming and being a stroke family was filtered into its essential essence and interpreted in an overarching theme with three sub-themes.

From analysis, themes have been explored and expressed both temporally and in personal, relational context. The temporal aspect is shown in how the themed experience changed over the six months and the personal and relational aspects in how they were different within and between participants. Each theme example is presented in three paragraphs. The first paragraph gives context, the second an excerpt example and the third the interpretation of meaning. The next section will discuss the ethical considerations of the study.
Procedures: Undertaking the Study. This subsection will look at how this study balanced all the parts and the whole. It includes the ethical considerations, recruitment, interviews, and analysis and theme development of this study. The section will conclude with a discussion of how rigour was ensured throughout the study.

Ethics. Ethical approval has been granted for the Parent Project (Appendix B) which included approval for this study. The main ethical considerations were sensitivity to family members involved as stroke can be a difficult subject to explore. While in-depth interviews may bring up distressing memories or thoughts, they can also be beneficial. One participant commented that the interview was the only time they had to reflect and think about themselves.

No participants became distressed when re-visiting their experiences. There was however accommodation that the interviews would be stopped and participant offered counselling services if they became upset by discussing their experience of the stroke. The counselling services would have been provided from the budget of the Parent Project.

The participants had contact details of the principal investigator Dr Dianne Roy and were encouraged to ask any questions they desired about the study or the Parent Project. This was aimed at reassurance and maintaining clarity of participant expectations of the study. The participants were able to withdraw from the study at any time and remove part or all of their interview data at any time up until two weeks after the interviews or on receipt on the copy of the transcript. No data were withdrawn.

The information that was recorded was personal. Transcripts and audio files were kept on a password coded laptop and a private password coded journal was also kept on the researcher’s tablet device. To uphold anonymity and confidentiality, each participant was given codes (Fam004 P001 – P003) and the research log/recordings were stored electronically and password protected.

When the participants were invited into this study, they were reminded how confidentiality was being maintained and gave continued verbal consent to proceed in this study. The participants gave their initial informed written consent when recruited into the Parent Project (Appendix C). The transcriptionist also signed a confidentiality agreement before transcribing the transcripts verbatim.
Intellectual property and data will remain with the study/Parent Project consistent with the Unitec Intellectual Property policy. Data will be securely stored in line with Unitec protocols for five years after the completion of the Parent Project before secure destruction.

**Recruiting Participants.** The sample for this study was drawn from participants already recruited to the Parent Project. The procedures for sampling and recruitment which received ethics approval (Appendix B) within the Parent Project included:

- Purposive sampling was used to recruit up to five families/whānau.
- Potential participant families/whānau were identified by clinical staff when a client was admitted to a local hospital following a first-ever stroke.
- Clinical staff provided information sheets (Appendix D).
- Criterion for family/whānau inclusion was that the primary caregivers as well as other family/whānau members agree to participate.

A family who were already participating in the Parent Project were invited to join this study. The initial invitation was made by the Parent Project’s principal investigator and was then followed up in a phone call from me. The recruited participant family were three female non-blood relatives who identify as ‘family’ to the stroke survivor. This is consistent with the Parent Project’s definition of family/whānau which is viewed broadly to include people who have a close relationship with the stroke survivor. The three participants were the stroke survivor’s wife and two of her female friends whose relationships to the stroke survivor and his wife were like a sister and an adult daughter.

**Interviews.** The interviews were arranged at a convenient place for both the participant and the researcher which was at the participants’ homes. The participants were all interviewed separately. All interviews took place in 2012.

A digital audio recorder and the interview schedule were taken into the interviews. Face-to-face conversational interviews were considered more appropriate than telephone interviews as they contribute nonverbal communication such as facial gestures, which adds richness to the participant’s expression, and may change or enhance interpretation. All interviews took between one to two hours in length.
Specific structured questions for the interviews at six months were derived from listening to the early interviews and from knowledge gained in completing the literature review for this study’s proposal. A practice interview with a colleague was also completed before the interviews happened.

In all interviews, open questions were asked such as “Can you tell me what happened when he had the stroke?”, “Can you please tell me about your experience after the stroke?”; Open questions were aimed at enabling the participants’ narrative to be delved into, with closed questions used to clarify points of interest.

For ease of analysis and expression, participant’s codes were given pseudonyms. The stroke survivor was called Dave. His wife (Fam004 P001) was called Ivy, P002 and P003 were called Jane and Deb respectively.

The interview schedule at six months was as follows:

- I would just like you to say in your own words how you, what’s been happening over the last three months … since the last interview?
- How do you feel about that?
- How is your situation re-funding?
- Is there anything you need?
- Are there any positives from the stroke?
- How has your (Ivy and Dave’s) cat been since the stroke?

Questions that were specific to individual interviews were also created.

- Has the stroke changed your relationship with Ivy or Dave? (Jane and Deb)
- Has having had cancer changed your view on the stroke? If so how? (Jane)
- Are you still having girlie days? (Ivy)
- Has your relationship changed since the stroke? If so how? (Ivy)
- Does Dave still think of you as his whole life? (Ivy)
- Do people still expect you to help with Dave’s exercises? (Ivy)

**Pre-suppositions.** As described by van Manen (1997, p. 46) ‘explicating assumptions and pre-suppositions’ of the phenomenon by the researcher is an important part of ‘turning to the nature of the lived experience’ as well as showing transparency of the findings. My pre-
suppositions and assumptions of the experience of a family living with a stroke survivor were discussed with a member of the research team. This was completed in a recorded interview before the participant interviews but after the literature review for the study proposal. A reflexive journal was started at the time when the study proposal was accepted and continued throughout the study. Audio tape reflections were also recorded after each interview.

My pre-suppositions assumptions and experience with the phenomenon:

- I am a 32 year old male with a therapeutic massage background.
- I am an Osteopathic student with some background knowledge of pathophysiology of stroke
- I have no clinical experience with anyone who has had a stroke.
- I have no previous experience with a family member or friend having a stroke
- I completed a proposal for the study, which included a literature review so I have some idea of the academic knowledge
- I assumed that different socioeconomic groups will react differently to a stroke because of different economic, education and family backgrounds
- An assumption of mine was that while the stroke literature shows positive effects, the primary experience would be negative

**Data analysis: Theme development.** I audio recorded my reflections of the interviews separately and directly after each interview. When analysis began I listened to the audio files while having the transcripts available to clarify specific wording. During this process any relevant thoughts and or potential themes were stored on a password coded electronic journal on my tablet. The analysis procedure for initial theme development included first reviewing the three transcripts from each participant individually. Then all transcripts were screened across each time period (6 weeks, 3 and 6 months). Recorded notes were then reflected on and initial themes consolidated or changed.

Excerpts were taken and diarised giving examples of theme thoughts. I presented initial thoughts to nursing students a few months after analysis began. I found this useful as a sounding board for theme ideas and consolidation. I then reflected on origins of the initial themes and checked that each theme was driven by data and not my pre-suppositions or assumptions. At this stage rough writing began as guided by van Manen (1997), and was followed with continual writing and rewriting.
Themes were further consolidated through continual reflexion and regular meetings with the research team. During the analysis period research team meetings were held approximately once a month for approximately 12 months. When themes were consolidated, in-depth analysis was structured around individual theme development.

The next stage of deeper analysis began with my going over each interview focusing directly on one theme at a time and noting in the journal everything that was relevant to each theme. I then mind mapped all the notes of each interview and audio recorded a discussion with myself linking all the aspects (notes) of the theme together. Finally each theme was consolidated across participants at each interview period. Further mind maps and wind maps were produced (windmaps focused on strength and direction of communication lines on each interview narrative) along with audio recorded self-reflection of each map, see Appendix E.

Once this was done for each theme across the time periods a meeting was scheduled with the research team to discuss the initial analysis. Rewriting continued, excerpts were clarified moved or deleted. During these meetings I was introduced to the work on ‘Caring’ by Noddings (1986), and the doctoral dissertation by Nortvedt (1996) ‘sensitive judgment’, which significantly affected the theme’s development and interpretation. A final diagram showing how the overarching theme and sub-themes fitted together was designed (Appendix E, 4). Examples of mindmaps/windmaps and a table displaying theme development are shown in Appendix E. An example of expanded themes that were condensed for the manuscript is provided in Appendix F.

Ensuring rigour. Ensuring rigour in qualitative research is extremely important, for without rigour it is difficult to assess truthfulness. Without truthfulness all findings becomes largely a creative endeavour, arguably meaningless from a scientific perspective. Ensuring rigour in qualitative research has evolved over time and the best ways to evaluate it remain debatable (Pereira & Rebelo-Botelho, 2011; Ryan-Nicholls & Will, 2009). As qualitative research has different aims and methods from quantitative research using the same assessment criteria for rigour is inappropriate (Ryan-Nicholls & Will, 2009).

Because there are so many different types of methodologies in qualitative research, it is hard to come to a consensus or even if there should be a consensus on tools for assessing rigour (Rolfe, 2006). In an article on novice researchers’ experiences with rigour in qualitative research Pereira and Rebeło-Botelho (2011) describe how confusing and scary maintaining rigour can be for a novice researcher. Pereira and Rebeło-Botelho (2011) also
acknowledge that while maintaining rigour is important it should not be at the expense of the data.

Koch and Harrington (1998) make a case for reflexivity in an article on rigour. In Gadamerian philosophical hermeneutics, there is an assumption that any consciousness (of researcher and participant, and reader) is influenced by the historical context and pre-understandings of any given phenomenon. Participant, researcher and reader have these contexts and they all reflexively interact influencing each other. Koch and Harrington (1998) recommend the researcher keep a reflexive journal to maintain transparency and trustworthiness. The concept is that if the author can record the process of studying the phenomenon as it happens to later effectively display the inner workings of the process and show how the process fits with the writing, the reader can then understand the author’s perspective on the phenomenon and trust how the meaning was attained.

In this study I recorded my experiences of the phenomenon, my assumptions, and pre-understandings before the first interview. I kept a reflexive research journal, and audio tape recordings noting initial thoughts and analysis. Theme progression and development throughout the entire process was recorded including any transitional thoughts. To give the Reader confidence in the process regular meetings with the research team discussing emerging themes were also recorded and analysis was carefully described in the methods section to give confidence to the reader of process. I continually reflected on the themes, especially considering where the themes originated, as well as producing direct excerpts in the manuscript to show the truthfulness of the data. As Koch and Harrington (1998) explain giving a reflexive account of the research process enables the reader to make their own decision about the plausibility of the research.

In summary methods used for assessing and maintaining rigour in qualitative research are still debatable. However giving a reflexive account of the research process displays the transparency and trustworthiness of the researcher. In hermeneutic phenomenology there is an assumption that neither the researcher nor the participant or reader can remove the influence of their personal historical context or pre-understandings of the phenomenon. With a reflexive account the reader can make up their own mind of the trustworthiness, meaning and the transferability of the research.

This is the end of section one which describes the literature on the stroke experience and the undertaking of the study including methodology, method, participant recruitment and
rigour. The next section is a manuscript that is intended to be submitted into the New Zealand nursing journal *Nursing Praxis*. 
References


Section Two: Manuscript

Abstract

Introduction: Stroke is the third largest cause of death in New Zealand and is a major cause of disability. While a lot is known about the stroke survivor and the primary family caregiver, little is known about how stroke affects the survivor’s wider family.

Aims: This study’s aim is to investigate the experience of becoming and being a family member of someone who has had a stroke, over the first six months from the initial stroke. It is part of a larger longitudinal four year project exploring the stroke family lifeworld.

Method: The method used was hermeneutic phenomenology as guided by Max van Manen (1997).

Results: The stroke survivor is not the only person who needs care. The overarching theme is duty of care. There are three sub-themes: care is ‘different for different people’; there are care ‘expectations of self and expectations of others’; and care brings ‘strain’. All are significant in the family experience. The family have expectations and obligations of their own duty of care and these are also influenced by sources outside the family. In addition there are considerations of fairness regarding the sometimes competing needs of the survivor and the caregiver.

Conclusion: Strains on the family change over time. Competing values of mercy and fairness within this family take up time and risk disengagement of the family from the stroke survivor’s progress.

Key words:
Stroke, family, duty, care, experience, New Zealand.

Introduction and Background

Stroke is the third largest cause of death in New Zealand and is a major cause of disability. An estimated 45,000 people are living with a stroke in New Zealand and around 70% of them are dependent on others to help them with their daily activities (Stroke Foundation of New Zealand, 2013; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). While a lot is known about the impact of stroke on the survivor and the primary
caregiver little is known about how stroke affects the wider family. This study is part of a larger longitudinal project being undertaken by researchers from the Department of Nursing, Unitec Institute of Technology and the Waitemata District Health Board, Auckland New Zealand.

**Aims**

The aim of this study was to investigate the phenomenon of the experience of becoming and being a family member of a stroke survivor over the period of six months from the initial stroke.

**Methods**

This was an exploratory study using hermeneutic phenomenology research methodology. Data collection was via semi-structured interviews and was guided by the processes described by van Manen (1997).

**Participants**

One family participated in this study and included the spouse of the stroke survivor and two relatives. All of the participants were healthcare professionals. The family was recruited from the Parent Project.

**Data Collection**

Face-to-face, semi structured interviews were undertaken at six weeks, three and six months post stroke. The interviews were between one to two hours in length and were held at a mutually agreed location.

**Ethical Considerations**

Ethics approval was granted by the Northern X Regional Ethics Committee (NTX/11/EXP/062). The main ethical considerations were confidentiality and the potential emotional harm that in-depth interviews could have on participants. Interviews could have been stopped at any time and participants were offered funded counselling services. In fact no participant used the services and some participants commented that the interviews helped them process and reflect on their experiences. Privacy was maintained through anonymisation of participants’ information.
Data Analysis
All interviews were transcribed verbatim and anonymised prior to analysis. Data was analysed thematically. Theme consolidation was developed over time via writing, reflecting and rewriting. The researcher had regular meetings with the research team to discuss theme progress. Mind maps were also used to explore themes and they were recorded in a reflexive journal.

Findings: Duty of Care
The overarching theme was ‘duty of care’. Societal, personal and perceived pressures from healthcare professionals over issues surrounding duty of care was identified as the principal concern of this family’s stroke experience. Duty of Care was expressed through three sub-themes: ‘Different for different people’; ‘Expectations of self and expectations of others’; and ‘Strain’. These themes interacted between one another and contributed to the primary author’s interpretation of the stroke experience (see Figure 1).

According to the Oxford dictionary duty of care is “a moral and legal obligation to ensure safety or well-being of others” (Duty of care, 2014). Considering the moral basis for caring, Noddings (1986) describes how caring for someone is not just about a person’s actions. Noddings suggests that caring is about connection, how fully a person considers and has empathy for the care recipient’s reality. Caring is also a choice which is sometimes natural and effortless but at other times and in other situations requires effort and is a response to moral obligation or duty.

Nortvedt (1996) discusses the moral aspects of the ethic of care, contending that moral perception (ability to perceive a recipient’s reality) is a crucial skill to fully care for a recipient’s needs. Nortvedt contends that, in caring, principles of mercy, fairness and justice are used to help all parties achieve an effective care relationship. He explains that fairness is used to guide care decisions for large populations, but that in face-to-face relationships, the principle of mercy is more appropriate.

In this closer relationship, the extra resource provided may come at the expense of another person, but will still be ethical. Thus fairness is an example of caring over a wide population and care decisions that are just for all patients as opposed to merciful decisions on an individual basis that might burden others. An example of the ethical challenge is where one patient’s care comes at the expense of other patients’ resources. Nortvedt argues that if
moral perception is concerned with the patient’s condition and not the patient the moral judgement becomes impartial and therefore fits in a justice ethic. Therefore the skill and maturity of the nurse’s moral perception and ability to balance the wider needs and the individuals needs have great bearing on a successful outcome.

In this article, mercy refers to care actions that are given to an individual beyond standard care in recognition of high needs. Over time, shifts in needs and capacity to care influence care responses, both expected and given, and these in turn shape the family’s perception of what care they deserve and ought to receive. The family’s moral perception and their view of the health system are challenged by questions of fairness, justice and mercy. These perceptions affect how the family care for one another and contribute to family strain and their care capacity. A description of the stroke family and a time line of the analysis are given in Tables 1 and 2.

(Insert Tables 1 and 2 here)

**Subtheme: Different for different people.** The research data revealed caring as complex and multi-layered. Different people show their care in different ways and for different reasons. This relates to each participant’s expectations of themselves and others within the family as well as society’s wider expectations.

The consequences of stroke are different for different people. Ivy and Dave were almost expecting the stroke to happen. Before the stroke they were forewarned by their doctor that Dave’s lifestyle and co-morbidities would likely lead to a stroke. The event was quite different for Jane, who was shocked and upset when she found out. While Deb had expected the stroke she felt much more immediate concern for Ivy than for Dave when she heard the news.

*I mean the stroke was kind of like inevitable really because of all his health problems leading up to it. So it wasn’t a surprise......... I wouldn’t like to see [Ivy] struggling caring for Dave either. I don’t think that’s really fair ‘cause she’s like worked hard all her life and I don’t, I don’t think she should have to do that, I don’t, and I really, I’ve already told her that she shouldn’t become his caregiver and I really wouldn’t want, I wouldn’t let that happen to Ivy. (I, Deb)*

Deb had personal experience of her own parent’s strain as caregivers and knew what Dave’s stroke could mean for Ivy. Deb feels a duty and responsibility for Ivy’s care and moved from caring about *(she shouldn’t become his caregiver)* to caring for *(I wouldn’t let that happen).*
Caring is also dependent on location, knowledge, experience and family relationship. Early on Ivy explains how she meets an old neighbour in the hospital after Dave’s stroke. The neighbour’s husband had recently had a stroke and her way of showing her duty of care for him was to stay by his bedside constantly. Ivy on the other hand made sure she took time to look after herself.

I said [to the neighbour], “You’ve got to take care of number one….. if and when he comes home, you’re going to have to have your health like I am”. And she [Ivy’s old neighbour] said, “Well how many girlie days have you had?” I said, “Well I have about two a week, I know he’s in good hands”. I just say to Dave, “that’s it, I’ve got to go to this or do that” and he understands. (1, Ivy)

Perhaps because of her healthcare professional background Ivy could see the need to stay healthy and prepared for the burden of caring. There was already knowledge that caring for the stroke survivor at home would be a burden.

Stroke changes lives. These changes may be different depending on the background of the people affected by stroke. As time moved on at three months after the stroke Ivy was coming to terms with the changes the stroke has made in her life.

I get the feeling of relief rather than sadness. I mean there’s sadness there but not that I can’t cope with it and the fact that he is probably in a better position where he is than here. (2, Ivy)

The relief Ivy felt was the relief of a burden lifted and the sadness was for a life changed. She felt ambivalence around her duty of care for Dave as, although she would have liked to have him home, she acknowledged that the care in the rest home is better than she could have achieved at home.

The participants in this study show care for different reasons and in different ways. They also have different expectations around care. They have expectations on who should be doing it, how it should be done and the location. The next theme explores these expectations, identifying how they are different and how they vary and change from the initial stroke.

Sub-theme: Expectations of self and expectations of others. Stroke requires a response from family. Family members’ responses to stroke depend on their expectations of their role in caring for the stroke survivor and the other family members. Different
expectations are expressed by family members, government and healthcare institutions. These expectations of care have to be weighed against the participants’ capacity to respond, considering other duties, obligations and their own health.

Early on Deb and Jane feel they have a role in caring for Ivy and Dave after the stroke. This expectation has to be measured against other duties and emotional safety. Caring as part of the stroke family is only one duty among many.

I think, there is a danger [that] certain people, [could] become too dependent on you and that’s not possible because you’ve got another side to your life. So, I’ve always found when I have offered assistance that you need to be just a wee bit careful that you don’t get eaten alive but in this case I’m sure it won’t be so. (1, Jane)

There is an implicit expectation that they have a duty of care especially toward Ivy. They worry that the duty will become all-consuming. Jane talks of her concern that the recipient could become dependent and her as a carer could become overwhelmed.

There are also expectations wider than the family. Rest homes have a duty to be fair to all their patients and to use their resources wisely. Government also has a duty to be just, with responsibility to the wider society and the taxpayer. As a consequence of these different duties, mid-way through at three months Ivy feels pressure to take on the primary caregiver’s role.

I get the certain feeling that because they know I’m a [health professional] that I’m actually going to be in there doing his exercises and doing 110 things, I’m being very careful to withdraw from that because I’m his wife and his friend but I’m not his nurse... I know that some of the wives do, do some of the minor exercises etc. (2, Ivy)

While the Rest home and Government may expect the duty of care to be placed on the stroke survivor’s wife, Ivy has consciously chosen not to take on the caregiving role; she is his wife and friend. She still feels societal pressure and expectation from other wives, rehabilitation staff and government to take on the duty of care. The family also have a strong impression that Dave and the healthcare professionals expect he will go home. Ivy and Deb report that the rest home staff asked Ivy to think about selling their family home to get one that better suits Dave’s needs.
Ivy’s expectation that she would be shown understanding and given mercy was not met. Her hope that the duty of care would be maintained by the rest home staff is not fulfilled. Instead she feels forced to say: “I’m not ready to have him home”. Ivy knows the limits of her ability to care for Dave. If she relinquishes her resolve and takes on Dave’s care she is concerned about what that will mean for her role as his wife.

Stroke burden changes over different periods. Expectations and decisions about deciding if how and when to care are challenging for the family. As time goes on questions of moral judgement around care including the values of mercy, fairness and justice are raised and become tiring and time consuming for the family. The next theme will discuss the personal and financial strains that stroke brings.

**Sub-theme: Strain.** The burden of fitting in care around life’s other on-going responsibilities and priorities proved draining. By six months the stroke experience became the new norm for the wider family. The prolonged concern and duty of care became tiring.

For Jane the immediate nature and extra energy devoted for caring for Ivy and to a lesser extent Dave caused conflict with other now more immediate duties.

*I am concerned [about Ivy’s own health] and sometimes I feel I almost need time out. That sounds a bit mean but I just backed off just a couple of weeks ago because I had a few problems with a grown up daughter and I just really needed to have just one thing to concentrate on at the time. My work’s lovely and very involved and very busy and I just recognise that there’s a limit to what I can cope with. (3, Jane)*

While Jane remained concerned for Ivy’s health by six months she feels a need for time out away from the duty of care. Other more immediate duties such as her daughter and work take precedence. Sometimes the wider family will feel the need to pull away, to re-prioritise and recognise self-limits in order to fulfil the duty to self of self-care.

Financial strain was a consistent theme throughout the interviews. Instead of reducing the burden the perception is that government departments increase the strain on the stroke family.

*About three or four days after his stroke I learned, to my horror, that WINZ [Work and Income New Zealand] will take away his pension……. Being on the other side (of the health system) is just no joke ….. The WINZ experience was probably the worst*
thing that Dave and I experienced as professionals. You're just simply not a human being.” (I, Ivy)

The financial strain was immense, possibly the biggest strain of the family’s stroke experience. The strain of potentially losing their home through inability to pay the mortgage because of the loss of Dave’s pension causes Ivy to feel that the government is not fulfilling its duty to care for them. The strain was not helped by Ivy’s perception of being treated like a case number.

Early on out of a sense of duty Deb took on the power of attorney if both Ivy and Dave become incapacitated. As time changes so do the family duties as they are continually reassessed. Over time strain builds and irritation increases.

Like with this whole thing about getting Dave a power wheelchair, Ivy has been trying to use every avenue that she can [including Deb’s work] to get him a power wheelchair and Dave is actually able [to use] a manual wheelchair. .........I do feel that Ivy has pushed the boundaries (3, Deb)

By the end of the six months Deb is experiencing a number of conflicts. Deb perceives Ivy as blurring her professional and personal boundaries by using Deb’s connections to access an electric wheelchair for Dave. Deb’s opinion is that Dave would benefit in the exercise involved in using a manual wheelchair, and her professional view is that other patients have a greater need. There are conflicts between the values of mercy and fairness.

Deb is concerned with the amount of energy her duty of care towards Ivy and Dave is consuming at the expense of her own immediate family. This is causing some resentment around the caring role she has assumed. Deb’s concern is that the mercy Ivy is demanding in getting an electric wheelchair to lessen her own burden is unfair to Dave in that it undermines his rehabilitation. She is conflicted between Ivy’s need for mercy and Dave’s right to fairness.

**Discussion**

In this study the participants are all non-blood family, females with their own families. They are all healthcare professionals which makes this sample unusual in that they have professional as well as personal perceptions regarding mercy and fairness in the care of stroke survivors and their families.
As family they initially have a strong sense of mercy for Ivy as Dave’s wife rather than as his caregiver. Ivy is a reluctant caregiver, preferring the role of wife and advocate for Dave which was supported by the other family members. This is tempered as Dave’s rehabilitation progresses. Dave’s right to fairness around his rehabilitation and his preference to return home conflicts with Ivy’s request for mercy. She is a small woman who is concerned about being the primary caregiver for Dave who is a big man. This value conflict places strain on the family.

Early on, Ivy felt insecure regarding Dave’s future and their financial stability. Wallengren, et al. (2008) described a similar experience as “Uneven ground”. The uneven ground continues for Ivy as she is constantly uncertain about whether she has to assume Dave’s duty of care.

Haley et al. (2009) and Pereira and Rebelo-Botelho (2011) found positive aspects of caregiver stroke experiences including valuing life more and growing closer to the stroke survivor. Greenwood et al. (2009) found that a commonly identified satisfaction was that the stroke brought greater family closeness. In this study a positive aspect was that Dave became determined to recover and improve his general health after the stroke.

Duty of care became the primary focus for the family. Moral judgements were made around who should provide the care and where Dave should reside. Balancing family expectations and the different care needs increased family strain. Lutz et al. (2011) suggests that family members often expected that stroke rehabilitation would continue until survivors had reached their pre-stroke lives or at least independence. Dave’s family’s expectations did appear to be different from the rest home’s staff expectations.

Lutz et al. (2011) described “self-advocacy” as recognising personal limits which helps spouses avoid crisis but pointing out that this advocacy was often not supported by healthcare professionals. Ivy knew her limits and what role she was able to play but did not feel that the healthcare professionals showed her any mercy. Instead she felt a sense of enforced duty that threatened her health and potentially her relationship with Dave.

Smith et al. (2008) found that older caregivers aged between 58-77 years tended to be overwhelmed by the volume of information and were technologically illiterate when compared to younger caregivers. They preferred encouragement to remain positive, whereas younger caregivers valued educational material and required greater co-ordination and
delivery of the information. Ivy, who was technologically savvy, felt well informed probably because she has a healthcare background.

Financial strains are common (Bulley et al., 2010) and are recognised in this study. Bulley et al. (2010) also described emotional strains, where the physical care is prioritised over the emotional burden. These were also experienced in this study.

In this study the family were preoccupied with moral and ethical judgments regarding who is most in need of care, the stroke survivor or the spouse. Trying to balance their duty of care to both Dave and Ivy with other responsibilities brought strain. Moral questions around care distracted family members from the possibility of the stroke survivor coming home. Processing these moral judgments appear to separate the family from the stroke survivor’s progress. Considerations of family dynamics may be useful areas of further research.

**Recommendations: Further Research and Practice**

Further research into family centred approaches to stroke care and recovery seem warranted. Aligning healthcare professionals and families’ expectations throughout the stroke recovery with the stroke survivor’s progress may help improve return home outcomes. Considering how stroke care may affect family relationships may improve family health when deciding whether a stroke survivor should return home.

**Strengths and Limitations**

A strength of this exploratory study was that the rich data gained from the three female participants through in-depth interviews. Another strength was the age range of the participants (40-70 years) which allowed experience between generations to be available for analysis.

A weakness was the relatively short length of the study; six months does not allow for long term analysis. The homogeneity of the study participants was also a weakness. Having no male, nor non-Caucasian participants, nor people from socioeconomic groups other than middle class, limited the study’s perspective which may reduce transferability of findings.

**Conclusion**

The data and findings of this study will give strength to the Parent Project. The main findings related to duty of care and how care may be different between family members depending on what other responsibilities they have. Balancing these responsibilities can be a strain on the
family. Assessing expectations for family members from the beginning and monitoring moral questions of fairness, mercy and priorities between the stroke survivor and the spouse as the recovery progresses may help professionals in improving successful home transfers after stroke.

**References**


Figures and tables:

Figure 1: Duty of Care flow chart, how the themes interact
<table>
<thead>
<tr>
<th>Pseudonyms</th>
<th>Role</th>
<th>Age</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dave</td>
<td>Stroke survivor</td>
<td>70’s</td>
<td>Retired healthcare professional, multiple co-morbidities before stroke.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Does not return home after stroke.</td>
</tr>
<tr>
<td>Ivy</td>
<td>Spouse</td>
<td>70</td>
<td>Recently retired healthcare professional, hip replacement after retirement</td>
</tr>
<tr>
<td>Jane</td>
<td>Equivalent to Ivy’s sister</td>
<td>60’s</td>
<td>Practising healthcare professional</td>
</tr>
<tr>
<td>Deb</td>
<td>Equivalent to Ivy’s daughter</td>
<td>40’s</td>
<td>Full time practicing healthcare professional, part time student</td>
</tr>
</tbody>
</table>

Table 1: Pseudonyms and participant background
**Timeline.** Interviews six weeks, three and six months after stroke

<table>
<thead>
<tr>
<th>Month</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>Dave has stroke, Ivy feeling relief, Deb and Jane give support primarily to Ivy. Deb takes on power of attorney if Ivy and Dave become incapacitated.</td>
</tr>
<tr>
<td>February</td>
<td>Deb recommends rest home where her husband works, which Dave moves in to. Ivy helps Dave access an intensive rehabilitation program (IRP). Jane and Deb think it is unlikely that Dave will go home. (6 weeks after stroke)</td>
</tr>
<tr>
<td>March</td>
<td>Ivy struggles with WINZ. Dave is doing well in IRP. Ivy feels pressure to take Dave home but doesn’t feel able. Deb and Jane feel in conflict between mercy towards Ivy and fairness for Dave.</td>
</tr>
</tbody>
</table>

Table 2: Timeline of Significant Events
Section Three: Appendices

Appendix A: Guidelines for Manuscripts Submitted to Nursing Praxis

While we encourage authors to be creative in the way they present their information, the following requirements must be met:

Manuscripts should be word processed, formatted for A4 size paper, with double line spacing, page numbers on the bottom right side of the page and the manuscript title in the header of each page. Use a plain font throughout (Arial, Calibri, or Times New Roman). Include an abstract of no more than 300 words, summarising the article. For research articles the abstract must include information about the research design, participants, and data collection and analysis methods.

Include a maximum of six (6) keywords. Generally manuscripts will not exceed 3,500 words, however longer articles will be considered as long as they are focused and concise. If the article is a research report then details of ethical processes followed must be included in the body of the manuscript.

Tables and figures each need to be presented on a separate page at the end of the manuscript. Indicate where in the manuscript the table or figure should be inserted. Generally these should be inserted AFTER the text where they are first referred to.

No details of the author are to be displayed on the manuscript, please provide these on the docx pdf Authors Submission Form 2013.pdf (0.51MB). The Editorial Board reserves the right to modify the style and length of any article submitted, so that it conforms to the Journal format. Major changes to an article will be referred to the nominated author for approval prior to publication.
Appendix B: Ethics Approval

Health and Disability Ethics Committees

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unions Building
650 Great South Road, Parnell
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 308 9105
Fax (09) 308 9101

7 April 2011

Dr Dianne Roy
Dept of nursing
Faculty of Social & Health Sciences
School of Health Sciences
Unitec New Zealand
Private Bag 92 25
Auckland 1142

Dear Dianne

Ethics ref: NTX/11/EXP/062 (please quote in all correspondence)
Study title: Improving support for families/whanau of clients post stroke (phase two): longitudinal study of experiences of family/whanau members

Principal Investigator: Dr Dianne Roy
Co-Investigator: Ms Sue Gasquelin, Shirin Caldwell, Ms Judy McKimm

Thank you for your application, received 4 April 2011. This study was given ethical approval by the Chairperson of the Northern X Regional Ethics Committee on 6 April 2011.

Approved Documents
— Protocol V#1, 5 April 2011
— Participant Information Sheet/Consent Form V#1, 5 April 2011
— Interview outline V#1, 5 April 2011

This approval is valid until 30 November 2015, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations
All significant amendments to this proposal must receive prior approval from the Committee.
Significant amendments include (but are not limited to) changes to:
— the researcher responsible for the conduct of the study at a study site
— the addition of an extra study site
— the design or duration of the study
— the method of recruitment
— information sheets and informed consent procedures.

Administered by the Ministry of Health  Approved by the Health Research Council  http://www.health.govt.nz/ethicscommittees
Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

**Annual Progress Reports and Final Reports**

The first Annual Progress Report for this study is due to the Committee by 7 April 2012. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

**Requirements for the Reporting of Serious Adverse Events (SAEs)**

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

- are unexpected
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely

[Signature]

Pat Chainey
Administrator
Northern X Regional Ethics Committee
Email: pat_chainey@moh.govt.nz
Appendix C: Consent Form

<table>
<thead>
<tr>
<th>Language</th>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>I wish to have an interpreter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaf</td>
<td>I wish to have a NZ sign language interpreter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero</td>
<td>Ae</td>
<td>Kao</td>
</tr>
<tr>
<td>Cook Island</td>
<td>Ka inangaro au i tetai tangata uri reo</td>
<td>Ae</td>
<td>Kao</td>
</tr>
<tr>
<td>Cook Island Māori</td>
<td>Ka inangaro au i tetai tangata uri reo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fijian</td>
<td>Au gadreva me dua e vakadewa vosa vei au</td>
<td>Io</td>
<td>Sega</td>
</tr>
<tr>
<td>Niuean</td>
<td>Fia manako au ke fakaaoega e taha tagata fakahokohoko kupu</td>
<td>E</td>
<td>Nakai</td>
</tr>
<tr>
<td>Sāmoan</td>
<td>Ou te mana’o ia i ai se fa’amatala upu</td>
<td>Ioe</td>
<td>Leai</td>
</tr>
<tr>
<td>Tokelaun</td>
<td>Ko au e fofohu ki he tino ke fakaliliu te gagana Peletania ki na gagana o</td>
<td>Ioe</td>
<td>Leai</td>
</tr>
<tr>
<td>Tongan</td>
<td>Oku ou fiema’u ha fakatonulea</td>
<td>Io</td>
<td>Ikai</td>
</tr>
</tbody>
</table>

- I have read and I understand the information sheet dated 5th April 2011 for volunteers taking part in the study designed to find out about the experiences of families/whānau of people who have had a stroke. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect the continuing or future health care of my family/whānau member.
- I understand I am free to withdraw any or all of my interview data. If I decide to withdraw my interview data I know I will need to contact the principal researcher within two weeks of completing each interview.
- I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- I understand that information gathered during participation in the research will be treated confidentially and stored securely.
- I consent to my interview being audio-recorded
- I know whom to contact if I have any questions or concerns about the project. (Note: The principal researcher for this project is Dr Dianne Roy - Ph. 098154321 ext 8307 or droy@unitec.ac.nz).
- I agree to take part in this research.
I …………………………………………………………………………. (full name) hereby consent to take part in this study.

Signature: ……………………………………………… (Participant) ………. (Date)

Project explained by: …………………………………

Signature: ……………………………………………… (Researcher) ………. (Date)

The participant should retain a copy of this consent form.

This study has received ethical approval from the Northern X Regional Ethics Committee (Ref NTX/11/EXP/062). If you have any complaints or reservations about the ethical conduct of this research, you may contact them at (09) 580 9063. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix D: Participant Information Sheet

Improving support for families/whānau of clients post stroke (phase two):
Longitudinal study of experiences of family/whānau members

Participant Information Sheet

You are invited to take part in a study that aims to improve support for family/whānau of people who have experienced a stroke. I am Dr Dianne Roy, a nurse and senior lecturer in the Department of Nursing at Unitec, and I am leading a small group of other nurses and health professionals in this research.

Why is this study important?
Approximately 8000 New Zealanders a year have a stroke. There are 56,000 stroke survivors in New Zealand, many of whom live with impairment and need significant daily support. It is believed that more national support is needed for stroke clients and their families/whānau.

Purpose of the Study
The aim of this study is to better understand the experiences of families/whānau of people who have a stroke so that we, as health professionals, might provide better care and support for families/whānau in the future. We hope to find out more about what it is like for you and your family/whānau in the weeks and months following your loved one’s stroke. We are inviting you, as a family/whānau member of someone who has recently experienced a stroke, to participate.

What it will mean for you?
You will be asked to meet with one of the research team for a series of face-to-face interviews over the next four years. We will arrange a mutually agreeable time and place for the interviews. The interviews will be audio-recorded and later transcribed into written form. We will contact you well in advance of each interview to see if you still wish to participate and to arrange a date, time and place for the interview.

During the interviews we will ask you about your experiences of being a family/whānau member of someone who has had a stroke. You will be free to choose how much or how little you wish to tell us about your experiences. During the interviews we can stop and start the recorder as many times as you might need. While many people find it helpful to talk about their experiences, others may find themselves thinking and talking about things that could be stressful. If you were to become distressed, the interview would be discontinued and assistance offered.

Each interview will take about an hour and will occur about nine times over the next four years; the first one as soon as possible, then in six weeks, three months, six months, 12 months, 18 months, two years, three years and four years.

Your Rights and Privacy
Participating in the study is voluntary (your choice). The care of your family/whānau member will not be affected on the basis of your decision to participate. You do not have to give a reason for not participating. You can withdraw from the study at any time.
Because of the method of data analysis to be used in this study it is essential that the interviews are recorded. Only those people who consent to the interviews being recorded can be included as participants in the study. You will be given the option to receive a copy of the recording. Once each interview has been completed you will be sent a transcribed (written) copy of what was said in the interview. If you wish to withdraw any or all of the information you discussed with us you can do so within two weeks of receiving the written copy by contacting a member of the research team.

All audio-recordings and written material will be stored in locked filling cabinets and computer files will be protected by passwords. Only the research team, including research assistants, will have access to the interview material. Every attempt will be made to avoid identification of you or any person or place in any reports prepared from the study. Your name will not be disclosed in any publication resulting from the study; nor will such information be available to any other participant in the study.

Any Questions?
Please contact us if you have any questions, now or in the future. We want to make sure you understand the study and feel well informed about what we are doing and why. I (Dr Dianne Roy) am the contact person and my details are below.

If you have any questions or concerns about your rights as a participant (someone who takes part in this research) you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Phone 0800 555 050; Email: advocacy@hdc.govt.nz.

To ensure ongoing cultural safety Nga Kai Tataki - Māori Research Review Committee Waitemata DHB encourage those who identify themselves as Māori and who are participating in health research to seek cultural support and advice from either Mo Wai Te Ora – Māori Health Services or their own Kaumatua or Whaea. For assistance please contact the Services Clinical Leader for Mo Wai Te Ora – Māori Health on 09 486 1491 ext: 2324 or the Māori Research Advisor on 09 486 1491 ext: 2553

What do I do next?
If you are willing to participate in this study please contact me (Dr Dianne Roy) or the person who has given you this information sheet and we can arrange a suitable time and place for completion of the first interview.

Thank You for your time in reading this information and for considering our request.

Contact Details Principal Researcher:
- Dr Dianne Roy - Senior Lecturer, Department of Nursing, Unitec Institute of Technology. Phone 09 8154321 ext 8307 or 021 581 096, Email: droy@unitec.ac.nz

Other Researchers
- Sue Gasquoine - Head of Department, Department of Nursing, Unitec Institute of Technology.
- Shirin Caldwell - Lecturer, Department of Nursing Unitec Institute of Technology.
- Judy McKimm - Dean and Professor of Medical Education at Swansea University, UK.
- Gerry Fennelly – Charge Nurse Manager, Muriwai and Huia Wards, Waitakere Hospital.

This study has received ethical approval from the Northern X Regional Ethics Committee (Ref NTX/11/EXP/062). If you have any complaints or reservations about the ethical conduct of this research, you may contact them at (09) 580 9063. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix E: Mind Maps and Table Example of Theme Progression

1: Mind/Wind map examples. Expectations mind map at three months for Ivy

2: Mind map for everyone at Six weeks
3: Wind map for Abby around communication at six months.

4: Duty of care mind map as whole
5: Table displaying theme development example of Expectations

<table>
<thead>
<tr>
<th>Initial distraction</th>
<th>Initial themes</th>
<th>Nurse presentation</th>
<th>Final interpretation</th>
</tr>
</thead>
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<td>There are also expectations wider than the family. Rest homes have a duty to be fair to all their patients. Government has a duty to be just, too, both caring for the wider society and the taxpayer. At three months Ivy feels pressure to take on the primary caregiver’s role. I get the certain feeling that because they know I’m an [health professional] that I’m actually going to be in there doing his exercises and doing 110 things, I’m being very careful to withdraw from that because I’m his wife and his friend but I’m not his [primary caregiver] ....... I know that some of the wives do, do some of the minor exercises etc. (2, Ivy) Ivy has consciously chosen not to take on the caregiving role; she is his wife and friend. She still feels societal pressure and expectation from other wives, rehab staff and government to take on the duty of care. The family also have a strong impression that Dave and the healthcare professionals expect he will go home. Ivy and Deb report the rest home asked Ivy to think about selling their family home to get one that better suits Dave’s needs. months.</td>
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Appendix F: Developed Work Condensed for the Manuscript

This subsection will show expanded themes that were omitted from the manuscript because of word count. These writings give a fuller account so the reader has a more in depth explanation of the work that was condensed for the manuscript. The intention is to give more clarity to the findings.

Different for different people. Stroke means different things to different people. Ivy and Dave were kind of expecting the stroke happening. They were forewarned by their doctor that Dave’s lifestyle would likely lead to a stroke. This is quite different from Jane, who was initially shocked and upset when she found out. While Deb had expected the stroke she felt much more immediate concern for Ivy than Dave when she heard.

*I guess we had both been anticipating the stroke for some time because he’d had a number of TIA’s [transient ischaemic attacks] prior to that [the stroke] and it was just, and our doctor said to us that he probably would have one [a stroke] and he wasn’t behaving himself over the diabetic eating.* (Int. 1, Ivy)

*I was very, very upset for both of them because they’ve been very good to me over the years and it just is, sort of quite a drastic thing to happen to one.* (1, Jane)

These reactions and feelings are history and life experience dependent. Ivy and Dave knew the stroke was coming yet patiently waited for it to happen. The stroke was quite unexpected by Jane and perhaps more emotional for her because of her own past health experience. She knows how easily life can be taken suddenly and drastically. Jane also shows early signs of indebted moral duty they’ve been very good to me over the years.

Duty of care changes over time and is different between family members. Jane moves from caring about Ivy and Dave as friends to caring for them both soon after the stroke. Jane shows her care in different ways than Deb. Jane cares for Dave by thinking about his needs, getting him things she feels he would enjoy such as books on fishing and educational aspects around stroke and rehabilitation. She shows her care for Ivy by making sure she gets out and has fun, taking her out on girlie days, concerts and courses.

*I’m probably into the practical problem solving mode and just ensuring that if he’s likely to be in hospital over Christmas then I know Ivy does have other support but just making sure that both of them do have support, particularly over that time and that Ivy gets out to some fun things.* (1, Jane)
Jane wanted to express her care and support through practical problem solving for Dave and ensuring Ivy stays in good spirits and has fun things to do over the potentially lonely time of Christmas. Jane is showing empathy for their reality thus showing her care.

At six months the family have a difficulty in reconciling different expectations of care. The family’s duty of care toward Ivy is challenged by a sense of fairness to Dave. Deciding whose narrative to support is difficult.

Yes, It’s very difficult. I really, I don’t know though if I can see all points of view because I’m a girl but I just know, if Dave, well if Ivy feels it’s too hard to manage then it is too hard to manage. She’s the only one who really knows......... (3, Jane)

Jane can see Ivy’s point of view much more than Dave’s. She has solidarity and her duty of care toward Ivy as a girl and she’s the only one who really knows. As the stroke family is all female, a supporting male narrative may not be heard.

Duty of care changes relationships and makes them different. An example of this is how Jane balances moral perception and judgement within a duty of care. Early on Jane did not think her relationship with the Ivy or Dave had changed but at three months she does.

Um, yes I think it has. How has it changed it? It’s very hard to say. I guess, Ivy and I are friends and friends support each other, but I guess it’s just remaining neutral, recognising that it’s a very difficult situation for both of them, not just for Ivy, and just being there to give appropriate help or at least the offer of help. (3, Jane)

Jane’s relationship has changed from a caring about to caring for relationship under her duty of care to Ivy as a friend. She also recognises her responsibility in the moral dilemma between mercy for Ivy and fairness to Dave. Her role has changed from supporting Ivy’s narrative as a supportive friend to remaining neutral as she recognises the difficult situation for both of them.

**Expectations for self and Expectations for others.** Another example of the call to care from the family is through moral debt. Deb feels an expectation of herself to care because of an indebted past.

*It was really hard when I had the little children and not a lot of people bother with you when you're stuck at home with little kids and Ivy would always keep in touch and I remember at the time not really appreciating what she was trying to do but when I*
Look back now I think whenever I’ve had like a professional crisis she’s always been on the end of the phone and I think now I need to be there a bit more for her. (1, Deb)

Deb shows ambivalence she feels a need (duty) to care for Ivy to show Ivy her appreciation for the care that Ivy showed her in the past but she also feels she needs to be at home with her family if she is not at work. Caring is really hard time consuming and difficult to balance when she has other commitments. While caring can help bring families together, it can be an extra burden in an already busy world.

Ivy had not expected to be a caregiver when she retired although Dave’s health declined rapidly making Ivy effectively a full time caregiver before the stroke. Ivy’s relief when the stroke happened was because she finally had an end to the burden of care, an end to the not knowing. When the stroke happened she felt able to give that responsibility and burden to the hospital. Dave’s health had deteriorated over the last few days before the stroke and he was only getting out of bed to eat.

I sort of was waiting for something to happen and sure enough at 4 o’clock on the 3rd I heard a thump as he fell out of bed and a sort of a cry and when I went in he was lying on the floor and I just knew that he’d had a stroke and it sort of was almost a relief in a way to know that this had happened........ I just went into action mode I suppose and I had thought it all through previously and I just made him comfortable, told him what happened, came downstairs, rang the hospital and yeah I suppose there was a certain kind of relief as well as a dealing with the emergency. (1, Ivy)

Perhaps the strain of not knowing when the stroke was going to happen was more of a burden than the actual stroke event itself? Ivy was waiting or expecting something, that she knew was a stroke. Perhaps she was waiting for mercy and she knew the stroke was that mercy. The sense of relief is mercy received; burden lifted the burden that duty of care brings.

Stroke is like a call to care, a call of duty. People’s expectations around care affect how those calls are heralded and heard. Different calls go and come from family members, government and healthcare institutions. These expectations of care have to be weighed by the participants against other duties, obligations and their own health.

The wider family feel they have a role in caring for Ivy and Dave after the stroke. There is an implicit expectation that they have a duty of care especially toward Ivy. This expectation has
to be measured against other duties and emotional safety. Stroke is only one duty among many.

I think, it depends on the person but I just think there is a danger with certain people, certainly not Ivy, which maybe they become too dependent on you and that’s not possible because you’ve got another side to your life. So I think, I’ve always found when I have offered assistance that you need to be just a wee bit careful that you don’t get eaten alive but in this case I’m sure it won’t be so. (1, Jane)

Answering the call to care can be worrying for the wider family. There is a worry that the duty will become all-consuming. Jane talks of the risks of caring and the expectation that the recipient can become dependent and you can be eaten alive.

In the early period after the stroke the family express their duty by supporting Ivy’s narrative. The general expectation is that Dave will only go home if it is safe and realistic for Ivy to have him home. Professional knowledge of limited resources, restricted timelines of care and broader fairness are put aside in order to show their moral support for Ivy.

Within the first six weeks, questions rise as to whether Dave will ever go home. The family have expectations of care for both Ivy and Dave. While there is hope of Dave’s recovery, there is concern for Ivy’s physical wellbeing and ability to care. Jane expects any decisions about Dave coming home will be carefully discussed with friends and family for the best outcome for the whole family.

I’m sure that a decision will be reached that had been thought over carefully and discussed with friends and family. Dave is a realistic person and I think he wouldn’t want to put Ivy under stress that was not good for her in the way of being able to actually manage, particularly the physical side of care...... I think that [physical stress on Ivy] would probably be why it wouldn’t be possible for Dave to go home. (1, Jane)

Jane says Dave is realistic and will therefore place Ivy’s care and stress levels before his own desire to go home, somehow seemingly ignoring that Dave has just had a stroke and is in need of care where he is more likely just thinking of himself. Her expectation that the rehabilitation and hospital staff will do what is best for the whole family seems to be disregarding wider resource limits and governmental drive to have patients in their homes.
I think it’s probably going to be inevitable that he will need to go into care. .... my concern is for Ivy, that I don’t want her life, quality of life to suffer because she’s forced to be a caregiver for Dave ‘cause I think she’s probably done enough of that already (1, Deb)

Deb’s expectation is that Dave will stay in care. Deb supports Ivy’s narrative and in doing so overlooks any duty of care of Ivy or the family may have. Her belief is that Ivy’s quality of life would suffer if Dave went home. Deb thinks Ivy has done enough caring. Deb feels the duty of care resides with the rest home.

The fact that [Dave’s] un-killable, I think it’s highly likely that he may come home, but I’m not setting my heart on it. I’m still sort of keeping my options open and being as positive as possible. Now I’ve got plans of what to do it makes coping so much easier (1, Ivy)

Ivy is almost ambivalent as she jokes that Dave is unkillable which gives her hope and positivity that he will be returning home but she is also circumspect; protecting her emotions by not placing her heart on it. Romantically she would like him home as the healthy stubborn man she married. But the pragmatist in her knowing Dave’s unhealthy history is keeping her options open for future contingencies depending on Dave’s recovery. Having these plans and expectations on what may happen allows her to cope.

There are expectations wider than the family. Rest homes have a duty to be fair to all their patients. Government has a duty to be just in caring for both the wider society and the taxpayer.

“I said to Dave the government are pushing for people such as yourself to be at home and looked after.” (1, Ivy)

Ivy feels the pressure of the government’s policies and society’s expectation pushing to have Dave home. She uses the push to motivate Dave. The whole family is challenged by trying to fulfil their own and their perceptive perception of society’s expectations around their own duty of care.

Expectations change over time. By three months Ivy’s expectation is bleaker that Dave probably will not come home as he cannot yet walk. Dave is still doing all he can to be fit enough to go home.
I’ve met that and I’ve accepted it and the fact that he’s so close we can still communicate and I feel as if I can now start to plan some life for myself alongside with him. It’s a different journey but it’s a journey and it will definitely include him. (2, Ivy)

Ivy feels a duty to manage Dave’s expectations. There is a split in expectations; Dave is still putting all his energy into recover with the sole focus of coming home although Ivy feels he hasn’t realised it will not happen. Ivy’s journey has changed her expectation has moved from living a life with to a life alongside Dave. She has internally met with the reality of a life without Dave in her life and accepted him not coming home. She is still planning a life alongside him, including him.

At three months Dave with Ivy’s help qualifies for an intensive three month rehabilitation program. The consent form for the program says that the aim is to give patients the potential to improve enough to go home, or at least gain more independence and quality of life. The form suggests that the program is not simply about getting the patients home. What else may have been communicated to Ivy is not known.

An assessment of Dave was to be made at three months after the start of the program to evaluate ability but it is not known what would constitute his capability to go home. Ivy’s expectation is that he would have to be able to walk independently by himself. Ivy feels she would not be able to physically cope if he could not walk independently as she is a small woman and Dave being a big man.

The family have the strong opinion that the healthcare professionals also expect Dave will go home. Ivy and Deb report the rest home asking Ivy to think about selling their family home to get a one storey to better suit Dave’s needs. Additionally Dave’s sister from Christchurch suggested divorce, if Ivy did not want him home.

In a family meeting at six months the rest home has a dialogue with Ivy and Deb about Dave going home. There is a perceived overarching expectation from the rest home/rehabilitation program that Ivy should take on the duty of care for Dave.

When they were having that meeting [in the rest home about his care], I had got to the point where I said well I cannot have him home in the state he is in now and I knew that the program would finish in 12 weeks and I didn’t think that that 12 weeks, from my point of view, made him functional enough to come home. He believed he
was incredibly functional, which he was, comparatively, and I got a feeling from the team which is a bit of pressure that that’s what would happen, that he would be sent home. So I have to say I don’t think I’m ready to have him home. (3, Ivy)

Ivy’s expectation of mercy and hope that the duty of care would be maintained by the rest home at six months is not being heeded. Instead she feels she is forced to refute (I’m not ready to have him home) the expectation on her to take on the duty of care. Ivy is very clear about the role she is able to play, she knows her limits. If she relinquishes her resolve and takes on Dave’s care what will that mean for her role as wife?

Expectations, moral judgements of mercy, fairness and justice are tiring and time consuming for the family. Stroke brings burden over different periods. The next theme will discuss the personal, financial and professional strains that stroke brings.

**Strain.** Stroke brings the strain of change, the strain of loss, and the fear of the potential burden of caregiving. For Ivy Dave had been slowly changing from the man she married. With Dave’s health issues Ivy has had to prepare for Dave’s potential death for a long time.

*I sort of feel as if I’ve done my grieving over the last five years really. I mean he’s been pretty sick, ..... I’ve been working my way through that process knowing that this would happen, I knew the stroke would happen, and there were three outcomes. Either he could die or he could end up like he is now or he could come home and then I’d have to face the carer issue and when I think about it I’ve been his carer for the last five or six years without sort of getting a title. (2, Ivy)

Strain is not always because of the stroke. The stroke meant an end to the burden of caregiving. Ivy talks of three options; 1, he would die, the burden of care gone, the burden of loss accepted. 2, end up where he is now in a rest home, burden of care taken by others and 3, taking him home would mean facing up to the truth of the burden that caregiving brings.

Taking on the duty of care may also signal the end of their marriage as it has been up to now, as Ivy relinquishes the wife role for the carer role.

Stroke initially creates strain in an already busy world. Ironically life does not stop because of a stroke. Stress comes in financial, emotional and professional ways that cause strain among the wider family. Communication and past circumstances have a big effect on the ability of family members to deal with the strains that stroke brings.
Ivy felt she was unofficially caring for Dave a long time before the stroke. The burden of caregiving is emotionally and physically draining. Ivy felt Dave was in denial about his level of health before the big stroke and Ivy felt enormous strain from Dave not understanding how dependant he was on her.

“It got to the point where I was in tears and I rang the GP and said, “could we come and see you ’cause I said this man is driving me nutty” (1, Ivy)

Ivy was frustrated to the point of tears. Strained to tears, Ivy called for help for her own physical and mental wellbeing before being driven nutty. She felt the strain of not being able to meet Dave’s expectation of care and inability of him to hear her own need for care.

Stroke initially creates strain in an already busy world. The burden of fitting in care around life’s other on-going priorities is draining. The balancing act is on-going. Jane explains:

The awful thing about today’s society is we get so involved. I’ve got grandchildren. Often I’m looking after them on the days of the week that my daughter works..... It’s just really the practicalities of being able to give sufficient time to friends and still get on with your own life. So that’s just back to a balance I guess. (1, Jane)

A balancing act of continually juggling keeping all the balls in the air is tiring. Duty of care after a stroke is just another ball. Jane explains that society has an expectation of being deeply involved committed to each ball to the point of being awful. Giving sufficient time to and care to everybody you care about is difficult to balance. This creates an environment of potential burnout.

Another example of the burden of care is shown when Deb first hears about the stroke. Responsibilities of work, immediate family, study and duty of care after the stroke can be overwhelming. A perception of failing to meet those responsibilities may bring feelings of guilt or disappointment.

I heard [about Dave’s stroke] either the day or the day after and obviously my natural tendency would be to rush around there. But unfortunately I’ve got three teenage children and my husband also works and I work. I would have liked to have been able to offer more support but it’s pretty much only been phone calls and emails. (1, Deb)
Deb wanted to rush over and help them but was unable because of other commitments. She feels a need to apologies to Ivy because she has only been in phone and email contact. The expectation and desire to do more is a burden, she feels *unfortunate* that she cannot do more because of her family and work.

Strains from duty of care can be both professional and personal. Early on before the stroke Deb seems happy to take on a degree of professional care in helping to get a scooter.

> *In desperation to try and get him out of the house she [Ivy] even tried to get me to write a supporting letter to the Lottery Grants Board so that he could get a mobility scooter. So I did that for them and I gave them all the application forms but the GP didn’t actually support it ‘cause he said that Dave should be walking. So, but I do think that probably the GP should have supported it* (1, Deb)

Deb shows her duty of care early by filling out the applications to get the scooter to help Ivy’s strain of *desperation*. At this time Deb disagrees with the GP as she *supports* Ivy. Deb highlights Ivy’s request for mercy against the GP’s push for fairness and accountability of health. Later this changes.

By six months the stroke experience becomes the new norm for the wider family. The prolonged concern and duty of care becomes tiring. The immediate nature and extra energy put aside for caring becomes pulled away by other now more immediate duties.

> *I am concerned [about Ivy’s own health] and sometimes I feel I almost need time out. That sounds a bit mean but I just backed off just a couple of weeks ago because I had a few problems with a grown up daughter and I just really needed to have just one thing to concentrate on at the time. My work’s lovely and very involved and very busy and I just recognise that there’s a limit to what I can cope with.* (3, Jane)

While Jane is still concerned for Ivy’s health, by six months she feels a need for *time out* away from the duty of care. Other more immediate duties arrive from other areas of her life *daughter, work*. Sometimes the wider family will need to pull away to re-prioritise and recognise *self-limits* in order to fulfil the duty to self of self-care.

Financial strain is a consistent theme throughout the interviews. Instead of reducing the burden the perception is that government departments increase the strain to the stroke family. Balancing mercy and justice is a continual challenge.
About three or four days after his stroke I learned, to my horror, that WINZ will take away his pension if he’s in hospital longer than 14 weeks and everybody was looking surprised because it seems to be a new edict, .............which means that his money goes to the hospital to help for his care and I will go on a single independent benefit and we’ve got a mortgage to pay and I thought my god. (I, Ivy)

“Being on the other side [of the health system] is just no joke ...... The WINZ experience was probably the worst thing that Dave and I experienced as professionals. You're just simply not a human being.” (I, Ivy)

The financial strain is immense, possibly the biggest strain of stroke experience. The strain of potentially losing their home as they still have a ‘mortgage to pay’, when Ivy feels the government has a duty to care to them. The strain is not helped by the perception they were treated like numbers and ‘not human beings’.

Emotional strains become more apparent at six months; Ivy feels that Dave’s personality has changed for the worse. She finds it hard communicating with him as he seems harder and more negative. There is also strain of past experience.

“I think the one thing that I dreaded about the stroke and it happened in the mini stroke in March was the personality change.” (I, Ivy)

“I think the put downs and the dourness of the Scottish personality. I think, yeah, and he gets irritable and grotty. I just couldn’t stand that all day. That’s not him.” (3, Ivy)

Duty of care is tested and strained by personality change. Strain of put downs, irritability and dourness is more than Ivy can stand. Ivy had to look after her father after a stroke as a child. She has first-hand knowledge of how stroke can change someone she loves and how difficult it can be to look after a big heavy man. The idea of taking on the emotional burden of caring day in day out let alone the physical stain is something she dreads.

Given the Nursing Praxis journal guidelines, the amount of findings within the manuscript was restricted by word count. These expanded themes show the amount of work that has been put into developing the themes. They also give greater depth and background to the findings.