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This Thesis entitled ‘A longitudinal hermeneutic enquiry into the lived experiences of the wider family of a stroke survivor, at two years post stroke’ is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy.

Candidate’s declaration

I confirm that:

- This Thesis represents my own work.
- Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.
- Ethics Approved by the Northern X Regional Ethics Committee (Ref NTX/11/EXP/062).

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A longitudinal hermeneutic enquiry into the lived experiences of the wider family of a stroke survivor, at two years post stroke

Raymond Daniels

A thesis submitted in partial fulfilment of the requirements for the degree of Master of Osteopathy, Unitec Institute of Technology, 2015
Abstract

Aim: To explore the lived-experience of two family members of a stroke survivor.

Background: The diverse consequences of a stroke upon the stroke survivor have been established in literature. The effect on the wider family members however has had limited investigation, especially over the two year period post-stroke. The widespread consequences of a stroke are important because they may negatively affect both the caregiver and the wider family. This study explores the lived-experience of two family members of a stroke survivor, over the first two years post-stroke.

Design: A qualitative exploratory study using hermeneutic phenomenology.

Methods: Purposive sampling recruited a family with two participants. Data were collected at six weeks, 12 months, 18 months and 2 years post-stroke through face-to-face, open interviews.

Results: The lived experience of both participants varied considerably in regards to the effect of the stroke and day to day life. A theme of ‘Hostage to Duty’ was strongly identified with the wife of the stroke survivor, whereas the theme 'Back on Track’ was identified with the daughter.

Conclusions: The lived experience of the family of a stroke survivor is unique for each individual and varies considerably. The findings of this study highlight the difference in each participant’s experience over the two year period, from stroke onset. The spouse of the stroke survivor experienced significant caregiver burden over the two year period. The impact on the daughter however, was considerably less burdensome.

Key words: Stroke, hermeneutic phenomenology, caregiver, survivor, family, experiences.
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Preface

This research study explored the lived experience of two family members of a first time stroke survivor. The two year period following the stroke event was explored. The thesis is presented in three main parts. Part one includes two chapters. Chapter one is a literature review to help familiarise the reader with the background of stroke and its impacts on the caregiver and family’s experience post-stroke. Chapter two discusses the methodology and research methods.

Part two is presented as a manuscript with related appendices in the format required for publication in the Journal of Clinical Nursing. Part three includes the appendices which contain documentation of ethics approval, participant information, interview schedules, the data analysis, with the development of themes and the journal publication guidelines.
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Glossary

**Stroke survivor**: a person who has had a stroke (ischaemic or haemorrhagic), without mortality.

**Stroke family**: a family that has a stroke survivor member.

**Extended / wider stroke family**: a family member of a stroke survivor. For example; grandchild, child, partner, parent or grandparent.

**Primary caregiver**: a person who provides unpaid help and care for a stroke survivor. The care involves everyday tasks of daily living, due to the impairments and disability in the stroke survivor. The primary caregiver is often a spouse or adult child, but rarely could be another family member, friend or neighbour. In this project, the primary caregiver predominantly refers to the spouse of the stroke survivor, unless otherwise stated.

**Post-stroke**: the time period following a stroke event. There are three phases recognised in the post-stroke event. The first is the acute phase, usually with the stroke survivor in the hospital. Next is the rehabilitation phase, commonly when the stroke survivor is discharged from hospital and integrated into their own home / community. The last phase is the transition into life after stroke.

**Longitudinal impact**: the long-term consequences / complications to either the stroke survivor or the wider family, as a result of the stroke. In this study, the longitudinal impact refers to the impact of a stroke over an extended period of time, primarily into the third phase post-stroke and beyond.
Part one
Chapter One: Introduction

This introduction provides a general overview of the widespread consequences that a stroke has on the stroke survivor, as well as the wider family. The recent literature on stroke will be explored, which includes the epidemiology, recent trends and further complications. The section below also orientates the reader with the current study and highlights the need to further investigate the experiences of stroke survivor family members, especially over a two year period following a stroke.

Stroke is a major public concern world-wide (Baumann, Le Bihan, Chau, & Chau, 2014; World Health Organization, 2014), as well as in New Zealand (McNaughton, McRae, Green, Abernethy, & Gommans, 2014). Approximately 9,000 New Zealanders have a stroke annually, resulting in adult disability (Stroke Foundation of New Zealand, 2013). According to Mohd Nordin et al. (2014), stroke has shown to be the primary cause of ongoing disability in adults, and as the world population ages, disability will continue to negatively affect the general public in the next two to three decades. Mohd Nordin et al. (2014) also state that improvements in medical science have resulted in the survival of two thirds of stroke patients. This has caused an increase in the prevalence of stroke survivors, and as a result the number of stroke survivors living with disabilities (Mohd Nordin et al., 2014). The stroke event can cause many survivors to live with impairment and in need of significant daily support (McNaughton et al., 2014; Stroke Foundation of New Zealand, 2013). Support needs often cause stroke survivors in New Zealand to depend on their primary caregivers, who are usually family members (Parag et al., 2008). Often these caregivers choose to care for their family member, even though respite care is available. This may be slightly different overseas, where caregivers may be forced to care for the stroke survivor. Choosing to care may also be influenced by differences in the public health system or due to cultural differences.

Family members who adopt a caregiving role are usually the spouse (Draper & Brocklehurst, 2007; Tunney & Ryan, 2014) or the offspring of the stroke survivor (del-Pino-Casado, Millán-Cobo, Palomino-Moral, & Frías-Osuna, 2014). To provide the on-going help and support needs for a stroke survivor, the family caregivers usually sacrifice their time and also experience a negative impact. Moreover, the caregivers often feel unprepared for their care
giving role (Creasy, Lutz, Young, Ford, & Martz, 2013). It is important to understand the experience on these caregivers, as well as the wider family, so that proper intervention and support can be provided. Ultimately, improved interventions and support to caregivers may increase the sustainability of the family caregiving (Bulley, Shiels, Wilkie, & Salisbury, 2010) and improve outcomes for the entire family. There is a lack of research investigating the wider family’s experience, especially the longitudinal impact over two years.

The study explores the experience of two family members over a two year period following a stroke. To explore the two year journey, data were collected and analysed from different time points, beginning during the acute phase (six weeks after the stroke), then at 12 months, 18 months and two years post-stroke. The data from the unique, stand-alone study contribute to a larger longitudinal project (Appendix A) exploring the experiences of five different families after a stroke event.

There are numerous studies which have focused on the impact of a stroke on the stroke survivor, whilst very little research has been done on the stroke survivors’ family and their experiences. Literature does show that the family members of the stroke survivors are negatively affected and consequently have their lives disrupted (Balhara, Verma, Sharma, & Mathur, 2012; Lee & Mok, 2011; Lutz, Young, Cox, Martz, & Creasy, 2011). The consequences of a stroke can be far-reaching and even life-changing, so this lack of research into the experience of family members is a concern.

A literature review revealed that there are few studies which focus specifically on the lives and experiences of stroke families. One study that investigated the acute phase after the stroke recognised that the first six weeks post-stroke is a particularly stressful period for carers (Ilse, Feys, de Wit, Putman, & de Weerdt, 2008). Although the study by Ilse et al. (2008) highlights a negative impact in the acute phase, investigation over the two year period remains limited.

In response to the gap in knowledge of the stroke family’s experience over a two year period, this study aims to explore the two year journey for the stroke family. The study will also help provide a better understanding of the stroke families’ multifactorial and unique experience.
**Literature review**

The following section contains a literature review. There is an extensive body of literature on the primary caregivers of stroke survivors, but fairly limited research on the wider family. Therefore, this literature review primarily focuses on the caregiver, and where possible, discusses the wider family’s experiences. Firstly, the literature review introduces the reader to the background of stroke, in terms of the epidemiology and the impact on the stroke survivors. The review then discusses the primary caregiver’s experience of stroke, addressing the negative impact and further repercussions of the stroke. Lastly, the review highlights the wider impact of the stroke, specifically pertaining to the wider family.

**Literature search strategy**

The literature review was conducted using online databases, including Science Direct, Pubmed, Medline and Ebscohost. A mixture of the following key words was used: caregiver, caregiving, stroke, stroke family, wider family, two years, post-stroke, outcomes, impact and experience. For example, one of the literature searches using Ebscohost combined the words stroke, caregiver and burden. This particular search sought material from 2004 – 2014 and yielded 178 articles. Articles that were included for review were related to stroke, caregiving, brain injury and lived-experience, with an emphasis on current literature specifically within the last ten years. Many of the articles included were published within the last five years (2010 – 2015).

**Background of stroke worldwide and in New Zealand**

A stroke happens when blood flow to and around the brain is interrupted. The stroke can be classified as an ischaemic stroke, which is the most common type, or a haemorrhagic stroke (Health Navigator, 2014). The lack of blood supply centrally results in tissue necrosis of the brain, which may cause significant traumatic consequences (Stroke Foundation of New Zealand, 2013). Fernandez, Eisenschenk and Okun (2009) report that brain tissue necrosis (due to a stroke event) can cause a wide array of symptoms. These symptoms include motor or sensory deficits, which can potentially cause permanent physical disability. The caregiver of a stroke survivor can provide significant support in terms of physical help, rehabilitation and general health and well-being, which the stroke survivors can benefit from. The literature review below will explore the consequences of stroke globally and in New Zealand.
An estimated 15 million people experience a stroke worldwide annually, with about five million deaths and a further five million people who are left with permanent physical impairment, placing a burden on their family (World Health Organization, 2014). Wang, Rudd and Wolfe (2013) investigated the trends in stroke incidence with the South London Stroke Register between 1995 and 2005. The overall stroke incidence declined by nearly 40 percent. This decline in stroke incidence was predominantly observed in those who were older than the age of 45, and no significant changes were found in people between the ages of 15 to 44. The overall decline in stroke incidence may be due to an improvement in stroke prevention, as well as an improved diet and healthy living (Wang et al., 2013). The outcome of a stroke depends on the severity of brain tissue necrosis and the area of brain injury (National Stroke Association, 2014), ranging from a variety of stroke related complications to death (Sun, Lee, Heng, & Chin, 2013). Fortunately, however, the mortality rate of patients discharged home is relatively low (Mutai, Furukawa, Araki, Misawa, & Hanihara, 2013).

In New Zealand, approximately 9,000 people have a stroke annually, of which approximately 33% are fatal (Stroke Foundation of New Zealand, 2013). Worldwide, stroke is claimed as the third leading cause of mortality (Baumann et al., 2014). Stroke is reported to be the third largest killer in New Zealand, with nearly 60,000 stroke survivors and many of them living with physical or mental impairment, needing significant support on a daily basis (Stroke Foundation of New Zealand, 2013). These aforementioned statistics show that stroke is one of the main causes of disability in adults, leading to many stroke survivors depending on their caregivers for support. Unfortunately, caregivers rarely receive preparation to support stroke survivors and commonly experience poor mental and physical health (Salter, Zettler, Foley, & Teasell, 2010). Moreover, caregivers may often feel ill prepared to deal with these consequences and adverse effects (Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014). If no effective primary stroke prevention strategies are introduced, the number of stroke survivors in New Zealand is projected to increase, with annual health costs potentially exceeding $700 million in the future (Feigin, Krishnamurthi, Barber, & Arroll, 2014).

The literature above shows the high prevalence of stroke and the impact that it has on the stroke survivors, their caregivers and the New Zealand health system. Although recent literature reflects the global effect on caregivers for an ill or disabled family member (Wittenberg & Prosser, 2013), the knowledge about the impact on the wider family of the stroke survivor in New Zealand is still fairly limited.
The background and impact on stroke survivors

A stroke event can cause permanent physical changes and have a devastating effect on the life of the stroke survivor. The consequences of a stroke are dependent on factors such as the location and severity of the cerebral trauma. Heeley et al. (2011) suggest that people who live in relatively more deprived areas in socioeconomic terms experience higher rates of stroke. This may be due to a relatively higher number of risk factors in these individuals such as the prevalence of hypertension, diabetes and cigarette smoking (Heeley et al., 2011), as well as fewer resources. The impact of the stroke is influenced by the degree of brain injury and will determine the support needs of the stroke survivor. The following section will examine literature relating to the stroke survivor and then focus on the caregiver and family members.

Stroke phases

The time period after the stroke can be broken down into three stages: hospital stay, the transition from the hospital to the community and community living (Gillespie & Campbell, 2011). Three slightly different stages are identified by Bakken, Kim, Finset and Lerdal (2012) as acute, rehabilitation and life after stroke. Vogen, Maruff and Morgan (2010) also refer to the first 12 months after the stroke as the ‘acute’ period. Although the post stroke trajectory can be broken down into different phases, there is no universal agreement. This is potentially due to different definitions of the stroke phases which are used in different studies. Although numerous studies have focused on the acute and rehabilitation stages, considerably fewer have investigated the longitudinal impact.

Stroke survivor’s needs

Danzl et al. (2013) undertook a qualitative investigation into the experience of stroke for thirteen survivors. The stroke survivors described a need for better education around stroke, clear communication from health providers, and an appropriate discharge plan. The authors also highlight the importance of emotional support from family, friends and faith communities. Kessler, Egan and Kubina (2014) confirm a need for more emotional support for stroke survivors in their study. Sixteen new stroke survivors and seven supporters were interviewed, which revealed that stroke survivors generally wanted more emotional support, especially when they were “feeling overwhelmed by the unknown” (p. 9). Kessler et al. (2014) propose that increased peer support for stroke survivors is associated with decreased loneliness, better social skills, feeling socially accepted, and more acceptance of the stroke.
Baumann et al. (2014) studied the experience of 94 stroke survivors at home in Luxembourg, two years after the event. The authors found a high proportion of stroke survivors reported a lack of knowledge in terms of information needs, a lack of financial help and a lack of community services. In addition, the study found that the stroke survivors’ perceived quality of life was “markedly low for the following domains: emotion, sleep, cognition, communication, mobility, mental feelings, pain and fatigue” (p. 15). Raju, Sarma and Pandian (2010) found that the presence of anxiety and depression were predictors of impaired quality of life in stroke survivors. The caregiver’s quality of life was however not investigated.

**Other consequences**
The consequences of a stroke are variable. McCarthy, Powers and Lyons (2011) found that stroke survivors may experience a range of social complications. These include relationship problems and psychological issues, including “emotionality, mania, psychosis, anxiety, and depression” (p. 139). Of these self-reported psychological impairments, depression was stated to be the most common. In addition to these potential consequences, the stroke survivor can also be affected physically and functionally, which may include motor, visual, sensory and language impairments (Baumann et al., 2014).

Bergström, Eriksson, von Koch and Tham (2011) report an association between the life satisfaction of a stroke survivor and their caregiver. In fact, this study mentions the importance of a dyadic perspective and identifies a reciprocal influence between the stroke survivor and the caregiver, especially in terms of self-reported life satisfaction. The impact of stroke is well investigated in the acute period, immediately following the stroke event (Jones, O'Keeffe, Kingston, & Carroll, 2013; Lawrence, Kerr, Watson, Paton, & Ellis, 2010; Plank, Mazzoni, & Cavada, 2012). There is however considerably less research focussing on the impact of stroke throughout the two year journey post stroke, especially on the caregiver. Therefore, the following section will examine the literature relating to the caregivers of stroke survivors.

**Background on stroke survivor caregiver**
A stroke event can cause a severe burden on both the stroke survivor and their caregiver. Jaracz, Grabowska-Fudala and Kozubski (2012) mention that there is well documented research which highlights the negative impact that a stroke can have on patients and that
“considerably less is known about its impact on their caregivers” (p. 224). A study conducted by Cecil, Thompson, Parahoo and McCaughan (2013) reports that many different factors may influence how a stroke can affect the caregiver and how they cope. Cecil et al. (2013) identified three broad categories; “the impact of the stroke event on the carer, the extrinsic factors that support the caring scenario and the intrinsic factors that help a carer to cope with the new role” (p. 1761). With the impact on the caregiver being dependent upon several factors, it is reasonable to suggest that the impact can vary immensely. As mentioned previously, the caregiver of a stroke survivor is usually a family member (Bastawrous, 2013; Cameron et al., 2014; Kitzmüller, Asplund, & Haggstrom, 2012; Majerovitz, 2007).

Different studies define the term ‘caregiver’ differently, which has raised some concern about the generalisability of some research findings (Bastawrous, 2013). For example, the informal (unpaid) caregiver could be the child, child-in-law or a close friend (Ogunlana et al., 2014). The caregiver is usually, however, a family member and commonly the spouse of the stroke survivor (Draper & Brocklehurst, 2007; Tunney & Ryan, 2014; van Mierlo et al., 2014). Therefore, the literature review below will focus on the impact of stroke on the spouse of the stroke survivors. In addition, the remainder of the literature review will refer to the caregiver as the spouse of the stroke survivor, unless otherwise stated. Limited research has investigated the experiences of the stroke survivors’ children who are in their adulthood.

The impact on the caregiver
Lutz et al. (2011) completed a qualitative investigation into the experience of 19 stroke survivors, as well as 19 family caregivers in Florida. The authors state that the caregivers faced different challenges as they journeyed through three stages of the stroke trajectory, these being the initial crisis of the stroke, expectations for recovery, and the crisis of discharge. Some of the challenges that the caregivers faced included financial burdens, medication management and administration for the stroke survivor, extra tasks and responsibilities such as household maintenance, laundry, garden work and meal preparation. In addition to these, some caregivers reported feeling “overwhelmed, abandoned and isolated” (p. 793), due to their added responsibilities. During the ‘crisis of discharge’ stage, the stroke survivors were reportedly sent home quicker than anticipated, which caused increased stress on the caregivers who also felt underprepared.
Some positive aspects

In contrast to the previous section, the experience of being a caregiver can also be positive. Mackenzie and Greenwood (2012) reported improved relationships, feelings of love and devotion, feelings of appreciation by the stroke survivor, becoming a better person and increased appreciation of life. Family relationships are important and can also strengthen during difficult times (Hunt & Smith, 2004). The next section will focus on the negative outcomes of a stroke, as the literature generally shows that the impact of providing care for stroke survivors is predominantly negative (Majerovitz, 2007; Parag et al., 2008).

Negative life changes

Peyrovi, Mohammad-Saeid, Farahani-Nia and Hoseini (2012) found an overall negative change in the lives of caregivers who took on the caregiver role. The functional disability of the stroke survivors significantly predicted the negative life changes in the 60 family caregivers studied, and that 40% of the caregivers were at risk of depression. The Auckland Regional Community Stroke study assessed stroke survivors and their caregivers at 6 and 18 months after stroke onset. At six months, the caregivers reported lower health-related quality of life (Parag et al., 2008). Similar results were found by Larson et al. (2005), who report that “the experience of informal caregiving is a complex phenomenon. It has an impact on all aspects of the carer’s life” (p. 442), also affecting the psychological aspects of their partners’ quality of life.

Lurbe-Puerto, Leandro and Baumann (2012) investigated the feelings and experiences of 46 caregivers in Luxembourg and North East Portugal. Decreased time for relaxation, deterioration in health and loss of intimacy with their spouse were some of the reported impacts amongst the caregivers. Lurbe-Puerto et al. (2012) report that the participants living in Luxembourg experienced “less of a burden, and the stroke-related repercussions for the caregiver’s family and social life were less” (p. 731), which may have been related to higher educational levels, lower rates of unemployment, easier and quicker access to medical care in Luxembourg and a younger overall age of the caregivers in Luxembourg. Despite these findings, caregivers from both geographical locations experienced slightly increased burden as a result of their caregiving duties.
It is evident that ‘caregiver burden’ is a common negative consequence for stroke caregivers (Bastawrous, 2013; Bergström et al., 2011; Brinda, Rajkumar, Enemark, Attermann, & Jacob, 2014; Jaracz et al., 2012; Ogunlana et al., 2014; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005; van Mierlo et al., 2014), and therefore, will be further discussed below.

A discussion of ‘caregiver burden’

The term ‘caregiver burden’ is multi-dimensional and there is no single definition of the concept (Bastawrous, 2013). Bastawrous states that if the certain measurements of caregiver burden are not properly explained or justified, then the interpretation of the study results will be difficult. Different theories can be used to guide research into the topic of caregiver burden. Two theories used by Bastawrous are “stress theory and role theory” (p. 435). In addition, Bastawrous mentions a conflict in role, which he considers to be particularly important when discussing the experience of burden in women and adult children caregivers. Majerovitz (2007) highlights the multifaceted predictors of caregiver burden and the multidimensional nature of caregiver stress.

A systematic review of 24 studies found that 25 – 54% of the caregivers experienced burden, which remained elevated for an ‘indefinite’ period of time following the stroke (Rigby, Gubitz, & Phillips, 2009). Vincent, Desrosiers, Landreville and Demers (2009) also highlight the burden experienced by the caregivers in their study. Questionnaires were used to assess the levels of burden in 197 participants. Vincent et al. (2009) however found a general decline in burden over time, despite reports of a greater impact on the caregiver’s social life initially and higher levels of burden up to six months. Both studies reveal the presence of caregiver burden, even though it was experienced at different levels.

Vincent et al. (2009) suggest that the best predictors of burden were the caregivers’ characteristics, such as gender, retired occupation, low level of schooling, older age, and hours of care given. The stroke survivor’s characteristics also influence the burden on the caregiver, including depressive symptoms, poor motor function, deficits in verbal comprehension, difficulty in gait and neurological deficit. Tooth et al. (2005) similarly identify the burden and poorer health status in carers, as a result of spending considerable time caring for stroke survivors. Although the above mentioned predictors of burden may be useful, there is a diversity of predictors that influence caregiver burden (Bastawrous, 2013; Majerovitz, 2007; Vincent et al., 2009), which will be examined next.
Factors influencing caregiver burden

Bhattacharjee, Vairale, Gawali and Dalal (2012) investigated the factors affecting caregiver burden. The study which was based in India, reported that the following factors were all related to high caregiving stress: female gender, a younger age, long caregiving hours, being the daughter-in-law of the stroke survivor, anxiety, disturbed sleep and financial stress. Another study also based in India, investigating 199 caregivers, found very similar results. The authors found that 70% of caregivers reported increased workload, 76% reported anxiety and depression, 43% reported disturbed sleep and more than 80% of the caregivers reported financial worries (Das et al., 2010). It was mentioned that the caregivers who were looking after “patients with dementia and depression experienced greater stress” (p. 2965). Although duties of care between relatives are different in different countries, it is clear that caregiver burden is a worldwide concern.

Oliveira et al. (2013) investigated the prevalence of ‘caregiver role strain’ and the accuracy of clinical indicators for this term. Of the 42 participants, 73.8% were diagnosed with caregiver role strain. Oliveira et al. (2013) mention that clinical indicators, or the defining characteristics of the caregivers, such as “lack of time to meet their own personal needs, removal from social life, increased emotional strain and changes in leisure activities” (p. 215) were found to have a connection to the diagnosis of caregiver role strain. In other words, the presence of these clinical indicators could help identify potential caregivers who were at risk of experiencing strain during their caregiving role. Brinda et al. (2014) also mention that the amount of time spent supervising the stroke survivor significantly increased the burden on caregivers, who reported being unhappy, had a lack of time for themselves and felt they were losing control of their own lives. The functional disability and daily help requirements of the stroke survivors also increased the burden on some caregivers (Brinda et al., 2014).

Other determinants that increase caregiver burden are impaired cognitive, physical and mental health of the stroke survivor, as well as older age and male gender, according to Rigby et al. (2009). Balhara et al. (2012) report that a multitude of factors contribute to the burden on caregivers, which include "fatigue, emotional distress, restricted social life, changes in family life, relationship difficulties, balancing responsibilities... uncertainty about recovery, lack of caregiving skills, and financial issues” (p. 33). The literature above highlights the complex presentation of caregiver burden, which can further lead to a wide variety of demanding consequences and will be further explored below.
Caregiver physical and mental health

The consequences of a stroke are increasingly recognised as a significant health concern for the caregivers (Brinda et al., 2014; Rigby, Gubitz, & Phillips, 2009; Tooth et al., 2005). The health concern identified in the literature addresses both the physical and mental health of caregivers, as a result of stroke. Yiengprugsawan, Harley, Seubsman and Sleigh (2012) performed a large scale cross sectional study, which sent out questionnaires to distance learning Open University students who were stroke caregivers living in Thailand, between the ages of 15 to 87 years. A questionnaire was sent out in 2005, to which 87,134 participants responded. A second follow-up questionnaire was sent in 2009, with 60,569 respondents. The authors found that full-time adult caregivers “experienced consistent adverse physical and mental health” (p. 1), such as lower back pain and poor psychological health. These findings are particularly relevant for caregivers in the Thai community, due to the magnitude of the study.

There are also potential psychosocial impacts on caregivers (Cheng, Chair, & Chau, 2014; Visser-Meily, Post, van de Port, van Heugten, & van den Bos, 2008). Visser-Meily et al. (2008) associate the declining psychosocial functioning of the caregivers with the stroke survivor’s impairments, especially when the patients have cognitive and communicative impairments. This may be due to changes in who the stroke survivor once was, or perhaps as a result of ineffective communication which could put strain on the relationship. The relationship between the stroke survivors physical disability and the psychiatric morbidity or strain levels in their caregiver in a complex one, and therefore makes it difficult to confidently predict which caregivers are most at risk (Draper & Broklehurst, 2007).

A systematic review by Cheng et al. (2014) investigated the effects of psychosocial interventions on the psychosocial and physical wellbeing of stroke survivor caregivers. Caregivers who received psycho-education, which specifically intended to equip them with problem solving skills, as well as skills in coping with stress, appeared to have a slightly more positive effect on both the physical and psychosocial well-being of the caregivers. The findings also suggest that the use of a social support group significantly reduced the caregiver burden when compared with their baseline data. Caregivers who received problem solving skills training via telephone experienced a significantly lower level of burden. These results shed light on some effective strategies to help address the issue of caregivers being mentally affected as a result of becoming a caregiver of a stroke survivor.
Life satisfaction of caregiver

Baumann, Couffignal, Le Bihan and Chau (2012) investigated the life satisfaction of 62 caregivers two years after the stroke event. The findings suggest that there is an association between the stroke survivor’s life satisfaction and the caregiver’s life satisfaction. The authors conclude that the caregiver’s life satisfaction was lower in caregivers of stroke survivors who experienced emotional issues and impaired memory function. Baumann et al. (2012) reported that some of the family caregivers felt exhausted as a result of having to cope with the stroke survivor’s physical disabilities and psychological problems.

Similarly, Visser-Meily et al. (2008) found that 51% of the 119 caregivers in their study experienced “high levels of burden, depressive symptoms and dissatisfaction with life” (p. 157), measured one year after the stroke. The researchers also reported that about 50% of the caregivers said they were not satisfied with their own leisure time or with life as a whole. Bergström et al. (2011) investigated the dyads’ combined life satisfaction one year after a stroke, to gain a better understanding of the relationship between caregiver burden and their life satisfaction. The results revealed that dissatisfied dyads reported a significantly greater burden on the caregiver.

Quality of life of caregiver

Burden has also been shown to affect the caregiver’s quality of life (Carod-Artal, 2012; Hussain, Abdullah, Esa, Mustapha, & Yusoff, 2014; Ogunlana et al., 2014). Ogunlana et al. (2014) investigated the strain and burden experienced by the stroke caregivers of stroke survivors, as well as their quality of life (QoL). The results of the study suggest that the stroke survivors’ level of disability had a significant influence on the QoL of the caregiver. In addition, the caregivers’ QoL was inversely correlated to their reported burden. In other words, an increased burden of caring for a stroke survivor may have a negative effect on the caregiver’s QoL.

Similarly, Akosile, Okoye, Nwankwo, Akosile and Mbada (2011) identify the correlation of adverse self-reported QoL for stroke caregivers in Nigeria. Akosile et al. (2011) propose that the following caregiver variables were significantly related to lower self-reported QoL scores; female gender, closeness in relationship to the stroke survivor and an older age. Larson et al. (2005) suggest that the the psychosocial factors such as “life situation, wellbeing, social network, education and economy are important in predicting QoL among spouses of
stroke patients” (p. 439), even though these factors may change over time. Not surprisingly, a weaker economic situation, such as giving up work or expensive medication predicted a lower QoL in the caregivers. This might not be transferable directly to New Zealand context, as many stroke caregivers may already be retired and the New Zealand government subsidizes medication.

Predictors of life satisfaction

Significant predictors of a caregivers’ life satisfaction include the caregiver’s health, the stroke survivor’s age and educational status (Hussain et al., 2014). The researchers also state that the better the caregiver’s health status, the better their life satisfaction, whereas an older age of the stroke survivor and a lower level of education were also associated with decreased caregiver QoL. Yu, Hu, Efird and McCoy (2013) examined 121 stroke survivor and caregiver dyads and found “higher educational levels, planning and active coping strategies were positively associated with the caregivers’ QoL” (p. 222). Some of the other coping strategies included maintaining an interest outside of their caregiving situation and seeking emotional support. If healthcare professionals can identify caregivers who are at risk and understand the different coping strategies, then they may be able to assist the family caregivers to participate in these stress-reducing strategies, as Lee and Mok (2011) suggest.

Anxiety and depression

As burden increases, caregivers have an increased likelihood of experiencing feelings of anxiety and depression (Balhara et al., 2012; Denno et al., 2013; Jaracz et al., 2012). Denno et al. (2013) suggest that the severity of depression also increases at the same time as the burden of caregiving increases. In another study of 199 stroke survivors by Das et al. (2010), anxiety and depression were found in 76% of caregivers. Balhara et al. (2012) report that the sex of the caregiver (being female), is a strong predictor of the levels of anxiety and depression. Baumann, Lurbe-Puerto, Alzahouri and Aiach (2011) analysed the associations between the stroke survivor’s disability and the impact that it had on the caregiver’s lives. A total of 215 caregivers were included in the study, which found that an increased dependency from the stroke survivor lead to social repercussions for the caregivers, such as increased feelings of isolation. In addition, the authors suggest that being male was strongly associated with feeling of injustice, whereas women generally reported struggling with the physical demands of providing care.
Adding to the findings above of anxiety and depression in caregivers, Wallengren, Friberg and Segesten (2008) identify that there is a presence of emotional strain, anxiety and uncertainty in caregivers. Research has shown that anxiety predominantly emerges in the acute stage among caregivers and stroke patients following a stroke (Greenwood & Mackenzie, 2010). Although the previous studies highlight that anxiety can surface initially, and be experienced for weeks to months, further investigation is required to determine if anxiety continues to be manifest in the long term.

**Change in role from wife to caregiver**

Cao et al. (2010) state that all of the 10 caregivers in their qualitative investigation mentioned a change in their roles after the onset of their husband’s strokes. These significant role changes were due to increased responsibilities and additional chores, such as mowing the grass, driving and home repairs. Cao et al. (2010) also report that the caregivers experienced barriers to activity and changes in the meaning of activity and health. The barriers to activity were reportedly due to a lack of time and energy, as well as guilt, as their partners were no longer able to participate in certain activities that they previously did together. Literature also highlights that there is sometimes a role reversal in the relationship between the caregiver and the stroke survivor (Tunney & Ryan, 2014). The findings by Graven, Sansonetti, Moloczij, Cadilhac and Joubert (2013) also found a change in role in the caregivers, as well as tension in the relationship between the stroke survivor and the carer. Caregivers need to be supported in their change of role and life changes, which may negatively affect their quality of life and the sustainability of providing care (Bulley et al., 2010).

**Caregiver loss of personal time**

The increased responsibilities and chores of being a caregiver can significantly affect the caregiver’s personal time (Cao et al., 2010). In fact, Lurbe-Puerto et al. (2012) report that caregivers found little time for relaxation and experienced a deterioration in their health. Similarly, Gosman-Hedstrom and Dahlin-Ivanoff (2012) also recognise the carers’ need for time to themselves. Social repercussions and expressing needs such as increased time for their own personal leisure was also identified by Greenwood, Mackenzie, Cloud and Wilson (2009) as one of the negative impacts of providing care for the stroke survivor, specifically at one year or later post-stroke. These findings are congruent with the Auckland study by Parag et al. (2008), who report that caregivers experienced less social time with family and friends due to their role as a caregiver.
Saban and Hogan (2012) undertook a qualitative investigation into the experience of 46 female caregivers. One of the identified themes was ‘losing a life that once was’ (p. 5). Two of the four subcategories were ‘missing personal time’ and ‘facing an uncertain future’. The loss of personal time was a constant issue, and the demands and increased responsibilities left little personal time for the caregiver. Likewise, Tunney and Ryan (2014) identify a loss of privacy for the stroke survivor caregivers in their study.

**Uncertainty and an unpredictable life**

The caregivers’ feelings of an uncertain future, as suggested by Saban and Hogan (2012), were related to the potential of another stroke event. One participant in the study worried that “another stroke may be looming” (p. 6). Gosman-Hedstrom and Dahlin-Ivanoff (2012) also reveal that older women who were living with and providing care for their partners experienced feelings of uncertainty and unpredictability, fearing that the stroke could happen again. As a result of the stroke, many of the 16 the caregivers lives had changed drastically and they felt tied to their home, being always on call to help their husbands (Gosman-Hedstrom & Dahlin-Ivanoff, 2012). This consequently led to the women having to negotiate time for themselves and time to manage everyday life activities. For example, Gosman-Hedstrom and Dahlin-Ivanoff (2012) explain that “negotiation with their partners on a daily basis to get things done with the everyday activities at home was common. Their partner followed them around though; the men could only be alone for a short period of time…” (p. 593). Again, these findings highlight the loss of personal time that the caregivers may experience.

**The unmet needs of caregivers**

There is extensive literature to suggest there are unmet needs of caregivers. These needs include physical, supportive, emotional and information needs, which will be reviewed below.

**Physical needs of caregivers**

A stroke event can often cause physical disabilities in the stroke survivors, resulting in an increased physical demand from the caregiver (Greenwood & Mackenzie, 2010). A literature review by Hafsteinsdóttir, Vergunst, Linderman and Schuurmans (2011) found that caregivers reported needing physical help with lifting and moving the stroke survivor. As mentioned before, Bulley et al. (2010) state that the carers of stroke survivors reported an increase in both the caring and domestic workloads. Plank et al. (2012) also recognise that stroke
caregivers are persons in need of practical and emotional support. Likewise, Steiner et al. (2008) highlight the physical concerns that stroke survivor caregivers have, such as strain due to frequently bending and lifting.

**Emotional impact on caregivers**

Research has found significant emotional distress in caregivers of persons with traumatic brain injury (Sander, Maestas, Clark, & Havins, 2013). Emotional distress is also a common phenomenon among stroke survivor caregivers, and where “significantly related to self-esteem, threat appraisal, and difficulty with dependent-care tasks” (Bakas & Burgener, 2002, p. 40). Cameron, Cheung, Streiner, Coyte and Stewart (2011) investigated the unique influence of the stroke survivor’s psychological and behavioural symptoms on the caregiver emotional distress, using 399 stroke survivor and caregiver dyads. The results show a higher level of self-reported emotional distress in the caregivers, when the stroke survivors had increased cognitive impairment and depressive symptoms. Other contributing factors which increased the emotional distress on the caregivers included, female gender and poorer physical health (Cameron et al., 2011).

Parag et al. (2008) also found that over half the 167 caregivers in their study reported lower energy levels and less time for family and friends at six months post stroke, with “59% reporting that life in general had changed for the worse” (p. 551). Creasy et al. (2013) report that emotional and behaviour changes in the stroke survivor caused emotional distress for the caregivers. The study by Pierce, Thompson, Govoni and Steiner (2012) also found that the majority of the 60 caregivers in their study, who were white women living in northern Ohio or southern Michigan and caring for their spouses, reported emotional strain on a daily basis. The emotional strain which was experienced during the first year was broken down into three categories; “being worried, running on empty, and losing self” (p. 9). Tunney and Ryan (2014) also highlight the potential for a stroke event to have a negative effect on the caregiver’s emotions. This qualitative investigation of 10 caregivers found that many of them commented on the emotional strain that they experience. One caregiver stated that it was the change in her husband’s personality that put a strain on their relationship. Even though this was a small study, it is in line with the findings from a wide range of literature, which identifies the emotional strain that caregivers may face.
Information needs

Literature also emphasises the information needs of caregivers. A qualitative analysis by Bulley et al. (2010) reports that stroke caregivers found the “emotional and cognitive changes in their partners particularly distressing and would have valued more information and help” (p. 1406) with the increased workload, both physically and emotionally. Tunney and Ryan (2014) also identify a lack of information provided to caregivers. A mixed method descriptive survey was done with 19 family members and 23 practitioners by Roy, Gasquoine, Caldwell and Nash (2015). This was to gain a better understanding of the participant’s opinions on the information provision post-stroke. The authors found that the quality and time that they received the information was variable, where most families described being “overwhelmed initially with information they could not absorb; then later floundering as they had to find their own way through the maze” (p. 7). Roy et al. (2015) concluded that the information received by most families was problematic which was potentially related to the nature of the stroke experience, the shock of the sudden onset and the changes in the family dynamics, which Gillespie and Campbell (2011) also identify.

An integrative review by Robinson (2014) investigated both the patient and family’s experience of palliative care in the hospital. Some positive experiences were reported, however, the patients and their families reported that there was a poor standard of communication with the health professional. The type and quality of information that they received was criticized and they reported having difficulty in understanding what was said, especially due to jargon when conversations involved the prognosis of the patient. Families also felt that they generally could have been better informed with what was happening and constantly had to find staff to “get updated information about the patient coupled with the fact that staff rarely approached them to ask whether there was anything they needed to know, which left the family feeling dissatisfied” (p. 29).

The information needs of caregivers vary according to the severity and the different stages of the stroke (Hassan, Mohamed Aljunid, & Davis, 2012). Vincent et al. (2009) also state that the results in their study of 158 caregivers in Canada reinforce the view that information, training and support should be tailored to the needs of stroke caregivers. Lawrence et al. (2010) suggest that the information provided to the stroke caregivers was potentially given to them when they were not receptive and that there might not have been enough verbal reinforcement. Furthermore, Lawrence et al. (2010) report that the information and advice
provided to the family, for example advice on how to maintain a healthier lifestyle was often confusing and contradictory. Stroke survivors and caregivers want the information they receive to be tailored to both their needs and their situation, which was found in a systematic review (Hafsteinsdóttir et al., 2011).

**Support needs**

A need for improved support has been strongly identified in the literature. Visser-Meily et al. (2005) found that 20% of the 194 caregivers who were studied were not supported by the rehabilitation team. Tunney and Ryan (2014) also highlight a need for ongoing support for caregivers. Adriaansen, van Leeuwen, Visser-Meily, van den Bos and Post (2011) similarly recognise that over time, the stroke survivor caregivers experienced a decline in social support. Furthermore, Adriaansen et al. (2011) suggest that there was a positive association between the levels of social support and the caregiver’s life satisfaction. Caregivers can experience a sharp decline in health care support once the patient has been discharged (Danzl et al., 2013; Salisbury, Wilkie, Bulley, & Shiels, 2010). Brinda et al. (2014) report a need to support caregivers, as well as the management of older, dependant people with chronic disabling diseases. Yiengprugsawat et al. (2012) also conclude that their findings should raise more awareness of the unmet needs and support requirements of caregivers and that this requires further study.

The findings by Rigby, Gubitz and Phillips (2009) state that further research is needed to help identify stroke caregivers who are in need of support, and the authors suggest that appropriate intervention plans should be implemented. Despite a general lack of support for caregivers, which has been identified in the literature, Cecil et al. (2013) identify the diverse and unique support needs of caregivers. Furthermore, Mak, Mackenzie and Lui (2007) highlight that the caregiver’s needs change after discharge. For example, before discharge, the caregivers mentioned a need for emotional support and information requirements. Post discharge however, the caregiver’s needs changed to more practical problems such as a lack of help in providing care for the stroke survivor and “a lack of caring equipment in the home” (Mak et al., 2007, p. 976). The needs between the individual caregivers were also different. For example, some caregivers mentioned financial difficulties, whereas other caregivers expressed their concern about the lack of support from their general practitioners. Therefore, it is clear that the unique support needs of the caregiver have to be tailored, as they are influenced by many factors.
The literature emphasises the need to provide advice and support, to both the stroke survivor and carers. Cameron, Naglie, Silver and Gignac (2013) revealed in their qualitative study that the caregivers received a large amount of support from family and friends during the inpatient phase but the support decreased over time. The caregivers stated that they would have appreciated continuing support once they returned home. It is obvious that the caregivers can provide invaluable support to the stroke survivors during the recovery and rehabilitation, as well as community re-integration. However, because it is not standard clinical practice to efficiently prepare and give ongoing support to the caregivers, many caregivers experience stress, burden and other negative consequences as identified, which can unfortunately threaten the sustainability of ongoing care from the caregiver. Therefore, ongoing needs assessment by healthcare professionals may be useful to improve the caregiver outcomes and provide appropriate interventions.

**Interventions for caregivers support needs**

Different interventions have been tested to identify and address the unique support needs of the caregivers. Cameron et al. (2014) hypothesize that the Timing it Right Stroke Family Support Program (TIRSFSP) which they developed, will result in family caregivers reporting better perceived support and better mental health in comparison to standard care. This is based on preliminary findings, where the TIRSFSP was pilot tested and found that the “needs of those caregivers who have limited experience with stroke, difficulty obtaining information, and difficulty navigating the health care system” (p. 12) are being met. The TIRSFSP also emphasizes that the caregivers’ unique support needs change over time. Cameron et al. (2014) suggest that improving the timing of when support is provided to the caregiver may address their changing needs and may help the caregivers to feel better prepared for their role. A targeted intervention, such as a stroke support group during which caregiving training could be acquired, may alleviate the burden on caregivers and improve their quality of life (Ogunlana et al., 2014). These findings are in accordance with Jaracz et al. (2012), who similarly suggest a targeted intervention such as training in basic nursing and personal care techniques which can enhance the caregiver’s ability to cope with stress, improve their caregiving skills and reduce the physical dependency of patients.

Therapeutic telephone contact during the first three months may also be particularly helpful to caregivers of stroke survivors (Pfeiffer et al., 2014). Perrin et al. (2010) developed and implemented the ‘Transition Assistance Program’ for the caregivers of stroke survivors. The
program included developing the caregiver’s skills and problem solving. Perrin et al. (2010) report that the Transition Assistance Program “effectively reduced caregiver strain at the three month follow up” (p. 605). Further research is however required to validate the effectiveness of the program, especially over the two year period post-stroke. Although the literature reveals a variety of interventions to address the caregivers support needs, Shyu, Li-Min, Min-Chi and Sien-Tsong (2010) suggest that intervention programs needs to be individualised, which can help improve the quality of care provided by the caregiver. The caregivers play an important part of the rehabilitation and long term goals. Therefore, if healthcare professionals can recognize the impact on the caregivers and provide effective intervention, the outcomes of both stroke survivors and their caregivers may be improved.

The literature reviewed above highlights the many potential consequences of a stroke event, specifically on the stroke survivors and their primary caregiver. Research and understanding of the wider stroke family, however, remains fairly limited. The literature has primarily focused on caregivers who are spouses of the stroke survivor, with some investigations into the adult children as the primary caregivers. Bastawrous (2013) reports that the caregiving role of adult children (for their ageing parents), usually occurs with the additional responsibility of their own family obligations. Further research needs to include the wider family members beyond the primary caregiver, to gain a better understanding of the wider stroke family’s experience.

**Impact on the wider family, beyond the caregiver**

The onset of a stroke can be very rapid and consequently may be experienced as an unexpected and frightening event for the stroke survivor, the caregiver and the wider family. For example, the stroke survivor could lose their job as a result of physical disability which could have financial implications. The stroke survivor might require their adult children to provide care, resulting in extra responsibility and pressures on the caregiver. The consequences of a stroke vary considerably and can also extend to the wider family. In the section below, the literature will examine how the wider family is affected by a stroke event.

**Family needs and support**

In a literature review, Gillespie and Campbell (2011) identified dynamic changes in the emotional well-being of the wider family of the stroke survivor. These changes may be
influenced by the stroke survivor’s recovery, as the condition of the stroke survivor may either improve or deteriorate further. The stroke survivor’s caregiver and relatives are able to provide support and help, which the stroke survivor can benefit from. For example, a relative could offer to drive the stroke survivor to an appointment, due to the stroke survivor’s physical limitations, which might also give the caregiver a break from their full time caregiving duties. Therefore, the relatives are important for both the stroke survivor and their primary caregiver. Gillespie and Campbell (2011) report that little research has been undertaken to investigate the experiences of different stroke family members. In addition, Gillespie and Campbell (2011) state that “supporting families and carers in recognising their needs… and asking for help when it is needed are vital to the sustainability of the care-giving role” (p. 45).

Stroke survivors who are discharged home are often dependent on both the primary caregiver and other family members (Forster et al., 2012). Typically, these family members have neither volunteered nor chosen to be the caregiver (Smith, Lawrence, Kerr, Langhorne, & Lees, 2004). Cameron et al. (2013) found that most families in their qualitative investigation of 24 family caregivers gathered and supported each other. There is however, as the previous literature review identifies, an increased strain for the carer and the wider family in their unexpected roles.

**Family changes and challenges**

A stroke event can cause significant changes to the family dynamics. Some families cope better than others, with the changes and challenges being influenced by the severity of the stroke. Gillespie and Campbell (2011) suggest that a stroke event can lead to family challenges and extend beyond the patient. Much of the research currently reported in the literature into the ‘family’ of a stroke survivor can be misleading, as studies include participants who are the spouse or sometimes the adult child, but might not investigate the experience of the whole stroke family. Moreover, the different family members of the stroke survivor could experience distress differently. For example, as Gillespie and Campbell (2011) identify, the partner of the stroke survivor might be affected by loss of intimacy, whereas the adult caregiver could face difficulty in balancing responsibilities for their own family. Further investigation into the wider family’s experiences is therefore needed. This further exploration can help identify the support needs of the wider family, where health providers can provide the appropriate intervention.
Cecil et al. (2013) highlights the negative impact on the caregiver’s family life after stroke. All 30 primary caregivers that were interviewed reported a change in lifestyle, which included a restriction to their former and social life, a loss of friends and a struggle with family finances. The caregivers needed help and support in their caregiving roles (Cecil et al., 2013). This study did include primary family caregivers who were not the spouse of the stroke survivor, however, only one participant from each family was interviewed, which once again limits the understanding of the wider, extended family’s experience.

Family relationships affected over the long term
Kitzmüller et al. (2012) interviewed 40 participants and revealed interesting themes which gave insight into the long-term experience of family life post stroke. One of the themes, ‘the family as a lifebuoy’, highlighted that family support is essential. The theme, ‘absence presence’, shed light on the relationship between the parent and the child. The study found major changes in the daily lives of family members and difficulty in their responsibly as a parent. The theme, ‘broken foundations’ identified changes in the marriage relationship and the theme ‘finding a new marital path’ also highlights the changes that can occur, and showed how the couples coped with the changes. Although the majority of the participants were stroke survivors and their caregivers, the wider family was also involved as they supported the caregiver and helped with the children. Kitzmüller et al. (2012) recommended that further investigation is required, especially into the experience of the stroke survivor’s children.

Family distress predictors
The impact of a stroke on the wider family varies between families and through different stages after a stroke, although there is little reported research. Gan, Campbell, Gemeinhardt and McFadden (2006) investigated 66 patients with acquired brain injury and 148 family members, to identify predictors that would influence the family system function. The families, which included the spouses, siblings and parents “reported significant distress in family functioning” (p. 587), which was associated with distress in the entire family system. Gan et al. (2006) also report that two of the predictive factors of increased family distress were caregiver strain and female gender in the person with the acute brain injury.

Effective family interventions
Illness in one family member can ultimately affect others in the family (Mattila, Leino, Paavilainen, & Astedt-Kurki, 2009). Mattila et al. (2006) undertook a systematic review of
international databases between 2001 and 2006. The authors investigated nursing intervention studies, which were targeted at patients with chronic diseases (stroke, cancer, Alzheimer’s) and individual family members. The results showed that the interventions, which included elements of teaching, counselling and education, were effective in relieving the burden and depressive symptoms in family members, and promoted their quality of life and ability to cope. Jones et al. (2013) identified the prevalence of psychological issues for both stroke survivors and their families. The authors mention that intervening at the psychological level can facilitate meaningful outcomes for both the stroke survivor and their family.

A family centred approach

As highlighted above, there is limited research which focuses on the experiences of the stroke survivor’s wider family. It is therefore important that research explores the experience of stroke families by including participants beyond the primary caregiver. Recent literature is also suggesting that family members need to be much more involved. The findings by Cao et al. (2010) “emphasize the importance of husband-wife dyad and a movement toward a family centred care approach” (p. 35). Visser-Meily et al. (2006) support the idea of a family centred approach for all the family members, which includes the stroke survivor. The authors support that a family centred approach should be considered throughout all the stages of the rehabilitation process. Smith et al. (2004) also identify the need for a family centered approach, which needs to be conducted prior to hospital discharge. A family centered approach is important during the rehabilitation process and up to three years after stroke onset, as shown in a study of 78 couples (Achten, Visser-Meily, Post, & Schepers, 2012).

Through the research studied, it is clear that efforts should be shifted from patient-centred rehabilitation to a family centred rehabilitation (Achten et al., 2012; Cao et al., 2010; Peyrovi et al., 2012). Healthcare and rehabilitation which focuses on the family as a whole could improve the effectiveness of the rehabilitation processes, as suggested by Visser-Meily et al. (2006) and thus improve the outcomes for both the stroke survivor and their families.

Further research needed into the wider stroke family

Most of literature above does highlight the significant impact of a stroke, specifically on the stroke survivor and the primary caregiver. Limited research has been conducted on the wider family and family relationships, which shows the need for further investigation. Furthermore, the literature suggests that more studies are needed to address the longitudinal impact on the
wider family. Therefore, further exploration specifically into the wider family’s experience over a two year period would be useful to gain a better understanding of their life changes and needs. The longitudinal impact of a stroke on the wider family (beyond the primary caregiver) remains limited, especially two years post stroke.

Summary

The literature review highlights the widespread impact of a stroke event, particularly on the primary caregivers. The research pertaining to the wider family is however limited, especially over the two year period following the stroke. The research identified multiple factors and influences that may contribute to the negative impact on the stroke survivors and caregivers.

The literature reveals well documented caregiver burden, distress, anxiety and many other negative consequences, as well as unmet support and information needs. Many of the studies show that caregivers also report a decrease in their quality of life and a change in their former role, especially for female caregivers looking after their husbands. However, both the stroke recovery and the caregiving roles are unique for different families, as determined by the severity of the stroke and a variety of other factors. Therefore, the stroke survivor and caregivers require personalised support needs throughout the post-stroke journey.

Recent literature suggests the importance of the movement towards a family-centred approach, which is to be considered throughout the entire rehabilitation process. This family-centred approach purportedly improves the effectiveness of the rehabilitation, as well as the outcomes for both the stroke survivor and their families, as the previous section highlights.

A lot of the current literature which focuses on the ‘family experiences’ rarely includes participants who are not the primary family caregivers. Due to the lack of research, this study aims to investigate the needs and experiences of both the caregiver and another family member of the stroke survivor. This will help to gain insight into the family members’ needs and the influencing factors. To date, very limited research has focused on the family’s experience over the two year period following a stroke.
Chapter Two:  The research methodology

This chapter will discuss the research methodology. Initially, the need for a qualitative study is discussed. The parent project is then introduced. Thereafter, hermeneutic phenomenology will be addressed and explored. The final section will then discuss the topic of rigour and how it relates to this study.

The need for a qualitative study

The literature review in chapter one highlighted that a stroke often has widespread consequences, affecting the stroke survivor, as well as the stroke survivor’s wider family. The literature also reveals that the impact of a stroke can affect families differently, depending on the severity of the stroke. Although there is a wide range of literature that has investigated the impact of a stroke on the primary caregiver, limited research has focused on the wider family, especially over the two year period following the stroke event. The lack of research has led to the medical system and healthcare professionals having a limited understanding about how the wider family is affected. This hinders the healthcare professional’s ability to provide appropriate intervention.

Assessing the physical progress of a stroke survivor may not always provide an accurate reflection of their recovery, or the burden that is placed on the wider family. This may be due to a decline in the stroke survivor’s mental and cognitive capabilities, such as mood swings, memory loss and change in personality. For example, the stroke survivor may improve in balance and coordination and therefore, quantitative investigation may suggest the stroke survivor is improving rapidly. However, failing to assess and identify the stroke survivor’s mental and cognitive decline could potentially cause healthcare professionals to miss the impact on the wider family. Therefore, an exploratory design was utilised to provide a better understanding of the families’ experience post-stroke.

Van Manen (1997) suggests that qualitative research is suitable in situations where little is known about a phenomenon and enables the researcher to explore a certain phenomenon in detail, without the restraint of prior beliefs or assumptions. Qualitative research attempts to understand, gain insight and describe human meaning, which is based on close examination of
spoken or written words (van Manen, 1997). A qualitative study, as decided by the parent project was judged as appropriate to better understand the wider families’ lived experience over the two year period following a stroke event. The interviews used in this study present rich data to contribute toward a better understanding of their two year journey.

The larger longitudinal parent project
This current study is a unique standalone investigation into the lives of one of five families from the larger, five year longitudinal project (see Appendix A). The larger project aims to improve support and outcomes for the families of a stroke patient after the stroke event. As this study focuses on the experience of the wider family two years after the stroke, it will contribute its data, data analysis and findings to the larger project. The larger project is collecting data over a five year period, between 2011 and 2015, for five different stroke families. There are at least two participants in each stroke family: the primary caregiver and another family member, for example, the daughter of the stroke survivor.

Hermeneutic phenomenology
This research study will continue the use of hermeneutic phenomenology as established by the parent project. This methodological approach is informed by the writings of Martin Heidegger [1889 – 1976] and Hans-Georg Gadamer [1900 – 2002] (as cited by Dowling, 2004; Laverty, 2003; Mackey, 2005), to provide a deep understanding and interpretation of the phenomenon of living as a stroke family over the two years following a stroke. Procedures for the study are guided by phenomenological methods described by van Manen (1997). Hermeneutic phenomenology provides a theoretical framework for this study which focuses on uncovering meaning in lived experiences pertaining to specific phenomena. There has been some confusion between the terms ‘phenomenology’ and ‘hermeneutic phenomenology’ and they can be used interchangeably, as Laverty (2003) explains, without distinguishing the historical and methodological differences between them.

Laverty (2003) also explains that “hermeneutic phenomenology is concerned with the life world or human experience as it is lived. The focus is toward illuminating details and seemingly trivial aspects within experience” (p. 7). This is to create meaning and achieve a better sense of understanding (Laverty, 2003). Similarly, van Manen (1997) describes that it is the study of the lived experience of a person or the life world. Research which utilizes a hermeneutic approach can be described as interpretive and concentrates on the historical
meaning of experiences and how they develop, which affects the individual being studied (Laverty, 2003). Furthermore, Laverty (2003) mentions, the two central positions of hermeneutics, which are prejudgement and universality, which Dowling (2004) explains in the following way; “the participants who express themselves and the persons who understand are connected by a common human consciousness, which makes understanding possible” (p. 35), which Laverty suggests should not, nor can be disposed of.

Phenomenology views human experience as a valuable source of knowledge (Mackey, 2005). Dowling (2004) mentions the role of the researcher in the ‘hermeneutic circle’ and explains that the researcher needs to remain ‘open’ and embrace what is meant by the other person, without attaching our own fore-knowledge. This helps to “understand the meaning of something held by another” (Dowling, 2004, p. 36). Finally, hermeneutic phenomenology attempts to understand “how people make meaning of their lived experience” (Starks & Trinidad, 2007, p. 1372), by the use of close analysis and deep description. Therefore, hermeneutic phenomenology was deemed as appropriate for this study, which was guided by the work of van Manen (1997) and will be explored in the ‘methods’ section.

A unique study
Hermeneutic phenomenology acknowledges that individuals have their own context and history that is incorporated into who they are as a person. This context or history influences how each person views the world, or the phenomenon. Therefore, the results from this study will be unique and a stand-alone piece of work, as each individual’s responses and experiences are different. Similarly, the researcher cannot be separated from their contextual underpinnings, which influences the way they view the world, analyse data, or report experiences. Each participant involved in the study has their own individualised context, and views on a phenomenon. Therefore, each smaller study within (and contributing to) the larger parent project will be unique and distinct from one another. Instead of finding one single answer or truth, phenomenology seeks to find a coherent and legitimate account by paying attention to the participant’s words (Pringle, Drummond, McLafferty, & Hendry, 2011). So even if the same participants are interviewed in a different study or at a different time period post stroke, the participant’s description of their experiences, as well as the researcher’s experiences will be unique. Each study can be conducted as an entity/research project in its own right, while informing the parent project.
Evaluating quantitative and qualitative research

The criteria applied when evaluating (and ensuring) quality is different between qualitative and quantitative research. According to Morse, Barrett, Mayan, Olson and Spiers (2002), the results of good quantitative research are valid and reliable, where validity means the study design should be suitable to measure what it set out to measure, whereas reliability means the results of a study should not fluctuate drastically when conducted among other populations that are comparable to the sample group. In qualitative research, however, rigour or trustworthiness has been suggested as an equivalent to validity and reliability (Morse et al., 2002). In other words, “rigour” can be viewed as the overall term for evaluating the reliability of qualitative research.

Rigour in qualitative research

In qualitative research, rigour can be seen as the integrity and competency of the research, or a way of showing how legitimate the research process is (Tobin & Begley, 2004). Without rigour, research can be seen as worthless, fictional, and potentially lose its utility, as Morse et al. (2008) suggest. Furthermore, Tobin and Begley (2004) suggest that “the rejection of rigour undermines the acceptance of qualitative research as a systematic process that can contribute to the advancement of knowledge” (p. 388). This next section will explore how rigour can be assessed.

Assessing rigour

There are different ways or criteria in which rigour can be assessed. Credibility, dependability, confirmability and transferability/fittingness are four common criteria that can be utilized as a framework for determining rigour in qualitative research (Cope, 2014; Houghton, Casey, Shaw, & Murphy, 2013; Stanley & Nayar, 2014). These four criteria were originally coined by Lincoln and Guba (1985), and will be discussed below in relation to the current study.

Credibility

The credibility of the research is concerned with the quality of the methodology that is used to do the study and can be achieved by choosing methods consistent with the research topic (Morse et al., 2002). Credibility can refer to the value or how believable the findings are, which can be achieved through different strategies such as member checking, peer debriefing, triangulation and prolonged engagement with the data (Houghton et al., 2013). Tobin and
Begley (2002) suggest similar strategies including “peer debriefing, prolonged engagement, persistent observation and audit trails” (p. 392). Darawsheh (2014) views reflexivity as a strategy to attain rigour in qualitative research, as well as an introspective process which helps the researcher become more ‘transparent’ when presenting their influence on the research process. Furthermore, reflexivity can be employed to help increase the confidence, congruency and credibility of findings as well (Bover, 2013).

To help establish credibility in this study, the above mentioned strategies were incorporated such as prolonged engagement with the data over a 12 month period and ongoing journal reflections. Furthermore, the process of data analysis included regular meetings with supervisors and peer researchers. These meetings were all audio recorded, where discussion and peer debating helped to ensure the findings were trustworthy and stayed true to the data.

**Dependability**

Reflexivity can also be viewed as a strategy that improves the dependability of the study (Darawsheh, 2014). Dependability ensures that consistency of the data analysis is kept transparent. This was achieved by making the study steps, considerations and decisions documented, making the study process clear and easily understood (Knudsen et al., 2012; Morse et al., 2002). An audit trail, as mentioned before, can be used to meet the criteria of dependability (Houghton et al., 2013). Dependability was achieved through continuous use of audio and written reflections when working with the data. Documents, ideas and preliminary findings are provided (Appendix B) which show the development of themes.

**Confirmability**

The accuracy and neutrality of the data can be referred to as the confirmability, which is closely linked to dependability (Tobin & Begley, 2004). Confirmability can be demonstrated by describing how interpretations and conclusions are established, and by illustrating that the findings are directly derived from the data (Cope, 2014). Furthermore, Cope (2014) suggests that confirmability can be demonstrated by “providing rich quotes from the participants” (p. 89), which gives a picture of the emerging themes. Some of the participants quotes from this study are available in the ‘development of themes’ section in Appendix B. Direct quotes from the transcripts are also provided in part two of the study, where they are discussed. Presenting the participants direct quotes helps to further establish the trustworthiness of the study, where the reader can agree with researcher’s interpretation or differ in opinion.
Transferability

Houghton et al. (2013) explain, transferability (or fittingness) “refers to whether or not particular findings can be transferred to another similar context or situation” (p. 13), where the emphasis should be on ‘thick descriptions’. Appendix B provides a presentation of this study’s findings with the use of mind-maps, figures and direct quotations. Graneheim and Lundman (2004) suggest that the transferability of the findings can be enhanced by vigorously presenting the findings, with the appropriate quotes, however, it is also the description of the context of the study and the methods that contributes to the transferability. Regardless of what is done, the reader ultimately has to decide whether the findings are transferrable to another context or not.

Rigour was enhanced by discussing different interpretations of the same data, between the researcher and two experienced supervisors. This discussion led to an agreement on the different themes and sub-themes. One example of this was the evolution of the theme ‘trapped’ into the theme of ‘hostage to duty’ (see Appendix B, mind map 1). To further enhance rigour, Braun and Clarke’s (2006) six step approach to thematic analysis was utilized, in addition to the six steps outlined by van Manen (1997), which are discussed in the methods section below. The framework outlined above by Cope (2014) and Houghton et al. (2013) also helped to set in place a trustworthy qualitative study, which is unbiased and true to the data obtained from the interviews. The following section will discuss the methods used in this qualitative study.

Methods

As the methodology was discussed in the previous section, this section will focus on how the study was conducted. Van Manen’s (1997) approach to hermeneutic phenomenology will be explored. Later on in the chapter, the six phase guide to thematic analysis by Braun and Clarke (2006) will also be discussed. The work of van Manen (1997) and Braun and Clarke (2006) proved to be very useful, enabling the phenomenon to be truthfully explored, as well as increasing the trustworthiness of this study. The rest of this section also discusses participant recruitment, ethical considerations, the process of data collection and data analysis.
Van Manen’s six step approach

The six step approach by van Manen (1997) provides a ‘methodical structured’ approach for the entire research method (1997, p. 30). Van Manen’s approach provides some structure but also gives flexibility to emphasize certain steps. This allows the researcher to move back and forth between the steps, which can be a circular and repetitive process. The six steps are explained below.

Step one – Turning to the nature of lived experience

This step involves formulating a research question. The phenomenon of interest in this study was the experience of being a family member of a stroke survivor. To get a better understanding of the ‘nature of lived experience’, the researcher “sets out to make sense of a certain aspect of human existence” (p. 31), as van Manen suggests. This involves orienting to the phenomenon, formulating the phenomenological question and explicating assumptions and pre-understandings (van Manen, 1997). The researcher for this study was oriented to the phenomenon through discussions with the parent project research team. The phenomenological question “what is the longitudinal experience of becoming and living as a stroke family/whānau?” had already been formulated within the parent project. The researcher also explicated his assumptions and pre-understandings through reflecting on his knowledge about stroke and his previous experience with stroke. This was done by the use of an interview with a classmate.

Step two – Investigating experience as we live it

This step is concerned with methods used to investigate the question established in step one, for example, the use of in-depth face-to-face semi-structured interviews as discussed earlier on. The interviews enabled the researcher to probe and explore the participants’ own unique experience through the use of open ended questions and specific probing questions. The researcher set out to make sense of the participant’s life and story, exploring their journey. The research questions were therefore targeted specifically to what the participant was experiencing at the time of the interview and how their life had changed as a result of the stroke. Therefore, the interviews were seen as an appropriate method to execute step two.
Step three – Reflecting on the essential themes which characterize the phenomenon
This step emphasizes the analysis process, which includes reflecting on all the possible themes which were identified within the data. Van Manen explains that this reflection process consists of “reflectively bringing into nearness that which tends to be obscure” (van Manen, 1997, p. 32), and believes that any experience or activity can be questioned about what it is that constitutes the nature of that particular lived experience. Within this step van Manen offers some processes for uncovering thematic aspects of the phenomenon (data analysis), which are explored below.

Step four – Describing the phenomenon in the art of writing and rewriting
Again, this step is also particularly important in the analytic phase. Through writing and rewriting, the researcher intends to portray the participant’s feelings and thoughts, or at least give an accurate account of his or her experience. It needs to be mentioned that “a phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description” (p. 31), as van Manen explains. Nevertheless, the process of writing, reflecting and rewriting was done by the researcher for this study. This writing and rewriting shifted the analysis to a deeper level and aimed to provide precision or fullness of detail.

Step five – Maintaining a strong and orientated relation to the phenomenon
In this step, van Manen explains that the researcher needs to pay special attention and stay focused on the research question. Van Manen puts it this way, “Unless the researcher remains strong in his or her orientation to the fundamental question... there will be many temptations to get side-tracked or to wander aimlessly and indulge in wishy-washy speculations” (van Manen, 1997, p. 33). As discussed previously, the interview schedule helped to remain focused the on the research question but also gave the participants the opportunity to tell their story and experience. Through the writing and rewriting phases of the data analysis, the researcher kept asking himself the question “so what?” and “what is this telling me?” For example, “what is this [data from a previous transcript] telling me about the experience of being a family member of a stroke survivor at 18 months?” A question like this helps the researcher maintain a strong and orientated relation to the phenomenon.
Step six – Balancing the research context by considering both the parts and the whole

Finally, van Manen states that the sixth step requires the researcher to constantly consider the context or the ‘total textual structure’ (p. 33). Van Manen also advises that “at several points it is necessary to step back and look at the total, at the contextual givens and how each of the parts needs to contribute toward the total” (p. 34). One way that the researcher was able to consider the context as a whole was through summarizing each interview transcript into one A4 page (Appendix C), and then reviewing and compiling every single summarized page to create a timeline over the two year period (Appendix D). This enabled the researcher to see the development of certain themes, for example, the overarching theme ‘hostage to duty’, as a summary of all the previous experiences gave the overall context. As stated earlier, the researcher can move up and down between these six steps. Van Manen explains that there may be a ‘dynamic interplay’ among these six research activities, instead of having a strict starting or finishing point.

Participant sample and recruitment

In contrast to quantitative studies, this qualitative study utilized a small sample size with an emphasis on gathering deep rich data, which gave insight into the participants’ individual and unique experience of being the wider family of the stroke survivor. This study was allocated a family that was already enrolled with the larger parent project.

Sampling and inclusion criteria

The same inclusion criteria that was used in the larger project was utilised in this study. Both the primary caregiver and another member of the wider family consented to participate in the study. The stroke event had to be the first ever stroke for the stroke survivor. Participants were contacted and had to agree to be interviewed (as they did for the previous interviews at different time points after the stroke). The process of gaining consent enabled the interview to take place at the two year mark post stroke. The exclusion criteria used by the larger project was also adopted for this study: minors under the age of 16 were excluded from participating in the study. To enable exploration of the phenomenon of the wider family’s experience, this study required the primary caregiver and at least one other family member to be interviewed. By having at least two family members partake in the study avoids the issue of limiting the experience to only the primary caregiver. This way, the extensive impact can be explored on the wider family.
Recruitment
After patients were admitted to the stroke rehabilitation ward at an Auckland hospital, the clinical staff identified potential participant families, who were invited to participate in the five year longitudinal study, which would involve interviews at different time points. The willing participants were provided with an information sheet (Appendix E) and their contact details were passed on to the parent project’s lead researcher. The lead researcher then contacted each of the participants and provided all the necessary information. Arrangements were made to sign consent forms and to organise the interviews.

For this study, the lead researcher of the parent project once again contacted the participants to see if they were still willing to participate in the study and to be interviewed again at two years after the stroke. Once consent was granted, the researcher for this study then contacted the participants himself, in order to gain verbal consent and organise an interview at a convenient date and time, which happened to be exactly one week after the two year anniversary since the stroke.

The Participants
Two people who were family members of the stroke survivor participated in this study. These two participants and the stroke survivor are recognised as family three in the larger project. Family three are Pakeha New Zealanders. The male ‘stroke survivor’ was 76 years of age at the time of the ischaemic stroke, on the 11th October 2011. Initially hospitalised in acute facilities and rehabilitation wards, he was discharged home on the 25th November 2011. He has made significant progress post stroke but still lives with residual left hemiparesis, which negatively affected his vision in the left eye (right eye is prosthetic) and uses a walker for mobilisation. He also has a pre-existing heart condition, and experienced a heart attack many years prior to the stroke event.

Participant one (P1) is the 71 year old wife of the stroke survivor and mother of participant two (P2). P1 has not been in paid employment since having her children. She lives in her own home, a two bedroom unit in a retirement village. P1 and the stroke survivor had planned the move to the retirement village prior to his stroke, but the actual process of moving to a different home occurred while the stroke survivor was in acute and rehabilitation services.
Participant two (P2) is the 48 year old daughter of P1 and the stroke survivor. P2 is married, with two school aged children and she lives in her own home about 30 kilometres from P1 and the stroke survivor. Her father-in-law had a stroke in 1997 and made a good recovery.

Ethical concerns
Ethics approval for this study has been granted, in conjunction with the larger parent project by the Northern X Ethics Committee (Appendix F), which included the requirement for consultation with Maori. Approval was also received from the Waitemata District Health Board’s Awhina Knowledge and Research Centre (Appendix G), which included consultation and approval from the Nga Takaki Maori Research Review Committee. The research process and consultation were informed by the ‘Guidelines for Researchers on Health Research Involving Maori’ (Health Research Council of New Zealand, 2010), which acknowledged and took into consideration the Treaty of Waitangi. Although ethics approval had been granted, the researcher had to be mindful of other relevant ethical considerations. These include; obtaining participants consent prior to interviews, giving the participants the opportunity to review the transcripts for accurate representation, security and anonymity of the data, and finally the ability for participants to withdraw from the study.

Confidentiality
Confidentiality of the participants, interviews and transcripts was maintained by keeping all recorded information in secure, password protected computer files. The anonymity of the participants is preserved by using identification numbers in the data collection process. The data were anonymised and sent back to the lead researcher of the larger parent project. The transcriptionist was also asked to sign a confidentiality agreement (Appendix H). Both participants will be offered a copy of the final findings or articles. This will be done following the completion of the study or publication of articles. In accordance with Unitec Institute of Technology’s regulations for research projects, all interview recordings, transcripts, emails and analysed data will be kept for five years following completion of the larger project. After this time, all documents relating to the study will be deleted and destroyed.

Participation
Verbal consent was gained when organising an interview time, and again before the interview commenced. The participants were asked to choose the interview location. Even though participants had the right to a support person, the participants chose to be interviewed alone.
and in their own home at a convenient time. The researcher thanked both participants for their continued participation throughout the two year investigation and they were given a petrol voucher straight after the interview. No participants withdrew from this study.

**Emotional issues**
There was a possibility that sensitive topics and emotions could surface during the interviews, as the participants were asked to explore and articulate their own experience of how the stroke had impacted on their own lives. Memories of different issues may potentially have surfaced emotional feelings, associated with their experience. If a participant became overly emotional or distressed, the interview would have been stopped and assessed at the time. If required, the participants would have been offered a referral for counselling. As the researcher does practical work with members of the public (as a requirement of the degree being studied), facing issues of the patient breaking down or experiencing distress were topics that were covered in previous study. No participants experienced distress such as crying. In fact, both participants reported the benefit of being able to share their experience.

**Participant passing away**
One of the potential obstacles to the research was the death of either the stroke survivor or the wider family who would be interviewed. Fortunately, no participants passed away in this portion of the wider study.

**Data Collection**
To gain an understanding of what is currently known about the phenomenon of the lived experience of the wider family, a literature review was conducted. Gaps were identified in the literature and these topics were included into the semi-structured interview schedule.

**Preparing for interviews**
The transcripts from six different previous interviews were reviewed, which involved listening to the audio recording and reading through them, helping to prepare an interview schedule for this study (Appendix I). The six interviews were conducted with both participants at six weeks, 12 months and 18 months. These earlier interviews were conducted by clinical research assistants and along with the interviews at two years will contribute to the data set for the larger parent project.
Reviewing the previous transcripts gave the researcher for this study the opportunity to make notes and identify different types of questions and the type of response they elicit. Appendix B, figure 2 shows appropriate use of closed questions to verify known fact, for example the date of the stroke. Open-ended questions were predominantly used in this study. For example, the opening question in the two year interview was “Tell me what was going through your mind on that day?” This style of questioning gave a rich account of the participants experience (van Manen, 1997), as they could openly express their feelings and talk about the journey. Knudsen et al. (2012) state that the interviewer should attempt to use open-ended questions in semi-structured interviews. Follow-up and probing questions were also incorporated to give some direction, while still allowing the participants to tell their story, and further explore certain topics.

The review of the previous interviews also helped to produce follow-up questions for the interviews at two years post stroke, where some topics were further explored. An example of this was when Participant one was asked about her frustrations, as that was an issue in the previous interview at 18 months post stroke (Appendix B). The questions predominantly focused on the participant’s experience at the time of the interview. Once a final draft of the interview schedule was obtained, practice interviews were conducted with the researcher and one of the research supervisors. These practice interviews were audio recorded to identify any areas of weakness (questions that were closed and gave little information in the response) and strengths (questions that followed up on certain topics and probed the interviewee to further explain what was said and meant). Verbal feedback was also given from the interviewee (research supervisor), who had experience in completing a qualitative study which involved multiple interviews and hermeneutic phenomenology.

The interviews
As mentioned before, the study participants were contacted to organise a time and place for the interview two years post stroke. The interviews were semi-structured face-to-face in-depth interviews. In semi-structured interviews, the researcher asks the participants to give an account of their experience of the phenomenon under study, where the interview evolves as a dialogue between the interviewer and the study participant (Knudsen et al., 2012). Therefore, this study used semi-structured interviews, as they appeared to be the most appropriate form of data collection for this study. The interviews were guided by an interview schedule, current literature, and phenomenological underpinnings as described by van Manen (1997).
The interview schedule (Appendix I) was developed from a combination of previous interviews, which provided some structure but also allowed participants the freedom to express what they considered important, and describe their own experience at the time of the interview. The purpose of conducting interviews was to collect information rich data that portray how their experiences had changed over the two year journey. Van Manen (1997) suggests that interviewing the participant allows the researcher to remain focused on the lived experience, in comparison to a written journal which becomes reflective. In addition, researching the lived-experience is an essential requirement to help provide a better understanding of a phenomenon (Kitzmüller et al., 2012).

Participants were given plenty of time during the interviews to consider and reflect on their issues, which can keep the interview atmosphere relaxed and open (Knudsen et al., 2012). In addition to this, the participants were asked where they would like the interview to take place (which was at home for both participants), and there was some small talk before the ‘official’ interview was conducted to create a relaxed relationship between interviewer and interviewee. The wife and the daughter of the stroke survivor were interviewed separately. The interview with the wife was 55 minutes in duration, and the interview with the daughter was one hour and eleven minutes in length. Although a suitable length for a semi-structured open-ended interview varies depending on the participants’ experiences with the topic, Knudsen et al. (2012) suggests that one to two hours of dialogue is appropriate. This length of time allows the participants to summarize the accounts that they find significant and meaningful to the topic, and also allows and the interviewer to ask more in-depth questions concerning specific aspects of their experiences.

Conducting interviews longer than two hours will not necessarily result in richer data (Knudsen et al., 2012). Once the participants had shared their experiences and everything in the interview schedule was covered, the participants were asked ‘given that these series of interviews is all about your experience, your perceptions and what you’ve been feeling, is there anything that we haven’t covered today about what you’ve experienced that we might not have spoken about?’ Both participants replied with a ‘no’. The participants were then thanked again and the interview stopped.
Data Set
Braun and Clarke (2006) explain that the “data corpus refers to all data collected for a particular research project, while data set refers to all the data from the corpus that is used for a particular analysis” (p. 79). The data set for analysis in this study included transcripts of interviews from 6 weeks, 1 year, 18 months and 2 years post-stroke, with a total of eight transcripts.

Reflective Journal
A reflective journal was used to write down thoughts and feelings throughout the research process. At times, an electronic version was also used to type down certain ideas, thoughts or other reflections. In addition to this, audio recordings were used to verbally articulate ideas and further reflect. These audio recordings were also utilised to allow contemplation, review of the participants’ experience and analysis of themes and findings. This enabled the researcher to go back and reflect on previous time periods, for example, the moments just before or after the interview was conducted. See Appendix J for an excerpt.

As highlighted earlier, reflexivity can be seen as the process of self-reflection that a researcher engages in, or an “introspective process” (Darawsheh, 2014, p. 562). This helps to create an awareness about feelings, actions and perceptions. Darawsheh also views reflexivity as a strategy to meet the criteria of rigour and improves the transparency in the researcher’s role in analysing data, which can be used alongside peer debriefing and audit trails to promote rigour.

Data Analysis
Thematic analysis
Thematic analysis can be used to help identify, analyse and report patterns or themes within the data (Braun & Clarke, 2006). Thematic analysis, as van Manen (1997) states, is the “process of recovering a theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (p. 78). Thematic analysis also offers a more accessible form of analysis, in comparison to grounded theory and discourse analysis, especially for researchers who are early in their qualitative research career. (Braun & Clarke, 2006). Therefore, thematic analysis was deemed as appropriate and was used for this study.
There is “no one set of guidelines to follow” (Braun & Clarke, 2006, p. 93) when it comes to thematic analysis. Themes or patterns within the data can be found in an inductive way or a deductive (or theoretical) way, as explained by Braun and Clarke (2006). An inductive approach means that the identified themes are strongly connected to the data. In addition, Braun and Clarke (2006) suggest that inductive analysis is “a process of coding the data without trying to fit it into a pre-existing coding frame, or the researchers’ analytic preconceptions” (p. 83). In this sense, an inductive approach to thematic analysis is driven by the data and was used in this study, making it unique and a study that stands-alone from the parent project.

Thematic analysis typically focuses on one level of analysis to identify themes. Braun and Clarke (2006) suggest that with a semantic approach, “the themes are identified within the explicit or surface meanings of the data, and the analyst in not looking for anything beyond what the participant has said” (p.84). To obtain a deeper understanding, thematic analysis at a latent level was used to identify underlying themes. The development of these themes involves interpretative work, which is not just descriptive (Braun & Clarke, 2006). In this study van Manen’s (1997) approach to isolating thematic statements was used alongside the step-by-step guide to doing thematic analysis by Braun and Clarke (2006).

**Van Manen’s approach to thematic analysis**
Van Manen (1997) describes three approaches to help uncover or ‘isolate thematic aspects’ (p. 92), which include the wholistic or sententious approach, the selective or highlighting approach and finally, the detailed or line by line approach. In the wholistic reading approach, the researcher looks at the text as a whole and then formulates a phrase which attempts to express the fundamental meaning of the text as a whole. The highlighting approach requires listening to or reading the text several times, and asks the question “which statements or phrases seem particularly essential or revealing about the phenomenon or experience being described?” (1997, p. 93). The researcher then highlights or underlines these statements, as the researcher did through every interview transcript (Appendix B, figure 2). Finally, in the detailed approach, the researcher looks at every single sentence or groups of sentences and asks, as van Manen proposes “What does this sentence, or sentence cluster reveal about the phenomenon or experience being described?” (p. 93). These three approaches were used in this study.
Six step approach by Braun and Clarke

The six step guide described by Braun and Clarke (2006) was also utilized. The six steps almost parallel the work of van Manen (1997) and the approaches complement each other.

Step one, is a process where the researcher familiarizes themselves with the data. This usually involves ‘repeated readings’ (Braun & Clarke, 2006, p. 16), where the researcher looks for patterns and the meaning of what was said. Step two, involves generating initial statements or words formulated from what was ‘in’ the data. This can be an ongoing organic process (Tuckett, 2005). In this study, this was done by manually writing down notes and highlighting key words or phrases (Appendix B, Figure 2). Step three involves searching for themes, where the different statements identified in phase two are gathered. The researcher then matches the preliminary themes with their data extracts (direct quotes) which back up and support the idea or theme. For an example from this study see Appendix B (Figure 1). The different themes are then discussed and slowly start to develop (Appendix B, mind map 1 – 4). Step four involves refining the themes where Braun and Clarke suggest the “data within themes should cohere together meaningfully” (p. 91). Step five involves ‘defining and naming themes’. In this study, this was completed after a thematic map was created in the previous step. As part of the refinement process, subthemes were also identified. Finally, the sixth step is the task of the write-up or the report, which Braun and Clarke suggest should provide sufficient evidence of the themes and “tell the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis” (p. 93).

Because of the parallels in the approaches and guidelines offered by van Manen (1997) and Braun and Clark (2006) both were used alongside each other in this study.

Doing the analysis

All the interviews were audio-recorded and then transcribed verbatim by a professional transcriptionist. Once completed, transcripts were then checked for accuracy against the audio-recording and anonymised by the researcher. The transcripts needed to accurately represent what was said from a verbal account, in order to portray information that was true to what the participant said and what was meant. This included attention to nuances of language and punctuation, as punctuation can alter the meaning of a sentence. For an example “I hate it, you know. I do,” Versus “I hate it. You know I do” (Braun & Clarke, 2006, p. 88). The participants were also given the opportunity to review the transcripts and make any changes if
they wished, however, no changes were made. Final transcripts were read and re-read by the researcher multiple times to ensure familiarity and once familiar with the data, data analysis began.

A hard copy of all eight interviews was printed off and these used for analysis (six previous data sets and the two interviews conducted two years after the stroke onset). The three approaches to isolating thematic statements described by van Manen (1997) were incorporated in the process that the researcher used to go through each interview transcript, line by line and highlight words or phrases that seemed of significance and that reoccurred (steps one and two - Braun & Clarke, 2006). Once significant words and phrases had been identified for each interview, these were gathered together and themes/subthemes were being explored. Brainstorms were done with two supervisors which helped to group preliminary themes (Appendix B, mind map 1 -3), until eventually, themes started emerging. The themes were then tested in context of the interview and what was said by the participants to ensure that they were ‘true’ to the data (steps three and four - Braun & Clarke, 2006).

During the entire analysis process themes and experiences were reflected on, as well as contexts and specific use of words from the family. This continual reflection helped to ensure accuracy in representing the participant’s experiences of the phenomenon. The emerging themes were presented to a class of fellow students and research staff, which gave valuable feedback towards identifying themes or topics that may have been missed. In order to give a better understanding and maintain orientation to the phenomenon of life two years after the stroke, each transcript was summarised into one A4 page to give an overview of the participant’s experience. The summary page included the key ‘stand out’ statements, which were backed up by several quotes from the participants (Appendix C). Once this was done for every transcript, a timeline was created to give a bigger overview of the two year journey (Appendix D) which helped to identify emerging themes.

After the emerging themes had been identified and backed up with quotes, an even more in-depth reflective process was undertaken, which van Manen (1997) suggests, aiming to maintain a strong orientation to the phenomenon. This was done by repeated readings and spending a considerable amount of time analysing. Braun and Clarke (2006) warn that this process can be endless and go on “ad infinitum” (p. 92). Again, the findings from the more in-depth analysis were discussed with two research supervisors. The findings were questioned as
to ‘how’ they were obtained, which were justified by the context of what was said and how it was said in the interview. For example, the tone of the participant’s voice and body language when talking about her frustrations, as well as several direct quotes. This process helped the emerging findings to stay ‘true’ to the data and the participant’s experience.

Another research presentation was made in a research forum, which enabled the experienced research staff and students who were completing a thesis to query or challenge any themes. This helped validate the findings. A third presentation to a class of nursing students was done. The presentation was also used as an opportunity to obtain help from the audience, to choose between the best quotes that would help strengthen certain themes. A class vote was done, where quotes were shown on a slide show. The audience was then asked by show of hand to nominate which quote they thought best fit the description of a theme. The quotes with the higher amount of votes were used.

**Changing Themes**

The themes for the participants changed slightly over the course of data analysis. This was as a result of questioning the data and discussions between the researcher, other researchers (also involved in the larger longitudinal parent project), and the research supervisors. For example, a subtheme of ‘accepting and moving on’ emerged, however, once questioned and discussed, the subthemes evolved into a slightly adapted version of ‘coming to terms and moving on.’ Themes were created through a discussion of ideas and were written down on a white board (Appendix B). Specific words used by the participants were also analysed (in context). The meanings of these words were looked up and synonyms were also considered, to see whether they accurately summed up the participants’ experience. For example, one participant used the word “unsure,” when talking about her feelings of the future. The word “uncertainty” was used instead.

The manuscript in the next part will include an in-depth description and interpretation, and discussion of the study’s findings, which slowly evolved with much discussion, mind maps, writing, testing, and rewriting.
References


Saban, K. L., & Hogan, N. S. (2012). Female caregivers of stroke survivors: Coping and adapting to a life that once was. *Journal of Neuroscience Nursing, 44*(1), 2-14. doi: 10.1097/JNN.0b013e31823ae4f9


Part Two: The Manuscript

The following manuscript is structured according the guidelines specified by the *Journal of Clinical Nursing* (Appendix K). The referencing however is yet to be formatted as per journal requirements. The manuscript starts with the abstract, and then continues with the introduction, background, methodology, findings and then concludes with the discussion.
A longitudinal hermeneutic enquiry into the lived experiences of the wider family of a stroke survivor at two years post stroke

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A longitudinal hermeneutic enquiry into the lived experiences of the wider family of a stroke survivor, at two years post stroke

ABSTRACT

Aim: To explore the lived-experiences of two family members of a stroke survivor.

Background: The diverse consequences of a stroke upon the stroke survivor have been established in literature. The concomitant effect a stroke has on the wider family members, however, has been limited. The widespread consequences of a stroke are important because it may negatively affect both the caregiver and the wider family. This study explores the lived-experience of two family members of a stroke survivor, two years post-stroke.

Design: A qualitative exploratory study using hermeneutic phenomenology.

Methods: Purposive sampling recruited a family with two participants. Data were collected at six weeks, 12 months, 18 months and 2 years post-stroke through face-to-face, open interviews. A hermeneutic phenomenological approach guided thematic analysis of data.

Results: The lived experience of both participants varied quite considerably, in regards to the effect of the stroke and day to day life. A theme of ‘Hostage to Duty’ was strongly identified with the wife of the stroke survivor, whereas a theme ‘Back on Track’ was identified with the daughter.

Conclusions: The lived experience of the family of a stroke survivor is unique for each individual and varies considerably. The findings of this study highlight the difference in the participant’s told-story over the two year period, from stroke onset. The wife of the stroke survivor experienced significant caregiver burden over the two year period post-stroke. The impact of the stroke on the daughter’s life however, was considerably less burdensome.

Relevance to clinical practice: The findings from this study highlight the significant burden on the primary caregiver of the stroke survivor, which potentially increases over time. Therefore, the wider family’s individual needs should be assessed and identified, where appropriate support and intervention can be provided accordingly.

Key words: Stroke, hermeneutic phenomenology, stroke survivor, post-stroke, family, experiences.
Summary box: ‘What does this paper contribute to the wider global clinical community?’

- Identifies the unique lived-experience of different family members of a stroke survivor
- Shows the severe negative impact of the stroke on the caregiver, when there is a decline in the mental and cognitive capabilities of the stroke survivor.
- Highlights the potential for a continual increase in caregiver burden over time

INTRODUCTION

This study is part of, and contributes to a larger five year longitudinal parent project. The larger project originated in 2009 when a Charge Nurse Manager from a local hospital approached the Department of Nursing at Unitec Institute of Technology about possible research collaboration. This was as a result of the Charge Nurse Manager identifying a need to improve support for families of clients who have had a stroke. The parent project recruited five stroke families. There was variation in the number of people from each family, from two to four participants. This study focused on one stroke family, who had two participants, to explore their lived-experience over the two year period following the stroke.

A stroke event can cause many survivors to live with impairment and in need of significant daily support (McNaughton, McRae, Green, Abernethy, & Gommans, 2014; Stroke Foundation of New Zealand, 2013a). The support needs often cause stroke survivors to depend on their primary caregivers, who are usually family members (Parag et al., 2008). Gillespie and Campbell (2011) identify a lack of available research into the experience of the wider family of a stroke survivor, which this study investigates.

A family member who adopts the main caregiving role is usually the spouse (Draper & Brocklehurst, 2007; Tunney & Ryan, 2014). To provide the on-going help and support needs for a stroke survivor, the caregivers usually sacrifice their time (Gosman-Hedstrom & Dahlin-Ivanoff, 2012) and can be negatively affected. Moreover, the caregivers can feel unprepared in their care giving role, as Creasy, Lutz, Young, Ford and Martz (2013) found in their study of 17 caregivers. It is crucial to understand the experience of these caregivers, as well as the wider family so that proper intervention and support can be provided. Ultimately, this may increase the sustainability of the family caregiving and improve outcomes for the entire family. There is a lack of research investigating the wider family’s experience.
BACKGROUND

Stroke is the third leading cause of mortality worldwide (Baumann, Le Bihan, Chau, & Chau, 2014) and the third largest killer in New Zealand. Approximately 9000 people have a stroke annually, which can leave survivors with impairments, who may require significant daily support from their caregivers (Stroke Foundation of New Zealand, 2013a). Feigin et al. (2014) suggest that the number of stroke survivors in New Zealand is projected to increase in the future, with annual health costs potentially exceeding $700 million if no effective primary stroke prevention strategies are introduced. Although the outcome of a stroke depends on the area and severity of brain tissue necrosis, stroke is a major cause of adult disability (Stroke Foundation of New Zealand, 2013b). The impact of a stroke is well established in the acute and rehabilitation period, however few studies have looked at the impact beyond six to 12 months, particularly in the extended family of the stroke survivor.

Caregiver burden is a common consequence of stroke (Bastawrous, 2013; Brinda, Rajkumar, Enemark, Attermann, & Jacob, 2014; Jaracz, Grabowska-Fudala, & Kozubski, 2012; Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014). The degree of disability in the stroke survivor influences the impact on the caregiver (Jaracz et al., 2012). Lurbe-Puerto et al. (2012) found that some of the reported repercussions on the 46 caregivers interviewed included decreased time for relaxation, deterioration in health and altered sex life. Lurbe-Puerto et al. (2012) also state that the caregivers represent “a population at risk, which healthcare professionals can help by providing domestic assistance, undertaking coaching activities, encouraging favourable attitudes and offering reassurance” (p. 726).

Many other negative impacts on the primary caregiver have been established, such as decreased quality of life (Carod-Artal, 2012; Hussain, Abdullah, Esa, Mustapha, & Yusoff, 2014; Ogunlana et al., 2014), anxiety and depression (Balhara, Verma, Sharma, & Mathur, 2012; Denno et al., 2013; Jaracz et al., 2012) and change of role (Cao et al., 2010). The potential negative impact on the life of the caregiver is wide-ranging. Therefore, it is important for health professionals to identify and understand to what extent the caregiver and family is affected, specifically over the two year period following a stroke. This can enable health care professionals to support caregivers in their role, to increase the sustainability of family caring for stroke survivors, as well as improve the outcomes for the entire family. The reviewed literature highlights the importance of further investigation into the lived-experience of the wider family.
METHODOLOGY

Aim: To investigate the phenomenon of living as the wider family of a stroke survivor.

Methodology: As little is known about the longitudinal lived-experience of the wider family of a stroke survivor, this qualitative study utilised a hermeneutic approach to obtain rich and meaningful data.

Participants: Purposive convenience sampling was used to recruit participants. The participants were first recruited to a larger five year longitudinal project, from a stroke rehabilitation ward. The two participants in this study were family members of a first time stroke survivor; the wife who is the primary caregiver, and an adult daughter.

Data collection: The participants were interviewed at six weeks, 12 months, 18 months, and 24 months post-stroke, which were audio recorded and then transcribed verbatim. The semi-structured interviews were conducted in the participant’s home at a time that suited them. The interviews held at 12, 18 and 24 months post-stroke used interview schedules, informed by the literature, clinical expertise and the previous interviews with each participant. These earlier interviews were conducted by different researchers, which contributed to the larger parent project. Interview duration ranged from 55 to 71 minutes.

Ethics: The Northern X Regional Ethics Committee (Ministry of Health, New Zealand) granted ethical approval for this study (NTX/11/EXP/062). Ethical considerations included patient confidentiality and potential harm. Participants signed consent forms at the beginning. No incidences occurred. Participants were offered a copy of the transcripts if they wished and were given up to two weeks to withdraw their data from the study. No patients withdrew. Patient confidentiality was preserved by password protection of the participant’s information and anonymised data. The transcriptionist signed a confidentiality agreement before transcription commenced. No incidences occurred.

Data analysis: The data set included a total of eight interviews. Data analysis utilised hermeneutic phenomenology, informed by the writings of van Manen (1997), and used thematic analysis informed by Braun and Clarke (2006). The emerging themes and sub-themes were discussed and developed further with two experienced research supervisors.
Rigour: Rigour can be seen as the integrity or a way of showing how legitimate the research process is (Tobin & Begley, 2004). Rigour was established through the guided work of van Manen (1997). The six step by Braun and Clarke (2006) was also utilised to ensure the data analysis produced findings that were ‘true’ to the data, which accurately portrayed the experience told by the participants.

FINDINGS

Themes and sub-themes

There were two main themes and several sub-themes that emerged in the findings that related to the individual participants own unique experience:

1) Hostage to Duty
   a. Supported through shock and uncertainty
   b. Frustrating, draining but not complaining
   c. Watching, wishing and waiting

2) Back on Track
   a. Supported through shock and uncertainty
   b. Coming to terms and moving on
   c. Accepted reality

The overarching theme of Hostage to Duty relates to participant one (P1), whereas the overall theme of Back on Track relates to participant two (P2). Initially, both participants go through a similar experience, where a sub-theme of ‘supported through shock and uncertainty’ emerges straight after the stroke event. Once both participants overcome the unexpected feelings of shock, the experiences of both participants diverge.
THE JOURNEY OF PARTICIPANT ONE

Hostage to Duty

For P1, the journey leads into the main theme of ‘Hostage to Duty’. This theme slowly develops over the two year period for the wife of the stroke survivor. After the initial experience of shock, the sub-theme of ‘frustrating, draining, but not complaining’ emerges, specifically around 12 to 18 months. Following this, the sub-theme of ‘watching, wishing and waiting’ surfaces around 24 months after the stroke. The impact of the stroke on the wife can be seen from the onset, where there is a gradual increase in caregiver strain. A few factors which contribute to the increased strain for P1 are: a duty to care for her partner, a loss of personal time and a decline in her spouse’s cognitive ability such as memory loss. Some of the sub-themes and underlying issues resurface and show at different stages. For example, the experience of uncertainty was revealed initially and then again at two years post-stroke. Some themes and sub-themes do, however, ‘overlap’ slightly, instead of being categorized perfectly and separate from one another. The themes and sub-themes are explored below.

a. Supported through shock and uncertainty

The wife of the stroke survivor described the stroke event as an unexpected and traumatic experience. The stroke happened suddenly and without warning. The event was traumatic because it was unknown whether the stroke survivor would survive the night in hospital. To add to the stress, the stroke survivor had a minor heart attack the following evening. The family supported each other during these unanticipated events. P1 and her spouse were in the process of moving to a retirement village when the stroke occurred, making it an even more traumatic experience.

“Yeah, it was quite traumatic. Yeah, thinking I’m never going to be ready in time” (p. 2, Int. 1).

Although the stroke event was a shock for P1, she was very well supported. P1 had support from her family, including her son who flew back to New Zealand from his home overseas. She also had support from the medical staff at the hospital. P1 reports that the medical staff was wonderful and that she could not fault any of them.
“They both [P1’s children] said ‘if you want us we’ll be there in a flash.’... I know they’re there if I need them, which they are. I have called for help a couple of times and they’ve been there.” (p. 12 – 13, Int. 1)

The stroke event initially caused a lot of uncertainty for P1. After the stroke, P1 was unsure of what was to come, however, she was hopeful. As the initial feelings of shock were overcome, uncertainty slowly started to emerge. Only time would tell what was going to unfold.

“... it just depends on the individual I think [what to expect]. They [medical staff] said he’d probably never get rid of his walker but I don’t really know. Time will tell I think. It’s a long term thing, and who knows.” (p. 6, Int. 1).

b. Frustrating, draining but not complaining
As time passes by, there are some physical improvements with the stroke survivor, however, there is a decline cognitively and mentally. This leads to frustration for P1, which further leads to strain. At the 12 month interview, P1 reports that she needs to be alert continually and mentions the stressfulness of the situation, stating that she needs time out. Regardless, P1 is still very hopeful. She is unable to do the things she wants to do, due to the physical limitations of the stroke survivor. Furthermore, she talks about being on the verge of falling to pieces, since the previous interview.

“... Yeah, I said to the doctor, I said I wasn’t sleeping and he said ‘have you got any frustrations.’ And I just looked at him and went... [firmly] right. He didn’t want to put me on sleeping pills and I didn’t want to go that way either and then I remembered I had that [Rescue remedy] still sitting in the cupboard. So I thought I would try it and it’s worked well.” (p. 2, Int. 5)

Due to the physical limitations of the stroke survivor, such as his limited eye sight (one prosthetic eye and the other one affected by the stroke), the stroke survivor requires a lot of help and assistance from P1. This leads to a dependency from the stroke survivor, which causes the stroke survivor to be in close proximity to P1 most of the time. She reports that she needs a break and that being the caregiver can be draining.
“The doctor’s nurse said last week ‘you’ve had any time out yet?’ and I said no, and she rolled her eyes, but it is hard because he [stroke survivor] doesn’t see how I need time out.” (p. 4, Int. 4)

With the stroke survivor’s dependency on his wife, she reports having to be very alert in case he falls over. This causes a change in their relationship. P1 now pays most of her attention to her partner and has adopted more of a caregiver role. When interviewed 12 months after the stroke, P1 was asked if she had become more of a carer than a partner. Her response was “Mm. Mmm. Very much so” (p. 13, Int. 4). The impact of the stroke is evident in the post-stroke life of P1. The journey shows P1’s experience and challenges. Despite the frustration and lack of time to herself, P1 remains hopeful and does not overly complain.

“Oh yes. We haven’t done anything and I said to somebody, I said to a couple of people, next year I’m going to be a social butterfly, I’m going to join in on all these things. The year’s up, we’ve been here a year, I have, and so next year it’s all on, go to different things.” (p. 4, Int. 4).

c. Watching, wishing and waiting

The next phase of the journey reveals an even greater strain than before, due to her caregiving duties. At the interview two years after the stroke, P1 reports that the previous six months have been increasingly stressful. Life has changed as a result of the stroke and P1 wishes that the situation was different. She mentions that the stroke survivor now occasionally gets bad tempered, which upsets her. She also states that her husband dislikes crowds. This ultimately has had a social impact on her, as he does not like her to go anywhere without him, which P1 says is ‘a bit of a nuisance’. P1 also reports that she ‘can’t get away from him’ which limits her time to herself. These comments illustrate that P1 might feel trapped and tied to her husband. P1 reports that she lives day by day and does not know what is going to happen next, illustrating that the feelings of uncertainty resurface again two years post-stroke. Her husband has stopped improving physically and P1 mentions that he looks frail.

“We’re not getting any better, he’s at a plateau, they’ll only get worse. In sort of ways not waiting, but you know, waiting for another stroke to happen, which is probably on the cards somewhere along the line. Mmm.” (p. 19, Int. 6)
In the two year post stroke interview, P1 reports that a consequence of her husband not wanting to be seen when out (by people he did not know), probably stopped her from going out to things and enjoying events held in the retirement village. P1 feels confined and there is a strong sense that she is a captive in her own home. This is because she feels it is her duty to care for her partner, and as a result, has to sacrifice social opportunities.

“*They have day trips here but they're all a bit awkward for [stroke survivor] and they were doing a trip to [off-shore island] where you stay on the boat all the time and I said oh that will be alright... So I said to the organizer what about [stroke survivor]’s walker, could we go on that with [stroke survivor]’s walker, and he said 'no not really' he said, ‘there’s no room to manoeuvre a walker around but he’d be alright with his stick’, and then somebody else piped up, ‘the toilets are upstairs remember, he’d never get up there’. So that was the end of that trip.*” (p. 16, Int. 6)

At the two year interview the sub-theme ‘watching, wishing and waiting’ powerfully emerges. P1 mentions having to be very watchful over her husband. She also reports that she is always aware of where he is and what he is doing.

“*Yeah it was actually [disappointing to miss out on day trip]. Yeah... If he managed without, with only a stick, it would be alright. Then you've got to have eyes in the back of your head in case he falls over a matchstick or something.*” (p. 16, Int. 6)

Throughout the journey, P1 appears to be hopeful. However, two years after the stroke, P1 notices a decline in her spouse’s mental capabilities and may be in the process of losing hope. She states that his memory is now failing terribly. The aforementioned findings portray the huge impact of the stroke, on the life of P1 over the two year period. The initial shock of the stroke is overcome, followed by a realization that life will be different. The journey ultimately evolves into the overarching theme of ‘Hostage to Duty,’ where P1 feels it is her responsibility and duty to care for her husband. There is some overlap between P1’s experiences in the previous two sub-themes. The feelings of frustration and uncertainty also resurface and show the gradual increase in strain on P1. Although both P1 and P2 are initially affected in a similar way, their individual journeys post stroke are very different, which shows the uniqueness of their experience. The journey of P2 is explored next.
THE JOURNEY OF PARTICIPANT TWO

Back on Track

The journey of P2 illustrates a very different experience to P1. Initially, P2 also experiences a stage of shock and uncertainty but the follow-on sub-theme is ‘coming to terms and moving on.’ This sub-theme slowly evolves into the sub-theme of ‘accepted reality’. These three sub-themes loosely follow a chronological timeline and ultimately show how the journey of P2 leads to an overarching theme of ‘Back on Track’ (Appendix B, Mind map 4).

a. Supported through shock and uncertainty

The stroke event was an unforeseen occurrence and quite a shock for P2. This is the nature of stroke events, as there may be no warning signals and family members can feel unprepared. Similar to P1, P2 was also well supported. A year after the stroke, P2 starts to accept the situation and move forward. At two years, she has accepted it and is not hugely affected in her day to day life.

“Yes, it was completely out of the blue, I think. Yeah. They [parents] had made arrangements to sell their house and move into [retirement village] and that was a few weeks before...” (p. 1, Int. 1)

In addition to the stroke event being a shock, it was also a traumatic experience. On the night of the stroke, the family were not sure if the stroke patient would survive. It was also traumatic for P2’s son, the grandson of the stroke survivor. The grandson stayed awake until approximately midnight, sending text messages to find out about his grandfather’s progress. In addition, the stroke survivor also had a minor heart attack the following evening, leaving the family with additional distress and concern.

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“In addition to the stroke event being a shock, it was also a traumatic experience. On the night of the stroke, the family were not sure if the stroke patient would survive. It was also traumatic for P2’s son, the grandson of the stroke survivor. The grandson stayed awake until approximately midnight, sending text messages to find out about his grandfather’s progress. In addition, the stroke survivor also had a minor heart attack the following evening, leaving the family with additional distress and concern.

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Despite the massive upheaval, P2 was well supported. P2 reports that the hospital staff were helpful throughout, she was well informed and her support needs were met. P2’s family and friends also supported her and helped out. The neighbours were able to look after her younger children, enabling P2 to spend a lot of time at the hospital in the initial stages. P2’s husband drove her around in the early stages and cared for the children, again enabling her to visit the hospital. Her employer was supportive as well.

“I rang my boss’ wife about half past seven on the Wednesday morning and just told her that dad had had a stroke and she just told me to take all the time I needed. So that wasn’t too difficult.” (p. 3, Int. 1)

b. Coming to terms and moving on

One year after the stroke, P2 is busy going through the process of accepting the consequences of the stroke on her father and she is moving on with her life. She reports that her life has not changed dramatically as a result of her father’s stroke. P2 appears as though she is coming to terms with her father’s physical impairments and mentions that ‘it’s just become a part of life’ (p. 8, Int. 4). When P2 was asked to pass on a piece advice to families perhaps with a similar experience, she suggested the following:

“...I think I would tell them that so long as the person survives that things do get better but never to expect them to be 100% the same person that they were before the stroke... but that it does get better and you just have to learn to adjust with it ... and their family have to be prepared to accept their limitations because there are going to be, if you’re lucky you can do everything that you did do before, but if you can’t then you have to accept that and either find some way of doing it differently or put it behind you.” (p. 15, Int. 4)

P2 has two children who are involved with sport at school and P2 reports that she is busy with her own life. She finds it a challenge to set time apart on a weekly basis to visit her parents, due to the busyness of her own life.

“We’re busy with our own families. I know that we need to make more of an effort, but it can be difficult to do.” (p. 3, Int. 4)
P2 states that her mother is the healthiest she has ever been and seems to be coping well. There appears to be a mismatch between P2’s understanding of how her mother is coping and the reality. This issue will be addressed in the discussion. P2 also reports that her father appears to be slightly steadier on his feet. The life of P2 has not changed drastically as a result of her father’s stroke. It appears as though P2 is moving on with her life.

“I think I’m probably a bit more aware of it [change to P2’s life] but no, I don’t think it’s changed. I haven’t changed anything. Nope.” (p. 14, Int. 4)

c. Accepted reality

Two years after the stroke, P2 has accepted the fact that her father will most likely not improve any further. Her life is almost back to the way it was before the stroke, which the two year interview identifies.

“I mean I always did, I always did ring and talk to my mother two or three times a week. So it hasn’t changed, maybe the context of the conversation has changed a bit I think but I think we’re probably back to the way we were before he had the stroke…” (p. 8, Int. 6)

P2 finds it difficult to visit her parents as often as she would like to, perhaps causing feelings of guilt and dissonance.

“Because I work full time, then I’m out of the house every single day of the week. So I don’t go and see them every Sunday because I like to have one day a week at home. So, but that doesn’t stop me from feeling guilty because I haven’t” (p. 10, Int. 5)

The findings show that P2 is busy with her own family and other commitments. Two years after the stroke, P2 is in a very similar situation as what she was at 12 to 18 months post-stroke. She mentions other obligations in her life that need attending to and feels that her parents are well supported if required.

“I’ve still got my own husband and children to look after too and I know that there’s help there if they need it. There’s buttons [emergency call buttons] and other people around. It’s not like they're living in a house separate from other people. So there is a lot of support around if they needed it.” (p. 7, Int. 6)
DISCUSSION

The findings reveal two very different experiences. Both participants go through a traumatic experience of shock and uncertainty. After this however, the participants experience two different journeys. The wife (primary caregiver) of the stroke survivor experiences an enormous change to her life and the impact of the stroke is shown throughout the two year journey. The strain and burden on P1 is evident and a change of role is also established. The journey of P1 is encapsulated in the theme, ‘Hostage to Duty’, where the stroke survivor becomes her full responsibility and it is her duty to care for him. On the contrary, P2 goes through a process of acceptance and slowly starts moving on. She gets back into the busy routine of her life and two years later, she is ‘Back on Track.’ Throughout this study, data analysis, findings and interpretations were discussed and debated with both peer researchers and two research supervisors. The findings from this study are a reflection of how the effects of a stroke on the wider family can vary considerable. A further discussion follows below.

JOURNEY OF PARTICIPANT ONE – HOSTAGE TO DUTY

Supported through shock and uncertainty

Despite the shock of the stroke, P1 reported feeling well supported by the health professionals and her family. The adequate support experienced by P1 is contrary to the findings in the literature, which identify support needs (Brinda et al., 2014) and information needs (Baumann et al., 2014; Roy et al., 2015; Tunney & Ryan, 2014; Visser-Meily et al., 2005; Yiengprugsawan, Harley, Seubsman, & Sleigh, 2012). Therefore, it seems plausible to suggest that the health professionals appear to be improving in their ability to identify these needs and provide appropriate intervention.

A stroke event is often unexpected, initially traumatic and can have far reaching consequences for the stroke survivor’s family members (Gillespie & Campbell, 2011), especially the primary caregiver (Peyrovi, Mohammad-Saeid, Farahani-Nia, & Hoseini, 2012). Other studies highlight the well documented complications of caregiver burden (Bastawrous, 2013; Brinda et al., 2014; Jaracz et al., 2012; Ogunlana et al., 2014), which P1 evidently experiences at the time of the stroke and throughout the two year period after the stroke. Cameron et al. (2014) suggest that incorporating services and strategies to improve caregiving duties may enhance
their positive experience of providing care, ultimately enhancing the sustainability of the caregiving situation. P1 did not seek further services, for example, respite care which was an available option. Feelings of guilt perhaps persuaded her to care for her husband herself, as she did not ask for extra support. P1 mentioned that she did not once go out on her own, or have a break from her full-time caregiving duties. Therefore, it seems likely that extra support from family or other means could have taken some of the strain off P1 and possibly ‘enhance’ her experience of providing care, as Cameron et al, (2014) suggests.

**Frustrating, draining but not complaining**

A systematic review by Rigby et al. (2009) report that a good proportion of caregivers experience caregiver burden, which remains elevated for an ‘indefinite period’ following a stroke. Vincent et al. (2009) on the other hand, suggest a general decline in caregiver burden, measured at three weeks, six weeks and six months. The findings from this thesis however, suggest that caregiver burden, in this case, slowly increases up to two years, which may be a new finding in research. This requires further exploration to be confirmed. Risk factors that can increase the burden on caregivers need to be identified, so that effective intervention can be provided accordingly, which Rigby et al. (2009) also propose. Interestingly, Bhattacharjee et al. (2012) mention that female gender, long caregiving hours and disturbed night sleep were all factors relating to high caregiving stress. All these factors were present for the caregiver in this study, which may have contributed to the increasing stress which she experienced, even though her daughter was under the impression that her mother was coping well and was ‘healthier than ever’.

Despite the noticeable physical improvement of the stroke survivor, P1 experiences increased feelings of frustration due to the cognitive decline of the stroke survivor such as memory loss, mood changes and personality changes. Baumann et al. (2012) report that life satisfaction of the caregivers in their study was negatively affected when caring for patients with impaired memory. In addition, Baumann et al. (2012) state that some of the caregivers reported being exhausted, possibly due to the stroke survivors physical capabilities, but also due to the stroke survivors’ psychological problems. This study also identifies a change in role in the caregiver, which is in line with the literature (Cao et al., 2010; Tunney & Ryan, 2014). Cao et al. (2010) report that the caregivers experienced barriers to activity, which is also evident in this study. This is likely due to the stroke survivor’s physical impairments, and the caregiver’s reluctance to leave him at home alone, which hinders her ability to partake in social events at the
retirement home. The social impact on P1 is also influenced by the stroke survivor’s dislike of crowds and not wanting to be situated in social environments. P1 is always in close proximity to the stroke survivor, which negatively affects her social life.

The frustration and strain experienced by P1 may also be linked to the dependency of the stroke survivor. Ogunlana et al. (2014) suggest that the stroke survivors’ level of impairment has a significant influence on the quality of life of the caregiver. This is also consistent with the finding from Jaracz et al. (2014). Literature illustrates how a stroke can negatively impact the caregivers own personal time (Gosman-Hedstrom & Dahlin-Ivanoff, 2012; Lurbe-Puerto et al., 2012), as well as their social lives (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Parag et al., 2008). Gosman-Hedstrom and Dahlin-Ivanoff (2012) mention the caregivers feeling ‘tied to the home’ and needing time for themselves, which is similar to the findings in this study. The fact that she only had one day for personal time to herself (without the stroke survivor around her), since the interview six months earlier reveals the full time requirement of her caregiving role, with extremely limited time to herself.

Watching, wishing and waiting

The stroke survivors eye sight is compromised (one prosthetic eye and other affected by the stroke), which requires the caregiver to constantly walk in front of her husband and in a sense, guide him. P1 herself describes the need to be very watchful over her spouse. This again influences the strain and demand that is placed on P1, as she feels it is her duty to care for her spouse, which is a lifelong commitment ‘until death do us part’. The worry and uncertainty experienced by P1 is also identified in the literature (Gosman-Hedstrom & Dahlin-Ivanoff, 2012; Saban & Hogan, 2012). Initially, P1 appears to be hopeful. However, two years after the stroke, P1 notices a decline in her spouse’s mental capabilities and is in the process of losing hope. The findings show the negative impact on the life of the caregiver. It seems plausible to suggest that P1 wishes the circumstances were different, enabling more time to herself. P1 also mentions the possibility of another stroke and gives the impression that she is waiting for one to happen. The impact of a stroke on the wider family, specifically two years after the stroke event has not been well investigated. Therefore, further research is required around this time period to gain a deeper understanding.
JOURNEY OF PARTICIPANT TWO – BACK ON TRACK

Supported through shock and uncertainty
The stroke event was also traumatic for P2 and P2’s son. Her wider family was also affected to some degree, as her brother flew back to New Zealand from his home overseas. There is very limited research into the effect of a stroke on the extended family (including the grandchildren), however, this study identifies how far reaching the consequences may be. P2 was also well supported by family, neighbours, work and the hospital staff. This is in contrast with the findings of Tunney and Ryan (2014), who identify a lack of support and a lack of information being provided to stroke caregivers.

Coming to terms and moving on
There is a strong sense that P2 goes through a process of acceptance at 12 months. At 18 months, she feels that her parents are coping well. The findings by Jones et al. (2013) found that psychosocial difficulties became more apparent. This was identified specifically around the six month review in the rehabilitation process, despite a good initial medical recovery, which are similar to the findings of this study. As mentioned before, it is possible that P2 does not see the full extent of the strain on her mother (P1), as there seems to be a mismatch between the reality of the strain on the mother and the daughter’s perception of her mother being fit and healthy, as she is often in the gym. The psychological decline in her father is also perhaps not noticed as much by P2, as she struggles to see him often. Furthermore, P2’s mother states that the stroke survivor is ‘on his best behaviour’ when other family is around. Therefore, the cognitive decline and personality changes seen by P2 may not be an accurate representation and therefore, P2 may find it easier to accept the situation and move on with her life. This is only a suggestion however, which warrants further investigation.

Accepted reality
At the two year interview, the findings in this study suggest that P2 has moved on with life and has now accepted her father’s limitations. With the lack of research, it is unknown how the stroke event affects different family members, especially as the impact varies considerably and is influenced by the severity of the stroke. It seems reasonable to suggest that the busy day-to-day life of P2, the prior experience of her father in law having a stroke, and the readily available support for P2’s parents (from the retirement village) all contribute to P2 being able to move on with her life and accept the situation. Despite this, P2 still experiences feelings of
guilt with the dilemma of balancing her own busy schedule (family and other commitments) and finding time to visit her parents. A snippet of the life of the daughter can be provided by this study. Since only one of the children of the stroke survivor was interviewed, it is a limitation of this study. The literature aimed specifically at the children of stroke survivors is very limited (Kitzmüller, Asplund, & Haggstrom, 2012), especially over the two year period following a stroke and therefore requires further exploration.

CONCLUSION

After the initial shock of the stroke event, the lives of family members can be affected entirely differently. The daughter slowly starts to accept the effects of the stroke, as she observes her father is improving physically. Her life returns back to way it was, or even perhaps a ‘new’ normal, where she is busy with her own family responsibilities. She feels her parents are well supported by the retirement village and the theme of ‘Back on Track’ strongly develops two years post stroke. The wife of the stroke survivor on the other hand, tends to feel increased feelings of frustration due to the immense changes in her life. The stroke survivors mental capabilities start to decline, such as memory loss and personality changes. She feels tied to her spouse, confined in her own home and experiences an enormous loss of personal time to herself. The strain on her life is evident, as a result of her caregiving duties, where the theme of ‘Hostage to Duty’ powerfully emerges. These findings highlight how the individual journey differs for both the mother and the daughter of the stroke survivor, throughout the two year period following a stroke. The findings also suggest a need to help identify a gradual increase in caregiver burden so that appropriate intervention can be provided. However, further research is needed to confirm these findings, specifically over the two year period.

RELEVANCE TO CLINICAL PRACTICE

This study identifies an overarching theme of ‘Hostage to duty’ for P1. The results also reveal the strain and the experience of living with and providing care for her husband who had the stroke. The findings give insight into the complexity of being the full time caregiver as an older woman and caring for her spouse in a retirement home, as well as a potential for increasing caregiver burden over the two year post stroke journey.
References


Saban, K. L., & Hogan, N. S. (2012). Female caregivers of stroke survivors: Coping and adapting to a life that once was. *Journal of Neuroscience Nursing, 44*(1), 2-14. doi: 10.1097/JNN.0b013e31823ae4f9


Part Three: Appendices
Appendix A: The larger longitudinal parent project

What is the larger parent project?

A longitudinal (five year) study investigating the experience of becoming and living as a stroke family/whānau.

Specifically, we hope to articulate:

* Why some families/whānau cope better than others
* If and how client age at onset of stroke impacts on the experience of families/whānau and their support needs
* The information and education needs of stroke families/whānau
* How nurses (and others in the healthcare team) might better support stroke families/whānau through all phases of the stroke trajectory (acute, rehabilitation, and life after stroke).

The study has its origins in late 2009 when the Department of Nursing at Unitec was approached by a Charge Nurse Manager, at an Auckland hospital about possible research collaboration. The manager and his staff had identified a need to improve support for families/whānau of clients who have had a stroke. As one practitioner said during one of our early conversations about the research programme, “the client moves on but sometimes the family doesn’t; they get stuck.” In 2010 the first stage of the five year longitudinal project was commenced; data analysis is being completed currently.

There is a significant body of knowledge on the pathophysiological consequences of stroke and stroke rehabilitation, particularly as it pertains to the person who has experienced the stroke. Little is known, however, about the impact of stroke on the family/whānau. Much of the existing research that reports ‘family experiences’ seldom includes family members other than the primary caregiver; often wife/husband/partner. This study aims to provide new understandings of the experiences and needs of members of extended family/whānau.

The study will utilise hermeneutic phenomenological methodology informed by the writings of Martin Heidegger and Hans-Georg Gadamer, to provide an understanding and interpretation of the phenomenon of ‘becoming and living as a stroke family’ and illustrate the impact it has on participants’ lives. Procedures for the study are guided by phenomenological methods described by van Manen (1997). Findings from this study have the potential to change practice and improve the care and support provided to ‘stroke families/whānau’.

This study has ethics approval (for five years) and funding to cover costs including transcription of interviews etc. to June 2016

To discuss further, please contact me on 021581096 or ext 8307 or droy@unitec.ac.nz

Thanks, Dianne Roy, Associate Professor, Department of Nursing.
Appendix B: Development of themes

Figure 1. Isolating thematic statements, interview six, participant two.
Figure 2. Coding interview one, participant two.
Further development into preliminary ideas (during meeting and discussion with research supervisor).

Mind map 1.

Mind map 2.
Development of themes and sub-themes

Mind map 3. Findings for participant two.
### Appendix C - Summary of interview one (into one A4 page):

**Significant statement and preliminary ideas.** Shocked, traumatic but also well supported.

<table>
<thead>
<tr>
<th>SWIP 2 Interview 1</th>
<th>Themes</th>
<th>Sub-themes (Acute phase 1-6 weeks)</th>
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</thead>
<tbody>
<tr>
<td><strong>Shocked &amp; Unexpected</strong></td>
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<tr>
<td>&quot;Yes, it was completely out of the blue, I think. Yeah.&quot; (Pg. 1)</td>
<td>(Pg. 1)</td>
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<tr>
<td>&quot;So it was a bit, it was weird for something like that to happen out of the blue.&quot; (Pg. 1)</td>
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<tr>
<td><strong>Traumatic experience</strong></td>
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<td>&quot;He was having trouble with his heart too &amp; when he got agitated or started sweating, the heart monitor would go down to zero, which was yeah, which was really&quot; (Pg. 2)</td>
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<tr>
<td>&quot;And we were saying at this thing going down to zero &amp; wondering if he was just going to have a heart attack &amp; die right there.&quot; (Pg. 3)</td>
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<tr>
<td>&quot;So that was a bit traumatic.&quot; (Pg. 3)</td>
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<td><strong>Concern (for P1)</strong></td>
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<tr>
<td>&quot;So it took her all day, and it wasn't worrying because she was there on her own &amp; they were in the middle of parking.&quot; (Pg. 2)</td>
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<tr>
<td>&quot;The first night in the hospital (son) didn't stop looking me ... and he was worried &amp; he was&quot; (Pg. 2)</td>
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<td>&quot;leaving me right up until just before we left the hospital I think.&quot; (Pg. 3)</td>
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<td>&quot;I think for a while I'll probably still worry 'cause you do it not just about dad but mum as well.&quot; (Pg. 3)</td>
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<td><strong>Support</strong></td>
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<tr>
<td>&quot;...and just told her that dad had a stroke and she (daddy's wife) just told me to take it all that I needed. So that wasn't too difficult.&quot; (Pg. 3)</td>
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<tr>
<td>&quot;The weekends I would pick mum up from home &amp; take her... So there was a lot of driving... So it sounds like a lot of family support &amp; people pulled together - yeah, pretty much.&quot; (Pg. 4)</td>
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<tr>
<td>&quot;Yeah, the neighbours have been really good. I mean they said anytime we need, they're there&quot; (Pg. 4)</td>
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<td>&quot;Yeah he has (husband)... He drove me around; he drove me to the hospital the first couple of times... but he's looked after the children so that I can come to hospital.&quot; (Pg. 4)</td>
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<tr>
<td>**Well informed</td>
<td>Info needs met**</td>
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<tr>
<td>&quot;Yeah, I think they're (staff at the hospital) been pretty good.&quot; (Pg. 5)</td>
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<tr>
<td>&quot;Is there anything that could have helped you during the past 6 weeks that hasn't been available? Do I don't think so.&quot; (Pg. 5)</td>
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<tr>
<td><strong>Time will tell \ Ticking Time Bomb</strong></td>
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<td>&quot;No, yeah I think so, but you still sort of get the impression that he's (55) got a ticking time bomb in the chest there somewhere...&quot; (Pg. 10)</td>
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<td>&quot;You can't help wondering whether... how long it can go on for but then you know, you just have to take one day at a time.&quot; (Pg. 10)</td>
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<tr>
<td><strong>Fear of the past \ Family history</strong></td>
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<tr>
<td>&quot;So have you been living with a worry for the past... Probably, probably. None of his family, his brother, his mother or his father saw 60.&quot; (Pg. 9)</td>
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<tr>
<td>&quot;Yeah, so, family history's not that awesome.&quot; (Pg. 9)</td>
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<tr>
<td><strong>Hopeful expectation</strong></td>
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<tr>
<td>&quot;It gives you hope, when you know, that somebody else has been there &amp; done that.&quot; (Pg. 9)</td>
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Appendix D: Timeline (Overview of theme development)

**Participant 1:**

*Interview 1, 6 weeks*
- Shock, traumatic, hopeful, unsure (of future)/time will tell, frustration (early signs), well informed/information needs met, support.

*Interview 4, 12 Months*
- Physical improvement (S.S), need for space/alone time, watchful/alert 24-7, hopeful, tired/strain, unappreciated, support (slowly decreasing), change of role, coping, neglect (hint of it)

*Interview 5, 18 Months*
- Difficult journey, frustration, physically okay/cognitive decline (S.S.), watchful/alert 24-7, tired, busy/routine, selfless, hopeful, unsure/uncertainty (of future).

*Interview 6, 24 Months*
- Ticking bomb, attachment/stuck to S.S., dependency (S.S), alert 24-7, social impact, in need of a break/future plans, emotional strain/frustration, mental/cognitive decline, duty to care/hostage to duty, independent (not wanting to burden P2 - daughter), loosing hope.

**Participant 2:**

*Interview 1, 6 weeks*
- Shocked/unexpected, traumatic experience, concern (for P1), supported, well informed / info needs met, time will tell/ticking time bomb, fear of past (family history), hopeful expectation.

*Interview 4, 12 Months*
- Moving on/back to normal, acceptance, zero change/still the same (few things), busy, physical improvement/coping (S.S), sense that p1 needs a break, concern for future/unconcerned at present, info needs met.

*Interview 5, 18 Months*
- Busy, guilt/dissonance, sings of concern, in need of break (P1 - mum), alone time lost/attachment (P1), not much change, familiar/similar previous experience (father in law also had stroke), perkiness (P1 - mum).

*Interview 6, 24 Months*
- Moving on with life (unaffected), at ease (with situation)/unconcerned, aware of burden for P1, mental decline (S.S), busy with own life, info needs met, hostage to guilt/duty (P1 - mum), no relationship change (with both parents), acceptance, change of role.
Appendix E: Participant information sheet

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

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

Why is this study important?

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

Purpose of the Study

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

What it will mean for you?

You will be asked to meet with one of the research team for a series of face-to-face interviews over the next four years. We will arrange a mutually agreeable time and place for the interviews. The interviews will be audio-recorded and later transcribed into written form. We will contact you well in advance of each interview to see if you still wish to participate and too 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 filing 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.
Appendix F: Ethics approval

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unitec Building
650 Great South Road, Penrose
Private Bag 92 523
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

7 April 2011

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

Dear Dianne

Ethics ref: NTX/11/EXP/062 (please quote in all correspondence)
Study title: Improving support for families/whanau of clients post stroke (phase two): longitudinal study of experiences of family/whanau members
Principal Investigator: Dr Dianne Roy
Co-Investigator: Ms Sue Gasquoine, 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.
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

Pat Chainey
Administrator
**Northern X Regional Ethics Committee**
Email: pat_chainey@moh.govt.nz
Appendix G – Awhina Knowledge and Research Centre Approval

Monday, 18 April 2011

Dr Diane Roy
Department of Nursing
Faculty of Social and Health Sciences
Unitec, New Zealand

RE: improving support for families/whanau of clients post stroke (Phase Two): Longitudinal study of experiences of family/whanau members

Tena koe Diane,

This letter is to advise that your application was again discuss at the last meeting of the Nga Kai Tataki Maori Research Review Committee. We are pleased to advise that your application was approved, however please not the following recommendations:

1. Coding must be used on all documents containing participant feedback:
2. Tape cassettes used to record participant feedback must be coded and no names should be written on tapes so as to protect participant confidentiality;
3. Some Maori participants may show sensitivity about being tape recorded in interviews, please ensure that participants are aware before any interviews that they will be recorded in advance.

This approval is subject to the condition that before preceeding researchers must advise any Maori participants that they should seek support from their own whānau, Kaumatua or Kuia or their local Maori Health Services.

Please send Nga Tataki – Waitemata ‘MRRC’ a 1-2 page summary of your findings once your research is complete.

Tanekaha Rosieri
Chairperson
Nga Kai Tataki ‘MRRC’

Giovanni Maihi Arr
Maori Research Advisor
Knowledge Centre
Appendix H: Transcriptionist Confidentiality Form

Stroke Family Whānau Study

NON-DISCLOSURE OF INFORMATION

Transcribing Typist

I  __________________________________________________ agree not to disclose the name of, or any information that would lead to the identification of the participants in the research study being undertaken by Dr Dianne Roy and colleagues.

The audio-recordings, transcription hard copies, and computer files will not be made available to anyone other than the researchers and will be kept securely while in my possession.

I will not retain any copies of the audio-recordings, computer files, or transcriptions.

Signed:  ________________________________
Name:  ________________________________
Date:  ________________________________
Appendix I: Interview schedule

Interview Schedule

Introduce myself and what I do (student at Unitec), and briefly explain plan for today
Gain consent and mention that I might jot down some notes about things I might ask later

Intro
- Thanks for agreeing to meet with me today & continuing to be a participant
- Today is the 17th of Oct. My name is Ray & I’m about to interview (Name)
- Now this interview is 2 years since (S.S) had his stroke. So for this interview, I would like if we could reflect on the 2 year anniversary, and then perhaps talk about what has happened since the last interview, with some follow up questions to finish off with. Are you okay with that?

Open Questions
1) So with the 2 year anniversary being last week, what was going through your mind on the day?
2) It has been about 6 months since the last interview... How have YOU been?
   a) And how is the entire situation going [with you caring for (S.S.)]?
3) One of your New Years resolutions was to get out more & become a social butterfly, how’s that worked out?
   b) Do you find you have enough time for yourself?
      - Did you manage to go on those tiki tours you mentioned in the last interview? Next year’s resolution anything?
      - In the last interview, it appeared as though you might have needed some time alone, is that correct?
      - Still putting S.S first at this point or taking more time for yourself? *** Great, everybody needs alone time.
4) Have there been any major changes in the last 6 months that you can think of? Days to yourself?
   b) Still have to be called 24/7 stressful...
   c) Last one a disaster...

Health
5) How has your health been in the last 6 months?
   - Sleeping patterns & rescue remedy
   - Colon screen & next check up
   - Still doing zumba & gym? Anything else you do to get out and stay healthy?

S.S
6) You mentioned in the last interview, that he was looking frail and showing his age... How’s that progressed?
   - Also touched on last time that he could say hurtful things... How’s he been? Pick battles?
7) You mentioned with a bit of luck, things would get better, reflecting on that, how are things getting on? Hope?
8) So there has been some progress made (even though slow), has there been any more improvements? Plateau?

Coping
9) In previous interviews, you mentioned a few frustrations, how’s that been?
   - How you coping/handling them? [tougher times]
   - Still a matter of taking each day as it comes? Perhaps a turning point?
   - Any personal achievements that you’ve reached (touched on it before – social butterfly)? And S.S?
10) You also said there were times where you felt you were going to fall to pieces, still get those feeling?

Information Needs
11) In your experience, are there any information needs that may have not been met [since the stroke]?
12) Is there anything that you wish you were told in your journey?
   - Any service you may have wanted?
13) Is there any advice you would pass on to a family in a similar situation?

Relationships
14) Let’s talk about relationships, how’s your relationship with your daughter? And S.S? Rest of family? Support?
15) Finally, what your expectations for the next couple of months to a year?

Conclusion
Appendix J: Reflective journal (excerpt)

Instead of using memory, the reflection journals (electronic, audio and written) were used throughout the research process, helping to stay true to the data and to maintain rigour. The following is an example from the written journal, which was recorded straight after the interview on the 17th October, 2013. Family three, participant one (P1), interview six:

“… there are so many things that she wishes she could do and she has all these plans as well, which she is unable to do, as she is constrained by (stroke survivor). Due to his physical capability, him not liking crowds, his impaired vision (one prosthetic eye) and his mental state (lack of confidence) and dependency, it affects her ability to go out and have time to herself. The situation seemed quite stressful for (P1)…. It appears to be a duty at times, with no option or choice but to put (stroke survivor’s) needs first and sacrifice her own freedom and wants, to care for him.”

The above excerpt gives a very general picture of what the researcher’s thoughts and feelings were minutes after the interview. It also highlights the strain experienced by P1 and her lack of freedom to do what she pleases. This bit of reflection, along with other entries, helped with data analysis, which also strengthened the theme of ‘Hostage to Duty’.
Appendix K: Journal of Clinical Nursing Guidelines

Original Articles:
Should be between 3,000 - 5,000 words long, double spaced with a wide margin (at least 2cm) on each side of the text. The main text should be structured as follows: Introduction (putting the paper in context - policy, practice or research); Background (literature); Methods (design, data collection and analysis); Results; Discussion; Conclusion; Relevance to clinical practice. The number of words used, excluding abstract, references, tables and figures, should be specified. Pilot studies are not suitable for publication as original articles.

Manuscript Format and Structure
All manuscripts submitted to JCN should include a covering letter stating on behalf of all the authors that the work has not been published and is not being considered for publication elsewhere. If the study that is being submitted is similar in any way to another study previously submitted/published or is part of multiple studies on the same topic, a brief sentence explaining how the manuscript differs and that there is no identical material should be stated in the cover letter upon submission.

No identifying details of the authors or their institutions must appear in the manuscript; author details must only appear on the title page and will be entered separately as part of the online submission process.

Title Page: (needed for all manuscript types) must contain both a descriptive and concise title of the paper; names and qualifications of all authors; affiliations and full mailing address, including e-mail addresses, contact telephone number (and Twitter username if you would like this published). The title page must also contain details of the source(s) of support in the form of grants, equipment, drugs or all of these.

Structured Abstract: (not needed for Research In Brief articles or Commentaries) should not exceed 300 words and should accurately reflect the content of the paper. The abstract should not include references or abbreviations and should be provided under the headings: Aims and objectives; Background (stating what is already known about this topic); Design; Methods (for both qualitative and quantitative studies state n); Results (do not report p values, confidence intervals and other statistical parameters); Conclusions (stating what this study adds to the topic); Relevance to clinical practice; Keywords.(Please note that you are asked to add your abstract and keywords into a box when submitting your paper, but both abstract and set of keywords should also appear at the beginning of your actual manuscript - main document) file.

Summary box: (needed for all manuscript types) should contain 2-3 bullet points under the heading 'What does this paper contribute to the wider global clinical community?'

Keywords: (needed for all manuscript types) the keywords that need to be entered within your manuscript (up to 10), are words associated with the paper, which will allow it to be easily cited after acceptance. These are different from the keywords chosen from a list during the submission process; these keywords are to assist the Editors in searching for reviewers to review the manuscript.

Headings and Sub Headings: (needed for all manuscript types): please present headings in the manuscript in bold capitals, sub-headings in lower-case and bold, and subsequent headings in italics.
Full name of author: Raymond Daniels

Full title of thesis/dissertation/research project: A longitudinal hermeneutic enquiry into the lived experiences of the wider family of a stroke survivor at two years post-stroke.

Department of: Osteopathy

Degree: ................................................................. Year of presentation 2015

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