A Stroke of Grief and Resilience: A Hermeneutic Enquiry at 2-Years Post-Stroke
**Abstract:**

Stroke is considered “the second leading cause of death worldwide” (Feigin et al., 2014a, p. 245), with an estimated 50,000 stroke survivors in New Zealand (NZ) at present (Feigin, Krishnamurthi, Barber, & Arroll, 2014b, p. 61). The incident of a stroke can be considered “a traumatic life altering event” (Pierce, Thompson, Govoni, & Steiner, 2012, p. 258), with weighted consequences extending beyond the stroke survivor to influence their social network, including their family/whānau (Hunt & Smith, 2004).

The stroke recovery process has been defined or described as three phases, namely acute, rehabilitation and life after stroke (or chronic phase) (Hafsteinsdóttir, Vergunst, Lindeman, & Schuurmans, 2011). During this process stroke survivors are discharged from hospitals to ‘at home care’. The majority of this care is provided by family, friends or whānau, who considered the stroke and return home as “a devastating experience” (Dyall, Feigin, Brown, & Roberts, 2008, p. 188). This expression was attributed to the altered family dynamics (Dyall et al., 2008). The current qualitative study focused on 2-years post-stroke, to explore the experiences of a stroke family along their journey. More specifically it seeks to answer the research question of "What are the lived experiences of family/whānau of a first-time stroke survivor, 2-years after the initial stroke?" The study aimed to investigate the phenomenon of life as a stroke family/whānau at 2-years post-stroke. This included examining the family/whānau’s needs at 2-years and how healthcare professionals might improve the support and outcomes for stroke families. This was achieved through utilizing a hermeneutic phenomenological methodology with in-depth face-to-face interviews and thematic data analysis of interviews at 6-weeks, 1-year and 2-years post-stroke.

The key themes that emerged were 'the shocks of life and death', ‘unconditional devotion’ and ‘continual change’. These demonstrated the immense devotion and resilience demonstrated by the family although they experienced numerous setbacks and shocks. The grief experienced by participants both in anticipation and following the stroke survivor’s death is also explored. The variety of experiences between participants also indicated the need for future research and interventions to better support stroke families.
Acknowledgements:

This thesis is more than just a research project. It has taken many years of preparation and study to achieve the knowledge and skills required to complete such a project. For all those involved along the way I would like to truly thank you for your assistance, time and encouragement.

I would like to thank my research supervisors, Doctor Elizabeth Niven and Sue Gasquoine for their time, knowledgeable guidance and timely correspondence. Without your input this document would not be at the standard I aspired to reach.

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Through my deepest struggles and greatest joys I will lift my eyes to the Lord above, for He is my shelter, my protector and has guided me through this process and I trust will guide me through that which is to come. “To God be the glory forever and ever! Amen” (Gal. 1:5 Good News Translation).
Preface:

This thesis is structured into two sections followed by the appendices. Section one is further divided into two chapters. Of these two chapters, chapter one consists primarily of an introduction to research and the relevant background literature presented in a literature review. Chapter two describes how this research was completed. This includes the processes, methodology and methods that were used. Section two is written in manuscript format, which mimics the article that will be sent for publication in the journal *Age and Ageing*. The appendices include the confirmation of ethical approval for the research, the consent forms, interview guide and supplementary information demonstrating a snapshot of the research process that was conducted.
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Glossary

**Stroke:** Is considered a cerebrovascular accident. It “is a form of acquired brain injury and a major cause of death and disability” (Wolters Gregório, Visser-Meily, Tan, Post, & van Heugten, 2011, p. 188). A stroke occurs when the blood supply to part of the brain is disrupted by an embolism (dislodged blood clot or foreign matter), thrombosis (blood clot) or haemorrhage (ruptured blood vessel). Another definition of stroke is; “a heterogeneous group of disorders involving sudden, focal interruption of cerebral blood flow that causes neurologic deficit” (Beers & Berkow, 2006, p. 1789).

**Transient Ischemic Attack (TIA):** Is also called a mini-stroke. TIA is a stroke that occurs over a shorter period of time (up to 24 hours) with similar symptoms as a stroke, and a shorter recovery time frame. A TIA can also be considered a warning sign for a stroke.

**Aphasia:** Inability or difficulty in the formation (speaking and reading) and comprehension of language resulting from damage to the part of the brain that controls these functions. Types of aphasia include anomic, receptive, expressive and global aphasia.

**Anomic Aphasia:** Trouble accurately recalling and naming objects, places, people or words.

**Receptive Aphasia:** Difficulty comprehending written or spoken language.

**Expressive Aphasia:** Difficulty communicating thoughts via writing or speech.

**Global Aphasia:** Severe or near complete loss of receptive and expressive language function.

**Caregiver:** “The term ‘caregiver’ includes ‘carers’ or ‘informal carers’ and refers to someone who provides support to a partner, spouse, relative, friend or neighbour,
without payment” (Mackenzie & Greenwood, 2012, p. 1415).

**Stroke Survivor:** The individual who suffered a first time stroke.

**Family:** “Family carers were defined as family, friend, or significant other undertaking residential caring duties or non-residential caring duties that required more than minor adjustment of carers’ lifestyles” (Mackenzie et al., 2007, p. 112).

**Whānau:** The Māori term used to refer to extended family, family unit or friends. “It is a diverse unit based upon a common heritage and within this structure certain responsibilities and obligations are expected and maintained” (Corbett, Francis, & Chapman, 2006, p. 256).

**Parent project:** The longitudinal research that includes six smaller studies within Phase Two. The parent project was initiated in 2010 is ongoing and aims to improve support for stroke families/whānau.

**Study:** The section of research conducted by individual researchers (including myself) at set time points, which contribute to the longitudinal parent research project.

**Dependence:** The act or state of relying on something or someone. For example relying on someone for financial assistance or support.

**Independence:** Self-reliance, self-governance, or freedom from someone or something.

**Grief:** The multidimensional response of deep mental anguish or sorrow most commonly experienced following bereavement. The response of grief can include emotional, physical, social, cognitive, behavioural and spiritual elements.
Hemiplegia: Paralysis affecting one side of the body (Marieb & Hoehn, 2007). It can be congenital (since birth) or acquired as a result of a stroke, brain injury or illness.

Hemiparesis: is a lesser form of hemiplegia with partial paralysis or muscular weakness.

Paralysis: Loss or impairment of voluntary and involuntary movement or function and sometimes sensation of a body part as a result of nervous system or spinal cord damage (Marieb & Hoehn, 2007).

Post-stroke: The period of time following the initial stroke.
SECTION ONE

Chapter One: A Literature Review and Research

Rationale

The chapter that follows includes the relevant literature pertaining to this study including the process of literature retrieval and management. The impact and incidence of strokes are also noted as well as the relevant context for stroke caregivers. Furthermore the shortcomings in the literature as well as the support for this study are described.

Literature review:

The literature review that follows explores the literature review procedures, need for further research and current limitations in the literature. It also provides understanding and background information upon which to base later data analysis, findings and discussions. The literature review seeks to provide insight and background surrounding the impact of a first-time stroke on the stroke survivor's family/whānau. Some of the specific subsections of the literature review will cover the impact of stroke, globally and within NZ, on primary caregivers and also the impact and consequences of a stroke. Specific consideration is also given to the longitudinal impact of a stroke to set the scene for the 2-year follow up study. This study set out to answer the question "what are the lived experienced of family/whānau of a first-time stroke survivor, 2-years after the initial stroke?"
Literature search:

Literature searches were conducted to inform the research in the process of investigating the question of 'what are the lived experiences of family/whānau of a first-time stroke survivor, 2-years after the initial stroke?' The literature searches also had a secondary focus on the supportive or informational needs, improvements in communication and coping determinants or abilities of stroke families/whānau at 2-years post-stroke. The literature searches were completed through the use of Unitec and University of Auckland library databases. These included AMED (Alternative medicine), CINAHL: Cumulative Index to Nursing and Allied Health, Cochrane Library, Ebsco health databases, MedlinePlus, Mendeley, Pubmed, Scopus and ScienceDirect. Google scholar was also used to locate articles missed by these databases, or where the full text was difficult to obtain. An abbreviated list of search terms included; stroke, post-stroke, cerebrovascular accident (CVA), experience(s), need(s), information, family/families/whānau, caregiver(s), caregiving, 2-years, mortality, grief, rest home, qualitative, phenomenological, and New Zealand. These were used in alternating combinations to retrieve the required articles/information. From the retrieved articles, selection occurred firstly according to the relevance of the article's title, abstract and keywords. Articles that appeared only slightly useful were set aside to be further reviewed based on the articles content.

Furthermore, because this study is part of a parent research project, the research leader also provided a folder with background literature used to establish the parent project. Inter-researcher communication, informal discussion emails, and a hospital visit assisted in the retrieval of other forms of information including PowerPoint presentations, documents and pamphlets, which provided additional knowledge and information.

Procedure of reviewing the literature:

All articles were reviewed electronically with selected articles being printed for further review and notation. Articles were numbered, catalogued and a summary with key
words was used to summarise the content of the articles. This allowed effective retrieval when necessary.

The impact of stroke:

According to the literature the incident of a stroke can be considered “a traumatic life altering event” (Pierce et al., 2012, p. 258). A stroke also has significant consequences spanning beyond the stroke survivor which affects their social network, including their family/whānau and community (Hunt & Smith, 2004). Depending on the location, type, and severity of the stroke, stroke survivors can suffer a variety of impairments, such as personality changes, aphasia, cognitive impairment, depression, anxiety, and physical disability. These impairments affect not only the stroke survivor, but also their next of kin, friends and caregivers. Specific impairments namely aphasia, paralysis and depression will be explored in greater depth in later sections, in relation to a specific stroke survivor.

The variable nature of a stroke incident also results in varied outcomes and recovery times. For example, a stroke in the temporal lobe may alter the stroke survivor’s hearing, language comprehension and memory, while a stroke in the cerebellum can cause gait, coordination, balance and speed difficulties or disturbances (NeuroAiD, n.d). In an attempt to define the stroke recovery process, three phases are described, namely acute, rehabilitation and life after stroke (or chronic phase) (Hafsteinsdóttir et al., 2011). Of these the acute phase (within six months after discharge) can be divided further into “the stroke crisis, expectations for recovery, and the crisis of discharge” (Lutz, Young, Cox, Martz, & Creasy, 2011, p. 789). If the individual has a second stroke there can be some setbacks and the recovery cycle may start over.

Following the initial stroke, stroke survivors are at ongoing risk of a recurrent stroke or other vascular complications. It was suggested that within the five years following the stroke there is a 25% risk of a ‘recurrent’ stroke (Lawrence, Kerr, Watson, Paton, & Ellis, 2010). The risk and occurrence of a second stroke is noted as being an “independent predictor of disability, institutionalization and death” (Licon, Evangelista, Mastroli, & Whitaker, 2014, p. 109). Due to this increased risk and associated consequences, lifestyle changes are introduced while the stroke survivor is still in hospital to reduce
the risk of a second stroke. These changes can relate to physical activity, alcohol consumption, an unhealthy diet and tobacco use (Lawrence et al., 2010). It was also reported that family members fear the occurrence of a second stroke, thus it is important for them to be well informed of the risk factors, stroke survivor's medications and lifestyle changes recommended (Lawrence & Kinn, 2013). Informational and supportive needs of stroke survivors and their families will be explored in later sections of this literature review.

The incidence of stroke in New Zealand (NZ):

At present stroke is considered “the second leading cause of death worldwide” (Feigin et al., 2014a, p. 245). In NZ it is estimated that there will be roughly 50,000 stroke survivors by 2015 (Feigin et al., 2014b), in an estimated population of over 4,500,000 (Statistics New Zealand, 2014). In addition and contrary to stereotypes these and other strokes do not only affect older people (Stroke Foundation of New Zealand Inc., n.d.-a). It is also worth noting that the majority of the stroke survivors in NZ rely on care and support to some degree (Stroke Foundation of New Zealand Inc., n.d.-b). Thus based on these figures and information the incidence of stroke is of concern locally and globally. Therefore there are ongoing efforts by the government and health organizations such as, the World Health Organization (WHO) to address the incidence and repercussions of a stroke. The WHO contributes numerous documents on stroke, including the global burden, stroke related death, the economic impact and risk factors (World Health Organization, 2013). Yet addressing the stroke dilemma is particularly difficult as the risk of having a stroke is multi-factorial. Some influencing factors are smoking, predisposing medical conditions, obesity, hypertension, diabetes, reduced physical activity, an unhealthy diet and in high-income countries the increasing percentage of elderly people in the population (Norrving & Kissela, 2013).

The incidence of stroke is currently mismatched between high and low-income countries, due to a variety and combination of risk factors. In 2009 it was reported that the incidence of stroke for low and middle-income countries had increased, while the incidence decreased for high income-countries (Feigin et al., 2014a; Feigin, Lawes,
Bennett, Barker-Collo, & Parag, 2009). This is supported by the observed decreased stroke rate in Auckland between 1981-2003 (C. S. Anderson et al., 2005; K. Carter et al., 2006). This trend however, may not be applicable nation-wide as it has been offset by the increased incidence of strokes “in Māori and Pacific people in NZ over the last two decades” (Feigin et al., 2014b, p. 61). A possible contributing factor is the higher incidence of diabetes among Māori and Pacific people aged 40 years or over, compared with Europeans (Joshy et al., 2009).

These ethnic differences are worth considering, as NZ is an ethnically and culturally diverse nation. Additionally such differences have the potential to result in discrepancies, such as the increased stroke data among Pacific and Māori compared to NZ/Europeans (K. Carter et al., 2006). Regardless of the discrepancies, NZ research reported that Māori have the same expectations as other ethnicities following a stroke (Corbett et al., 2006). Nevertheless, Māori stroke survivors and caregivers reported a lack of information, support and education provision, which will be explored in greater depth later. Furthermore the expectations placed onto Māori also differ, for example a study by Corbett et al, (2006) described how some of the hospital staff expected the whānau to take over bathing, toileting, personal care and feeding. Additionally at 12 months post-stroke Māori stroke survivors are three times more likely to be reliant on care and assistance than Pākehā, thus resulting in further discrepancies (Dyall et al., 2008). The combination of these factors and lack of appropriate care within the community, result in decreased service utilization and increased burden for Māori (Corbett et al., 2006). This burden can expand further as the disparities between ethnic groups worsen (K. Carter et al., 2006).

**Caregiving for stroke survivors:**

**Background information:**

For the most part stroke survivors are discharged from hospitals to ‘at home care’, to be cared for by family, friends or whānau. The stroke, coupled with the return home after hospital discharge, was considered “a devastating experience” by caregivers and stroke
survivors as it resulted in altered family dynamics (Dyall et al., 2008, p. 118). One phenomenological study reported that “family members experienced “being-in-the-world” differently” after a stroke (Lawrence & Kinn, 2013, p. 592). Despite the new reality family caregiving did have some positive consequences. For example “family support for stroke survivors result in more effective rehabilitation and may have a buffering effect on future psychosocial problems” (Mackenzie & Greenwood, 2012, p. 1414). Although involving family in rehabilitation improves the stroke survivor’s outcome, health professionals frequently do not involve family members in rehabilitation (Lawrence & Kinn, 2013).

Of note is that there are various structures of stroke care including uni and multi-disciplinary teams (L. N. Smith, Craig, Weir, & McAlpine, 2008). Similarly rehabilitation can vary from conventional rehabilitation, where the majority of care is hospital based, to early supported discharge, where rehabilitation is predominantly home based. At five years post-stroke, early supported discharge resulted in fewer days in hospital care and less resource utilization, compared to conventional rehabilitation (Thorsén, Widén Holmqvist, & von Koch, 2006).

**Caregiving changes over time**

In the acute rehabilitation phase stroke caregivers experience increased responsibility related to caregiving, which in turn has many knock-on effects. Several documented knock-on effects include a reduction in social activity, breakdowns in communication and the deteriorating quality of relationships over time, irrespective of stroke severity (Hunt & Smith, 2004). Increased caregiving demands also resulted in caregivers having to decrease work hours, or stop working, thus resulting in a reduction or loss of income (Dyall et al., 2008). Another consideration is the impact of guilt on caregivers, particularly if they reduce or cease to engage in activities. The activities may be those previously completed with the stroke survivor, or caregivers may feel guilty about leaving the stroke survivor behind or alone (Cao et al., 2010). It is also noted that some caregivers go through a period of trying to establish a balanced life in the presence of fear, guilt and personal freedom or requirements (Bäckström & Sundin, 2009).
Other changes over time and adaptations or alterations occur in the first year post-stroke as an attempt to adapt to a new norm of life (Saban & Hogan, 2012). These authors also reported that female caregivers feel overwhelmed by caregiving and trying to balance personal needs with those of the stroke survivor or household. As Saban and Hogan’s study was conducted at three to 12 months post-stroke some of the feelings may be less prevalent at 2-years. For example at one year post-stroke it was reported that the caregivers no longer felt afraid to leave the stroke survivor at home, thus allowing more time for other needs (Bäckström & Sundin, 2009). For the most part stroke survivors are aware that they are restricting their caregiver. As a result they feel guilty and might forego certain tasks or activities such as rehabilitation that may restrict their spouse or caregiver (Kitzmüller, Asplund, & Häggström, 2012). However not all stroke survivors or spouses are willing to compromise their independence to accommodate the needs or desires of their spouse (Kitzmüller et al., 2012).

Independence and role management also changes with time. For example after a year some family members or caregivers have learnt how to manage their original tasks and those previously completed by the stroke survivor (Lurbe-Puerto, Leandro, & Baumann, 2012). The management of such tasks and learning new tasks allows the process of change to occur in the lives of stroke families and caregivers. These changes may result in improved life satisfaction as the stroke survivors, or their caregivers adapt to life’s new norm (Achten, Visser-Meily, Post, & Schepers, 2012). In spite of the changes, adaptations or new norm, caregivers still experience some levels of stress regarding themselves and the well-being of the stroke survivor (Cecil, Thompson, Parahoo, & McCaughan, 2012; Pierce et al., 2012). It was reported by Lutz et al. (2011) that, although the level of stress may have decreased, in comparison to the acute phase, residual stress, strain and burden may still remain. These could be attributed to the stroke survivor’s initial transition from hospital care to at-home care (Lutz et al., 2011). A possible explanation for the variation between authors reporting improved life satisfaction (Achten et al., 2012) and persistent stress, strain or burden (Lutz et al., 2011) can be attributed to the dynamic journey or process of being a stroke family, resulting in varied experiences. Participant or individual variation also largely
contributes to the variation in findings observed. For example, stroke caregivers’ information and “educational needs varied throughout the course of their caregiving experience” (Washington, Meadows, Elliott, & Koopman, 2011, p. 41).

These preceding changes assisted to inform this study’s observations at 2-years post-stroke and provide context for other observed changes. One such example is the stroke survivor experiencing a seizure and being admitted into a rest home. The literature suggests stroke recovery is a continuum of adapting, coping and establishing a new reality for stroke survivors and their family. This recovery “is a dynamic process that cannot be encapsulated at one timepoint” (Langhorne, Bernhardt, & Kwakkel, 2011, p. 1700). Similarly the continuum keeps going until and potentially even following the death of the stroke survivor.

From the literature reviewed to date there is some variation in mortality rates along with variations between mortality rates of a transient ischemic attack (TIA) and strokes. For example at one year following hospital discharge from a TIA, 150 (5.4%) of 2802 participants had died, with 943 participants also requiring at least one readmission to hospital (Olson et al., 2013). Furthermore at one year post-TIA there is a 12.3% mortality rate (Kleindorfer et al., 2005). A Taiwanese study also indicated that 45.5% of 2129 first time stroke survivors were readmitted to hospital or passed away during the first year post-stroke (Lee et al., 2013). Several studies review acute mortality and one-year post-stroke or TIA morality rates (Andersen, Andersen, & Olsen, 2011; Kleindorfer et al., 2005; Olson et al., 2013), yet no studies have been located noting mortality rates at 2-years post-stroke. This being said one study with 583 participants, who experienced an ischemic stroke reported that 61 patients experienced a recurrent stroke and there were 185 deaths in the group during the 2-years post-stroke (Kolominsky-Rabas, Weber, Gefeller, Neundoerfer, & Heuschmann, 2001). Thus these authors indicate a stroke recurrence rate of between 10-22%.

**The support needs of caregivers**

Informational needs vary between stroke survivors and their caregivers, and also depend on the stroke severity and phase of recovery (Hassan, Mohamed Aljunid, &
In general, both stroke survivors and their caregivers experience a need for education, especially information that is not currently being provided in health care (Hafsteinsdóttir et al., 2011). These unmet needs were also apparent when requiring information to care for older individuals (on average 50 years and over), with chronic health conditions, such as a stroke (Washington et al., 2011). MacIsaac, Harrison and Godfrey (2010), also noted that the needs of stroke caregivers change “as the patient progresses across the continuum” (p. 40) of stroke recovery. This was found to be particularly relevant to stroke survivors and their caregivers when compared to other chronic health conditions (Washington et al., 2011). Additionally the desire and need for increased assistance, support and information was verbalised by Māori stroke survivors, and their caregivers (Dyall et al., 2008).

It was of note that the information and educational desires or requirements of patients does not correspond to the medical staff's perception of patients’ information requirements. Furthermore the views on patient education also differed between nurses and doctors. It was specifically noted that general practitioners (GP) were below average when compared to other medical practitioners for information provision (Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005). Thus there is a need for agreement between medical staff, stroke patients, their families and caregivers, to allow adequate education or information provision (Choi-Kwon et al., 2005). The information that is provided, preferable within twenty four hours, should be “proactive, individualized, understandable, and designed to meet caregivers’ unique needs” (Washington et al., 2011, p. 41). Information in a written format is also preferred (Wachters-Kaufmann et al., 2005). Lawrence et al. (2010), commented that written information was provided for some research participants, yet it was not reemphasized by verbal communication. Moreover the written information may be inappropriate for stroke survivor’s with cognitive impairments or aphasia. It is of utmost importance for medical staff to inform and support family members through the phases of stroke recovery (the stroke trajectory). One method of determining and ensuring family’s needs are met is through completing family assessments post-stroke (Lawrence & Kinn, 2013). For example, if medical staff identify that the stroke survivor has aphasia, the need to involve family members increases. Failure to involve family members and
caregivers in discussions and information provision leads to frustration (Lawrence et al., 2010). In summary it appears that information provision should be better-organized and synchronized to meet stroke family needs (Wachters-Kaufmann et al., 2005).

Along with information needs, stroke families also have a need for support. The major 'supportive' needs reported in Maclsaac et al.’s (2010) literature review were psychological, emotional and informational, with spiritual, practical and physical needs occurring less often. Hassan et al. (2012) indicated that the most sought after information, regardless of the stroke phase, was stroke-related information or physical care information. Other forms of information desired by caregivers included; nutrition, exercises and lifting or moving of stroke survivors (Hafsteinsdóttir et al., 2011). In regards to nutrition there was dietary information provided to stroke survivors with diabetes and dysphagia (Lawrence et al., 2010). Providing sufficient information for stroke family members and caregivers is essential. The reason is that, a lack of information triggers information searches, leading to increased anxiety and burden for exhausted or fatigued caregivers (Mackenzie et al., 2007).

**Caregiver provision of care:**

In general the majority of care for stroke survivors is provided by their spouses, which can result in negative consequences (Visser-Meily et al., 2006) and a clear need for support. It was also noted that “as the caregiver's health decreases, the patient's health and recovery will also likely suffer, leading to permanent placement in an institution” (Lutz et al., 2011, p. 787). Certain negative implications of caregiving may include reduced social interaction, isolation and little time to attend to personal requirements (Lawrence & Kinn, 2013). Psychological and emotional consequences as well as caregiver strain are also key (Wolters Gregório et al., 2011). Despite these negative consequences some of the reported benefits and positive elements of caregiving include; a feeling of fulfilment, improved relationships in regards to closeness and 'togetherness', and appreciating the chance to reassess their caregiving priorities (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Lawrence & Kinn, 2013). One debatable factor influencing the caregiver's positive or negative impact is their ability and strategy of
coping, (namely active or passive), which are influenced by educational level and age (Wolters Gregório et al., 2011). It was noted that younger educated spouse caregivers frequently utilized active coping strategies. In addition spouses who used passive coping styles, in either the acute or chronic phase of stroke rehabilitation, were predicted to demonstrate reduced psychological performance at one year post-stroke. For example holding a family gathering to discuss and determine the future requirements or plans is considered active coping. In contrast denial or avoidance of the situation is considered a form of passive coping.

**The impact of stroke survivor’s age**

The stroke survivor and family member’s age at stroke onset may have an impact on the experiences, recovery and stroke journey. Age of stroke onset is influenced by differences in ethnicity and gender. For instance, Māori tend to be younger than non-Māori when experiencing a stroke. Stroke onset was also documented to occur at a younger age in males than females (Dyall et al., 2008). This results in more female than male caregivers (Saban & Hogan, 2012). Younger females (under 75 year-old) provided the majority of care and took the responsibility for the more taxing caregiving duties such as toileting (Alliance, 2001). The caregiver’s age also makes an impact on the experiences of caregiving, opinions regarding care and informational needs. For instance, returning to employment and parenting were rehabilitation priorities and needs for younger stroke survivors (under 55 year-old) (Lawrence & Kinn, 2013).

Satisfaction in regards to caregiver support during rehabilitation was also reported in another study (Visser-Meily et al., 2005). They remarked that in their results, and contrary to previous studies, there were no variations in age, education or gender with respect to the satisfaction of stroke caregiving spouses. Although coping strategies as identified by Wolters Gregório et al. (2011), and satisfaction are not the same, it may be worth considering if indeed the results by Visser-Meily et al. (2005) are confirmed.

Smith, Gignac, Richardson, and Cameron (2008) reported the following differences in older (over 55 years old) and younger caregivers during the first six-months post-stroke. Younger caregivers require more information, desire more support or care
training, and can be more critical and criticize the healthcare system. Younger stroke survivors were also observed by family members to be recovering from the stroke, although some residual impacts remained. It was also of note that family members had expectations about the stroke survivor’s recovery, particularly for younger stroke survivors. When these expectations were not achieved it enhanced and reinforced the family member’s observation about the stroke’s negative impact. Failure to meet expectations also resulted in family member disappointment and feelings of loss and sadness. Therefore “It is essential that rehabilitation professionals ascertain patients’ and families’ expectations and work together with the family to achieve mutually agreed feasible goals” (Lawrence & Kinn, 2013, p. 193).

In contrast older caregivers focused on maintaining a positive outlook, viewed information as overwhelming at times, and were more likely to recognize positive aspects of healthcare. Regardless of age certain themes emerged. These themes included anxiety about a second stroke, the value of family/friends support, and the achievement of progress on the stroke survivor’s return home (S. D. Smith et al., 2008).

**Shortcomings in the literature:**

To date six articles have been located that relate to the experiences of stroke caregivers at 2-years post-stroke. Therefore it is difficult to draw conclusions using only published literature regarding the lived experiences of stroke caregivers at this point in the stroke trajectory. Additionally all of these articles conducted research on both the stroke survivor and caregiver(s). Four of these articles claimed to be focused on family caregivers, or have a family based approach, yet only primary caregivers had been included (Achten et al., 2012; Baumann, Couffignal, Le Bihan, & Chau, 2012; Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Lurbe-Puerto et al., 2012). One article did include spouses and children, but it was unclear if they were the primary caregiver or not (Kitzmüller et al., 2012). Another article provided a slightly different perspective, as their participants included the stroke survivor and family member of a young stroke survivor (Lawrence & Kinn, 2013). Family member was defined as “a self-identified group of two or more individuals who consider themselves to be a family” (p. 2). Young
stroke survivors were classified as aged between 18 and 55, as had been defined by "previous epidemiological and qualitative" research (Lawrence & Kinn, 2013, p. 2). As a result the participants of this study were not necessarily caregivers. Another aspect limiting the applicability of this study is that it was not longitudinal in nature as stroke survivors were between three to 24 months post-stroke.

The seventh article, which focused on "family caregivers' psychological well-being" (Cameron, Stewart, Streiner, Coyte, & Cheung, 2014, p. 1) reported interviews at intervals of 1, 3, 6, 12, 18 and 24 months post-stroke. These intervals are similar to those of the greater parent research projects within which this research is occurring. This parent research project is titled 'Improving support for families/whānau of clients post-stroke: A longitudinal study' and also conducted interviews at two additional times, namely as soon as possible and at 3-years post-stroke. Furthermore Cameron et al. (2014) include stroke survivor and only one family caregiver as their participants. They also excluded individuals who were unable to speak thus no stroke survivors with aphasia were included. The positive experiences observed by Cameron et al. (2014) may not be applicable to all participants and less so to stroke families who have a stroke survivor with aphasia.

At present there is little published research documenting the impact of a stroke on the family/whānau or the longitudinal changes. Despite the variations and limitations in the literature examined to date, some of the results and findings are still of relevance and importance to this study. The limited quantity of published literature is also an indication of the need of future research. One example of current and future research is the above mentioned parent research project. In summary the parent project ('Improving support for families/whānau of clients post-stroke: A longitudinal study’) is conducting a longitudinal qualitative investigation into the lived experiences of stroke family members or whānau. This wider project includes several researchers who are overseen by the parent project's primary researcher. More details pertaining to the parent project are provided in chapter two.
Support for this research:

There is a disproportionate amount of literature on stroke caregivers in comparison to ample literature on stroke survivors. There is also even less literature directly relating to the family/whānau or friends (Hunt & Smith, 2004). Stroke research has traditionally also focused on the stroke survivor or primary caregiver, not on “family functioning or to involve the entire family in an intervention” (Visser-Meily et al., 2006, p. 1559). This makes the parent research project unique.

In addition, stroke rehabilitation can occur over an extended period of time, as new changes become permanent to form a new way of life. Mackenzie & Greenwood (2012) described the process as “an ongoing appraisal of what the stressor means to that individual and how to respond. These responses may change over time as perceptions of the stressor change and the individual begins to cope” (p. 1413). At 2-years post-stroke some changes have already taken place, including neurological and psychosocial changes. Neurologically and functionally it can take 18-months to recover from a stroke (Lurbe-Puerto et al., 2012). Therefore “two years post-stroke seems an appropriate time to appraise the extent to which the stroke onset has affected individual reactions and family plans for the future” (Lurbe-Puerto et al., 2012, p. 727). Similarly other complications or consequences are also possible. For example during the first year post-stroke the stroke survivor may experience a further stroke, latent effects from the initial stroke, cardiovascular, digestive or respiratory disease requiring hospitalization, or even death (Lee et al., 2013).

Other research articles also confirm the necessity for longitudinal research. For example Hunt and Smith (2004) suggested longitudinally “following carers through the caring trajectory” (p. 1010). Hunt and Smith’s research also supported the use of interpretive phenomenology, as it “captured” the “sense of closeness” experienced within families (p. 1010). Longitudinal measures were also suggested to observe the psychosocial concerns that were apparent in the acute to early rehabilitation phase (Mackenzie et al., 2007). And finally “Longitudinal research is needed to track changes and positive influences on caregiving” as reported in a systematic literature review (Mackenzie & Greenwood,
Based on the current literature it is apparent that longitudinal investigations are required, thus providing support for the current 2-year follow-up study and the parent project.
Chapter Two: Undertaking Research:

Introduction:

The current research study is encapsulated within phase two of a larger parent stroke research project ‘Improving support for families/whānau of clients post-stroke: A longitudinal study’. Phase two is a “longitudinal qualitative study of the experience of becoming and living as a stroke family/whānau” as stated in the parent project’s ethical confirmation of approval. The ethical approval and update are in Appendices A and B respectively, while the participant information sheet, ethical consent form and inclusion flyer are in Appendices C, D and E respectively.

The parent project is divided into three phases spanning from April 2010 to December 2015, with phase two spanning from April 2011 to December 2015. Data collection for the proposed 2-year follow-up research was conducted between September and October 2013, thus allowing data collection at 2-years after the survivor’s first stroke. To minimise confusion the parent project is referred to as the ‘project’ while the current research contribution will be referred to as the ‘study’. Included within phase two are several smaller studies comparable with, or informing this study, including that of Fischer, Roy, and Niven (2014).

The material presented in chapter two includes a description of the research that was conducted. This section will present the research question, aims, objectives, methodology and methods of data collection, management and analysis. Ethical approval, rigour, participant involvement and the use of equipment are also included.

Research question:

What are the lived experiences of family/whānau of a first-time stroke survivor, 2-years after the initial stroke?
Aims and objectives:

The current study consists of two sets of aims and objectives. It has the over-reaching aims and objectives of the parent research project, as well as its own specific aims and objectives predominantly tailored to 2-years post-stroke.

**Aims:**

**Parent Project:**
- To improve support and outcomes for families/whānau of clients following a stroke.

**Current Study:**
- To explore the phenomenon of being and living as a stroke family/whānau at 2-years after a family member’s first-time stroke, and how the phenomenon evolves with time.
- To gain an understanding of the needs of first-time stroke family/whānau at 2-years post-stroke. This includes identifying ways in which healthcare professionals might meet these needs.

**Objectives:**

- **Current Study:**
  - **Primary Objective:**
    - To explore the lived experiences of family/whānau at 2-years post-stroke.
  - **Secondary Objectives:**
    - To collect and analyse data from participants regarding their experiences of being (and living as) a first-time stroke family/whānau.
    - To explore communication
      - Within the stroke family/whānau
      - Between the stroke family/whānau and healthcare professionals or individuals within the community.
    - To identify how stroke families/whānau cope with their circumstances.
    - To investigate to what extent stroke survivor’s age at onset impacts family/whānau
• To investigate changes or adaptations that arose along the continuum of living as a stroke family/whānau.
• To determine the informational needs of research participants and provide information on stroke family/whānau for future research.

**Research methodology:**

The methodology for this research project is hermeneutic phenomenology. The use of hermeneutic phenomenology is congruent with the parent project noted above in this chapter's introduction. Hermeneutic phenomenology was used for both the parent project and within this study, thus ensuring consistency of the methods and subsequent findings. The methodological approach is informed by the work of van Manen (1997). Hermeneutic phenomenology is a type of qualitative research design that "stems from the principles of Husserl" (Hunt & Smith, 2004, p. 1001). Hermeneutic phenomenology is focused on uncovering meaning in lived experiences pertaining to specific phenomena, in this case becoming and living as a stroke family or caregiver. Lived experiences refer to the participants reporting their perceptions and experiences of the phenomenon as they experienced them at the time. To do so they may refer to the past or future, yet the focus is on the present. Patetti (2008) referred to the 1927-1962 work of Martin Heidegger, mentioning that "Human beings, according to Heidegger, are active participants in their own experience, and as such, each of us uncovers our own truth and acquires knowledge specific to our situation" (p. 20). It is these experiences, truths and acquired knowledge that this research project sought to investigate in relation to the phenomenon of being a stroke family/whānau.

According to the phenomenological method, human experiences are considered to be subjective and expressed though the narrative of the participants (Lopez & Willis, 2004). In hermeneutic phenomenological research the “meanings are not always apparent to the participants but can be gleaned from the narratives produced by them” (Lopez & Willis, 2004, p. 728). Hermeneutic phenomenology also acknowledges that individuals have their own context and history that is incorporated into who they are. This context or history influences how each person views the world, or the phenomenon. Similarly
the researcher cannot be separated from their own contextual underpinnings (background or history), which influences the way they view the world, analyse data, or report experiences. In hermeneutic phenomenology it is acceptable for the researcher(s) to be considered inseparable from their personal context, including personal reflections (Laverty, 2008). Each participant and researcher has his or her own individualised context and way to view a phenomenon, or the data pertaining to it. Therefore each study within the parent project is unique and distinct from one another. So even though the same participants are used in different studies, the time periods, participant experiences and researchers’ experiences differ. Each study is thus conducted as an entity/research project in its own right, while informing the parent project.

In this study when considering data analysis preliminary themes emerged through reading, making key notations while analysing the transcripts and through listening to audio-recordings. Revision of the preliminary themes led to integral, finalized themes that the researcher considered to capture the essence of participant’s experiences. Through the course of the analysis, the researcher continuously engaged and reflected on the data to gain an understanding of what was said, what the participants meant by their narratives and what the possible experiences are that contribute to the narratives expressed. Personal reflection and reflection on themes and contexts assisted to gain an understanding of the phenomenon of living as a stroke family at 2-years post-stroke. This process was considered to be consistent with what van Manen (1997) describes as "discovery orientated", thus the researcher is aiming to determine through paying attention to the "subtleties" in the data "what a certain phenomenon means and how it is experienced" (p29).

Husserl suggested what is called 'bracketing' as a way of acknowledging and separating the researcher’s personal context and beliefs from those expressed by the participants (Laverty, 2008). Bracketing of preconceptions to the point where researchers start with a "blank slate" has been suggested to be of less value when conducting experience based health research (Thorne, 2011, p. 446). The reason being that personal judgements are key in acknowledging health requirements or areas requiring further research or investigation. Thus if the researcher is entirely separated or bracketed from the research
and findings the results may not achieve the purpose the research set out to investigate in the first instance. Although it is possible to acknowledge personal context or preconceptions and place them in a bracket as such, in this study the researcher is considered inseparable from their personal context. As a result another approach, namely that suggested by Heidegger was used. Heidegger suggested to make personal bias, beliefs or understandings apparent and thus acknowledge them in the research process and findings. These personal understandings, beliefs and bias were determined through personal investigation, reflection and acknowledging and notating what the researcher considered to be their bias, perceptions, presumptions, beliefs or other assumptions. For example the primary researcher of this study is a naive researcher who conducted the research as a component of her masters of Osteopathy studies. Nevertheless she acknowledged and documented her bias, including medical knowledge, view points and personal experiences with strokes and grief, which may have influenced the research process.

Although not separate as suggested by Husserl, the researcher was able to note their personal context and acknowledge this as a possible influence to the interpretation of the data and findings. This process of acknowledging and making personal bias explicit sought to ensure a truthful representation of the research phenomenon. Representing the phenomenon accurately also required the researcher to be sufficiently informed about the phenomenon, the research process and other relevant aspects. Thus additional reading was undertaken as required. The researcher also had a continual awareness of the ongoing research process and reflected on a regular basis to acknowledge personal bias, beliefs or context. Frequent interactions with research supervisors and fellow researchers from the parent project ensured that the researcher remained grounded within the research process.

In summary to gain information-rich data a qualitative approach was required, which was further specified as hermeneutic phenomenology. Hermeneutic phenomenology was primarily selected as it provided the researcher the opportunity to gain insight into the lived experiences of participants (stroke family members). Secondly hermeneutic phenomenology acknowledged the importance of context, which provides individuality
for each solo study in turn informing the parent project. Thirdly continuous and critical reflection was vital to ensure the experiences of participants were represented accurately. Finally, as little is currently known about the lived experiences of stroke family/whānau at 2-years, an investigational inquiry was vital.

**Research methods:**

**Participants:**

Purposive sampling was conducted in 2011 by the parent project’s research team to obtain participants who were representative of the study phenomenon. Participants were recruited from an Auckland hospital after the admission of a friend, or family member, who was experiencing a first time stroke. The recruitment ensured that the participants were the primary caregiver and any other family or friends who desired to participate. All stroke families recruited to the parent project included at least one family member who was not the primary caregiver. The five participant stroke families consisting of varied participant numbers and backgrounds. The current study includes one stroke family consisted of four members as participants. By chance the purposive sampling did not sample any Māori families. Therefore the data collected may not represent the experiences of Māori families/whānau, but is still of contextual relevance in NZ.

**Equipment and facilities:**

An audio-recorder was used for the interviews, and a transcriptionist for transcribing the audio-recordings. The parent project provided these. The interviews were conducted at the participants’ homes.
Procedures:

Nearing 24 months post-stroke the study participants were contacted by the lead researcher to establish a time for the interview. Subsequently interviews were conducted, recorded and the interviewer (myself) took additional field notes to frame the interview situation for subsequent data analyses. In regards to interview order, P003 and P004 were interviewed together, while P001 and P002 were interviewed together on a subsequent day.

Next the audio-recordings were sent to a paid transcriptionist for (verbatim) transcription. The transcripts were reviewed by the researcher to ensure accuracy. Subsequently the participants were provided the opportunity to view their transcripts and evaluate if their experiences were accurately represented. If participants wished to alter any transcribed information, it would have been possible to do so at this point in time, however the participants opted not to review their transcripts. Once finalised, data analysis commenced as discussed below. Relevant literature was reviewed throughout the research process to enhance the understanding of the phenomenon and inform the findings from the data.

The researcher engaged in verbal and internet based discussions with other qualitative researchers to enhance and solidify the researchers understanding of themes, ideas or other research concepts. These interactions, which included discussing various participant's perspectives, researcher's understandings or alternate interpretations allowed the researcher to gain a broader understanding of the participant's lived experiences, the research process and the emerging theme. Preliminary findings and themes were presented at Unitec research forums on several occasions. Furthermore the researcher was considered sufficiently skilful in the process of qualitative research to deliver a presentation to a research class for second year nursing students. This presentation featured as an introduction to qualitative research and was closely linked to the parent research project.

Formalising the preliminary and then final themes involved a process of engaging with the transcribed and audio data on multiple occasions. While engaging with the data the
researcher underwent a process of reviewing literature, writing various sections of the final thesis and preparing a research article for submission. Continual personal reflection was completed along with journaling as appropriate for hermeneutic phenomenology.

**Methods of data collection and analysis:**

**Data collection:**

Data collection took place at 2-years post-stroke in the form of semi-structured face-to-face in-depth interviews with the research participants. Prior to conducting the interviews the lead researcher of the parent project contacted the participants to ensure they were willing to continue their participation in the research. Once they agreed the primary researcher contacted the family members to arrange an interview date and location. On the set date the primary researcher conducted the interviews with the participants as noted in procedures above.

Both the interviews were audio-recorded and transcribed verbatim. The interviews were guided by an interview schedule, which is provided in Appendix F. The schedule guidelines were derived from previous interviews, current literature, and phenomenological underpinnings such as those of van Manen (1997).

For example van Manen describes that;

*the interview serves very specific purposes: (1) it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding for a human phenomenon, and (2) the interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience.* (p. 66)

The interview schedule provided structure to guide the interviews, while allowing participants the freedom to express what they considered important. The primary researcher provided further interview guidance according to the information provided
by the participants during the interviews. This guidance required active listening and appropriate use of non-verbal communication. Body language was also used to express interest, understanding or relevant emotions such as sympathy or empathy. This is in line with Lawrence and Kinn (2013) - “When adopting a phenomenological stance the principal skill required is the art of listening” (p. 3). Furthermore data collection by means of interviews is in line with hermeneutic phenomenology and elicits information-rich data. It further illuminated the experiences of the participants, and how they experienced the phenomenon of interest.

**Data management:**

The transcriptions and audio-recordings were labelled (named) according to the format already established by the parent project for this group of participants to ensure participant anonymity. The transcripts were printed and the primary researcher listened to the audio recording to ensure familiarity with the data and a "sound understanding of the content" (Eriksson & Tham, 2010, p. 186). On the subsequent occasion the same researcher listened to the recordings while making notations on the printed transcripts. The notations were to establish the essence of the interviews and gain an understanding of the participants' lifeworld (Eriksson & Tham, 2010; van Manen, 1997). On separate occasions the researcher listened to the audio recordings and noted key words on the transcripts. These key words were then entered into index sheets or tables of transcript key words, groups or themes for the researchers benefit, an example of which is provided in Appendix G. It also assisted the primary researcher in establishing the strength of certain groups of text, sub-themes or specific quotes. Themes or sub-themes were also established though the process of developing summary sheets to determine where the groups fit within the sub-themes and the sub-themes within the preliminary themes (Appendices H and I). While listening to the transcripts the researcher also made additional notes (Appendix J). From the preliminary themes the researcher reviewed the raw data, findings and themes in a process of refinement to establish the final themes (Appendix K and L). The process of refinement also involved discussions with the research supervisors and fellow researchers to ensure the interpretation of the data represented the participants' experiences accurately. This is suggested to improve the credibility of the themes or data (Pierce et al., 2012). During
this process the researcher also referred to previously noted comparisons (Appendix M). The process of establishing themes included measuring various aspects that appeared in the phenomenon of being a stroke family against each other to determine the strength of each group or possible theme. The groups or possible themes with enough strength were formalised and shaped into themes or subthemes. The groups or themes that did not appear to represent the phenomenon or that did not have enough strength did not get formalized into the final themes, as Hunt and Smith (2004) advocate. This process is further explained in data analysis below. Furthermore, supervisor assistance was also utilized in this process. Finally the data and transcripts were stored in a safe location and only the primary researcher and research supervisors had access to the data.

**Data analysis:**

The process of data analysis was not static, but rather a dynamic hermeneutic process. This process involved ensuring familiarity with the data, engaging with the data, and personal reflection. Each of these sub-processes and the allocation of data points will be expanded on as follows.

van Manen (1997) answers the question of "why do we need to collect the "data" of other people's experiences?" by saying that we do it because "other people's experiences ... allow us to become more experienced ourselves." (p. 62). To determine the experiences of becoming and living as a stroke family/whānau at 2-years post-stroke this current study utilized and analysed data from the same participants at three points in time (data points). These points in time included interview 1 (conducted as soon as possible following the stroke), interview 4 (at 12-months post-stroke) and in interview 6 (at 24-months post-stroke). Of these data points interview 6 was completed by the primary researcher and the other data points were collected and provided by the parent project. The inclusion of these data points were a part of the original research design, while the parent project's lead researcher determined the precise data points to be used. A brief digression is required to provide additional insight into the parent project and allocation of data points for this study, after which data analysis continues.
**Parent research project and data point allocation:**

The parent project is designed in such a way that there are multiple researchers involved within the wider parent project. Each of these individual researchers are assigned a unique component of research to complete, which is still considered a research project in its own right. To ensure a balanced representation of each stroke family/whānau’s experience at a set point, as well as longitudinally, a research schedule was developed by the lead researcher of the parent project. This pre-determined schedule ensured all interviews were thoroughly explored. The schedule also provided each researcher with a component to research that was still fundamentally connected to the parent project.

This way of assigning researchers individual aspects of the research to complete ensured a wider comparison between various data points within specific participants, between participants and also enabled a longitudinal insight to be gained. For example selecting these three data points ensured a comparison between the family/whānau’s experiences at 6-weeks post-stroke and at yearly intervals. More specifically the data rendered from interview 1 was predominantly related to the immediate future, the shock and implications for the family following the stroke survivor’s stroke. At interview 4 it was apparent that the participants had initiated various coping mechanisms and had progressed into the second phase of the stroke recovery trajectory, namely rehabilitation and potentially into the chronic phase (Hafsteinsdóttir et al., 2011). Both these interviews assist to provide insight for interview 6, as well as demonstrating the longitudinal journey that the family was experiencing.

Returning to data analysis, the final transcripts were read and re-read by the primary researcher to ensure familiarity according to “anthropological tradition of immersion in the data” (Cecil et al., 2012, p. 4). “Rereading is important as new ideas can be generated” (Hunt & Smith, 2004, p. 1002). New ideas were also generated through supplementing re-reading the transcripts with listening to the audio-recordings.
simultaneously. This allowed the researcher to determine tone of voice, emphasis and other sentence structures or grammar that was not apparent through only reading the transcripts. For example the specific use or lack of punctuation could vastly change the way an extract of data can be interpreted. Thus listening to the interviews ensured that the researcher was aware of the silent pauses, non-verbal gestures or emotions that were not noted in the transcripts. Aspects such as these are able to provide the researcher with insight regarding the participant’s experiences and improve data analysis. A key example of auditory assistance and importance was when P004 asked; “[d]o you feel like I’m supporting you?” (T6P4p56). On the transcript it is noted with a “[gasp sound]” prior, yet P004’s genuine realization and concern was not apparent without listening to the audio recording. Throughout the data there are many other examples to demonstrate the importance of utilizing both auditory and written data to establish themes and the participants’ experience of the phenomenon.

Once familiar with the data, thematic analysis occurred according to the iterative model (Ahluwalia et al., 2014). The iterative model requires analysing, testing and redefining over time, in what can be considered a cyclical process. A similar cyclical process has also been described in a study using interpretative (hermeneutic) phenomenological analysis (Hunt & Smith, 2004). The purpose of using this model was because it is excellent at deriving understanding, or themes from the contexts described by participants, including “identify family-centred needs, priorities and associated rehabilitation outcomes” (Lawrence & Kinn, 2013). The particular subcategory of the iterative model was inductive analysis. Inductive analysis was used to “condense raw textual data into a brief, summary format” (Thomas, 2006, p. 237). The point of inductive analysis is to recognize and contextualise core meanings, themes, or essence within the text. Meaning was also derived from the text through isolating statements, key words/phrases that were considered to represent the phenomenon (van Manen, 1997) at each time point. All-in-all the analysis occurred as is consistent with hermeneutic phenomenology, and as guided by the writings of van Manen (1997). To ensure that this phenomenological enquiry represented the participants’ experiences and perceptions (Hunt & Smith, 2004).
Another aspect of the data analysis was that the primary researcher had conducted a literature review prior to initiating the interviews and analysis. This ensured the researcher was sufficiently informed about the background literature of stroke caregivers and families. However in this research the researcher did not "shed all personal knowledge to grasp the essential lived experiences" as is suggested in Husserlian phenomenology (Lopez & Willis, 2004), instead she reflected and noted her personal knowledge in a research journal. Reflection was also apparent during the entire process of analysis. More specifically the researcher continually reflected on the themes, experiences, contexts and personal analysis of the data. These reflections were also completed in the form of journal writing as well as formulating tables. The reflection revolved around personal bias, themes, impressions or the influence of events on the process of analysis. This continual reflection helped to ensure the participants’ experiences of the phenomenon were accurately represented. Reflective practice and reflective writing is also advised by van Manen (1997).

Engaging with the data involved considering and determining what the participants expressed in their interviews. The key words, essence or topic of an extract would be categorized into groups with common meanings. Each of these groups were given a word or phrase as a label for the group of concepts or ideas. The group names were developed or formulated in two ways. They were either derived from the words used by the participants, or the researcher assigned words or phrases that were considered to capture the essence or best described the phenomenon, theme or aspect of discussion in the extract or groups of narrative. The key words or groups of concepts utilized were for the most part similar between the transcripts and reviewed by the researcher when required. These groups then assisted to inform and sculpt the preliminary themes and subthemes, which were formulated into final themes and sub-themes. This process was not possible without engaging with the data. For example when formulating the final themes, data extracts and quotes were used to inform and support the preliminary themes. The researcher also reviewed the data, index cards and transcript summaries to determine if alternative extracts supported the sub-theme, thus adding strength or contradicting the subtheme potentially negating the sub-theme. This process is comparable to another study guided by hermeneutical principles, which considered this
process of reviewing to establish ‘trustworthiness’ (Kitzmüller et al., 2012). The researcher also had to investigate and scrutinize the data to determine the reasons for certain comments and observed difference, both between participants and across interviews.

While engaging with the data the researcher also set aside time to reflect on the research process, data and personal bias. These times of reflection assisted in re-establishing researcher clarity and providing new insights. During these times of reflection there was still an ongoing awareness of the current study and the parts that were evolving. Max van Manen (1997) describes this as a painter preparing their canvas for the image to come (p. 167).

**Rigour:**

Qualitative research has an important role in furthering health research, yet the use of qualitative research is tremendously varied. As a result it is increasingly difficult to assess qualitative research (Ryan-Nicholls & Will, 2009). The assessment is done through readers to determine the rigour of the research presented. Rigour is considered the process or practice of thorough or meticulous examination of the relevant information and data. This process assists readers in determining the quality of the research presented. Two key principles of determining quality in qualitative research were presented by Meyrick (2006), namely systematicity and transparency. In the current study the same structure was followed for data collection, transcription and analysis as utilized within the parent project to ensure systematicity.

Along with systematicity, Lawrence and Kinn (2013) also note that transparency is key in qualitative research. Special emphasis was placed on transparency in phenomenological research to ensure rigour due to the variation in perspectives and context of researchers (Lawrence & Kinn, 2013). In this study the researcher sought to achieve transparency through documenting and reporting personal bias, background and thought processes. The thought processes were more related to the decisions or
interpretations made during data analysis. Some of the data analysis and production of these themes are provided in the Appendix K and L to show example of process.

Another process that can be used to establish rigour in qualitative research is the process of auditing. This refers to the ability of another researcher to be able to follow the process or audit trail laid out by the original researcher and produce similar findings and conclusions (Ryan-Nicholls & Will, 2009). Through a second researcher or external researcher(s) following the audit trail they are able to determine the dependability or strength of the findings and the research process. During the analysis process the researcher wrote about the findings and the supporting research together to ensure that indeed the findings were also supported by published research. An example demonstrating the process of reflecting on quotes and reducing them in size is presented in Appendix M. Once this was satisfactory the findings and supporting research were divided into the findings and the discussion. Separating the findings and the discussion in this fashion enables other researchers to determine when the interpretations are that of the primary researcher. Despite this attempt the researcher was aware and acknowledged that it is impossible in qualitative research “to separate results and interpretation, as the results are by the nature of the research interpretation of the data” (Gadoud, Taylor, & Hussain, 2013).

In addition audit trails have also been indicated as a strategy of credibility in qualitative research to attain rigour (Tobin & Begley, 2004). Credibility is considered comparable to internal validity in quantitative research. It is related to tactics of engaging with the data for extended periods of time, peer-interactions or review and providing audit trails (Tobin & Begley, 2004). To obtain credibility the primary researcher followed these recommendations and frequently interacted with other researchers and supervisors from the parent project. During the process of formalising the findings and discussion the researcher also remained alert to ensure the data was represented accurately.
Ethical concerns and approval in research:

Ethical conduct and approval are essential elements for all research, including this study. Ethical approval for this study was achieved through the parent research project. The reasons for this was because this study is incorporated into phase two of the parent research project. The approval was given by the Northern X Ethics Committee and Unitec Research Ethics Committee and is attached in Appendix A and B. The information sheet and consent form are also attached in Appendix C and D.

Additional ethical considerations and actions were taken throughout the study according to good ethical practice. These include obtaining participants consent prior to conducting the interviews, allowing participants the opportunity to review the transcripts for accurate representation, security and anonymity of the data. Additionally participant withdrawal could occur in two ways. Firstly, participants withdrawing from the study, remains an option at any time with no explanation required, yet their interview information does not get withdrawn unless they withdraw within two weeks after receiving their transcribed interviews transcripts. Prior to initiating the interviews the researcher re-affirmed verbal consent and thanked the participants for their time and participation following the interviews. During the interviews the researcher placed the recorder in a visible location and notified the participants when it started and stopped recording.

Dissemination of results will also be conducted in an ethical manner so as to not disclose the identity of the participants. This included anonymising participant names, locations and other identifiable details. Furthermore, participants will be contacted following the completion of this study, or publication of articles to provide them with a copy of the final findings or articles.
Researcher bias and background:

The primary researcher’s personal background and researcher bias includes family values, religious views, education knowledge, personal experiences and character. Although these potential biases are present each researcher has their own set of beliefs, background and opinion from which they view the world and analyse data. (Van Manen (1997) describe these as an individual’s context.) Through acknowledging these aspects it was possible to conduct analysis with the continual aim of remaining impartial. Acknowledging personal bias allows researchers to separate their personal experiences, bias and knowledge from the participant’s. Personal questioning occurred on multiple occasions to ensure the findings or analysis was grounded in the data.

Research limitations:

One limitation of this study was that the sample population was of limited size and consisted of only one family. This is appropriate, however, for in-depth qualitative research, and was deemed acceptable as the in depth analysis occurred over three data points. Another obstacle was the death of the stroke survivor, yet this did not influence data collection or analysis as the family member participants wished to continue their involvement with the project.

Conclusion:

'Section One' above provides an introduction to the research including the relevant supporting literature. It assists in framing the importance of research on and for stroke families or whānau. The process of undertaking research also assists to provide an understanding of the aims, process and methods of the research. In 'Section Two' the manuscript is presented, which includes the findings and discussion from the data collected.
References:


Lawrence, M., & Kinn, S. (2013). Needs, priorities, and desired rehabilitation outcomes of family members of young adults who have had a stroke: findings from a phenomenological


A Stroke of Grief and Resilience  

Maria Engelbrecht


SECTION TWO:

Manuscript:

To maintain consistency within the entire thesis the references in this manuscript have been completed according to the 6th version of APA referencing. Similarly in the manuscript the line spacing is set at one and a half spacing instead of double spacing as recommended in *Age and Ageing*. For the purpose of marking by the examiners the quote details providing the specific transcript (T), participant (P) and page (p) information are included. These will be removed for publication. Likewise prior to publication the researcher will ensure the word count and references are according to guidelines. See Appendix N for the manuscript instructions for authors.

In the manuscript the abbreviation/term SS is used for the stroke survivor. When SS is preceded by 'the' it means 'the stroke survivor', while when SS is used in isolation it refers to the stroke survivor as a person.
A Stroke of Grief and Resilience: A Hermeneutic Enquiry at 2-Years Post-Stroke

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A Stroke of Grief and Resilience: A Hermeneutic Enquiry at 2-Years Post-Stroke

Abstract:

**Background:** A stroke is a cerebrovascular accident which can have significant consequences for the stroke survivor, their family and friends producing altered life experiences and responsibilities.

**Objective:** The primary objective of this study was to explore the lived experiences of a family at 2-years after a first- time stroke.

**Design:** This study is encapsulated within a larger parent stroke research project 'Improving support for families/whānau of clients post-stroke: A longitudinal study'. The utilized methodology was hermeneutic phenomenology, informed by the works of van Manen (1997).

**Participants:** The four participants were recruited in 2011 by the parent project through purposive sampling from an Auckland hospital. The participants included the spouse of the stroke survivor (SS), two of their children and the partner of one of their children. These participants included the primary caregiver and were considered to represent the study phenomenon.

**Methods:** Thematic analysis was completed from three data points. Semi-structured interviews with all participants were completed as soon as possible following the stroke and at 1 and 2-years post-stroke.

**Results:** The key themes were ‘the shocks of life and death’, ‘unconditional devotion’ and ‘continual change’. These represent the devotion, grief and resilience demonstrated or experienced by the family along their journey as a stroke family.

**Conclusions:** This research highlights the lived experiences of a stroke family 2-years post-stroke and offers recommendations for future research and medical practice. This research recommends increased verbal and written communication between healthcare professionals and stroke families to improve service provision for stroke families.
Key words: Stroke, family, 2-years post-stroke, resilience

Introduction:

Stroke is a cerebrovascular accident, which has a tremendous impact on the stroke victim, their family and community (Hunt & Smith, 2004). Stroke survivors are also at an ongoing risk of a recurrent stroke or other vascular complications (Lawrence et al., 2010). The stroke survivor's care is predominantly the family or friends responsibility when stroke survivors are receiving 'at home care'. The stroke, coupled with the return home, was considered “a devastating experience” (Dyall et al., 2008, p. 188), and consequently “family members experienced 'being-in-the-world' differently” (Lawrence & Kinn, 2013, p. 592). Furthermore, Saban and Hogan (2012), note that the majority of adaptations and alterations occur in the first year post-stroke to adapt to a new norm of life. Therefore this study investigated the lived experiences at 2-years post-stroke.

Research Methods:

Methodology:

The methodological approach utilized was hermeneutic phenomenology informed by van Manen (1997). Hermeneutic phenomenology is a qualitative approach focused on uncovering meaning in lived experiences pertaining to specific phenomena, in this case, becoming and living as a first-time stroke family or caregiver. This approach was used to gain information rich data for analysis. Hermeneutic phenomenology provides researchers the opportunity to gain insight into the lived experiences of participants and acknowledged the importance of context and individuality. An investigational inquiry into the lived experiences of stroke family at 2-years post-stroke is also supported by hermeneutic phenomenology.
Participants:

Since this study is included within a larger parent stroke research project the participants had already been recruited. This was done through purposive sampling from an Auckland hospital in 2011. The participants consisted of four family members (P001-4), including the primary caregiver of a first-time stroke survivor, and were considered to represent the study phenomenon. In this case the participants were the husband of the stroke survivor, her son and daughter and her daughter’s partner. Each of these individuals had a role that they completed and represented within the family. These roles contributed to the variations in their opinions and experiences of the stroke survivor’s stroke and the life that followed.

Data collection:

Data collection took place as soon as possible following the stroke (interview 1), at 1-year post-stroke (interview 4) and at 2-years post-stroke (interview 6). The research assistant completed interview 1 and 4, while the primary researcher conducted interview 6. The interviews were in the form of semi-structured face-to-face in-depth interviews with the research participants. The first interview occurred in the study hospital and subsequent interviews occurred at the participants’ homes. All interviews were guided by an interview schedule, audio-recorded and transcribed verbatim. Transcripts were checked for accuracy, anonymised and participants were provided the opportunity to review their transcripts.

Data analysis:

Thematic data analysis occurred according to the iterative model (Ahluwalia et al., 2014). The particular subcategory of the iterative model was inductive analysis, which was used to “condense raw textual data into a brief, summary format” (Thomas, 2006, p. 237) and contextualise core meanings, themes, or essence within the text. The process of analysis involved ensuring familiarity with the data, engaging with the data and personal reflection. The data analysed included interview 1, 4 and 6, thus providing longitudinal insight into the phenomenon. The overall thematic inductive analysis was conducted in a
manner that is consistent with hermeneutic phenomenology, and was guided by van Manen’s approach (1997).

Ethics:

Ethical approval for this study was achieved through the parent research project via the Northern X Ethics Committee and Unitec Research Ethics Committee. (Reference number NTX/11/EXP/062). Participant consent was also attained in verbal and written format.

Funding: The funding for the transcriptionist was provided by the Unitec Institute of Technology Strategic Research Fund.

Findings:

The three prominent themes representing the participants' experiences at 2-years post-stroke are ‘the shocks of life and death’, ‘unconditional devotion’ and ‘continual change’. These are described below and a diagrammatic representation of the stroke family’s journey is available in Figure 1.

The shocks of life and death:

During the two years since the stroke survivor’s (SS) stroke the participants experienced numerous shocks. Specifically there were three focal shocks which related to the initial shock of the stroke, SS having a seizure and finally her death. Each of these incidents shared some similarities such as fright, panic, uncertainties, distress and making difficult decisions.
The initial impact of the stroke created numerous health changes for the SS as well as her family. For example the SS experienced aphasia, right-sided (dominant side) hemiplegia and some probable personality changes. For this and the subsequent shocks the participants described feelings of getting “a bit of a fright ... panic” (T1P002p2) and feeling “numb” (T1P004p2). They also noted that, “you just don’t know what to expect really.” (T1P003p1).

In the presence of shock the participants experienced uncertainty, such as; “how are we going to manage or how will we get on” (T1P001p19). Even amidst these questions and uncertainty the family continued to demonstrate underlying hope and possibly confidence in their capabilities to provide care. For example P001 (the SS' husband) remarked that; “I sort of think if I can manage alright... We’ll probably get through it alright” (T1P001p19). Furthermore the participants attempted to remain optimistic and realized the importance of family. They also implemented coping strategies such as staying positive as expressed by the SS’ son (P002);

“... it’s fair to say it’s been tough but we’re pretty lucky that we’ve got a family that’s really supportive. ... I’ll make sure we do keep positive and focused...” (T1P002p28).

Following SS’ stroke the family decided that they wanted her at home once discharged from hospital. However following her seizure (which occurred just prior to 18-months post-stroke) a unanimous decision was made to place SS into a rest home. This decision was made based on the information known to the participants at the time, which was that the seizure was caused by a urinary tract infection (UTI).

Nevertheless, with time some of the participants regretted their decision,

“... had we known that the seizure with mum was only a one off due to a UTI we would never had put mum into a rest home. We would have taken mum home again...” (T6P003p1-2).

Furthermore this regret about having “made this huge wrong decision.” (T6P003p14) left the SS' daughter (P003) and her partner (P004) with significant emotional distress. This was exacerbated by the deterioration of SS' health once in the rest home.

“So we were totally stuck. We couldn’t just bring her home. So ... that was frustrating, it was horrible.” (T6P004p5).
Although the decision was made unanimously the variation in perspectives left P003 and P004 with distress, while P002 considered their decision to be appropriate. These variations are a characteristic of human nature and a result of differences in participants’ experiences. These variations in characteristics may be of value for healthcare practitioners to note and advise families accordingly.

The abovementioned regret may have worsened with the third shock of SS’ death. Her death created varied experiences of shock ranging from P002 who potentially anticipated her death “... she wanted to give up...” (T6P002p10), to P003 who did not expect the death “... I actually thought mum would live for a long, long time...” (T6P003p30). Overall the family experienced the SS’ death as a “bizarre ending” (T6P002p32). This was potentially because the rest home staff did not meet the level of care and information provision expected by the participants. The discrepancy was so considerable the family saw it as negligence and responded by giving direct care to her themselves to supplement the care.

More than a week prior to her death SS refused to eat, thus she required oral supplements and assistance eating. She also indicated that she was experiencing pain through tapping her stomach region. On the day of SS’ death, P003 went to visit her and observed her mother’s neglect first hand. When she entered SS’ room her mother had been left unattended “lying in her bed ... just covered in vomit” (T6P003p20). The circumstances worsened when, following hours of waiting, the doctor had not yet attended to SS. Furthermore the family were informed by the rest home staff that they were not permitted to call an ambulance.

“... [S]o you can’t ring an ambulance, the doctor will be here when he will be here and your mother just, she’ll be fine,” (T6P003p21).

When the family eventually rang an ambulance in spite of the advice given it was too late and SS passed away shortly after her arrival at hospital. Thus SS’ death and the surrounding circumstances created a ‘bizarre’ experience and “... quite a shock” (T6P003p29-30). Moreover the theme of “the shocks of life and death” provides the context to understand the themes to follow. It also illustrates a component of what a stroke family might experience during the 2-years post-stroke.
Unconditional devotion:

The second key theme was ‘unconditional devotion’, with the most apparent example being when the SS transitioned from home-based care to rest home care. To demonstrate the two components of this theme the subthemes ‘transition from devotion to realization’ and ‘devoted until the end’ will be used.

Transition from devotion to realization:

This subtheme relates to the research participants’ experiences of change and transition brought about by the SS’ placement into a rest home. Following her stroke SS experienced some health related impairments requiring rehabilitation, which continued when she was discharged to home-based care. While at home the family continued to cater for SS’ needs with some external assistance and support, such as a speech therapist. Thus when SS was moved into rest home care it represented a turning point in the family’s journey as SS’ care requirements exceeded the family’s capabilities.

The magnitude of the transition becomes apparent when considering the participants’ previous determination not to place SS into a rest home; “We want her home and we’ll do what we can, what’s humanly possible.” (T1P002p12). However following SS’ seizures the family realized that home care was no longer a viable option. “… We had to say look, we can’t care for her at home, … I mean we’ve got to be realistic …” (T6P2p33). These extracts indicated the family’s transition and the “big decision to put [SS] into a home…” (T6P003p5) and partially relinquish care to the rest home. These or similar transitions and realizations may also be apparent in other stroke families.
Devoted until the end:

The devotion displayed in this stroke family was apparent throughout the entire journey, even until or surpassing SS’ death. This was evident through the participants visiting SS almost every day while she was in hospital, at home or in the rest home. They also brought her food, planned activities or day trips for her, did her washing and attempted to get her the care she required. In addition, their roles and responsibilities as family members or caregivers were connected to SS’ requirements and her place of residence. For example when SS went into the rest home the family “put [their] faith into them [the rest home]…. You would look after nana…” (T6P004p38). The rest home also encouraged the family to assume the role of visiting family rather than caretakers, indicating “… they didn’t want [P003] showering nana anymore…” (T6P004p16). Unfortunately for the family the level of rest home care was, in their opinions, inadequate and unsatisfactory compared to the care they provided at home. “[A]s time went on things were just not being done properly…” (T6P003p1-2). This mismatch of family expectations and the reality of care received, created considerable tension between the rest home staff and the family. Despite the tension, the family demonstrated their devotion to the SS through deciding to forego their roles as strictly visiting family. For example when SS refused to eat “… dad was taking baby food up there … and he’s spoon feeding her baby food and she’d spit it out…” (T6P003p19). This extract indicates that even though the SS was placed in rest home care, there was still a considerable amount of love, care and devotion from the family. The devotion also extended between the participants as the family tried to support each other and P001 following SS’ death. “… I feel sorry for him. I think oh, have a beer with him.” (T4P003p23). Overall this devotion surpassed personal differences in opinions or personalities, the difficulties faced and was present throughout SS’ life and following her death.
Continual change:

The final theme, ‘continual change’ alludes to the continuous change experienced or encountered by the stroke family on their journey. These changes included several obstacles or facilitators of change along the way, to which the family attempted to adapt. The change, as well as the ability to adapt, is important with regards to the concept of resilience (explored in the discussion).

After the stroke, the family remarked that “[e]verything in our life has changed completely” (T1P003p2), and continued to change. As a result the family had to restructure their lives to accommodate their new roles, responsibilities and adapt to their lives as a stroke family. This included both sets of participants expressing the need “…to make sure you have time out…” (T2P003p5). It is vital for healthcare professionals to acknowledge and advise or encourage family members and caregivers to take some “time out…” (T2P003p5) to ensure their own well being and that of the SS. Furthermore the participants also mentioned that there is a “…good bit of hope there and I think there’s a little routine developing now.” (T1P002p2). This hope was vital to adapt and assisted the family to look ahead, rather than being hindered by the change.

“…[T]he main things are just trying to plan the next day, thinking be sensible, … try to get back to as normal as possible. …” (T1P002p5).

This extract, within the first interview, indicates the realization that life has changed and the participants’ need or desire to restore life to a new normal. It also partially indicates the process of adapting or indicates the start of resilience. Around 18-months post-stroke new routines had been developed and mastered by the participants. For P003 and P004 this provided a sense of freedom gained, which was previously difficult or near impossible to achieve without adapting. For P003 this newfound freedom was paired with the guilt of temporarily abandoning her mother or that she “hadn't seen her [SS] for one day.” (T6P003p17). A possible method of reducing such feeling of guilt, might be through healthcare professionals advising stroke families of the common experiences of other stroke families. For example, mentioning that developing or implementing new routines can assist the process of adapting to the change, potentially
lessen perceived burdens of care, or that guilt is a normal emotion or experience in regards to leaving the SS alone or being unable to provide care at all times. It is vital that both healthcare professionals and families are aware of potential and common foreseeable changes or obstacles.

Although the participants transitioned and adapted to life as a stroke family their lives changed once again when SS had a seizure. This change pre-empted the process of re-adapting, seeking external assistance, through placing the SS in a rest home and consequently modifying the participants’ responsibilities, roles and routines. “… [I]t became like a routine again I guess…” (T6P003p17). However the process of adapting was not always easy. Particularly P003 “didn’t know what to do” (T6P004p16) temporarily when her role and routine changed when SS was in rest home care.

At approximately 21-months post-stroke SS died causing yet another change with varied implications for the participants. For example P001’s routine “stopped” (T6P003p54) leaving him wondering, “what do I do with my day?” (T6P003p54). P001 struggled to adjust his daily routines as SS’ death had left him without a needed routine and daily activities. Struck with grief, P001 was no longer willing to actively engage in activities or hobbies as he had done before SS’ stroke or death. Similarly, P003’s life had also become stilted by grief and feeling “unmotivated” (T6P003p67).

This final change incorporated the taxing process of adjusting to the loss and grief. Some facets of this adjustment includes; holding on to the loved one or their memories, while also realizing that they are indeed gone and life must continue. Although all the participants mourned for SS, “we all miss her” (T6P003p53) their experiences of grief and SS’ death varied. These variations in experiences and opinions indicate the complexity and diversity of experiences of loss and grief. For P002 SS’ death was in some regards “a relief... [because he] … couldn’t see her suffer” (T6P002p21). For others this was not the case. These variations in grief are an area where healthcare professionals can intervene to offer advice, support or other needed grief services for families who would benefit from such support.
Despite the variations in experiences it was possible to observe how the family started to adapt even if the experience of losing the SS was “...still really fresh” (T6P004p65). For the most part they were trying to move forward with their lives, to establish new routines or to support each other to establish new routines. This continuous need to adapt and continue with their lives, can be considered both coping and resilience. Contrary to comments such as “[t]here’s no real time limit on grief; ...” (T6P003p65) the participants did demonstrate signs of moving towards a new life where the SS was no longer physically present.

The findings above summarise this longitudinal investigation into the experiences of this stroke family over the 2-years post stroke. It includes the three key themes, namely ‘the shocks of life and death’, ‘unconditional devotion’ and ‘continual change’. All of these components fit together to describe their experiences and what life as a stroke family may be like. These themes will be discussed in the light of the surrounding literature.

**Discussion:**

The three themes noted in this study were considered to articulate the participants’ experiences. These themes were intertwined and apparent throughout the entire journey of being a stroke family. For example, the family would experience a shock, such as the SS’ stroke, seizure or death and subsequently demonstrate remarkable resilience to adapt to the new changes, while remaining devoted to the SS and each other. Following the SS’ death and while still grieving the participants demonstrated different degrees of resilience. These variations appeared to correspond to findings that resilience is associated with better quality of life and reduced depressive symptoms (Ott, Lueger, Kelber, & Prigerson, 2007).

During their stroke journey the stroke family transitioned through the three phases of stroke recovery: acute; rehabilitation; and life after stroke (or chronic phase) (Hafsteinsdóttir et al., 2011). Of these the acute phase has been further categorized to
capture the experiences of family members or stroke survivors (Lutz, Young, Cox, Martz, & Creasy, 2011). Similarly the various points of crisis along the journey (Lutz et al., 2011) and the importance of spouses in stroke rehabilitation has also been noted (Visser-Meily et al., 2006).

In addition to these three phases this stroke family also experienced what the researcher considered to be a 4th phase, namely ‘life without the stroke survivor’. This phase extended beyond the previously defined phases and in this case represented the ending or final phase of the participants’ recovery process. Furthermore, this phase required the family to adapt anew to the changes in their lives. This phase is likely to be explored by subsequent interviews and research conducted by the parent project, including what the participants’ experiences are at 3-years post-stroke.

The three influential experiences of shock had an undeniable impact on the participants’ lives (Bäckström & Sundin, 2009). For this family the first shock, SS’ stroke, resembled what has been described as “losing a life once lived” (Fischer et al., 2014, p. 7). The participants had to manage the initial shock and then start to adapt to the new life that was ahead of them. This process of adapting was unique for each person due to their personalised background, which subsequently influences the way they experience and perceive the world around them (van Manen, 1997). The influence of personal background on each participant’s experience of shock and loss was apparent in this and other stroke families (Fischer et al., 2014).

Another consideration is the information and support received by stroke families, as this is considered to differ in Europe (Bhalla, Grieve, Tilling, Rudd, & Wolfe, 2004) and potentially in New Zealand. Support is of particular relevance as emotional support has been suggested to assist individuals when they attempt to return to a point of balance following a crisis (Joseph, Williams, & Yule, 1997) such as a stroke. In this study during the acute and rehabilitation phase the family received assistance and information from various individuals and organizations. Despite recommendations pertaining to online or in-person support groups (Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007), the
participants did not appear to utilize such services. This may have been related to the participants’ ages or personalities. Instead, the participants suggested that it would have been useful to receive advice from other stroke families who had personally been through some of the struggles. This may be because the participants considered the advice given by healthcare professionals to be less applicable to their experiences. Information and support should be customized to the family’s circumstances according to their individual needs and desires (Hafsteinsdóttir et al., 2011). This can be achieved through communicating with the family to ascertain their needs and desires. Providing appropriate information may reduce the lack of preparation described by family caregivers following an initial stroke (Lutz et al., 2011) or subsequent health-related events. Suitable information was also indicated to inform and help family or stroke survivors make decisions (S. Anderson & Marlett, 2004; Baumann et al., 2012). In this study, participants valued and appreciated the stroke pamphlets and brochures provided in the hospital stroke ward. These pamphlets and brochures informed and satisfied the participants’ need for information, as well as provided them with a means of explaining to children or grandchildren what a stroke is. In contrast, verbal communication from healthcare practitioners often left the participants confused, frustrated or feeling that they were not sufficiently informed. This was particularly true for P003 and P004 who were not what they considered fully informed in their decision to place SS into a rest home.

When an individual experiences a stroke, it has significant consequences for their family, especially if they assume the role of caregiver (Hunt & Smith, 2004). Therefore, it is important to know both the positive and negative implications of caregiving. Some of these implications are apparent in the participants and include distress, altered relationships, love and devotion. Both love and devotion are considered positive features of caregiving (Mackenzie & Greenwood, 2012), with hermeneutic analysis indicating that “Willingness to take on the responsibility of caregiving originates in love” (Erlingsson, Magnusson, & Hanson, 2012, p. 645). Improved relationships and feeling “closer” (T1P002p5) was apparent in this study and has been investigated (Lurbe-Puerto et al., 2012) and reported by other studies (Mackenzie & Greenwood, 2012). In addition, when the children of a stroke survivor are not required to assume care, they report
closer relationships (Kitzmüller et al., 2012). Mackenzie and Greenwood (2012) observed in three studies, spanning six weeks to a year post-stroke, that caregivers report more positive benefits with time. This may hold true for the current study.

There are also negative features or consequences of caregiving, which, to some extent may be increased in primary caregivers. The primary caregiver was SS’ husband who was required, with the assistance of P003, to provide an almost all-inclusive level of care (Visser-Meily et al., 2006). The literature suggests that some of the negative implications of caregiving include; isolation, limited personal time, reduced social interaction, burden, distress, caregiver strain, as well as psychological and emotional consequences (Lawrence & Kinn, 2013; Losada et al., 2010; Wolters Gregório et al., 2011). In particular, caring for older persons can be connected to caregivers experiencing physical and psychological problems (Losada et al., 2010). This may to some extent explain comments by the participants pertaining to P001’s blood pressure and changes in his behaviour following a holiday. Although it is difficult to determine for certain if these participants gained satisfaction from caring they did not cease to provide care (L. N. Smith et al., 2004). This continuation of care demonstrated the participants’ devotion.

Providing support is essential, especially considering the unexpected and variable impact of a stroke and the unpredictable nature of tasks family caregivers are required to master (Gosman-Hedström & Dahlin-Ivanoff, 2012). The study participants’ caregiving tasks continued to change as their lives did, thus requiring a continual process of adapting their lives. In some regards this can be considered resilience, which is “a constant and positive adaptive trait” that is “a basic part of our healthy psychological makeup and is needed throughout the life span” (Boss, 2006, p. 27). It was also possible to observe resilience prior to the SS’ death in both the family’s ability to adapt and by the hope that they held onto that the SS would recover or survive. Moreover “When loved ones go missing physically or psychologically,” as may be the case with a stroke, the individuals sometimes get halted by the “hope that the missing will come back or recover” (Boss, 2006, p. 27).

When the SS died the family members were left with various experiences of grief, while attempting to adapt again to the ‘shock’. Among the participants there were three
different descriptions of grief. One of the participants (P002) appeared to be adapting reasonably well to the impact of SS’ death. A plausible reason for this may be that he considered his mother to have become a different person since the stroke and thus had been experiencing anticipatory grief (Doka, 2014) prior to her death. P002 also sought comfort in the thought that his mother was in a better place. This is one method for bereaved individuals to cope with the loss and emotional pain. Other coping strategies include both active and passive coping strategies of which passive coping is more common in the chronic recovery phase, but is considered dysfunctional (Wolters Gregório et al., 2011). As mentioned previously, when healthcare professionals observe that a family/whānau is not coping sufficiently appropriate support services should be provided or implemented.

In contrast P004 still considered the SS to be a part of her and P003’s lives and would greet SS’ photo, “good morning nana”. (T6P004p36). Such behaviour can be considered a part of the grieving process and a way of keeping the SS or her memory present in P004’s life or mind (Boss, 2006). Similarly talking about the deceased love one can also have significant therapeutic implications for the bereaved (Worden, 2008). Thus therapeutic interventions such as grief therapy or counselling may be of value to some bereaved stroke family members.

When SS died her husband (P001) and daughter (P003) struggled to continue with their lives due to grief. For example a part of P003’s “grieving process” (T6P004p67) involved her feeling “unmotivated” (T6P003p67) with tasks she usually enjoyed, such as gardening. It brought P001’s life to a standstill resulting in directionless passivity or inactivity. When trying to understand grief and loss, it is important to establish whether or not the deceased is considered a part of the bereaved individual’s psychological family, namely individuals whom the participant perceives as family (Boss, 2006). Furthermore, it is important to grasp that most individuals consider it challenging to cope with the reduction or loss of intellectual or meaningful interactions with the SS (Bäckström & Sundin, 2010; Gosman-Hedström & Dahlin-Ivanoff, 2012).
Finally as is apparent this process of adapting was not instant, but rather occurred over a period of time, like a transition (Joseph et al., 1997). This is supported by Boss (2006) who notes that resilience is defined as the ability to bounce back to a level of functioning equal to or greater than before the crisis” (p. 48). Amidst grief this process of resilience may take varied time frames, as supported by the participants “[t]here’s no real time limit on grief…” (T6P003p65) and Walter (2007) who suggested that “there should be no norms for grief” (p. 123).

Similar to other research (Bastawrous, Gignac, Kapral, & Cameron, 2014) P003 experienced additional strain such as reductions in leisure or personal respite, by assuming a caregiving role. She did not however, demonstrate the difficulty or challenges in the relationship with her partner noted by (Bastawrous et al., 2015). A possible reason for additional strain could be because caregiving has traditionally been the role of females, yet with increasing financial demands women have assumed other roles in the workforce, thus becoming “overburdened by conflicting physical and emotional demands” (E. A. Carter & McGoldrick, 1989, p. 319). Caring for a parent following a stroke can also result in restricted or reduced employment (Bastawrous et al., 2015).

**Recommendations:**

To assist with the abovementioned burdens and other stroke family needs it would be of value to complete further longitudinal research on stroke families, including the primary caregiver, as also recommended by Hunt and Smith (2004). Health interventions or support services should be provided for stroke families in the various phases of the stroke recovery process and be personalized to their circumstances (Hafsteinsdóttir et al., 2011). For example health professionals should communicate with stroke families or whānau to determine how they are coping, what their needs are and what they would consider of benefit to their situation. This is vital to ensure efficacy of care and efficient use of services, especially considering that medical staff have a different perception of the information and educational desires or requirements of patients (Wachters-Kaufmann et al., 2005). Therefore verbal communication from healthcare professionals,
particularly when pertaining to the SS’ health or other medical discussions, should be supplemented with the provision of written information. Furthermore, this particular stroke family would have valued interaction with other stroke families and discussions to share advice or experiences. Finally it would be of value to communicate with families/whānau' on a regular basis to allow the tailoring of service provision to the individual family/whānau's needs.

**Conclusion:**

This research thesis sought to answer the question ‘what are the lived experiences of family of a first-time stroke survivor, 2-years after the initial stroke?’ From the participants' interview data three key themes emerged, namely ‘the shocks of life and death’, ‘unconditional devotion’ and ‘continual change’. These themes indicated the resilience demonstrated by the family even while they experienced times of uncertainty or grief. This research has rendered additional in-depth information to assist future research or healthcare professionals. Finally this research may benefit other stroke families as it indicates possible experiences of a stroke family at 2-years post-stroke and their informational or supportive needs.

**Key Points:**

- Stroke results in life-altering changes and consequences for caregivers and family members, which required adaptation and resilience.
- Not all stroke caregivers and family member share the same experiences following a stroke.
- Stroke families require verbal and written information and support that is tailored to their situation.

**Conflict of interest:**

There is no conflict of interest.
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Figure 1. Events Timeline:
Figure 1: Events Timeline

Events Timeline:

The timeline below is a simplified diagrammatic representation of the stroke family’s journey, with the key events and their occurrence indicated.

Footnote:

Interview 2 and 3 were conducted by the same research assistant as interview 1 and . Interview 5 was conducted by another researcher involved in the parent project. Interview 6 was completed by the primary researcher who also analysed the data set compromised of interview 1, and 6.
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7 April 2011

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Faculty of Social & Health Sciences  
School of Health Sciences  
Unitec New Zealand  
Private Bag 02 25  
Auckland 1142

Dear Dianne

Ethics ref: NTX/1/EXP/082 (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 Gascoigne, 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/ethics-committees
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 Chaine
Administrator
Northern X Regional Ethics Committee
Email: pat_chaine@mohe.govt.nz
Appendix B: Northern X Regional Ethics Committee – Ethical Update

13 April 2012

Dr Dianne Foy
Unitec New Zealand
Dept of Nursing
Private Bag 92025
Auckland 1142

Dear Dianne

Re: 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. Protocol v1.0, 06/04/11; PIS/Cons v1.0, 06/04/11
Investigators: Dr Dianne Foy, Ms Sue Gascoigne, Shrinin Caldwell, Prof Judy McKinnon, Mr Derek Nash

Thank you for your progress report, received 29 March 2012 with the information sheet (version 1, dated 5 April 2011).

The study has received ongoing ethical approval for the next twelve months from the Deputy Chairperson of Northern X Regional Ethics Committee under delegated authority. Mr Derek Nash has been approved and added as co-investigator. The next progress report is due 7 April 2013.

It should be noted that Ethics Committee ethical approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please note that progress reports are the responsibility of the researcher and forms can be found on the website, www.ethicscommittees.health.govt.nz. Please complete promptly to ensure ethical approval is continued.

It would be appreciated if we were advised when the study is completed and also that an End of Study Report is sent promptly after completion in order to close and archive the file.

Yours sincerely

Cheh Chua
Administrator
Northern X Regional Ethics Committee
Appendix C: Participants 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 Diane 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.org.nz.

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

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: Ethics Consent form

CONSENT FORM: Experiences of families/whānau of people who have had a stroke

<table>
<thead>
<tr>
<th>Language</th>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>I wish to have an interpreter</td>
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<td></td>
</tr>
<tr>
<td>Deaf</td>
<td>I wish to have a NZ sign language interpreter</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Māori</td>
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<td></td>
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<tr>
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<td>Ka inangaro au itetaitangatauri reo</td>
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<td>Kao</td>
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<tr>
<td>Fijian</td>
<td>Au gadreva me dua e vakadewavosavei au</td>
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<td></td>
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<tr>
<td>Niuean</td>
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<td>E</td>
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<tr>
<td>Tokelaun</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Tongan</td>
<td>Oku oufiema’u ha fakatonulea</td>
<td></td>
<td></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/whānaumember.
- 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 E: Inclusion Flyer

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

Seeking Participants

We are completing a research study that aims 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 family/whānau in the weeks and months following a loved one's stroke.

We are looking for participants who are family/whānau of a person who has recently had a first-ever stroke.

We want to talk to a number of people from each family/whānau. This means that for you to be included in the study we require at least two members of your family/whānau to agree to participate.

We understand that this may be a difficult time for you and your family/whānau to consider our request. However, if you would like to find out more about the study, please talk to Gerry Fennelly, Charge Nurse Manager, Muriwai Ward, Waitakere Hospital or contact me (Dianne Roy).

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

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 F: Interview Guide

Interview Guide:

Purpose of an interview guide:

An interview guide will provide enough structure to guide the interviews, while allowing participants the freedom to express what they consider important.

Prior to conducting interviews the lead researcher Dr Dianne Roy will contact the family/whānau and obtain verbal consent for myself to telephonically contact the family/whānau and arrange an interview time. The interviews will be arranged between September and November 2013, which will be close to the 2-year anniversary of the stroke survivor’s initial stroke. As this can be a sensitive time within the family the interview will ideally not be conducted on the exact anniversary date.

On the interview day formal introductions will occur. This will be followed by some preliminary conversation associated with the day, weekend or other related matters to help build rapport and create a neutral and relaxed atmosphere. Subsequently an introduction of the interview structure, verbal assurance and reaffirming verbal consent obtained previously to conduct the interview will occur. The verbal assurance will pertain to whether participants wish to pause to gather their thoughts, compose themselves, stop the interview or reschedule the interview for a later date. During the introduction phase of the interview the audio-recording device will be placed where appropriate. Participants will be asked to consent to recording the interview and reassured that the information/recordings will remain confidential. Once all this is complete the first interview questions will be asked. These are listed as follows.

What experiences or events have occurred in your family/whānau since the previous interview (at 18 months)?

- How did you cope with these?
- How did this alter your perceptions, behaviours or attitudes? (Or how have your thoughts, perceptions, attitudes or behaviours changed since then?)
- How do you feel about it at this point in time?
- What need do you have for support, education or information at present?
  - In what way can these needs be better met?
- How can communication with families such as yourselves be improved?
- What are the main reasons your family has coped in the way it has?
- At present to what extent do you consider your age or the age of the stroke survivor (specify name or refer to as husband/wife/mother/father etc) to have had an impact on your lives?
  - Experiences
  - Desire for information
o Supportive needs

Once the previous transcripts have been viewed it will be possible to identify specific events or elements within the lives of the family/whānau to base questions on. The questions may include ‘how has this event or element changed/affected’

- family dynamics
- how you cope
- your interactions with others (including health professionals if applicable)
- your perception of the event/element/issue

Prompts derived from previous transcripts will be written on a piece of paper that will be taken into the interview to guide the interviewers questioning. Furthermore the previous interviews will aid in tailoring the interview questions, interviewers responses and emotions. This will include being sensitive to pauses, emotions and knowing when prompts are required. Finally the interview will be wrapped up by asking the interviewees if there is anything they wish to add or areas they feel have been missed in the interview. If they have any questions these will be answered as well as possible and if required further steps will be taken. Participants will also be thanked for their time and participation in the interview and research. The next phase of the research will also be affirmed and ensure the interviewees are aware of their contribution in checking the transcripts once they have been transcribed.
Appendix G: Table of Transcript key words, groups or themes:

This table and others, which have not been included, were used as an index sheet to note the key words and groups of meaningful text derived from the transcripts. These tables provided a quick and efficient method of locating quotes pertaining to specific key words or groups at a later date. They also assisted in determining the frequency of groups or key words. The page numbers are according to printed transcripts. This specific table is from the first interview with P001 and P002.

Key for Appendix G:

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<thead>
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<td>Transcript</td>
</tr>
<tr>
<td>RS:</td>
<td>Relationship</td>
</tr>
<tr>
<td>p.:</td>
<td>Page</td>
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<tr>
<td>®:</td>
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<td>9, 11®,18®,27</td>
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<td>Subcategory</td>
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<td>Notes</td>
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<td>2, 17</td>
<td>5 (p.18 – driving)</td>
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<td>5</td>
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<td>2, 3, 5</td>
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<td>10, 28</td>
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<td>Family, phone calls, hosp. p. 10. p.11. Feel better</td>
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<td>Friends</td>
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<td>14, 15</td>
<td>13</td>
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<td>Concerned, worried, not see SS in condition p.13. Phone calls p.14</td>
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<td>3, 10</td>
<td>7, 9, 11, 12</td>
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<td>p.11. Focus on SS, realistic</td>
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<td>13,17</td>
<td>13</td>
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<table>
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<tr>
<th>P001 – interview. Observations.</th>
<th>Trans 1 p.9</th>
<th>Hard questions, defensive, comfort zone, nervous, not use to talking about himself.</th>
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<tbody>
<tr>
<td>p.10</td>
<td></td>
<td>Blank mind, can’t think “yeah, no, I just can't, I don't know.”</td>
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<tr>
<td>p.21</td>
<td></td>
<td>Hard questions,</td>
</tr>
<tr>
<td>p.24</td>
<td></td>
<td>I wouldn't know about that one.</td>
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<td>Whatever it takes</td>
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<td>Death of P001 if SS stay at home.</td>
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Appendix H: Transcript Summary Interview 1

Interview 1 with P003 & P004 Transcript Summary:

This appendix is a portion of a transcript summary as titled above. It indicates how the researcher noted what they considered important and separated this information into sub-headings titled ‘themes/ideas’. Some of the sections not included in this appendix that are included in the original summary include; improvements, health, communication, resources, stroke related changes, grief, support, roles, realizations, hope/improvements and frustration.

Key for Appendix H:

<table>
<thead>
<tr>
<th>Symbol or abbreviation:</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>P3:</td>
<td>P003, daughter of SS</td>
</tr>
<tr>
<td>P4:</td>
<td>P004, partner of P003</td>
</tr>
<tr>
<td>p:</td>
<td>Page</td>
</tr>
</tbody>
</table>

Themes/ideas:

- When heard the news.
  - Panic
  - Scary
  - Uncertainty of what to expect/what will happen/ what she looks like at hosp.
  - Reaction: p19-20
  - More quotes also at this pg. p21.
  - P3 “that first night was horrible actually, and being really anxious about the doctors coming in the morning.” p27

- Life post stroke:
  - P3: Everything’s changed. Everything in our life has changed completely, right down where we were planning a trip to Samoa next year and that’s all had to be cancelled because our everyday life is now here at the hospital with mum. p2
o Starting to get a rhythm. **(Routines)**
   - **P4:** We’ve done alright though as far as time because we’ve sort of like sorted it out now where although everything has changed, we’ve still got, we’ve got things down to a T. p2
- Coping/not coping:
  - **P4:** Like remember that day, that morning you finally broke? p3 I was waiting for it because it was, it was just full on and you weren’t sleeping and you felt like you had to be here to answer for your mother because she couldn’t talk.
  - **Feeling responsible for mother/care.**
    - **P3** was feeling responsible for her mother. p3
    - **P3** Even right down to my family weren’t understanding what she was trying to say but I, yeah, so I felt I had to be here just to be the one to be saying yes and no for her or yeah. p3
      - **P3** (there is a distinctive difference between the level of understanding between the ladies and the males from the other transcript. The daughter appeared to be able to understand the smaller subtle eye gestures of the mother and thus felt compelled to help communicate for her.)
  - **P3:** “Nobody was eating” p3 & p5
  - **p5** BBQ and breaking down/not coping.
  - **P3’s** friend that came to see SS in hospital p5 talked about rest and taking time out.
- **Routines:** p10
  - Change in weekend plans, otherwise similar relationship.
  - Granddaughter brought up to see SS on weekends. p11
  - **At hosp:** P3 “Yeah well I am here, I missed yesterday.” p16
  - Sunday routine p24, P4 “So we’ve got it pretty planned out alright”
  - Washing routine: p32-33(brother and father incompetence)
    - **P3** The most simplest of task. They can’t carry out. It’s just like oh. p33
  - **Extra factors:** daughter and granddaughter. So slight extra components.
  - **Mothers possessions/presence:**
    - **P3** My nephew’s, I went down, when I did go down there my nephew’s partner was sitting in mum’s chair and I just, I felt sick, I don’t know where it came from but I just wanted to say to her get out of my bloody mother’s chair, who do you think you are to be sitting in her chair but you know, simple things like that, and I don’t know why I felt like that. p15
  - **First 72 hours.**
    - More quotes also at this page. p21.

**Family dynamics:**

**P3 p6**

- I had an older, like my brother, he kept saying that he, it would have been better if mum had just died and that was you know, it was kind of confusing me and upsetting me and my dad is, we don’t have the best relationship anyway. We do
and we don’t but we can disagree really fast on things. Dad’s, my dad’s an older school man and he just what the doctors say is you know, everything, and you’re not allowed to have an opinion on anything or you're not allowed to ask questions and I like to ask questions. So that kind of causes some disgruntlement and then I’ve got another brother who he kind of, he’s a little bit different [P03’s non-participant brother]. I wouldn’t say he’s mentally challenged at all. He works full time, he drives a car, he owns a house, but he doesn’t say a lot [P03’s non-participant brother] does he?

- And he kind of doesn’t get the chance to say a lot whereas if he does he’s kind of shut down really fast; yeah, from my dad and my older brother. My dad and my older brother seem to think that they can take over and do everything and you've just got to sit back and you're not allowed to say anything or just shut your mouth, don't ask doctor's questions. I think it’s good to ask questions.

- **P3 p6** daughter and father had argument and not seeing each other at time of interview. Brother is at hosp but they each do their own thing. (RS not as close as was suggested by the male participants)

- **P3** understands how long the mother’s day has been and what she has to go through. **p7**

- See resources or **p7**

- Dad and brother not listen according to **p8**
  - **P3** They don't listen.
  - **P4** thinks that **P3** listens and has a good connection with the hospital staff etc. **p 9-10**

- **Granddaughter:** she was explained what a stroke was understood it and was then taken to see SS.

- **Family closer:**
  - **P3** thinks possible not **P4** might think so. **P7**
  - **P4** “I mean he cares and he loves his mum and he cares and everything like that. It's just like just let her have a rest, you know.” **p7**
  - **P4** “It doesn't affect me.” **p8**.
  - **Mother daughter relationship:**
    - **p15** stopping over for a cuppa daily or every 2nd day.

- **Step family:**
  - Still have dinner with step family every weekend (Sunday) **p24**
  - **P3** We just buried [P04, daughter-in-law]'s pop yesterday.” **p28**
    - **p31** possibly also grief
Appendix I: Transcript Summary Interview 6

Interview 6 with P001 & P002 Transcript summary:

- Journey
- Care
- Support
- Information
- Family
- Health
- Dependence/Independence
- New reality
- Social life
  - Getting out and meeting people
- Family dynamics
- Care, support, services
- Decision making
- Death
  - Grief, anger, coping, blame
  - Process
  - Support – services
- Changes: before, during after
- Changes in opinion
- Work, Holidays, escape, break
- Care of self, self preservation
- Rest home – No choice but to put her in a home
  - Big step for the family- they were adamant to keep her at home/ SS out of a rest home.
- Change roles when SS in rest home – visitor not resident there.
- Lack or adequate care
- Reflection
- Voicing ideas & thoughts previously kept quite
  - Inner thoughts
  - Getting too hard
  - We tried – a self-comfort or admitting or a genuine attempt?
  - SS want to give up
- Emotions
A Stroke of Grief and Resilience

Appendix J: Researchers notes

While reviewing the transcripts the researcher listened to the transcripts while reading the written transcripts. During this process the researcher made a note of key ideas, quotes, key words, groups of meaning or possible future themes. Below is the first of three pages as a sample from the first interview and transcript by participant P003 and P004.

Key for Appendix J:

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<thead>
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<th>Meaning</th>
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<td>Page</td>
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<tr>
<td>P (1,2,3 or 4)</td>
<td>Participants</td>
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</table>

Researchers notes while Listening to Interview 6 with P001 & P002

- Initial impact:
  - 35-36 mins p19 shock, uncertainty
  - ~36.30 mins “was my biggest fear, is she going to have another stroke, and then these massive headaches set in and you think oh God does that mean she’s going to have another stroke” p20
  - Emotions 38-40.30 mins p21
    - 72 hours on stand by
    - Melt down 39 mins
    - Rehabilitation
  - First night 53 mins
    - Wants support p53/4 mins
    - Shock 55 mins
    - Anxious 56 mins

- Change in plans
  - 2 mins

- Routine
  - 2.30 mins p2-3
  - 6.25 mins
  - 18.40 mins
  - 46 mins
  - 107/7 mins p32/34 washing – brother/dad not doing it

- Breaking down/broke
  - early ~3 mins
  - 7 mins
• Friend influence 7 mins – 8.40

• Not eating 3.30mins

• Answering for mother 4 mins and prior. P3-4
  o Taking on responsibility
  o Mind set 6.30 mins
  o 8.40 mins

• Family:
  o not understanding 4.30 mins
  o Older brother P2– mother just died mentality ~8.50 – 9
  o Dad 9.10 mins- not good relationship
  o Other brother submissive/shut down.
  o Power P1/P2 (others have less of a say)
  o Do own thing – not closer ?
  o Wider family P4 13 mins
  o Granddaughter 18 ~ mins
  o In-laws: 46 mins p24
    ▪ 105mins p31/34– poppa passed away
  o P3/P4 take on responsibility
    ▪ Washing
    ▪ Toileting
    ▪ Being there
    ▪ P3 sit there through the night
Appendix K: Data analysis

This Appendix indicates how the researcher analysed the raw data (transcript) to and formulated the extract until it was condensed to enter in the findings.

Transcript:

P001:

“... I went in there and this [Nurse 2] was syringing that milk stuff into her mouth. We went there to tell her we had got her into a new rest home, to “hang on mum, we’re going to get you moved”, and this [Nurse 2] used to, and “I don’t think you should be putting that stuff in mum’s mouth, you’re going to make her sick.” She’s like “it’s alright she’s got to eat or drink something” and she kept pushing this shit in. I was thinking, I felt like saying “leave her alone.” And so we left there at 20 to 3 and had to come home to get [grand-daughter] from school and I was back there at about 3.30 and I walked into the room and here’s mum, they were going “she’s fine we’re checking on her every 15 minutes” and we walked into the room and she’s just lying in her bed and she’s just covered in vomit. There’s just vomit everywhere, and so I thought oh my God. So I went over and I felt the vomit and it was stone cold and I thought that must have happened just after I left so I rang the bell and they came in and I said” mum’s vomited everywhere.” Oh my goodness, you know. So they cleaned her up and dad ...”

First analysis:

SS death may have been experienced as “bizzare” because of the events surrounding her death. More specifically prior to her death SS refused to eat resulting in rest home staff force-feeding her “protein drinks” (T6P3p19). P003 voiced her concerns to the rest home nurse “I don’t think you should be putting that stuff in mum’s mouth, you’re going to make her sick.” (T6P3p20). SS had also been indicating (through tapping her stomach region / “side” (T6Rp20)) that she was experiencing pain. P003 had to leave the rest home to pick up her granddaughter from school, so the rest home staff assured her that
they would be “checking on her (SS) every 15 minutes” (T6P3p20). However when P003 returned an hour later she discovered her mum “just lying in her bed ... just covered in vomit (T6P3p20), indicating that SS had been unattended since her departure. In the hours that followed SS progressively worsened. When family members enquired why the rest home doctor had not seen to their mother/wife the rest home staff informed them that the doctor was still at clinic. She also told them the following;

“... I’m telling you you can’t ring an ambulance.” ... what’s wrong with your mother is she’s got norovirus ... no hospital in Auckland will take your mother with norovirus ... so you can’t ring an ambulance, the doctor will be here when he will be here and your mother just, she’ll be fine,” (T6P3p21).

These comments and events indicate why P002 thought his mother’s death was “bizarre” (T6P2p32). In addition P4 described the series of events as “the start of her death” (T6P4p21).

**Final analysis:**

More than a week prior to her death SS refused to eat, thus she required force-feeding and also indicated that she was experiencing pain though tapping her stomach region. On the day of SS’ death, P003 went to visit her and observed her mother’s neglect first hand. When she entered SS’ room SS had been left unattended “lying in her bed ... just covered in vomit” (T6P3p20). The circumstances further worsened when, following hours of waiting, the doctor had not yet attended to SS. Furthermore the family were informed by the rest home staff that they were not permitted to call an ambulance.

“... [S]o you can’t ring an ambulance, the doctor will be here when he will be here and your mother just, she’ll be fine,” (T6P3p21).
Appendix L: Refining Research

Extract from the theme ‘the shocks of life and death’ regarding the participants' information and expectation mismatch compared to the reality of care received.
Appendix M: Table of Comparison

Key for Appendix K:

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<td>TV:</td>
<td>Television</td>
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<td>R</td>
<td>Researcher</td>
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Table Comparing the Participants’ and Data Extracts.

Comparison: | Attitude                                                                 |
------------|---------------------------------------------------------------------------|
             | Whatever it takes T1.P002.p12                                             |
             | Death of P001 if SS stay at home. T6.                                   |
             | “it would kill her.” T3P001p13                                            |

TV | Can’t be watching TV | T1.P001.p25 |
---|----------------------|-------------|
    | “I just can’t be bothered with TV” T3P001p39 – bigger quote.    |

SS watching TV (T4P003p7)
Appendix N: Age and Ageing Instruction to Authors

Age and Ageing accepts qualitative research papers and recommends that manuscripts follow the requirements set out by the International Committee of Medical Journal Editors at www.icmje.org.

The journal also has other requirements including key points, privacy, formatting and referencing guidelines. These are listed below.

**Key points:** A recommended 5 short sentences summarizing the main message of the manuscript.

**Privacy:** To ensure participant anonymity.

**Formatting:** A maximum of 30 references, 4000 words (including tables and illustrative data), 3 tables or figures and 250 word structured abstract.

**Referencing:** Number the references in square brackets in the order they are cited in the text. Number the references in the reference list followed by the names and initials of all the authors, except when there are more than six authors then list the first three, followed by et al.