



Declaration

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This Thesis entitled **Different folks, different strokes: Becoming and being a stroke family during the first six months post-stroke** is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy.

Candidate's declaration

I confirm that:

- This Thesis 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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Different Folks, Different Strokes: Becoming and Being a Stroke Family During the First Six Months Post-Stroke

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A thesis submitted in partial fulfilment of the requirements for the degree of Master
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Abstract

Aim: To explore the lived-experience of becoming and being a stroke family during the first six months post-stroke event.

Background: The consequences of a stroke are far reaching and affect the whole family. Research has been limited with its exploration into the effects of stroke on family members beyond the primary caregiver. It is important to understand the wider family's experience of stroke because the whole family is involved in caring for the stroke survivor, either through supporting the primary caregiver, or sharing in the caregiving tasks. This study explores the lived-experience of two different families during the first six months post-stroke.

Design: Exploratory qualitative study using hermeneutic phenomenology.

Methods: Purposive sampling recruited two different families each with two participants. Interviews were conducted at three time intervals: six weeks post-stroke, three months post-stroke and six months post-stroke. Data were collected between October 2011 and April 2012.

Findings: The lived-experience of both families varied in the effects from the stroke event and challenges that each family faced. An over-arching theme of 'Different Folks: Different Strokes' was identified with three sub-themes: 1) Losing a life once lived. 2) Navigating an unfamiliar path. 3) Creating a sense of normal.

Conclusions: The data revealed that the journey to becoming and being a stroke family is complicated and brought different losses and challenges to the two families. One family felt supported into post-stroke life by positive interactions with healthcare professionals and family strength; whereas the other family felt unsupported by healthcare professionals and experienced family strain. Both families then tried to create a sense of normal in their lives once again with varying degrees of success.

Keywords: Stroke, Lived-experience, Phenomenology, Family, Caregivers, Life change.

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Preface

This research study explored the lived-experience of two stroke families during the first six months post-stroke of a first-time stroke event. This thesis is presented in three main parts. Part one is comprised of two chapters. Chapter one is a literature review to orientate the reader to the background of caring for a stroke survivor and the family experience post-stroke. Chapter two is a detailed methodology section followed by research methods.

Part two is presented in a manuscript with related appendices to suit publication in the journal *Kai Tiaki Nursing Research* utilising the stipulated formatting and referencing style. Part three is the appendices which contain documentation of ethics approval, participant information, participant interview schedule, guidelines for journal publication and a detailed break-down with examples of working with the data and formulating the main over-arching theme of this research.

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Glossary

Emotional distress: a term referring to negative feelings, such as low mood and anxiety that can cause other health-related illness if not improved (Greenwood & Mackenzie, 2010a)

Family function: family members working together as a team to care for a stroke survivor; includes family problem solving, team work, trust and support of each other, effective communication, behavioural control and affective involvement with the stroke survivor (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988)

Families: for the purpose of this study are viewed to include people in close relationship with the person who has a stroke and not limited to those with genetic links

Group-based intervention: group therapy with the aim of facilitating group support (Bowen et al., 2009)

Primary caregiver: for the purpose of this study is a person who is not paid to care for and carry out everyday tasks for a person with impairment; most often a spouse or adult child, but could be another family member, friend or neighbour. The person primarily responsible for caring for a person with impairment; may be used interchangeably with informal caregiver or family caregiver

Post-stroke: there are three phases recognised through research following a stroke event. The acute stage is usually thought of as the hospital phase. Rehabilitation is recognised as when the stroke survivor is being integrated into their own home / community. Transitioning into life after stroke (the third phase) is when the stroke survivor's rehabilitation has reached its maximum (Gillespie & Campbell, 2011)

Stroke survivor: a person who has had a stroke event and continues to live

Stroke family: a family that has a stroke survivor relative/member

Whānau: as per the Maori dictionary meaning (Moorfield, 2012); a family group, which can be used to include extended family members and sometimes used to include close friend

Part One

Chapter One: Introducing the Research

Introduction

The preface acquaints the reader to the thesis structure. This introduction orientates the reader to the research topic and how the research was conducted.

Stroke is a major public health issue in New Zealand and world-wide. Approximately twenty four New Zealanders have a stroke each day with around six of these being under the age of sixty five years (Stroke Foundation of New Zealand, 2013). There are around 60,000 stroke survivors in New Zealand with the number growing daily. Many are dependent on others for assistance with daily living (Stroke Foundation of New Zealand, 2013; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Stroke survivors are often left with on-going impairments and depend on others to assist with their daily living needs.

Stroke-related impairment is projected to increase in New Zealand. With medical advancements and stroke prevention education, stroke occurrence is falling by around one per cent per annum. However with appropriate medical intervention stroke mortality rate is falling faster at approximately 4.5 per cent per annum (Tobias, Cheung, Carter, Anderson, & Feigin, 2007). With the aging population and stroke mortality rates decreasing faster than stroke occurrence, stroke-related impairment is projected to continue to rise in New Zealand.

Stroke survivors often rely on family members to care for them and carry out basic daily tasks (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Family members, usually a spouse or adult child (Greenwood & Mackenzie, 2010b), often give their time for the stroke survivor's on-going support needs with everyday

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activities. With the projected rise of stroke survivors and stroke-related impairment there is due to be more stroke families in New Zealand. It is now more crucial to understand the whole family's experience of the stroke event so that appropriate intervention and support can be put in place to increase the sustainability of family caregiving. To date a number of studies have explored specific phases of post-stroke experience. However no study has been identified that investigates family experience beyond that of the primary caregiver post-stroke over an extended period of time.

This study explored the experience of two different families during the first six months post-stroke. Becoming a stroke family is a journey; therefore data from three different intervals in the first six months post-stroke were collected and analysed to interpret family experience from the acute event towards the rehabilitation phase of stroke. This stand-alone study contributes its data to a larger longitudinal project (Appendix A) which is exploring the experience of five families during the first four years post-stroke event.

There is considerable literature available to contribute towards understanding the primary caregiver's experience. Research into the phenomenon of stroke caregiving has identified that, on average, one out of three caregivers experience strain or considerable burden (Ilse, Feys, de Wit, Putman, & de Weerd, 2008). Family inclusion in stroke literature remains limited in exploring the wider family's experience post-stroke.

At the commencement of this study a comprehensive literature review identified a lack of literature and knowledge surrounding the experience and lives of stroke families. The first six months post-stroke has been identified through research as a fundamental time for intervention from healthcare professionals (Gillespie & Campbell, 2011). The stroke survivor's needs and patient factors are established around six months post-stroke, which influences the caregiver's emotional distress (Gillespie & Campbell, 2011). In response to gaps in knowledge of stroke family needs post-stroke the following study was undertaken to contribute to knowledge in the area of 'becoming and being a stroke family during the first six months post-stroke.'

Literature Review

The following is a summary of literature that contributes to the body of knowledge in the area of caregiving for a stroke survivor. The focus of this literature review is from the stroke survivor's primary caregiver point of view because that is the literature most readily available. Where possible the review discusses the experience of the wider stroke family. Firstly the literature review introduces the background of stroke and stroke survivors and outlines emerging findings on stroke survivors' outcomes, needs and assessments. The review then covers the primary caregiver's experience of stroke, caring for a stroke survivor and their support needs. This is followed by an outline of how stroke is thought to affect family beyond the primary caregiver. Lastly the literature review explores the influence interactions with healthcare professionals has on the primary caregiver and stroke families.

Literature Search Strategy

Literature included in the review was identified through an EndNote library shared with the larger project as well as database searches using EBSCO, Science Direct, Health Source and PubMed using keywords: stroke, stroke families, caregiver (caregiving) depression, experience and outcomes. Potential articles for inclusion were also identified through article reference list searches. Article inclusion criteria for review were: a topic of stroke or brain injury, stroke caregiving and any studies that identified family as well as lived-experience stroke studies; an emphasis on current literature was used.

Background of Stroke and Stroke Survivors in New Zealand

Stroke is a major public health issue world-wide and in New Zealand. A stroke occurs when blood supply to the brain is interrupted, which can cause permanent damage to the brain (Ministry of Health, 2012). Men and women have similar rates of stroke (Ministry of Health, 2012), however emerging world-wide statistics suggest an increase of stroke incidence in ages under 75 years (Feigin et al., 2014). Outcomes of a stroke are varied, ranging from death, to various stages of rehabilitation (Ministry of Health, 2012)

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back to community based living or remaining in a medical facility (Greenwood & Mackenzie, 2010b).

In New Zealand there are approximately 60,000 stroke survivors with the number growing every day (Stroke Foundation of New Zealand, 2013; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). The expected number of stroke survivors living with stroke impairment is projected to increase (Feigin et al., 2014; Greenwood & Mackenzie, 2010b). The stroke mortality rate is decreasing (Tobias et al., 2007) but many stroke survivors are left with significant long-term impairments. Furthermore, in New Zealand the burden of stroke falls disproportionately on Māori and Pacific ethnic groups. Māori adults are 1.3 times more likely to experience stroke than non-Māori (Ministry of Health, 2012). The mean age for first stroke is 61 years in Māori and 65 years in Pacific people, compared with 75 years in New Zealand European population (Dyall, Feigin, & Brown, 2008; Feigin et al., 2006). In particular, Māori women had 2.3 times higher rate of stroke incidence than non-Māori women in the Ministry of Health 2011/2012 survey findings (Ministry of Health, 2012). The high prevalence of stroke-related impairment, particularly in New Zealand, means stroke and its consequences on families/whānau is an important health issue.

Emerging Findings on Stroke Survivors' Outcomes, Needs and Assessments

Stroke survivors are often left with on-going support needs that may or may not be adequately met. Stroke patients need physical and emotional support (Parag et al., 2008); depression is present in one quarter of stroke survivors and is linked to poorer outcomes (Kouwenhoven, Kirkevold, Engedal, & Kim, 2012). The outcomes for stroke survivors are better when they feel part of the family because family function impacts on the stroke survivor's connection to family (Santos, Cecílio, Teston, & Marcon, 2012). Social networks and interactions with a spouse are important for stroke survivors (Brunborg & Ytrehus, 2013). Family function and family support are important for positively influencing the stroke survivor's outcomes.

Interventions may help to improve stroke survivor outcomes. White et al. (2012) recommend a longer duration of interventions past the acute stage post-stroke and into

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the rehabilitation and transition phases. Longer interventions could help decrease psychological distress in stroke survivors. Rothwell, Boaden, Bamford, and Tyrrell (2013) conducted an intervention at six months post-stroke which assessed stroke survivors' needs. The assessment was carried out in the stroke survivor's home with their primary caregiver (typically a spouse) present. They found at least half the unmet needs could be addressed through information and advice at the assessment point. Stroke survivors also reported feeling supported by having the needs assessment done and felt it was beneficial. Rothwell et al. advise introducing an assessment for the stroke survivor at six months post-stroke to establish any unmet needs the stroke survivor has. Both stroke survivors and their carers find difficulty in expressing their concerns to professionals therefore an assessment is crucial to identify their needs (Rothwell et al., 2013). To establish what interventions are needed for a stroke survivor it is beneficial for a needs assessment to be carried out at six months post-stroke.

Merlo, Goodman, McClenaghan, and Fritz (2013) implemented a novel task-specific intervention therapy for chronic stroke patients (time after stroke varied), every day for ten days aimed at treating gait, balance and mobility deficits. Seven out of eight patients enjoyed the intense intervention but found ten days was too short (Merlo et al., 2013). Stroke survivors have unmet emotional and physical needs following hospital discharge. Specific interventions for stroke survivors over a longer period of time are recommended with a follow-up assessment at six months post-stroke to establish any unmet needs. Improving stroke survivors' outcomes may improve family carers' outcomes.

Background of Stroke-Related Caregiving

Family members, usually a spouse or adult child (Greenwood & Mackenzie, 2010b), often give their time for the stroke survivor's on-going support needs with everyday activities. The Auckland Regional Community Stroke (ARCOS) study conducted in Auckland New Zealand between 2002-2003 reported that of the 1,172 stroke survivors interviewed, approximately 30 per cent were cared for by a family member at six months post-stroke (Parag et al., 2008). It is well documented that the caregiver's role is important for the stroke survivor's recovery and rehabilitation (Goodhead & McDonald, 2007; Greenwood & Mackenzie, 2010a, 2010b; Maclsaac, Harrison,

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Buchanan, & Hopman, 2011; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Research has demonstrated that family caregivers are important for the stroke survivor but suggests caregiving may lead to adverse health effects for carers. Depression and other emotional distress can develop in carers due to the physical, cognitive and emotional needs of stroke survivors (Gillespie & Campbell, 2011). The caregiver's role is important in the stroke survivor's recovery; research exploring the primary caregiver's wellbeing has increased healthcare considerations and knowledge of emotional distress associated with caregiving.

Stroke survivor's disability affects the caregiver's outcome. A recent study by Berglund and Johansson (2013) reported on caring for a spouse with a neurological disorder. The study included eighteen caregivers, fifteen of who were caring for a stroke survivor. The researchers found caregiver burden depends on the degree of the spouse's disability. McPherson, Wilson, Chyurlia, and Leclerc (2011) found caregiver quality of life decreases with increased stroke survivor impairments. Ilse et al. (2008) studied 90 stroke survivors and their primary caregivers (66 per cent partners and 33 per cent family relatives), at regular intervals over the first year post-stroke. Ilse et al. found one in three caregivers experienced strain, which became worse over time if the stroke survivor's physical and functional abilities did not improve from the stroke event. Peyrovi, Mohammad-Saeid, Farahani-Nia, and Hoseini (2012) found a relationship between caregiver's depression and the level of the stroke survivor's disabilities. The degree of the primary caregiver's burden, decreased quality of life, strain and depression have been associated with stroke survivors who have increased functional disabilities (Peyrovi et al., 2012). Therefore improving stroke survivor functional outcomes by implementing longer rehabilitation interventions would contribute to improving some of the carers' outcomes.

Effects on caring for a stroke survivor during the acute phase. Due to the sudden unexpected nature of stroke, family caregivers often feel inadequately prepared for their caregiving roles. A 2008 qualitative study contributes understanding towards the phenomenon of the experience of Māori stroke survivors and their family primary caregivers in New Zealand. Stroke was described as a frightening unexpected event (Dyall et al., 2008). Family members found interactions with healthcare professionals

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challenging and the stroke caused financial and social impacts on the family members (Dyall et al., 2008). The shock of the stroke event affects the patient and the family. In a qualitative study by Wallengren, Friberg, and Segesten (2008) to explore the caregiver's experience in the acute stage of stroke, the 16 primary caregiver participants (6 spouses, 8 daughters, 1 daughter-in-law and 1 friend) described the event as chaos. The researchers found it was important for the primary caregivers to reach a 'turning point' when their journey from being a family to becoming a stroke family begins (Wallengren, Friberg, et al., 2008). These studies suggest relatives may have health consequences following the chaotic situation from the acute onset of stroke and the immediate hospital stay.

The whole family is affected by a stroke event. The impact of a loved one's illness affects the family in many ways. There is direct impact from the illness and the hospital stay which can disrupt routines affecting the entire family (Lindhardt, Bolmsjö, & Hallberg, 2006). Hunt and Smith (2004) reported that the uncertainty and traumatic event of stroke was experienced by the stroke survivor and also by the four family caregivers included in the study. The carers experienced emotional strain during the hospital stay and needed time to adjust to life post-stroke. Stroke is an unexpected shock for the whole family. A recent study using grounded theory by de Palva, Valadares, and Silva (2012) explored the experience of nine primary caregivers to a first time stroke survivor during the hospital stay. The family participants included six adult children, two spouses and one sister ranging between 29 and 61 years old. The consequences of stroke and the need for caregiving were a cause for tension in the family. The participants felt it was important to be included in the care setting and in planning decisions for hospital discharge (de Palva et al., 2012). The journey of becoming a stroke family starts in the acute setting. The journey for families responsible for providing care to the stroke survivor can be completely life changing.

Primary Caregivers Need Time For Transition

The transition for primary carers takes time following a stroke event. The shock of the unexpected event followed by chaos may lead to grief and loss. Grief is experienced from the loss of former relationships with the stroke survivor (Saban & Hogan, 2012).

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Relationship and role transition takes time. Primary caregivers experience difficulty in adjusting to new roles (Gillespie & Campbell, 2011) and experience anxiety regarding the stroke survivor's return home (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010). Depression and other emotional distress can develop in carers weeks to months post-stroke event (Greenwood & Mackenzie, 2010b). Primary carers are at risk of becoming a second patient in the family because of their own general health decreasing (Sit, Wong, Clinton, Li, & Fong, 2004). The role and health of the primary caregiver is important, not only for them to be able to continue caring for the stroke survivor, but because their own health can deteriorate. Emotional distress in family carers can develop from the acute care setting.

Role change contributes to emotional distress in family carers. A number of studies report that a role change and loss of former identity in family caregivers contribute to emotional distress. For example, a change in role from spouse and lover to care provider or from an adult child to care provider contributes to a loss of former identity (Bowen et al., 2009; Dickson et al., 2010; Lindhardt et al., 2006). Primary caregivers take on the caregiving role in addition to their other roles and in doing so can lose their former identity.

Change and loss. The stroke event changes the identity and future of primary carers and contributes to emotional distress. In a meta-ethnographic review of stroke primary caregivers' experiences, change included role change, loss of former identity, autonomy and taken for granted futures (Greenwood & Mackenzie, 2010b). Saban and Hogan (2012) argue that the relationship change with the stroke survivor causes the most distress for family carers. In some instances the stroke survivor's personality can drastically change from the stroke event. Bäckström, Asplund, and Sundin (2010) found at one month post-discharge spouses experienced fear regarding loss of their former relationship and felt estranged from the stroke survivor/spouse due to personality and relationship changes. Relationship changes caused spouses to lose their own identity and also the marriage identity.

Change of former life. Another form of loss is from the change of life after stroke. A loss of freedom following the stroke event was reported by Wallengren, Segesten, and

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Friberg (2008) in a qualitative study at six months post-stroke. Loss of freedom was also reported by Greenwood and Mackenzie (2010b). An exploratory study interviewing six primary caregivers found that caregivers made significant adjustments to coping and adapting to their permanently changed lives. Carers neglected their own needs resulting in loss of self (Kenny, Sarma, & Egan, 2012). Primary caregivers can experience a loss of freedom and a loss from neglecting their own needs when caring for a stroke survivor.

An uncertain everyday life. Gosman-Hedstrom and Dahlin-Ivanoff (2012) explored older women's experiences of caring and living with their partners post-stroke. Sixteen older female carers were interviewed in four different focus groups. Findings revealed stroke changed the stroke survivor and the primary caregivers felt they were living with a different person (Gosman-Hedstrom & Dahlin-Ivanoff, 2012). Following the stroke, carers felt guilt, grief, fear of stroke happening again, as well as difficulty in negotiating time for themselves with or without formal care. All of these experiences led to an overall understanding that following stroke the carers had to negotiate mastery of an uncertain and unpredictable everyday life (Gosman-Hedstrom & Dahlin-Ivanoff, 2012). When family carers are faced with challenges they need to make significant changes in order to accept and adapt to life post-stroke.

Burden and strain. Research to date has recognised there are many factors that may lead to negative experiences when caring for a stroke survivor. One term often described in literature is caregiver burden. Family carers experience burden (Lutz & Young, 2010). Caregiver burden is thought to be greatest when the role begins (Parag et al., 2008). Caregiver burden is affected by caregiver background and context. Different illnesses are associated with different outcomes and directions; for example, the sudden onset of stroke has different pathways as a stressor than the gradual transition of cancer. The type of deficits or impairment related to illnesses are also important as context (Bastawrous, 2013). Cancer usually has physical decline whereas stroke has sudden physical, emotional and cognitive impairment involved. The burden associated with stroke caregiving may be contributed to by the sudden onset of stroke related impairments and the change of former life.

What is caregiver burden? Research to determine the factors that make up caregiver burden was conducted by Elmstahl, Malmberg, and Annerstedt (1996). A 22 item assessment scale survey was completed by stroke caregivers three years post stroke. The researchers found burden was comprised of general strain, isolation, disappointment and emotional involvement (Elmstahl et al., 1996). The term caregiver burden is vague and therefore there may be multiple definitions. Bastawrous (2013) recommends a framework in which role theory and stress theory are utilised. Research addressing caregiver burden is often related to gaining insight into the stress/strain relationship (Bastawrous, 2013). Focusing on emotional distressing factors such as role change, uncertainty and reduced autonomy would be more valuable than general burden and strain (Greenwood & Mackenzie, 2010b). Grouping negative experiences of primary caregivers into burden has multiple factors. Therefore findings that state the specific factors rather than grouping as burden are more helpful for understanding caregiver's experience.

Improving caregiver transition. A number of researchers suggest the dependency, health and recovery of the stroke survivor influence the emotional distress of the primary caregiver (Baumann, Couffignal, Le Bihan, & Chau, 2012; Ilse et al., 2008; Lutz & Young, 2010; Salisbury, Wilkie, Bulley, & Shiels, 2010). Research to further understand the various role/relationship demands, life change and challenges for primary caregivers may help to improve caregivers' outcomes.

Caregiving Impacts on Health and Well-being of Primary Caregivers

There are multiple factors that impact upon the health and well-being of primary caregivers. The transition of becoming a caregiver to a family member is challenging as significant adjustments of role, relationship and life need to be negotiated. Negative health impacts can develop in primary family carers post-stroke.

Grief and fatigue. The stroke event can cause negative health effects, such as grief and fatigue on primary caregivers (Hunt & Smith, 2004; Wallengren, Segesten, et al., 2008). Following a stroke event there is a risk of complicated grief where family members experience grief for the loss of a loved one still alive (Ghesquiere, Haidar, & Shear, 2011). Primary caregivers may suffer emotional exhaustion and compassion fatigue.

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Suffering, over-exposure and stress are all potential stimuli for developing compassion fatigue (Lynch & Lobo, 2012). Family caregivers can experience complicated grief and compassion fatigue following a stroke event.

Anxiety in carers. Uncertainty from the stroke event can lead to anxiety. Greenwood and Mackenzie (2010a) researched anxiety in primary carers of stroke survivors at one month and three months post-discharge from a stroke rehabilitation unit. Out of 45 primary caregivers, 14 at one month and 11 at three months had high scores for both anxiety and depression. Around half the carers had high scores in anxiety at both one month and three months post stroke (Greenwood & Mackenzie, 2010a). Uncertainty and unrealistic fears regarding future strokes are experienced in caregivers. Kenny et al. (2012) report a general unpreparedness for taking on the primary caregiving role, a constant state of anxiety of the here and now, anticipatory worry for the future and unrealistic fears created by anxiety. Addressing primary caregivers' anxiety and other emotional distress from caregiving would help to improve caregivers' outcomes.

Decreased quality of life. There is some evidence to suggest all domains of quality of life are affected following the transition of becoming a primary caregiver (Baumann et al., 2012). Relatives becoming primary caregivers to someone with a chronic condition report their situation as extremely demanding and a heavy burden which receives a lack of support from healthcare professionals (Öhman & Söderberg, 2004). A recent study found important factors associated with primary caregivers' decreased quality of life: females, older age, decreased income and less formal education were all associated with decreased quality of life. Conversely primary caregivers who had support from another person in their role had improved quality of life compared to those without support (Ovayolu et al., 2013). The researchers propose the correlation between decreased quality of life and less education is possibly due to the caregivers' decreased ability to communicate with healthcare professionals and access their information and support needs (Ovayolu et al., 2013). Caregivers receiving support in their role have better quality of life; there are several factors associated with decreasing quality of life for primary caregivers.

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Workload increases. Bulley, Shiels, Wilkie, and Salisbury (2010) interviewed nine primary caregivers at six months post-stroke to gain insight into the carer experience of life after stroke. Findings included changes to their domestic and caring workload following the stroke survivor's return home. Workload increased because the stroke survivor could no longer help out around the home with domestic tasks, which was more difficult when caring for children as well (Bulley et al., 2010). Workload increase also relates to the caring responsibilities which may or may not ease over time, depending on the stroke survivor's recovery (Bulley et al., 2010). When the stroke survivor returns home primary caregivers experience an increase in workload from domestic and caregiving tasks.

Findings from a large Auckland-based survey. Research investigating stroke primary caregiver experience at six months post-stroke uncovered areas of health concern. Parag et al. (2008) conducted a large Auckland population based survey utilising questionnaires and interviews with stroke survivors and their primary caregivers. They found at six months post-stroke carers had a significantly lower emotional well-being compared to stroke survivors. Almost all caregiver participants reported reduced energy levels, decreased physical health and reduced ability to cope with stress. All reported less social time with family and friends and 23 out of 62 caregivers reported a negative relationship change with the stroke survivor; whereas 32 reported a strengthened relationship (Parag et al., 2008). Caregiving for a stroke survivor reduced participants' social time with friends; the majority had emotional distress and lifestyle changes detrimental to their over-all wellbeing and health.

Caregiving can be a positive experience. Other researchers also report positive aspects of caregiving for a stroke survivor. Positive gains from caregiving include strengthened relationships with the stroke survivor (Gillespie & Campbell, 2011; Greenwood, Mackenzie, Cloud, & Wilson, 2009; Hunt & Smith, 2004), gains in abilities to cope with stress and an increased appreciation for life and relationships (Greenwood, Mackenzie, Cloud, et al., 2009). There are positive gains from caregiving as well as negative experiences.

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The previous paragraphs have introduced the multiple factors that contribute to emotional distress experienced in primary caregivers which can develop weeks to months after the stroke event. There are some positives to caregiving for a stroke survivor; however the negative experiences and health deterioration demonstrated from research to date far outweigh positive gains. Therefore primary caregivers have unmet support needs which need to be examined.

Carers' Support Needs Post-Stroke

Research has contributed an understanding of the negative impact of caregiving on primary caregivers for stroke survivors. Further research has investigated primary caregiver support needs post-stroke event. An overview of literature findings regarding primary caregiver support needs is outlined below.

Caregiver assessment tool. A mixed methods study conducted by MacIsaac et al. (2011) measured the usefulness of an assessment tool to help determine the needs of primary caregivers. Although further research is required to validate the study's assessment tool, findings suggest its use in hospitals could contribute towards increasing adequate support to primary carers by establishing their requirements. Supporting primary caregivers in their change of life from the hospital setting is important as emotional distress and lack of support have been identified as early as the acute stroke event.

Information needs. A cross-sectional study by Sit et al. (2004) to identify primary caregivers' needs included 102 primary caregiver participants who were sharing the same residence as the stroke survivor. The study included only one participant for each stroke survivor. The participants included 61 spouses, 31 parents, four siblings, two adult children and one grandparent. Sit et al. found at three months post-hospital discharge the primary caregiver's needs were inadequately identified. The participants reported meeting the physical needs of the stroke survivor was the most difficult task. After 12 weeks of caring for the stroke survivor at home nearly half of the participants reported somatic symptoms and fatigue to the extent they needed to see a doctor (Sit et al., 2004). Generally caregivers had a lack of quality information to meet their needs, caused by inadequate knowledge to differentiate between the urgency of symptoms, and information provided by healthcare professionals not matching their needs.

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Participants also reported a lack of feedback with regard to their caregiving and a lack of information on how to seek professional advice (Sit et al., 2004). Social support had a positive effect on primary caregiver health. Providing caregivers with adequate access to information and clearly identifying caregivers' needs as well as increasing social support are included in caregivers' support needs.

Physical support needs. Hafsteinsdóttir, Lindeman, Schuurmans, and Vergunst (2011) reviewed literature prior to and including 2009 on stroke patient and primary caregiver education needs post-stroke. Carers reported needing physical help with lifting and moving the stroke survivor as well as exercise help. The review also reports psychological and nutritional information needs (Hafsteinsdóttir et al., 2011). There may be different needs at different times depending on the recovery phase post-stroke (Hafsteinsdóttir et al., 2011). Physical help with the stroke survivor was highlighted as an area where family caregivers need urgent support.

Emotional support needs. Stroke survivors' personalities can drastically change from the stroke event. Caring for a stroke survivor with emotional and behavioural changes impacts on the primary caregiver, causing emotional distress (Creasy, Lutz, Young, Ford, & Martz, 2013). Information and support regarding personality changes to the stroke survivor is less readily available, even though when information was given to one participant she felt this helped her (Bulley et al., 2010). Information regarding changes to the stroke survivors' personality would improve primary caregiver emotional outcomes.

Individualised diverse support needs. There are many factors that impact on primary caregivers. The diversity of caregivers' lives needs to be taken into account when considering their support needs (Cecil, Thompson, Parahoo, & McCaughan, 2013). Kenny et al. (2012) recommend that healthcare professionals listen to caregivers' specific problems and needs which would help to identify and individualise caregiver support. A lack of on-going support services was noted for caregivers when the stroke survivor returned home (Salisbury et al., 2010). Primary caregivers' needs are diverse and carers benefit from individualised healthcare.

Stroke survivors' impairments increase support needs. The greater the stroke survivor's impairments the more support the primary caregiver needs (Peyrovi et al., 2012). The researchers recommend assessing the stroke survivor's abilities when considering caregiver support. Improving support services when the stroke survivor returns home is also recommended (Peyrovi et al., 2012). Assessing individualised needs for primary caregivers would help to support the diverse nature and specific needs of caregivers.

Primary caregivers' support needs include assessment tools to determine what each caregiver's specific needs are. Primary caregivers require adequate access to information from the acute stroke event, throughout the hospital setting and following the stroke survivor's discharge. Findings suggest primary caregivers require physical support needs predominantly, however emotional support was beneficial to one participant when it was provided. Stroke survivor impairments increase the needs of carers. Primary caregivers' support needs are diverse and considering individualised healthcare could improve primary caregivers' outcomes.

Considering the Primary Caregiver and Wider Family

There has been adequate research to outline the effects of caring for a stroke survivor on the primary caregiver. Some understanding of primary caregivers' experience, health impacts and support needs have been outlined above. However research inclusion and understanding of the wider stroke family remains limited. Literature has been focused mainly on spousal primary caregivers with some inclusion of adult children (particularly adult daughters) as primary caregivers. Research suggests the current trend is more adult children taking on the primary caregiving role for aging parents; the caregiving role usually occurring when the adult child has their own family obligations (Bastawrous, 2013). When primary caregivers are providing care to others, such as their children, as well as the stroke survivor, co-ordinating care becomes more difficult (Kenny et al., 2012). Research needs to include a wider range of primary caregivers and include other family members beyond the primary caregiver to determine the wider stroke family experience.

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Family as a source of strength. When faced with a stressful life event family strength is of utmost importance; family may gather and support each other through a stroke event (Niyomathai, Tonmukayakul, Wonghongkul, Panya, & Chanprasit, 2010). The primary caregiver often relies on other family members or friends to help support them in their role as primary caregiver. For example, in a study of the phenomenon of being a relative to a hospitalised elderly person researchers found that the primary caregiver would need support from other relatives if they needed to go out (Lindhardt et al., 2006). The primary caregiver relied on relatives because they could trust them compared to paid help. This was also found in the study by Sit et al. (2004) where the researchers report carers tended to turn to family and friends for support in their caring roles. Family is an important source of support to the primary caregiver.

Family dynamics may change. The family dynamics and relationships may change following injury and illness. Two studies discuss family changes after illness other than stroke. Former relationships and past issues within a family may dissolve or become stronger (Lindhardt et al., 2006). Different families have different abilities to cope following an injury or chronic illness. An increase in family demands and decrease in family strength and capabilities was found in families following a critical injury (Leske & Jiricka, 1998). Family relationships may strengthen or weaken during illness.

Different families may experience different distress. Gillespie and Campbell (2011) reviewed literature published from 1983 – 2010 with the aim of outlining the effects of stroke on family dynamics. Gillespie and Campbell argue stroke can lead to substantial family challenges and the effects of stroke extend beyond the patient. The researchers maintain the same uncertainty following a stroke event can occur for the patient and the families. However the use of the collective ‘families’ is deceiving as the majority of articles reviewed included individual participants who were the primary caregiver, a spouse or sometimes an adult child but not contributing to an idea of the experience of the whole stroke family. Different family members could experience distress for different reasons. For example, spouses might be affected by the loss of intimacy, while adult children could face challenges regarding balancing responsibilities for their own children and for their parents (Gillespie & Campbell, 2011). Further investigation into

the wider family's experience post-stroke is needed to identify stroke families' support needs.

Marital life and parent-child relationships are affected. A recent qualitative study by Kitzmuller, Asplund, and Haggstrom (2012) interviewed 40 participants once between three and 25 years post-stroke event. The majority of participants interviewed were stroke survivors and the spousal primary caregiver; however two adult children who were minors at the time of the stroke event were also included. Four themes were identified: family support is essential, challenges in marital life, family disruption and further marital changes (Kitzmuller et al., 2012). Wider family was also involved following a stroke event as they support the caregiver and/or help with the children. The researchers identified that family members of stroke survivors are considerably affected and recommend further investigation into the family as a unit and its individual parts. The research by Kitzmuller et al. contributes valuable insight into the long-term effects on marital life and considerations to the parent-child relationships. This study is limited by research design, as only one interview was conducted with each participant, ranging between three and 25 years post-stroke event. Therefore interviews were less likely to capture the acute and rehabilitation stages post-stroke and mostly provided only the long-term considerations of family relationships. Research with one interview may not sufficiently map the journey of what it is to become and be a stroke family.

Primary caregivers beyond a spouse. Cecil et al. (2013) contribute understanding towards family life after stroke by including a wider variety in the relationship of primary caregivers to the stroke survivor. Thirty primary caregivers were interviewed: 19 spouses, seven adult children, three sisters and one niece-in-law; carers ranged from 39-84 years old and the stroke survivors' ages ranged from 37-95 with varying health status. Two younger stroke survivors had returned to work, some had resumed driving and other activities while some were bedbound and unable to do much for themselves. For all participants the stroke brought about a change in lifestyle, including: a restriction of the former life, a loss of friends and social life and a struggle with family finances (Cecil et al., 2013). Primary caregivers needed help and support from family and friends in their caregiving roles (Cecil et al., 2013). This study has a wider inclusion of primary

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family caregivers other than a spouse; however there is only one participant from each family which limits the inclusion of each family's experience post-stroke.

Adult stroke survivors and their parent carers. Another recent study by Jones and Morris (2013) explored the experience of primary caregiver parents and adult stroke survivor children through semi-structured interviews. This research offers a different perspective on the primary caregiver relationship. Analysis captured several key issues: emotional turmoil, significance of parents, negotiating independence and changed relationships (Jones & Morris, 2013). Parents adjusted to their caring roles with ease compared to their adult children who found difficulty in being cared for as a child again (Jones & Morris, 2013). Jones and Morris conclude family support in the form of caring provides positive functional recovery and psychological well-being in stroke survivors. Negotiating the path of becoming a carer for a stroke survivor was easier for parents when it was their own child. This study may give valuable insight as more strokes are occurring under the age of 75 years (Feigin et al., 2014) and more parents could be caring for their adult stroke survivor child.

There is need for further stroke family studies. Many studies including the above four studies (Cecil et al., 2013; Gillespie & Campbell, 2011; Jones & Morris, 2013; Kitzmuller et al., 2012) that have been discussed in-depth are limited by not including any family member participants other than the primary caregiver. Each study contributes insight towards an understanding of family life post-stroke from the primary caregiver's point of view. Research that has encompassed stroke family relationships has highlighted the importance for further exploration into the wider family's experience post-stroke: as a family unit and as individual members. The lack of family participants included in research limits the understanding of the wider family experience of stroke. Research to explore stroke family life, each family member's experience and stroke family support needs is required urgently.

Stroke Families

Some awareness of different families' ethnicity considerations is important, especially with respect to Māori culture. Māori stroke survivors are more likely to be discharged into the care of the whānau after a stroke event compared to other New Zealanders

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(Feigin et al., 2006; Parag et al., 2008; Tobias et al., 2007). The younger age at first incidence of stroke and nature of whānau indicate Māori prefer to bring their family member home (Tobias, Cheung, & McNaughton, 2002). Therefore whānau are more likely to take on caregiving tasks in New Zealand. A study by Dyllal et al. (2008) found New Zealand health services were a challenging experience for Māori stroke survivors and their primary caregivers. Stroke families differ in their cultural beliefs. Cultural awareness is important for healthcare professionals to be able to have good communication with families.

Family relationships influence needs. Family relationships and strength help to support the primary caregiver in their role. Different factors may influence family coping. Family members may find it difficult or feel it is selfish to go out and enjoy themselves if the stroke survivor can no longer do so (Greenwood & Mackenzie, 2010b). Some families may therefore choose to avoid social opportunities. Niyomathai et al., (2010) investigated why some families seem to cope better than others. They studied six family units; their research suggests the possibility of different families' attitudes and coping abilities with the stroke event may influence the primary caregiver's ability to self-develop in their caring role. Niyomathai et al. found families who shared the family and caregiving tasks developed strengthened family relationships and faced caregiving challenges with a 'can-do' attitude. Families have different abilities at providing home caregiving and the requirements of family members need to be taken into account when making decisions for additional support (Niyomathai et al., 2010). Improving family inclusion in healthcare and supporting family relationship strength would be beneficial for improving primary caregiver outcomes.

Considering the whole stroke family. There is limited understanding of the dynamic experience and needs of individual family members following a stroke event. Further exploration into understanding families' experience would be useful to gain insight into the changes and coping mechanisms of family life post-stroke. How primary caregivers view healthcare interactions and a family-centred healthcare approach is examined next.

Interacting with Healthcare Professionals

Healthcare professionals are another important factor in the support of primary caregivers. Creasy et al. (2013) explored 17 caregivers' experience of interactions with healthcare professionals; 15 were primary caregivers: 13 spouses and two adult children, with the spouse of the adult children also included. Two interviews were conducted for each participant: one during the hospital stay and the other at four months post-discharge. Caregivers discussed numerous concerns about the care the stroke survivor received during the rehabilitation phase as well as concerns for their own lack of preparation for bringing the stroke survivor home (Creasy et al., 2013). Caregivers' interactions with staff were seen as disconnected and uninvolved. Caregivers felt they were perceived as bothersome and felt providers were too busy to interact with family members (Creasy et al., 2013). Caregivers wanted to be included in the healthcare setting but instead were predominantly uninvolved and ignored. Creasy et al. recommend care for the stroke survivor needs to be collaborative; both primary caregivers and hospital staff are involved in the care for the stroke survivor therefore they need to collaborate. Findings are similar to a previous study where primary caregivers were frustrated by staff in the healthcare setting (Lindhardt et al., 2006). Primary caregivers found it difficult to leave care to staff members as staff neglect increased carers concerns. The hospital experience was an emotional strain for primary caregivers where they felt powerless (Lindhardt et al., 2006). It is important for healthcare professionals to engage and listen to the primary caregiver's needs as well as keeping all family members informed and included in the healthcare setting.

Discharge planning. Primary caregivers need to be involved in discharge planning to feel prepared for the stroke survivor's return home. Salisbury et al. (2010) reported that primary caregiver participants experienced poorly organised discharge planning and felt unprepared for their new caregiving role. Researchers from a recent study found families anticipated hospital discharge and became concerned over the under-preparation for their caregiving role (Creasy et al., 2013). In the recommendations from a previous study, Shyu, Chen, Chen, Wang, and Shao (2008) advocate caregiver orientated discharge planning to help improve caregiver preparation and satisfy caregivers' needs. Carers in a group intervention with an emphasis on home visits and

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individualised health education had better preparation and satisfaction of discharge needs compared to a control group (Stewart et al., 2006). Another study has also supported family participation at the hospital setting (de Palva et al., 2012). Healthcare professionals need to support primary caregivers and wider family members during the acute stroke event and beyond into the stroke survivors recovery and rehabilitation. Primary caregivers need to feel included in the stroke survivor's discharge planning to support the transition of bringing the stroke survivor back home. Primary carers thrust into the role of caregiving without adequate healthcare interaction often feel unprepared and unsupported, which causes difficulty to establish a positive caregiving experience.

Support needs change. A recent qualitative study by Cameron, Naglie, Silver, and Gignac (2013) compared and contrasted the support needs of primary caregivers from the caregivers' point of view and from the healthcare provider perspective. Cameron et al. found that both caregivers' needs for support and the healthcare professionals most suited to providing support change across the stroke survivor's recovery trajectory. Healthcare professionals need to address the changing caregiver needs across the care continuum (Cameron et al., 2013). To decrease the negative experience and emotional distress associated with caregiving for a stroke survivor, healthcare professionals may need to further develop the support available across the care continuum. Therefore ongoing need assessments may be useful for implementing different interventions to improve caregivers' outcomes.

Emerging Caregiver interventions. A group-based intervention study to facilitate coping skills in new primary caregivers found that the intervention had a positive influence on caregivers' health (Robinson et al., 2005). Another intervention study by Stewart et al. (2006) connected established primary caregivers with carers beginning their roles via telephone communication as a way of supporting the new caregivers. Caregivers beginning their role praised the help and support they received from established caregivers and found it useful to talk to someone else in a primary caregiving role (Stewart et al., 2006). Group-based intervention and telephone support networks both had a positive influence on primary caregivers health.

A Family-Centred Healthcare Approach

Research has suggested that because stroke recovery and caregiving is a dynamic evolving experience, different support needs may be necessary at different times. Therefore ongoing needs assessments may be useful for implementing different interventions to improve caregiving outcomes. Specific interventions have had a positive influence on primary caregivers' health, such as the use of group-based interventions and telephone support networks for primary caregivers. Including the wider family in the healthcare setting has been identified through research as an important factor in supporting the primary caregiver. Little is known about the wider stroke family's experience and support needs. It is important for research to explore the experience of stroke families by including participants beyond the primary caregiver.

There is awareness emerging in recent literature that family members need to be much more involved in the acute healthcare setting. Research recommends healthcare professionals move from a patient-centred approach to a family-centred approach (Bowen et al., 2009; Cameron et al., 2013; Clarke, 2013; Creasy et al., 2013; de Palva et al., 2012; Greenwood, Mackenzie, Wilson, & Cloud, 2009; Lutz & Young, 2010; Santos et al., 2012). A family-centred healthcare approach means a central role for the family where the strengths and needs of all family members are included and considered throughout the phases of post-stroke life (Visser-Meily et al., 2006). Family-centred healthcare would improve the development of the stroke family's role in caring for the stroke survivor returning home or staying in a medical facility.

Summary

Stroke primary caregivers have been the predominant participants and focus of the reviewed literature, however the whole family is affected by a stroke event. There are multiple factors that contribute to negative emotional distress in primary caregivers which can develop weeks to months after the stroke event. Research has demonstrated a large number of caregivers have unmet information and support needs when caring for a stroke survivor. Stroke recovery and caregiving is a dynamic experience with evolving support needs throughout the post-stroke event.

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While some studies have included primary caregivers other than the stroke survivor's spouse, the inclusion and understanding of stroke families remains limited. Different family members may experience a stroke event differently depending on their relationship with the stroke survivor and relationship strength with other family members. Some families may cope better and share their caregiving tasks, acting as a team rather than leaving the caregiving responsibility to one person. Supporting primary caregivers is important because stroke survivors often rely on family members to assist with their daily needs. Considering the wider stroke family's support needs is also important because the whole family is affected by the stroke event; the primary caregiver needs assistance from other family members to support them in their caregiving role.

A family-centred healthcare approach may help families transition from the shock of the unexpected stroke event, feel included in the healthcare setting and support the transition of becoming a stroke family. Additionally, group-based interventions may be a valid way of encompassing the whole family's needs as well as providing additional support to the primary caregiver.

Research is needed to further explore the experience of stroke families. Investigation is needed to identify different family members' needs as well as different family factors that could influence the dynamics of healthcare support and interventions for stroke families. No research has been located to date that focuses on stroke families' experience of becoming and being a stroke family within the first six months post-stroke.

Chapter Two: Conducting the Research

Methodology

This section outlines the theoretical aspects of the chosen research method. To begin with, an examination of qualitative research methods is made. The chapter then moves on to explore hermeneutic phenomenology as a research method. There is an introduction to utilising van Manen's methods in qualitative research, particularly hermeneutic phenomenology, followed by an examination of rigour in qualitative research. The methods involved in undertaking this project are then discussed.

Why Qualitative Research?

The literature review revealed that the factors which influence how families are affected by a stroke event are not yet clear. Although numerous research studies have investigated the phenomenon of being a primary caregiver to a stroke survivor, there is still limited understanding of the phenomenon of becoming and being a stroke family. Limitations of research studies and therefore stroke family understanding mean the needs of stroke families are poorly understood. This study utilises an exploratory design because of the limited understanding of stroke families experience and needs. Qualitative research is suitable in situations where little is known about a phenomenon as it allows the researcher to explore the topic in detail, without the constraints of prior assumptions (van Manen, 1997). A qualitative study was warranted to better understand the complexity of families' experiences after stroke. Qualitative research provides rich data to contribute toward understanding the journey of becoming and being a stroke family.

Choosing Hermeneutic Phenomenology

There are a variety of approaches to qualitative research. Grounded theory seeks to describe and explain a phenomenon, anchoring the phenomenon to an abstract theory (Chamberlain, 1999). During the analysis with grounded theory the researcher seeks to

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hypothesise and give understanding to what is going on; ideas are tested with further data collection (Chamberlain, 1999). Grounded theory, while useful for forming hypothesis and theory, was deemed inappropriate for this study as providing insight into 'lived-experience' was the aim. In phenomenological research the researcher seeks a truth that resonates and adds understanding to the phenomenon (Pringle, Drummond, McLafferty, & Hendry, 2011). Phenomenology is useful when little is known about the phenomenon. Phenomenology asks for the nature of the phenomenon (van Manen, 1997) and assists with uncovering meaning (Pringle et al., 2011). Hermeneutics adds a fuller active description of the phenomenon (van Manen, 1997) by interpreting meaning (Pringle et al., 2011). Therefore both descriptive and interpretive elements are present in this study.

Because little is known about the phenomenon of becoming and being a stroke family, a method which allowed further exploration into meaning and interpretation was warranted. The research question, not the method, is the important starting point of investigation (van Manen, 1997). Hermeneutic phenomenology was chosen because the research question requires a phenomenological sensitivity to lived-experience and a hermeneutic ability to interpret the phenomena (van Manen, 1997). Hermeneutic phenomenology was used to provide both an understanding of the phenomenon and an interpretation of 'becoming and being a stroke family in the first six months post-stroke.' Both descriptive and interpretive elements are present in this study. Hermeneutic phenomenology was found to be the most useful method to provide understanding and interpretation while exploring many possibilities of the phenomenon.

Introducing van Manen's Approach to Research.

The difficulty with qualitative research and particularly hermeneutic phenomenology is there is often no single recipe for the investigation procedures; however there is tradition, a body of knowledge and insights (van Manen, 1997). Van Manen (1997, p. 27-34) describes six activities as an approach to help the investigator in hermeneutic phenomenology research. Van Manen's activities were used to guide this study. Specific details about the conduct of this study will be discussed in the next section, methods.

- 1. Turning to the lived-experience.** To begin the research process the researcher begins to orientate to the phenomenon, mindfully or thoughtfully pondering the phenomenon in the context of a real person (van Manen, 1997). The researcher forms a research question then continues to orientate to the phenomenon and records assumptions and pre-understandings involved with the phenomenon (van Manen, 1997). The phenomenon of interest in this study 'stroke families' was first identified by a charge nurse of a local stroke rehabilitation unit. It was observed in the healthcare setting that some family members of stroke survivors remained stuck after the stroke survivor had accepted the stroke and moved on. This observation led to a chain of events that started an investigation into stroke survivors and their families.
- 2. Investigating the phenomenon as lived-experience.** Hermeneutic phenomenology requires the researcher to stand and explore the fullness of life, seeing the phenomenon for what it is, yet actively exploring all aspects of the phenomenon. The research must capture the very nature of being, the very nature of living and stay true to the participant's lived-experience/the phenomenon. In order to stay true to the data van Manen (1997) recommends suspending any pre-ideas about the phenomenon. By doing this the researcher allows for a true interpretation of the participant's lived-experience without the researcher's own ideas. When commencing this study the researcher was interviewed by a peer researcher which uncovered preconceived ideas and previous experience of the phenomenon (see p. 35 - articulating assumptions).
- 3. Reflecting and considering themes of the phenomenon.** To grasp lived-experience true reflection and thoughtfulness must occur. The researcher must consider their own view point from their own experiences and actively make a distinction between oneself and the phenomenon (van Manen, 1997). This activity is most important during the research analysis phase. Emerging themes from the data were examined and actively reflected upon until the researcher was sure the true meaning of the participants experience was being captured.

- 4. Working and re-working with the data in language.** During the research process language and thoughtfulness is the method used (van Manen, 1997). This step is about the researcher's art of writing and re-writing when working with the data to express the phenomenon in the form of themes. Working with the data by writing and re-writing was an essential activity within the process of reflecting, refining and illustrating the phenomenon being investigated in this study.
- 5. Continuing to maintain a strong orientation with the phenomenon.** Hermeneutic phenomenology is a demanding research method and it is important for the researcher to maintain a strong orientation with the fundamental question; in this case: 'what does it mean to be a stroke family?' Without a true and complete focus on the fundamental question the temptation to wander aimlessly and get side-tracked with indulgent reflections and theories will overcome the researcher (van Manen, 1997). To be orientated to the phenomenon means to be wholeheartedly animated by the phenomenon in a full and true sense of what it means to be human, without settling for superficial or false orientations (van Manen, 1997). This was achieved by the researcher continually returning to the research question and directing herself to the phenomenon which ensured a strong orientation to the phenomenon.
- 6. Consider the phenomenon as a whole as well as its parts.** When engaging with the research question one is in danger of losing the point: to construct and present the researcher's interpretation of the data in relation to the research question. The researcher must continually consider the significance of the individual parts in the context of the overall study (van Manen, 1997). During the research process, working with the data and compiling the findings, the phenomenon was as important and inseparable from identifying the essential themes. The phenomenon 'becoming and being a stroke family' and the individual themes contributing to understanding the phenomenon are displayed with direct quotes from the participants.

Addressing Rigour in Qualitative Research

Rigour or trustworthiness of qualitative research and how that process can be achieved is discussed here. Rigour in qualitative research is open to debate because there are many aspects involved in how best to assess the process of rigour. This section will explore the range of criteria used to assess rigour in qualitative research.

Criteria for Assessing Rigour. A range of criteria for evaluating rigour exists (de Witt & Ploeg, 2006). It is of importance to note that criteria for validity and reliability as used in quantitative research cannot be directly transferred to the qualitative research process. Koch and Harrington (1998) argue that reflective, self-critiquing research with detailed explanations on how themes were identified and developed are the basis for rigour in qualitative research.

Ryan-Nicholls and Will (2009) argue that qualitative research is artistic and non-replicable; meaning each person's own experience is unique and the truth is relative. Balancing the focus and meaningfulness of the research with the outcome and control of the research process is difficult to achieve in qualitative research. To increase trustworthiness the researcher must not only state that something was done but explain how it was done (Ryan-Nicholls & Will, 2009). The important attributes of rigour include the use of logical systems which strengthen and increase significance of findings in the research. By collecting, analysing and presenting data systematically, findings and interpretations are open to evaluation and replication and unwarranted results can be identified and revised or refuted.

A framework which includes credibility, transferability, auditability and confirmability is recommended for use in qualitative research to increase the trustworthiness of the study (Ryan-Nicholls & Will, 2009). Houghton, Casey, Shaw, and Murphy (2013) suggest the use of a similar set of criteria: credibility, dependability, confirmability and transferability. These criteria used for judging trustworthiness in qualitative research are outlined below and discussed in relation to the current study.

Dependability. Dependability or auditability relates to reliability of the data. Providing an audit trail of decision making processes is a form of reliability. By providing a trail of decision making processes with regard to the data findings and interpretations gives

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evidence of how the researcher has made their decisions (Harding & Whitehead, 2013; Houghton et al., 2013). Reliability of data is increased through the use of reflexivity (researcher reflection) and use of an audit trail (Houghton et al., 2013). Both reflexivity and establishing an audit trail are important contributions to rigour in qualitative research. Dependability was achieved through the researcher engaging in audio and written reflections when working with the data which also provide an audit trail. Detailed descriptions and developing themes are provided, as well as a figure of themes established in the findings section of part two.

Credibility. The researcher must be able to use a reflective process and record bias so as to stay true to the data (Harding & Whitehead, 2013; Ryan-Nicholls & Will, 2009). Ryan-Nicholls and Will describe credibility as consistency; reliability of the research so another researcher can follow the audit trail. Houghton et al. (2013) define credibility as the value and believability of data findings. Credibility is achieved through prolonged engagement with the data, triangulation, peer debating and member checking (Houghton et al., 2013). Credibility relates to the research being neutral and free from bias as well as consistent and reliable.

Credibility was ensured in this study through the use of establishing pre-conceived ideas with regard to the phenomenon before under-taking this study; prolonged engagement with the data (analysis over an eighteen month period); on-going journal reflections to ensure the researcher's neutrality. Regular meetings with supervisors and peer researchers which were all audio recorded was also utilised as a form of peer debating, which ensures findings are not from a narrow perspective.

Fittingness. Research findings must fit and relate to the data in the study. Peer analysis checking can check fittingness of the data with peers, utilising acceptability of data analysis and the research process (Harding & Whitehead, 2013). The study findings must fit the data from which they were derived (Ryan-Nicholls & Will, 2009). During this study, fittingness of data findings was checked through discussions with a peer researcher and supervisors. Fittingness can be evaluated by the reader as findings are presented with direct quotes from the transcripts, which allows the reader to agree with or refute the researcher's interpretations.

Confirmability. Confirmability is the accuracy of the data (Houghton et al., 2013), relating to appropriate research questions, design and data presentation (Harding & Whitehead, 2013). Confirmability in qualitative research relates to research design as well as accuracy of data. Before under-taking this study appropriate research questions were explored. Data accuracy was achieved through utilising the other areas of rigour explored above.

Setting Rigour in Place

Rigour as a process in qualitative research needs to be addressed and set in place from the beginning or early stages of the study (Pereira, 2012). Rigour was established in this study through utilising van Manen's (1997) six activities which ensure the researcher engaged with the phenomenon and data appropriately from the start. In order to convey rigour when interpreting the data it is important to ground the interpretation to the participant's words (Pringle et al., 2011). Interpretations in this study were discussed with supervisors and a peer researcher which ensures credibility, fittingness and credibility of the findings.

Direct quotes from transcripts are provided in the findings section, part two of this study. By presenting direct quotes from the transcripts the reader can agree with or refute the researcher's interpretation. The approach of qualitative research is not to find a single truth but a coherent account which resonates with the reader. Trustworthiness of this study is increased by the researcher reflecting on the research phenomenon and engaging with the data. The framework steps outlined above add a truthful, unbiased interpretation of the phenomenon. Providing direct quotes from the data should enable the reader to navigate their way through the findings and make their own opinion of the fittingness and confirmability of the description and interpretations. Therefore the reader can come to their own assumptions of the trustworthiness of this study.

Methods

The methodology for this study was discussed in the previous section. This section now outlines how the researcher performed the study. When conducting this study the work of van Manen's (1997, pp. 30-31) six step formula was acknowledged by the researcher as important and was utilised to enable the phenomenon to be sufficiently and truthfully explored as well as increasing the rigour/trustworthiness of this study. The methods section will discuss details about the larger project, participant recruitment, ethical considerations, data collection, data management and data analysis.

The larger longitudinal project. This study is a separate standalone study generated from a larger longitudinal project investigating the lived-experience of stroke families (Lead researcher, Associate Professor Dianne Roy). This study will contribute its data, analysis and findings to the larger project. Researchers in the larger project are collecting data over a five year period (2011-2015) for five participating stroke families. Each stroke family has at least two participants: the primary caregiver and at least one other family member. The aim of the larger project is to improve support and outcomes for families/whānau of clients following a stroke.

Participant Sample and Recruitment

The aim of this exploratory hermeneutic phenomenology study was to gain insight into the lived-experience of becoming and being a stroke family during the first six months following a first time stroke event. Consistent with the exploratory nature of this study, a small sample size was utilised with an emphasis on obtaining a deep richness of data (van Manen, 1997). Purposive convenience sampling was used to recruit two families each with two participants who were previously enrolled in the larger project.

Sampling and inclusion criteria. The inclusion criteria for this study was consistent with the larger project. The primary caregiver as well as at least one other family/whānau member were required to agree to participate in the study. The relative's stroke had to be the first stroke event for the stroke survivor. Participants needed to agree to be interviewed to gain insight into their experience of the stroke event and post-stroke family life. The exclusion criterion was also consistent with the larger project: minors under the age of 16 were excluded from participating in this study.

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It was important for this study that the participants included in each family were the stroke survivor's primary caregiver and at least one other family member; this was to enable exploration of the phenomenon of the wider family's experience. By having at least two family participants for each family in the study the sample eliminates some of the limitations highlighted in the research discussed in the literature review.

Recruitment. Potential participant families were identified by clinical staff when a client was admitted to the stroke rehabilitation ward at an Auckland hospital following a first-ever stroke. Clinical staff provided potential participants with an information sheet (Appendix B) and obtained permission for their contact details to be given to the larger project's lead researcher who contacted them, answered any questions they had and made arrangements for signing of consent (Appendix C) and the initial interview. For this study participants were contacted by the researcher to obtain their consent for participation in this study's six month interview. When consent was granted the interview time and place was arranged.

The Participants. Two members from two different families (3 women and 1 man) who were family members of a stroke survivor participated in this study.

Family 1 includes a niece (41 years old) and nephew-in-law (36 years old) of a stroke survivor. The stroke survivor has children of his own but they do not live in New Zealand. The niece and nephew-in-law are considered by the stroke survivor to be his closest family. The stroke survivor had immigrated to New Zealand 15 years prior to the stroke event. His two adult children living abroad are legally recognised as next of kin. The niece and nephew-in-law have young children of their own. The niece is a registered nurse not currently working. The nephew-in-law is in paid full-time employment. The niece has a brother who also resides in Auckland and also has a close relationship with the stroke survivor. The stroke survivor was 81 years old at the time of the stroke event and had a pre-existing heart condition, having experienced a heart attack a few years prior to the stroke.

Family 2 includes the wife (64 years old) of the stroke survivor and an adult daughter (46 years old). The wife has not been in paid employment since having her children. The adult daughter has a husband; both are in full-time paid employment and have their

own children. The stroke survivor was 76 years old at the time of the stroke event and had a pre-existing heart condition, having experienced a heart attack many years prior to the stroke event.

Ethical Considerations

Ethics approval has been granted for this study in conjunction with the larger project by the Northern X Regional Ethics Committee (Ref NTX/11/EXP/062) (Appendix A). Ethical considerations for this study related to minimising participant harm, informed consent, data collection, anonymity and confidentiality, data security and withdrawal from the study. Guidelines from the Health Research Council of New Zealand were followed (Health Research Council of New Zealand, 2010). Consistent with the Treaty of Waitangi these guidelines include: protection, participation and partnership.

Protection. Potential participants were informed about this study via a participant information sheet and were asked to provide informed consent to participate in the larger project (Appendices B & C). On-going consent is important and for this study was verbally obtained before each interview, firstly by phone before arranging an interview time and place with each participant and then again on the day of the interview.

All interview recordings, transcripts, emails and analysed data have been stored in password protected computer files. Consent forms and the print transcripts have been kept separately from each other in locked filing cabinets to which only the researchers have access. All of these items will be kept for five years following completion of the larger project in accordance with Unitec Institute of Technology's regulations for research projects. After this time, all computerised files will be deleted and any hard copy information will be securely destroyed.

The participants are protected by confidentiality and whenever possible anonymity. The results were anonymised, data stored without participant names and identification codes used to identify family participants. The transcriptionist is also bound by confidentiality and signed a confidentiality agreement (Appendix D).

Participation. Participants were asked to choose the interview location. Participants had the right to a support person during the interview process if requested, none did.

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One interview was conducted at the hospital and the remaining eight were conducted in the participants' homes. Family 1 wished to be interviewed together. Family 2's participants were interviewed separately.

Participants were asked to explore and focus on the experience of their loved one's stroke and the impact of the stroke on their own lives. Participants could have become distressed by the interview when focusing on their experience because of strong emotions associated with their experience. In order to minimise participant risk if they did become distressed the interview would have been stopped and participants offered a referral for counselling. It should be noted that benefits to participants involved in qualitative research such as this study have been reported (McCoyd & Shdaimah, 2007). During the interviews no participant became distressed during the interview process and all reported the benefit of being able to share their experience.

Participants were asked for verbal consent before setting up the interview time and before commencing the interviews. Potential harm for participants was minimised through on-going consent and informing participants of their right to withdraw from the study at any time. Interview transcripts were sent to participants if they wished, participants had the right to withdraw the transcript data up to two weeks after receiving the transcript by contacting a member of the research team. Family 1 did not wish to receive their transcripts whereas both participants in Family 2 wished to and did receive a copy of their transcripts. No participants withdrew from this study nor requested withdrawal of, or any changes to, their interview data.

Partnership. Participants will be offered a summary of this study's findings and will be informed of any improved support services from the larger project. Their participation was recognised with a koha (gift) of a \$20 voucher after each interview.

Data Gathering: Capturing Lived-Experience

When beginning this study the researcher undertook an extensive literature review in order to begin to orientate to the phenomenon and the research question began to take shape. This study began an in-depth contemplation of 'what it is to become and live as a stroke family', with the focus on the wider family members, not the stroke survivor. Throughout this study it was paramount to maintain a strong orientation to the

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phenomenon, the research question. In order to achieve this the researcher continued to reflect on the real people and their real situations while centering on the research question.

Articulating assumptions. In hermeneutic phenomenology articulating what is already known and assumptions of the phenomenon is important so reflection can be made on the researcher's assumptions during interpretation (van Manen, 1997). Consistent with van Manen's recommendation, prior to data collection a peer interview was recorded which outlined the researcher's current knowledge and assumptions about the phenomenon. The researcher had some experience of family illness so it was particularly important to explore all points of that experience. Uncovering possibly taken-for granted assumptions is important (Lindseth & Norberg, 2004; Walker, 2011) because these would interfere with the data exploration process.

- I am a 29 year old female people-person with a therapeutic massage background.
- I am an Osteopathic student with some background knowledge of the pathophysiology of stroke.
- I have one family member who has had a stroke and understand how much it has changed his and his wife's quality of life.
- A close relative recently died in hospital three months after discovering cancer which caused me and my family a lot of emotional distress.
- The hospital experience was easy for us as a family because my mother is a nurse and she was able to communicate with the healthcare professionals easily.
- I completed a proposal for the study, which included a literature review so I have some idea of the academic knowledge in the field of stroke caregiving.
- I assumed that I would understand Family 2's experience of mother and daughter more easily than that of Family 1 because of my own position as a daughter.
- I assumed that Family 1 were going above and beyond what the stroke survivor expected of them.

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- I assumed the experience of becoming a stroke family would have similar elements to losing a loved one to an illness.

Reflection journaling. Once all assumptions were audio recorded a journal was started. A reflective journal process was utilised during the research process. The reflection journal was recorded and documented as verbal recordings, computer notes and hand-written notes. Throughout the research process on-going reflection and thoughts about the data were utilised to allow contemplation, orientation to the participants' experience and to remove researcher's bias whenever possible. Van Manen (1997) recommends recording assumptions of the phenomenon for allowing true interpretation of the phenomenon. These processes also assist in orientating to the phenomenon, which is important in preparing for data collection and data analysis as well as importantly providing an audit trail for the purpose of maintaining truthfulness and rigour.

Example from researcher's reflection journal. An excerpt from the research journal 13th June 2013: Family 2, Participant 2 (P2) Interview 2: P2 seems to be dealing with the stroke as a reflection on how her parents are coping. They now appear to P2 as carrying on with their lives similar as they did before. Although much has changed in P1's opinion of her life. P2 seems to want to focus on looking to the future and moving forward.

The above offers a reflection on the process of accepting the stroke event. P2 recognises her parents are starting to move on from the stroke and this enables P2 to also move forward from the stroke event.

Preparing for interviews. Data from the six week and three month interviews were conducted by a research assistant for the larger project and contributed to the data set for this study. Transcripts from these interviews and the literature review informed the interview schedule for the six month interviews (Appendix E). Transcripts and audio recordings of the interviews were reviewed and potential follow-up questions for discussion at the six month interview identified. Each interview schedule was discussed with the lead researcher of the larger project. A practice interview with a peer was performed before commencing stroke family interviews.

Data collection. Face-to-face interviews were identified as the most appropriate form of data collection for this study. An interview allows the enquiry to remain focused on the lived-experience compared to a written journal that becomes reflective (van Manen, 1997). Lived-experience is an essential requirement to enrich the understanding of the phenomenon (Lindhardt et al., 2006; Wallengren, Friberg, et al., 2008). Conversational semi-structured interviews were used to gather insight into each participant's experience; this style allowed a balance between flexibility and structure (van Manen, 1997). For example, the six month interviews began with a broad question along the lines of 'what is your experience of living as a stroke family now that six months has passed since your family member's stroke?' Specific follow up questions from reviewed transcripts were then asked as needed (Appendix E). Open questions were utilised to produce a rich accurate account of the participant's experience (van Manen, 1997) with some structure to maintain focus.

Participants were contacted two weeks before their six month post-stroke interview was due. The contact at this time was to ask the participants to participate in the six month interview. Once consent was gained, an interview time and place was arranged as specified by the participant. When making contact with the participants the researcher's approach was to establish a relationship of equality (Walker, 2011). A natural style of conversation was used such as "when will be convenient to meet with you?"

Walker (2011) suggests the interview location can impact upon the interview conversation. For this study it was important that participants felt comfortable so they felt free to discuss their lived-experience, which is why participants were asked to choose the interview location. The interviews were conducted in a natural conversation style. The interview structure was flexible to allow participants to discuss topics at their own wish, specific follow-up questions were asked if needed. Family 1 participants wished to be interviewed together for all three interviews. Family 2 participants were interviewed separately for all three interviews.

Eight interviews were conducted in the participant's home and one interview was conducted in the hospital. Interviews ranged from 50 minutes to two hours in length.

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When the participants had shared their stroke experience the interview came to a natural close of conversation.

Data set. The data set for analysis included transcripts from six week and three month interviews which had been gathered by a research assistant as part of the larger project. The six month interviews were conducted by this study. For this study a total of nine transcripts were included in the data set with a total of 11.5 hours of audio recorded interviews.

Data Analysis

Interviews were audio-recorded and field notes were recorded following each interview. Interviews were transcribed verbatim by a paid transcriptionist. Completed transcriptions were then checked for accuracy and anonymised by the researcher against the audio-recording. Participants were then given the opportunity to review their transcribed interviews and to add or delete anything they might wish. No changes were made to the transcripts by the participants. Preliminary analysis was completed for the previous six week and three month interviews to inform topic and follow up questions for the six month interviews. Analysis aimed to provide interpretation of participants' experiences of becoming and being a stroke family during the first six months post-stroke.

Analysis and interpretation of data aimed to identify common themes and extract meaning from participants' lived-experience. Data were analysed thematically, which is a systematic theme-identifying process (van Manen, 1997). Each transcript was read numerous times and then anything of interest or of significance within the text was identified as part of preliminary analysis. A presentation was given to fellow students and research staff to discuss some of the emerging themes within the transcripts which gave valuable feedback toward the identification of themes and others' opinions. In order to help the researcher maintain orientation to the phenomenon each transcript was summarised to capture the participant's experience. Following each transcript summary the full transcript was reviewed again, each paragraph was then broken down and given topic headings. After reviewing each transcript's paragraphs and topic

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headings numerous times, topic headings were summarised into emerging themes before moving on to the next transcript.

Once emerging themes had been identified an even more in-depth reflective process began with the aim of maintaining a strong orientation to the phenomenon (van Manen, 1997). The researcher continued to reflect and search for the meaning of what it is to 'become and live as a stroke family during the first six months post-stroke' during data analysis in order to stay truthful to the data and the participants' perspective. Two further research presentations were then conducted. The feedback from the audience of student and staff members was used to help validate themes by giving the opportunity for the audience to challenge theme ideas.

An over-arching theme of 'Different Folks: Different Strokes' was identified with three sub-themes emerging following the use of mind-maps and discussions with research peers. The three sub-themes are: 1) Losing a life once lived, 2) Navigating an unfamiliar path and 3) Creating a sense of normal. Each stage of the analysis process was recorded so the progression of the final themes can be identified by way of an audit trail. Journaling enabled reflection on emerging thoughts and monitored any potential influences such as pre-assumptions driving data interpretations.

In the findings section in part two the researcher's interpretation is provided in a systematic format with reference to the original text as a form of increasing rigour. A more in-depth description and interpretation of the study's findings is provided in part three (Appendix F) which was excluded from the manuscript due to the journal word limit. At all times the researcher's approach was strongly focused and as consistent as possible in order to stay truthful to the data, analysis and interpretations.

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Part Two: Manuscript

Prepared in accordance with the *Kai Tiaki Nursing Research* submission standards (Appendix: G).

In order to maintain readability and consistency of format throughout the thesis the tables and figure have been included in the text. Text is justified rather than left aligned and the text has been continued using 12 point Calibri rather than 12 point Times New Roman.

Different Folks, Different Strokes: Becoming and Being a Stroke Family

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Different Folks, Different Strokes: Becoming and Being a Stroke Family

Abstract

Aim: To explore the lived-experience of becoming and being a stroke family during the first six months post-stroke event.

Background: The consequences of a stroke are far reaching and affect the whole family. Research has been limited with its exploration into the effects of stroke on family members beyond the primary caregiver. It is important to understand the wider family's experience of stroke because the whole family is involved in caring for the stroke survivor, either through supporting the primary caregiver, or sharing in the caregiving tasks. This study explores the lived-experience of two different families during the first six months post-stroke.

Design: Exploratory qualitative study using hermeneutic phenomenology.

Methods: Purposive sampling recruited two different families each with two participants. Interviews were conducted at three time intervals: six weeks post-stroke, three months post-stroke and six months post-stroke. Data were collected between October 2011 and April 2012.

Findings: The lived-experience of both families varied in the effects from the stroke event and challenges that each family faced. An over-arching theme of 'Different Folks: Different Strokes' was identified with three sub-themes: 1) Losing a life once lived. 2) Navigating an unfamiliar path. 3) Creating a sense of normal.

Conclusions: The data revealed that the journey to becoming and being a stroke family is complicated and brought different losses and challenges to the two families. One family felt supported into post-stroke life by positive interactions with healthcare professionals and family strength; whereas the other family felt unsupported by healthcare professionals and experienced family strain. Both families then tried to create a sense of normal in their lives once again with varying degrees of success.

Keywords: Stroke, Lived-experience, Phenomenology, Family, Caregivers, Life change.

Background

Stroke is a major public health issue world-wide and in New Zealand. There are approximately 60,000 stroke survivors in New Zealand with the number growing every day (Stroke Foundation of New Zealand, 2013; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Emerging world-wide statistics suggest an increase of stroke incidence in ages under 75 years (Feigin et al., 2014). Stroke occurring at a younger age could mean a longer duration of care needed for the stroke survivor.

Family members, usually a spouse or adult child (Greenwood & Mackenzie, 2010b), often give their time for the stroke survivor's on-going support needs with everyday activities. Due to the sudden and unexpected nature of stroke, primary caregivers often feel inadequately prepared for their caregiving roles. The physical, cognitive and emotional demands of caring for a stroke survivor can cause depression and other emotional distress to develop in carers, weeks to months post-stroke (Gillespie & Campbell, 2011; Greenwood & Mackenzie, 2010a). Approximately one out of three stroke primary caregivers experience strain or considerable burden (Ilse, Feys, de Wit, Putman, & de Weerd, 2008). Research has established that caring for a stroke survivor is demanding and can have negative impacts on the primary caregiver. Primary carers may be at risk of becoming a second patient in the family because of their own general health decreasing (Sit, Wong, Clinton, Li, & Fong, 2004). Thus it is important for health professionals to support the role of primary caregivers to increase the sustainability of family caring for a stroke survivor.

There has been a growing volume of research with regard to caring for a stroke survivor. The research has been focused from the primary caregiver's perspective, while the inclusion of the wider stroke family remains limited. Primary caregivers often rely on other family members and friends for help and support (Cecil, Thompson, Parahoo, & McCaughan, 2013; Sit et al., 2004), because they feel they can trust them compared to paid help (Lindhardt, Bolmsjö, & Hallberg, 2006). Support networks available to primary caregivers vary and families may have different abilities to cope post-stroke. Families may gather and support each other through a stroke event. In a recent study families that coped better than others shared the caregiving tasks, had strengthened family

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relationships and faced caregiving challenges with a 'can-do' attitude (Niyomathai, Tonmukayakul, Wonghongkul, Panya, & Chanprasit, 2010). Understanding the wider experience of stroke families could help to increase the sustainability of family caring for a stroke survivor, as well as improving outcomes for the family, primary caregiver and stroke survivor. The reviewed literature conveys the importance of further exploration into the experience of becoming and being a stroke family including participants beyond the primary caregiver.

The Study

Aims

This study aimed to investigate the lived-experience of two stroke families, exploring the phenomenon of 'becoming and being a stroke family'.

Methodology

A qualitative study was selected as a deep rich data set was necessary because little was known about the phenomenon. The study utilised a hermeneutic phenomenological methodology informed by the writings of van Manen (1997).

Participants

Participants were first recruited to a larger longitudinal project (Unitec Institution, Lead researcher, Associate Professor Dianne Roy) from a stroke rehabilitation ward in Auckland. Purposive sampling recruited two families from the larger project. Two participants from each family who had a relative with a first time stroke were included. Family 1: A niece and nephew-in-law of the stroke survivor. Family 2: A wife and adult daughter of the stroke survivor.

Data Collection

Transcripts from interviews with both families at six weeks and three months from the larger project contributed to the data set. An interview schedule for each six month interview was prepared after reviewing previous transcripts. A face-to-face interview was scheduled with each participant at a place and time that suited them (all interviews were conducted in the participants' homes), interviews ranged between 50 – 120 minutes long.

Ethical Considerations

Ethical approval was granted by the Northern X Regional Ethics Committee NTX/11/EXP/062. Ethical considerations included potential harm and privacy. If a participant became distressed the interview could have been stopped at any time and the participant offered funded counselling. Participants were provided with a copy of the audio interview and transcripts if they wished and had two weeks after receiving the copies to withdraw their data from the study. All participants felt the interviews

were useful to allow them time to reflect and share their experiences. Privacy was maintained through password protection of participant information and anonymised data.

Data Analysis

A total of nine interviews was included in the data set. All interviews were transcribed verbatim then reviewed and anonymised prior to analysis. Data analysis utilised hermeneutic phenomenology informed by the works of van Manen (1997). Each interview was summarised into the participant's key experience. Each paragraph was then broken into a topic heading for developing theme identification. Emerging themes were discussed and developed further with peer researchers.

Rigour

Rigour was established in this study through utilising van Manen's (1997) six step activities which ensure the researcher engages with the phenomenon and data appropriately from the start. There is an audit trail of a reflective journal and audio recorded meetings which provide evidence of theme progression. Direct quotes from the transcripts are provided to help the reader agree with or refute the interpretations.

Findings

Drawing on the stories shared by the participants, this study uncovered the everyday realities of becoming and being a stroke family. The journey of becoming and being a stroke family varied considerably between the two families. The stroke outcomes and ability to progress towards a sense of normal from the stroke event were different. An over-arching theme of 'Different Folks: Different Strokes' was identified with three sub-themes which loosely relate to three timelines:

- 1) Losing a life once lived (6 weeks post-stroke).
- 2) Navigating an unfamiliar path (3 months post-stroke).
- 3) Creating a sense of normal (6 months post-stroke).

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Figure 1. Over-arching theme, sub-themes and topic headings

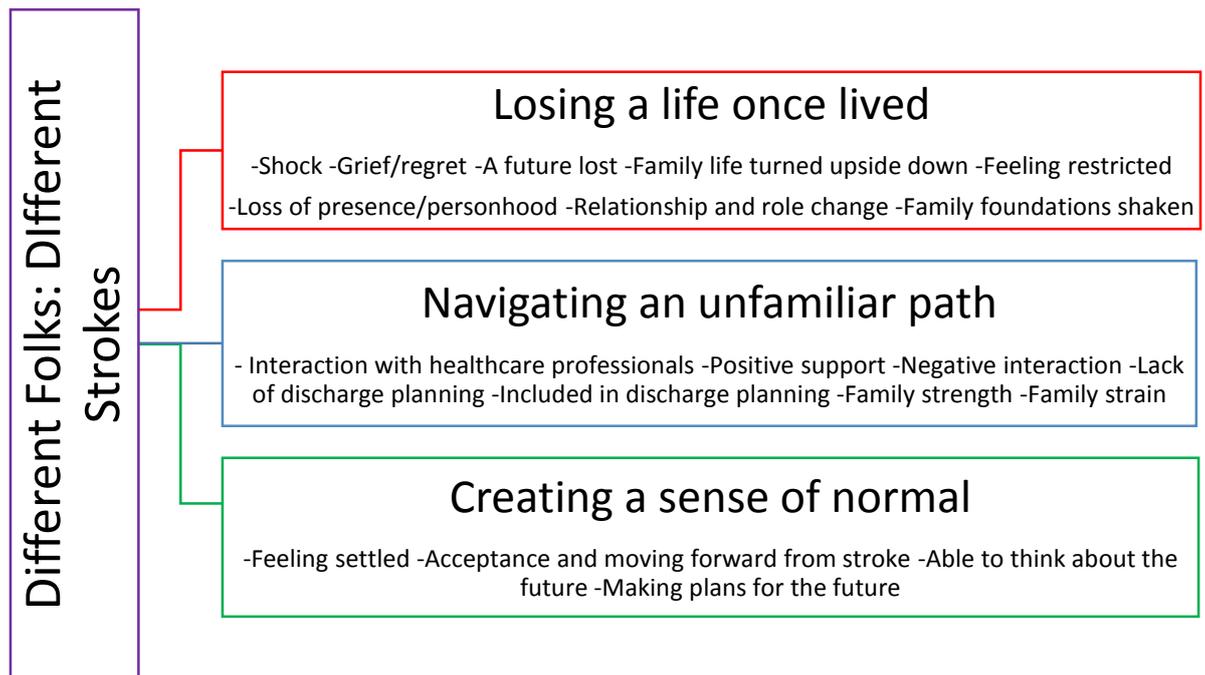


Table 1. Demographic of the two stroke family participants and stroke outcomes

Family 1	Family 2
Stroke survivor (SS1) 81 years old at time of stroke.	Stroke survivor (SS2) 76 years old at time of stroke.
P1: 41 year old niece of SS1. Registered nurse, not currently in paid employment. Married with children to P2.	P1: 64 year old wife of SS2, not currently in paid employment. Has adult children.
P2: 36 year old nephew-in-law, in paid full-time employment. Married with children to P1.	P2: 46 year old adult daughter of SS2, in full-time paid employment. Married with children.
SS1: hospital admittance 8 hours after stroke onset. Second stroke a week after first stroke.	SS2: hospital admittance within 30 minutes of stroke onset. No subsequent stroke.
Stroke impairments: Aphasia, memory loss, dysphagia, severe fatigue, foot drop, hemiparesis, unable to ambulate self.	Stroke impairments: Memory and behavioural changes, fatigue, balance problems, can ambulate with walker, eyesight impaired.
A complex stroke trajectory with health complications and a lack of recovery from stroke. 3 months post-stroke: SS1 still in stroke unit, hospital discharge imminent to a private hospital. 6 months post-stroke: SS1 in private hospital, P1&P2 still visiting SS1 daily.	Expected stroke clinical trajectory. At 7 weeks post-stroke SS2 moves to retirement village to live with wife (new home). Support and graded return home. At 6 months post-stroke SS2's rehabilitation is going well. P1 (wife) feels SS2 relies heavily on her.

Different Folks: Different Strokes

The over-arching theme of 'Different folks: Different strokes' was developed from the comparison of the two stroke families' journeys of becoming and being a stroke family. Both families experienced the stroke event as a significant life event which creates the point where loss of a former life occurs. The stroke brought different changes to the families' lives as well as different losses. Family 1 experienced guilt from the stroke event, while losses were mostly a loss of presence, personhood and family life turned upside down. For Family 2 the loss associated with stroke was different for the two participants. Family 2 Participant 1 (P1) felt restricted in her post-stroke life and had role and relationship changes with stroke survivor (SS2), whereas Family 2 Participant 2 (P2) experienced her family foundations shaken as the strength of her father/SS2, the head of the household had weakened.

Both families began to navigate the unfamiliar path of life after stroke. Family 1 experienced a complex stroke recovery trajectory, whereas Family 2 experienced a more straight forward clinical trajectory where the stroke survivor was able to rehabilitate and return home quite quickly. Family 1's stroke family life was further complicated by family strain with SS1's daughters, a lack of communication with the healthcare team, frustration with hospital protocols and further health setbacks which decreased SS1's recovery. In contrast, Family 2 was able to start moving forward from the stroke event and felt supported by the healthcare team. They experienced family strength as family gathered to support each other.

At six months post-stroke Family 1 were beginning to feel more settled; however a lack of support from healthcare professionals left them feeling isolated and unable to create a true sense of normal in their post-stroke lives. Family 2 started to create a sense of normal at three months post-stroke which was established further at six months post-stroke. While the journey of becoming and being a stroke family was not easy for both participants of Family 2, they were able to start to see a possible future again which helped to create their sense of normal. Family 2 participants began to feel established in their roles and accepted changes in life that the stroke event had caused.

1) Losing a life once lived

Stroke was a significant life event which marked the change from former life to post-stroke life. For both families the strong event created many losses. Strong emotions at the time of the stroke event were noted to impact upon the families' journey of becoming and being a stroke family. Both families experienced shock at the time of the stroke event because the stroke was unexpected. Family 1 also experienced feelings of guilt and regret for not finding SS1 sooner than they did.

Shock, guilt and regret.

(P1) I normally talk to him most mornings actually... time was ticking on and we hadn't heard from him. So it was about, mid-afternoon... we walked up as a family unit... We knew that he was inside... You just know something's not right... You're either going to find him alive or dead. [P2] called for an ambulance, and I spoke to (SS1) and he mumbled "yes, yes, yes, yes, yes" ... but he was sort of cold because he must have been there for... Seven perhaps in the morning and this was three in the afternoon. So he had been there for a good eight hours... (We) shouldn't have left it so late... and we should have done this and we should have done this and we should have, could of, would of, would of... (Interview 1, Family 1)

For Family 1 feelings of guilt continued to contribute to and dictate their actions towards visiting SS1 and feeling some responsibility for the health and failure to progress in recovery of SS1. The unaddressed feelings of guilt also created problems accepting and move on from the stroke event.

Family 2, P1 experienced the shock of the stroke event and felt resentment towards her husband/SS2 at the timing of the stroke which occurred three weeks before they were due to move from their family home into a retirement village. P1 and SS2 had a marriage where SS2 was the head of the household and was the organiser who took charge of the family. The stroke event meant P1 had to organise the house move. The feelings of resentment towards the SS2 hindered P1's ability to move on from the stroke event.

Resentment

I mean he could have waited... (Interview 2, Family 2, P1)

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Family 2, P1 experienced the loss of a planned future with SS2, now the future is uncertain.

A lost future.

Oh we were all looking forward to this (moving to retirement village). We were on a high and then everything went [noise made]. It wouldn't have been so bad if I didn't have to go to the hospital every day to see him. I was in hospital most of the day and then had to come home and do all the packing... Be bad enough coping with one thing without two things... Yeah, it was quite traumatic... (Now) I have no idea what's going to happen in the future. (Interview 1, Family 2, P1)

For both families the stroke event caused considerable change in their lives post-stroke. Family 1 experienced a lost presence because SS1 was a huge part of their family life. The effects of stroke caused Family 1 to experience a loss of personhood, as SS1 no longer recognised them and had communication difficulties. Family 1 also experienced guilt when they could not visit SS1 in hospital and private hospital as much as usual because of other family commitments with their children. Family life was turned upside down and they could no longer plan things in the future.

Family life turned upside down, guilt when cannot visit.

(P1) You do feel guilty. School holidays aren't very nice. I feel, I didn't go in yesterday and it's like [noise made]. [P2] did but then I resign myself to the fact that you can't do it... Yeah, and in the weekends we've currently... we can't plan anything... (Interview 3, Family 1)

Family 2, P1 experienced a change in her husband/SS2's behaviour along with a role and relationship change in the marriage. P1 felt restriction in her post-stroke life because of a loss of time and space to do her own things. It was no longer easy to take public transport and P1 faced challenges in daily living such as doing the shopping.

Feeling restricted.

He doesn't seem to understand that I need to get out though on my own... I'm here 24/7... Yeah, you've got to keep one eye on him all the time... (Interview 2, Family 2, P1)

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Family 2, P2 experienced a change to her family foundations, twice in one week she rushed to the hospital believing her father would die at any moment. The stroke meant P2 no longer felt certain of her parents' health. The stroke event caused concern for P2's children as well. The night of the stroke P2's son did not stop texting her because he was worried.

Family foundations shaken.

We just sort of sat around and stared at him (SS2) and he was having trouble with his heart too, when he got agitated or started spewing, the heart monitor would go down to zero, which was freaky. We were staring at this thing going down to zero and wondering if he was just going to have a heart attack and die right there... Then two days later mum (P1) rang me and told me that he'd had a heart attack... So that was a bit traumatic and we all raced into the hospital expecting that he was on his last legs. (Interview 1, Family 2, P2)

Loss associated with stroke means different things to different people and families. For Family 2, P2/adult daughter experienced a loss of family foundations whereas P1/wife of SS2 experienced feeling restricted in her post-stroke life. Family 1 experienced complicated loss, losing a presence and personhood as well as feeling guilt. The next theme discusses the families' journeys into post-stroke life.

2) Navigating an unfamiliar path

Families must face unfamiliar and sometimes difficult situations regarding changes to the stroke survivor, hospital visits, working with hospital protocols and interacting with healthcare professionals. Family 2 felt able to communicate with hospital staff and included with discharge planning, which enabled them to make a smoother transition into stroke family life. This contrasted with Family 1's bumpier ride from a lack of support, communication and interaction with healthcare professionals. The two families had different levels of support available in the form of extended family and friends. The interaction with other family members was identified in the data as an important area that either supports the stroke family or causes strain and hinders navigation into post-stroke life.

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Family 1 felt frustrated with the lack of support provided by the hospital staff. In particular they felt a sudden pressure when being told SS1 must be discharged with lack of warning. A lack of discharge planning was just one example of how this family was left in the dark about SS1's recovery, rehabilitation and future. The strained relationship with SS1's daughters overseas caused complications in Family 1's ability to navigate the journey to becoming a stroke family.

Negative healthcare interactions, lack of support with discharge planning.

(P2) We've been bombarded with a person that we have had as a normal person, he's had a stroke, we've never experienced anything like that, it's made a huge interruption into our life and it's been a pretty serious stressful situation... (Not knowing) where he's at and to not know what we need to do, who we need to contact, what the process is of private hospital, money, finances, for us, for him. All those unknown things to be confronted with and forced to find an answer and solution for; by being told by the hospital that he needs to go... We've got no idea. It's not like we do this every day. They do. That's what frustrates me; the support and the understanding of where we are at in our lives... (Interview 2, Family 1)

At three months post-stroke Family 2, P1 has experienced the transition of her husband/SS2 coming back to live in their new home at the retirement village. P1 felt the hospital healthcare team were "wonderful, I could not fault them (Interview 2)." P1 was able to trust the healthcare team and they included P1 in their discharge planning. P1 reported SS2's return home was a shock and P1 had not been given information on how to deal with SS2's behavioural changes. However P1 continued to feel well supported post-stroke by healthcare professionals, her adult children and friends in their village.

Positive interactions, healthcare support.

I'd had all the instructions before... in small doses when you can absorb small doses instead of getting it all at once (Interview 1, Family 2, P1).

(The) occupational therapist came with him on the Wednesday and then on the Saturday I picked him up and he spent the weekend at home. Then (hospital staff)

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found out what had happened over the weekend, got the report and we had the meeting, family meeting on the Friday... and then they said think about discharging but the physio said I want him another week and so he stayed another week and it was all geared up... (Interview 2, Family 2, P1)

Family 2, P2 continued to feel the need to be available for her parents. P2 Visited and stayed in touch more often than she used to. P2's family and friends supported her and made things easier for her to support and visit her parents. At three months post-stroke P2 reported the extra visiting to the hospital was stressful. She had seen changes to her parents since the stroke and was worried for her mum. P2 felt an ability to move on from the stroke event because she was seeing some positive changes and recovery in her father. P2 reported being happy with the level of services available for her parents.

The unfamiliar path of becoming a stroke family for Family 2 is aided by positive interaction with healthcare professionals and the family being able to gather together and support each other. For Family 1 the navigation of becoming a stroke family was hindered by obstacles of negative healthcare interaction and family strain. The next theme discusses the two families' abilities to create a sense of normal in their lives post-stroke.

3) Creating a sense of normal

Family and individual obligations must continue post-stroke. Both families faced on-going care commitments for the stroke survivor and life challenges. Findings revealed it was important for the participants to have calm and a sense of security again in their lives as soon as possible after the stroke event. At six months post-stroke both families were ready for a sense of normality, however the journey over the last six months and the stroke survivors' clinical trajectory was different for the two families. Therefore the ability to once again make sense in their stroke family life is experienced differently.

Family 2, P1 is able to start to plan for the future again. P1 experienced some frustration with her husband's recovery because she felt it plateaued; she also reported feeling low in energy as well as a continued restriction in her post-stroke life. P1's children continued to help and stay in touch more often than usual. Family 2, P2's parents' acceptance of the stroke allowed her to also accept it and move on. P2 felt her father's

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recovery was going well, but continued to worry for her mum looking after him. P2 felt less stressed about her parents' situation compared to the time of the stroke event and this contributed to creating a sense of normal.

Acceptance and moving forward from stroke.

I think we've all got used to it... now that they're settling into the village and they've got a few friends, they've accepted it both of them and just making the best of the situation and they're getting out and about, off for walks and things. So they're not letting it hold them back too much... It's just a matter of getting on with life and helping him be independent or helping both of them be independent. (Interview 3, Family 2, P2)

At six months post-stroke Family 1 felt settled compared to the chaotic situation in the hospital; but they were unable to create a true sense of normal in their lives because SS1's future was uncertain. They had realised and were beginning to accept that with SS1's continual health setbacks and decline he would not be leaving the private hospital to live with them in their home as they had imagined. Family 1 focused on making the most of every day they had left with SS1.

Feeling settled.

(P1) There was so much happening and it was so emotional and it was so exhausting. (SS1) transferred to [private hospital], which is where he is now and he seems very settled I think, as far as the environment and... himself I think he seems fairly settled there... We're a lot more settled... (Interview 3, Family 1)

The ability for families to create a sense of normal in their post-stroke lives was an important finding in the data. Each participant's ability to accept the stroke event and move forward from stroke was associated with more certainty regarding the future. Accepting the stroke and associated events appears to be an important part of creating a sense of normal.

Discussion

This study highlights the unique experience and journey of becoming and being a stroke family for two different families. Findings showed that both families' core experience

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could be grouped into three main sub-themes, which represent the approximate timeline post-stroke of six weeks: losing a life that once was; three months: navigating an unfamiliar path and six months: creating a sense of normal. A strength of this study is the inclusion of family members in addition to the primary caregiver, to provide some understanding of the phenomenon of being a stroke family. Analysis and interpretations were discussed and debated with peer researchers. A limitation of this study is that only two participants from each family were interviewed which limits the 'family story' and the wider picture of how other family members were affected by the stroke event. Because only two families were included in this study the findings may not be transferable to other stroke families.

Losing a life that once was. Stroke was found to have traumatic consequences for all four family participants as their lives were changed abruptly and irreversibly following the stroke. Findings in this study extend the findings of Hunt and Smith (2004), who suggested stroke affected the entire family, Kenny, Sarma, and Egan (2012), who suggested becoming a caregiver caused irreversible change and Saban and Hogan (2012), who found female carers, most often a spouse to the stroke survivor, experienced a loss of former life since the stroke event.

Loss was experienced differently by the two families; there are likely to be many factors that contributed to the different losses experienced by the two families. The role and relationship with the stroke survivor was different for each family. The extent of impairment and recovery for the stroke survivor also varied, and the stroke survivors being different ages created different expectations from the family members and health professionals. This finding is new in research and further exploration into the lives of stroke families is needed to extend these findings.

Individual members within the families experienced loss from the stroke differently. The wife of one stroke survivor experienced loss from marital change, role change and a restricted life; whereas her adult daughter experienced loss from changed family foundations, worrying about her mother in her new caring role and visiting her parents more. This finding confirms the findings of Gillespie and Campbell (2011) and

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Greenwood and Mackenzie (2010b) who both suggested family members experience different losses depending on their role and relationship with the stroke survivor.

Navigating an unfamiliar path. The stroke event affected both families in many ways. All participants experienced a sense of uncertainty and worry about the future, a phenomenon also found by Kenny et al. (2012). Findings from this study suggest stroke causes a large impact on the entire family due to stroke disrupting usual routines, which affected the participants and their children. The long term effects of stroke on family life was explored by Kitzmuller, Asplund, and Haggstrom (2012). Participants included two children who were minors at the time of the stroke event. The findings were similar to the current study, that stroke affected the lives of the entire family. Stroke meant both families had to navigate an unfamiliar path which included family challenges and interacting with healthcare professionals.

The families in this study needed support from other family members and friends, which is consistent with findings by Cecil et al. (2013). 'Family strength' (Niyomathai et al., 2010) was found to be important to improve outcomes for stroke families. Family strength was seen in Family 2, as the wider family came together to support the primary caregiver and each other. Family strength was also present in Family 1 between the two participants, however there was a strained relationship with the stroke survivor's daughters. Family strain was found to hinder Family 1's outcomes as a stroke family. Further research into stroke families is recommended to explore the concept of family strength or strain and how it impacts on the outcomes for stroke families.

Interactions with healthcare professionals were seen as an important influence on both families. Family 2 felt listened to, involved in and included in the healthcare setting and were able to relax and take time out from the hospital because they could trust the healthcare professionals, a finding also reported by Berglund and Johansson (2013). In contrast, Family 1 described negative interactions with some healthcare professionals, which decreased their trust in the hospital staff. Negative interactions with healthcare professionals were also reported by the participants in a study by Öhman and Söderberg (2004). Family 1 found it challenging to leave care to hospital staff and felt the need to 'stand guard' (Lindhardt et al., 2006). The lack of trust experienced by Family 1 consisted

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of a number of factors. They felt lied to and felt they had a lack of information and support from healthcare professionals, which increased their uncertainty, anxiety and frustration. Previous studies have also found interactions with healthcare professionals had an important influence on the primary caregiver (Greenwood & Mackenzie, 2010a; Lindhardt et al., 2006; Wallengren, Friberg, & Segesten, 2008). Further research to explore the influence of healthcare interactions on families is required to extend the findings from this and previous studies.

Findings in this study indicate family members need to be involved in the hospital setting. Involvement from healthcare professionals, sharing information with family and including family in care decisions may improve outcomes for stroke families. Previous studies have also suggested family involvement with care decisions would improve outcomes for family caregivers (Bowen et al., 2009; Creasy, Lutz, Young, Ford, & Martz, 2013; de Palva, Valadares, & Silva, 2012). Peyrovi, Mohammad-Saeid, Farahani-Nia, and Hoseini (2012) and Lindhardt et al. (2006) both recommended healthcare staff collaborate with family members regarding care and assessments for the stroke survivor and give adequate information regarding the stroke survivor's impairments. One family in the current study would have benefited from information from healthcare professionals about emotional and behavioural changes of the stroke survivor following the stroke, which has been suggested in earlier studies also (Bulley, Shiels, Wilkie, & Salisbury, 2010; Creasy et al., 2013).

Families in this study wanted to be involved with discharge planning. The family that was not included in discharge planning of the stroke survivor experienced anxiety regarding the stroke survivor's discharge from hospital, compared to the family that was included, who felt prepared for the stroke survivor's return home. Previous studies have also suggested family involvement in discharge planning to improve outcomes for family members (Creasy et al., 2013; Salisbury, Wilkie, Bulley, & Shiels, 2010; Shyu, Chen, Chen, Wang, & Shao, 2008).

This study revealed both stroke families had different needs at different times, which was also suggested by Hafsteinsdóttir, Lindeman, Schuurmans, and Vergunst (2011). As the stroke family moves along the recovery trajectory the caregivers' support needs,

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and the healthcare professionals most suited to providing support, change (Cameron, Naglie, Silver, & Gignac, 2013). Further research is needed to explore families' diverse needs post-stroke.

Creating a sense of normal. This study gives insight into becoming and being a stroke family. Families must create a 'new normal' (Saban & Hogan, 2012) by making significant changes and attempting to reconstruct their lives. Feeling stable as a family contributes to acceptance and adjustments following the stroke event (Greenwood & Mackenzie, 2010a; Kenny et al., 2012; Saban & Hogan, 2012). Families need to accept the stroke, or at least feel settled in their post-stroke family life, in order to create a sense of normal. This study found unresolved emotions, such as guilt and resentment, which occurred during the stroke event or post-stroke journey hindered the participants' ability to accept the stroke and move on. Further research is required to validate this finding as it may be an important factor for influencing families' abilities to accept the stroke event.

Findings in this study reveal it is important for healthcare professionals to support family. Previous studies also recommend that healthcare professionals include family members in the care for the stroke survivor from the hospital setting (Clarke, 2013; de Palva et al., 2012), listen to families' specific problems (Kenny et al., 2012) and consider families' dynamic needs (Gillespie & Campbell, 2011). Outcomes for Family 1 may have improved if healthcare professionals had supported the family and considered their 'diverse lives' (Cecil et al., 2013). Healthcare professionals need to establish who family is to the stroke survivor and support all family members in their stroke family roles.

Using a family-centred approach in stroke care may enhance family support and improve outcomes for stroke families. Previous studies have also suggested hospitals and healthcare professionals move from a patient-centred approach to a family-centred approach (Bowen et al., 2009; Cameron et al., 2013; Clarke, 2013; Creasy et al., 2013; de Palva et al., 2012; Greenwood, Mackenzie, Wilson, & Cloud, 2009; Lutz & Young, 2010; Santos, Cecílio, Teston, & Marcon, 2012). A family-centred approach would support the diverse nature of family and consider the strengths and needs of all family members (Visser-Meily et al., 2006). Family-centred healthcare would improve the

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development of the family's role in caring for the stroke survivor returning home or staying in a medical facility. A family-centred healthcare approach is recommended to best include and support families' diverse needs and nature.

Conclusion

Becoming and being a stroke family means finding a new way of being in the world. During the first six weeks post-stroke both families began to realise the effects of stroke on the stroke survivor and what it meant for them as a family and individually. Both families dealt with unfamiliar situations such as changes with the stroke survivor due to impairments, interacting with healthcare professionals, hospital protocols and changes to family relationships, which were strengthened or strained. By six months post-stroke both families were ready to create a sense of normal in their post-stroke lives with varying degrees of success. The experience, challenges, strengths, journey and outcomes for the two families are vastly different, therefore it is important to consider the distinct possibility that no two stroke events and families are the same.

Stroke recovery and caregiving is a dynamic experience with evolving support needs throughout the post-stroke event. Research is needed to further develop the assessments, support and interventions available from healthcare professionals across the care continuum to improve stroke family outcomes. A family-centred healthcare approach may help families transition from the shock of the unexpected stroke event, feel included in the healthcare setting and support the transition of becoming a stroke family. Further research into the experience of stroke families is warranted to further support this study and to explore family needs to improve the quality of support and outcomes for stroke families.

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Part Three: Appendices

Appendix A: Ethics Approval



Northern X Regional Ethics Committee

Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
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.

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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 B: 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

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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

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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.

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Shirin Caldwell - Lecturer, Department of Nursing Unitec Institute of Technology.

Judy McKimm - Dean and Professor of Medical Education at Swansea University, UK.

Gerry Fennelly – Charge Nurse Manager, Muriwai and Huia Wards, Waitakere Hospital.

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

Appendix C: Participant Consent Form



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

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

I have read and I understand the information sheet dated 5th April 2011 for volunteers taking part in the study designed to find out about the experiences of families/whānau of people who have had a stroke. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect the continuing or future health care of my family/whānau member.

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I understand I am free to withdraw any or all of my interview data. If I decide to withdraw my interview data I know I will need to contact the principal researcher within two weeks of completing each interview.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I understand that information gathered during participation in the research will be treated confidentially and stored securely.

I consent to my interview being audio-recorded

I know whom to contact if I have any questions or concerns about the project. (Note: The **principal researcher** for this project is Dr Dianne Roy - Ph. 098154321 ext 8307 or droy@unitec.ac.nz).

I agree to take part in this research.

I (*full name*) hereby consent to take part in this study.

Signature : (Participant) (Date)

Project explained by:

Signature: (Researcher) (Date)

The participant should retain a copy of this consent form.

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

Appendix D: 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 E: Interview Schedule for Participant

Interviews Six Months Post-Stroke

Consistent with hermeneutic phenomenology, interviews will be conversational in nature and digitally recorded. On-going consent will be confirmed with participants at the beginning of each interview and the opportunity given to participants to ask any further questions relating to the study prior to commencement of the interview. The researcher will ask a broad question along the lines of 'tell me about your experience of living as a stroke family now that six months has passed since your family member's stroke?' Interview trigger questions are anticipated to form an on-going conversation with participants from the previous two interviews about their experience of stroke and impact of stroke on their lives. The following are trigger questions from reviewed transcripts.

Family 1

- Did the stroke survivor transfer from hospital to private hospital? What information did they receive in regards to the transfer? Anything they could have benefited from knowing in advance? Did they have any support that helped? Any support they could have benefited from?
- What challenges are you facing now at six months post-stroke?
- What has family life been like for you since (relationship) had the stroke? What has this meant for you? For your everyday life? Employment? Children?
- How has the relationship changed with the stroke survivor?
- What has the impact of stroke been on relationships with other family members?
- What coping strategies / support networks have helped you?

Family 2, P1

- How has the relationship changed with stroke survivor now? Over the last six months?
- Has any other relationships changed? E.G with your children?
- What are your challenges now at six months post-stroke?

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- Is there any information or support that you could now or could have at any point benefited from?

Family 2, P2

- What coping strategies / support networks have helped you?
- Anything they could have benefited from knowing in advance? Did they have any support that helped? Any support they could have benefited from?
- What has family life been like for you since (relationship) had the stroke? What has this meant for you? For your everyday life? Marriage? Employment? Children?
- How has the relationship changed with the stroke survivor?
- How has relationships with other family members? Your mother? Your brothers?

Questions will not necessarily be asked sequentially as interviews will be 'conversational' and often participants in their response to the first general question may discuss some of the subsequent ones. Pauses, prompts and clarifying questions used as required.

Appendix F: Extended Findings Section

This included appendix is not the entire findings section for this study. The following is an example of the theme development for the over-arching theme ‘Different Folks: Different Strokes’.

Different Folks: Different Strokes

The journey of becoming and being a stroke family was vastly different for the two families. The data revealed many instances that contribute to the huge differences between the two families’ experiences and outcomes from stroke. The two families felt differently about their support needs being met. Family 1 had a negative experience during the hospital stay. Interactions with healthcare professionals left them feeling unsupported, frustrated and isolated, whereas Family 2 reported adequate support which met their needs. They had a positive experience during the hospital stay and when interacting with healthcare professionals. When comparing and contrasting the stroke survivors’ clinical trajectories it is possible there are many influences that contributed to these two different experiences and outcomes.

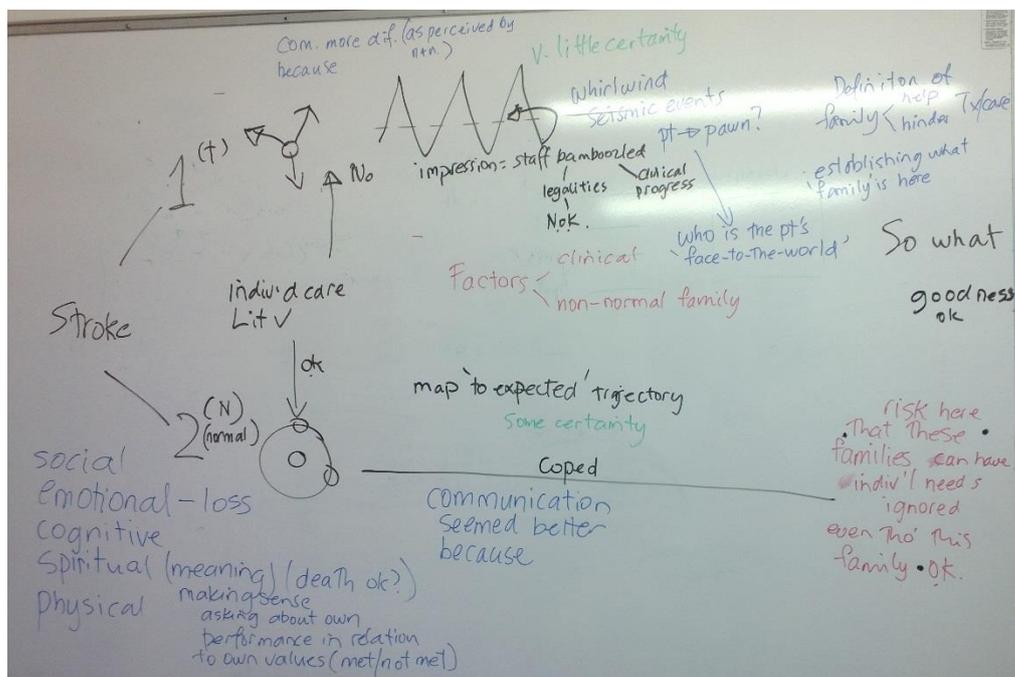
Table 1. Comparing each family’s hospital and healthcare experience

Hospital and healthcare experience	Hospital and healthcare experience
<u>Family 1</u>	<u>Family 2</u>
Whirlpool with seismic events	Acute stress which slowly eases
P1&P2 feel a lack of support, communication and information from healthcare professionals and hospital staff	P1&P2 Report feeling well supported, informed and communicated with by hospital staff.
Clinical trajectory uncertain	SS2 recovery maps clinical trajectory
Not legal next of kin to SS1	P1 has the opportunity to ask questions and SS2 has a graded return home
(The hospital staff treat us like a) <i>third party really, even though we’re there every day; It’s like, well I don’t know if</i>	(Hospital gave information needs?) <i>Oh yes. I’d had all the instructions before ... they’re very good there (hospital). You</i>

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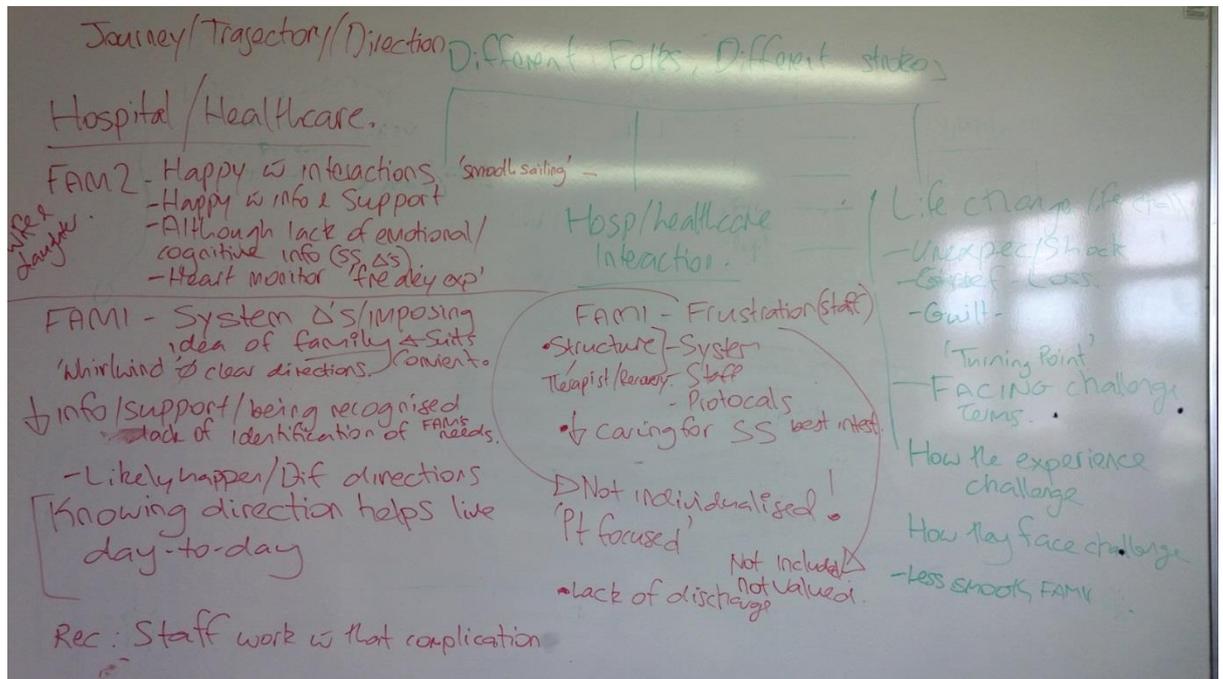
<p><i>we should be discussing it with you.</i> (Fam1,P1,Int3,pg 8)</p>	<p><i>get it all as you go along in small doses</i> <i>when you can absorb small doses</i> <i>instead of getting it all at once.</i> (Fam2,P1,Int2, Pg2)</p>
<p>Need for individualised care, establishing who family is and family meeting before the discharge event (at time of hospital admittance).</p>	<p>Risk of 'normal families' having individualised needs ignored.</p>

Mind map 1. Comparing what family is, healthcare communication and the clinical trajectory for both families



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Mind map 2. Comparing and contrasting both families' stroke journeys, particularly regarding the hospital experience and interaction with healthcare professionals.



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Table 2. Different Folks, Different Strokes: Paragraph topic overview for developing themes

	Six weeks post-stroke	Three months post-stroke	Six months post-stroke
Fam1 P1 & P2	<p>Shock. Uncertainty / Worry for SS1. Guilt / regret over delay in finding SS1 and 2nd stroke in hospital.</p> <p>Change of family life / turned upside down – visiting hospital as much as possible.</p> <p>Grieving for a person still alive / Loss of SS1's presence in the family home.</p> <p>Frustration with hospital staff / lack of assessments for SS1 / lack of information / excluded from decision making processes.</p>	<p>Frustration with hospital staff / feeling isolated and un-important to staff. Feeling lied to and lack of information from healthcare professionals. SS1's clinical trajectory unknown. Discharge unknown. Not included in decision making. Whirlwind of changes and seismic events in SS1's recovery & care.</p> <p>Family life disrupted. Family strength within their unit. Family strain within wider family with SS1's daughters.</p> <p>Visiting hospital every chance they can. Grieving for who SS1 was. Giving SS1 a voice when they he longer has one. Wanting the best for SS1. Hope & Loss of Hope.</p> <p>Post-stroke & hospital all consuming – Life on hold.</p>	<p>Still no clear sense of normal in family life. Living day by day. A little more settled. Loss of Hope / Grief.</p> <p>Family life disrupted. Family strength within their unit. Family strain within wider family with SS1's daughters.</p> <p>Struggling / frustration with stroke unit / private hospital & healthcare professionals. Lack of information / support & lack of inclusion in decision making & rehabilitation planning.</p>
Fam2 P1	<p>Shock / Trauma.</p> <p>Resentment towards SS2 for timing of stroke.</p> <p>Disbelief of stroke. Pushed to endurance levels.</p> <p>Family support & strength.</p> <p>Family gather.</p> <p>Loss of self / Loss of former life. Change to daily living.</p>	<p>Husband returning home a shock / graded return home, discharge planning. Resentment at stroke timing.</p> <p>Family support / family strength.</p> <p>Feeling restricted. Changes to husband. Changes to daily living</p>	<p>A sense of normal / daily routine. On-going support for stroke services. Family strength from stroke challenge.</p> <p>A lost future. Loss of self.</p> <p>Loss of time for self.</p> <p>Feeling restricted.</p> <p>Relationship change &</p>

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	<p>Change to husband. Future unknown.</p> <p>Good stroke unit experience / pleased with medical intervention. Felt adequate information, support. Discharge planning.</p>	<p>Lack of information regarding mood / behavioural changes to husband / SS2.</p> <p>Seeing improvements / working towards a new normal.</p> <p>Support & encouragement</p> <p>Creating a new life.</p>	<p>strain. Changes to husband.</p> <p>Looking back, a stressful life event. Low in energy.</p> <p>Lack of participation in social events / withdrawing. Frustration with recovery plateau.</p>
<p>Fam2</p> <p>P2</p>	<p>Shock. Anxiety, lack of information on first night.</p> <p>Being available to parents & family. Family gather together / family strength</p> <p>Hope.</p> <p>Needing time away from hospital too.</p> <p>Stroke effects far reaching.</p> <p>Family foundation shaken.</p> <p>Orientating to the effects of stroke.</p> <p>Family and friends support has made things easier.</p> <p>Family meeting helpful</p> <p>Death is inevitable</p>	<p>Visiting hospital was stressful</p> <p>Sees her Mum doesn't get enough time for self</p> <p>Changes since stroke to her life (seeing parents more)</p> <p>Some Permanent losses (in her father)</p> <p>Regaining some independence</p> <p>Happy with level of services available</p>	<p>Sense of normal life.</p> <p>Accepting stroke.</p> <p>Relationship change with parents. Supporting Mum / worry for Mum in her role.</p> <p>Changes to family foundation</p>

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Family 1 are not next of kin to the stroke survivor 1 (SS1). Therefore staff may have failed to understand their importance as family to SS1. They experienced a complex stroke clinical trajectory with many health setbacks which decreased SS1's recovery and rehabilitation. SS1 was not found until about 8 hours after the stroke. It is known that the quicker a person is admitted to hospital following a stroke the higher the chance of survival and improved outcomes, because the staff can administer medication and reduce brain swelling. SS1 suffered a second stroke within the first week of being admitted to hospital. The second stroke caused significant brain swelling and caused SS1 to be very sleepy. The family and doctors were not sure what kind of recovery SS1 would make.

Unknown recovery/future

(P1) The rehab doctor said (to SS1's daughters) be six to eight weeks and then hopefully go home and in the interim there may be a period where he will be put into a rest home... that afternoon [SS1] had a second stroke which sort of put things a little bit behind schedule... it was explained again that... every stroke is different, everyone sort of responds differently and because of the amount of swelling tiredness is very common and there may be times when he may not be responding to the type of intense rehab that they do on the ward that he will need to go into a private facility and rest...

(Interview 1, Family 1)

SS1 also suffered complications of infection and dehydration as well as the stroke related impairments which made Family 1 feel uncertain about the future.

Having setbacks to stroke survivor's recovery adds to a loss of hope

(P1) He had urosepsis just before Christmas and it knocked him completely. (Interview 2, Family 1)

Family 1 felt frustrated with hospital protocols and found the information from the staff confusing and contradictory. Family 1 were told one thing by one doctor and then something different by another member of staff. Family 1 also felt lied to, were unsure about the hospital staff's intentions and were unable to trust the healthcare professionals.

Hospital communication frustrating.

(P2) I find it a very unorganised situation where, because you don't know where it's going or where it's at already and then having all these mixed information from several staff, it just makes it even worse and really complicates things for us to an extent where it's kind of you're pulling your hair out almost....Like [P1] was saying, you get one doctor that's come to ask you if you've sorted out a home yet and then five minutes later it's mentioned that he's going to stay there for another week and that's the kind of thing that's just really unclear and obviously the other questions... Are the intentions right? Are they looking at putting him somewhere else because they need the space? Or what is it? 'cause those are the kind of questions you start asking yourself as well. (Interview 1, Family 1)

Family 1 had the complication of family strain with SS1's daughters. When the stroke first happened his daughters flew to New Zealand for two weeks and it was the first time P1 had met her cousins. So they went from no communication with the daughters to communicating daily through emails and Skype after the daughters returned back home (overseas). At three months post-stroke the relationship became more strained because they felt the daughters were trying to take control and manage SS1 when they were not even in the same country as SS1.

Family strain

(P2) We're not managing the situation anymore. They are now. (P1) They've taken over. We'll visit, we'll support (SS1) in every way that we can but (the daughters) can sort out ... the money, the house. ... I guess they possibly might be feeling that they were being left out or we were going to run off (with SS1's money). (P2) For us it's good because we can just focus on what we do... (P1) This (managing SS1's affairs) has been really stressful for our family and now we don't have to worry about anything (paying bills, looking after SS1's house). (P2) The only thing we have to do is during the day we just find our time to go in and make sure he's okay. (P1) ... we'll visit daily and we'll build up a good relationship with the staff (at the private hospital SS1 is about to be transferred to) that are going to be looking after him long term and that's all that matters. They can fight over who's getting the gold clock and stuff, 'cause I'm just a bit over it... So we'll visit daily, we'll look after him, make sure that he's okay and that's what we're going to focus on. (Interview 2, Family 1)

Family strain

(P2) That's our issue (with SS1's daughters), is the fact that we are here, we are doing everything with him, for him, because we're here. That's where you need to be and if (the daughters) think they can do it from the other side of the world then (they can). I mean (the stroke has) turned our lifestyle upside down, completely (handing over the responsibility of SS1's house and bills) I think for us now it's probably good ... (P1)... we might get a bit of normality back... (Interview 2, Family 1)

The strained relationship with SS1's daughters caused extra stress for Family 1 instead of supporting them in becoming a stroke family. Family strain, a complex stroke clinical trajectory, negative healthcare interactions and a lack of feeling supported decreased the outcomes for Family 1.

Family 2 is a traditional nuclear family that the hospital staff likely recognised as family more easily than Family 1. Family 2, P1 was with SS2 at the time of stroke and called for an ambulance immediately.

Shock of stroke event

I'd just gone to bed. He'd gone to the toilet and he yelled out to me and I said "what's the matter with you?" And he said I'm having a stroke and I said charming and that was it. I rang the ambulance and they came of course and the rest is history. (Interview 1, Family 2, P1)

Family 2 experienced a projected clinical recovery from stroke, meaning the staff were able to predict the likely outcome for the stroke survivor. The impairments SS2 was left with were mainly physical, balance and co-ordination. At the six weeks post-stroke interview the hospital staff had already discussed the likelihood of SS2 returning home because his recovery was going well.

Changes to stroke survivor

Well actually I think he can do a lot of things. It's mainly his balance that, and coordination and 'cause he's nearly blind because he only had one eye in the first place and now his sight's been affected so he can't drive anymore and oh, I don't know. It's just getting his balance and it's frustrating for him to not be able to do things but he knows how to do it... (Interview 1, Family 2, P1)

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...Somebody said after he'd had his weekend visit this weekend he could be discharged on Monday... (Interview 1, Family 2, P1)

Family 2, P2 was happy with the level of services and support available for her parents.

Adequate support services

Yeah I think so. I don't really think that I expect a lot. I mean I'm glad that there are services available to help them but I don't expect that people will come rushing out of the woodwork to help because mum and dad have always been fairly independent and I didn't, I wouldn't have expected them to have, even if it was available, wanted someone on their doorstep 24/7 because sooner or later you've got to get by I guess. (Interview 2, Family 2, P2)

Family strength was experienced in Family 2 in many ways. For P2 it was important to get to the hospital straight away on the night of the stroke to support her mother and see her father. P2 continued to worry for and support her mother through the shock of the stroke event.

Shock of stroke. Being available

My mother rang me on my mobile phone. I was out. Yeah. I answered the phone and she just said 'oh, your father's had a stroke', and I said 'where are you?' and she said 'we're at home, the ambulance is coming', similarly those words, and so I said, I think I wanted to know which hospital they were going to and I said I'd meet them there or meet them at home and she said she didn't know what hospital until the ambulance arrived. So we went home and rang, we weren't far away, and rang and organised for someone, our neighbours to look after the children. (Interview 1, Family 2, P2)

Family strength for Family 2 was also experienced with all of P1's adult children gathering around and helping out. A son visited from overseas and the other son helped her move house three weeks after the stroke event.

Family support. Strength

They've been running me backwards and forwards to the hospital over North Shore because I didn't want to drive ... they've been either taking me over or picking me up. They come after work and see if I'm ok, pick me up and that sort of thing and on the weekend they've been taking me and lots of other things. Helping me shift... (Interview 1, Family 2, P1)

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The journey of becoming and being a stroke family was different for the two families. Findings revealed it was important for family members to feel supported and communicated with by healthcare professionals. During the first six months post-stroke the information and support needs of the family members changed. Family strength and family gathering together increased the positive outcome for Family 2. It appears important for healthcare professionals to recognise the diverse nature of family, establish who family is and support their individualised needs.

By comparing and contrasting the experience of both stroke families in this study it was clear that the journey of becoming and being a stroke family was quite different for the two families. Analysis also explored the contrasting experiences of the two participants in Family 2, who had quite different roles and relationships with the stroke survivor. Both findings lead to the over-arching theme of 'Different Folks: Different Strokes'.

Appendix G: Kai Tiaki Nursing Research Submission Guidelines

SCOPE

Kai Tiaki Nursing Research is an internationally double blinded peer reviewed research journal that will publish original, full-length research manuscripts from New Zealand based nurse researchers (or other researchers where the research can be shown to have particular relevance to nursing in New Zealand).

In addition to research manuscripts, the journal will also publish letters to the editor and Journal Club articles. All research manuscripts and journal club articles will be subjected to the same robust review procedure. The aim of the journal is to promote a high standard of clinically related scholarship which supports the practice and discipline of nursing.

The language of the journal is English. Authors for whom English is a second language should have their manuscripts professionally edited by an English speaking person before submission to make sure the English is of a high enough standard.

SUBMISSION GUIDELINES

Kai Tiaki Nursing Research Editor-in-Chief welcomes research manuscripts in all areas of nursing. Authors should present original work, or new and original analysis of existing work. *Kai Tiaki Nursing Research* is particularly interested in Māori or Pacific related research.

Papers may be rejected on the grounds that the subject matter is too specialised, the contribution to nursing is insufficient, the topic has recently been published, or the quality of the work or the writing does not justify publication.

MANUSCRIPT TYPES ACCEPTED

Research Manuscripts

Original quantitative, qualitative and mixed methods research papers should be between 3000 and 5000 words in length for the main text, excluding the abstract, tables and references. They should be organised in logical subdivisions according to the

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recommended headings for the particular research method, which would normally include: Introduction, background, the study (with subheadings, aims, design/methodology, sample/participants, data collection, ethical considerations, data analysis, validity and reliability/rigour as appropriate, results/findings, discussion) and conclusion. In addition to those headings suitable for each study, all manuscripts should contain the following:

Title page: On the first page of the manuscript please include the title; names and qualifications of all authors; affiliations and full mailing address including email addresses, fax and a contact phone number. An author should be identified who is the agreed correspondent. The title should be concise, specific and clear. Normally a title would be no more than 7-9 words. Please ensure author's name (or authors' names) appears only on the title page and that there are no identifying comments on all other pages.

Abstract: This should appear on the first page following the title page, and should be limited to approximately 125-150 words. The information should be substantive, not descriptive and include the following headings: Aims (of the paper), Background, Methods (including year of data collection), Results/Findings, Conclusion.

Key words: This should consist of six key words which appear within the abstract.

Articles should be submitted to the Editor-in-Chief as per the usual submission procedures. They should consist of a brief background, a brief presentation of the data of interest and a very brief discussion of the significance of the manuscript or a specific aspect of the manuscript. Articles should be less than two pages (1500 words) and contain no more than five citations. No abstract or figures are required and no more than one figure may be included in the article. Queries relating to a submission may be sent to the Editor-in-Chief. The decision to accept or reject the paper will rest with the Editor-in-Chief.

Referencing

Kai Tiaki Nursing Research uses the APA Publications Manual. As per the APA referencing system, in text citations use the author-date method. Use page numbers in text only when you are quoting directly from a source. When a work has two authors,

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always cite both names every time the reference occurs in text. When a work has three, four or five authors, cite all authors the first time the reference occurs; in subsequent citations, include only the surname of the first author followed by 'et al.'. When a work has six or more authors, cite only the surname of the first author followed by 'et al.' and the year for the first and subsequent citations. If two references with more than six authors for the same year shorten to the same form, cite the surnames of the first authors and as many of the subsequent authors as are necessary to distinguish the two references, followed by 'et al.'. Refer to the APA Publishing Manual for further details.

ADMINISTRATIVE PROCEDURES

Submission of manuscripts

All manuscripts must be submitted electronically. Full instructions are given on the web site. To avoid excessively large files, which are time consuming for both uploading by the authors and downloading for the reviewing process, no file should be larger than 5 MB (5000K).

All manuscripts submitted to *Kai Tiaki Nursing Research* should include a covering letter stating on behalf of all authors that the work has not been published previously and is not being considered for publication elsewhere. **Please ensure author's name appears only on the title page and that there are no identifying comments on all other pages.**

Enquiries should be sent to:

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kaitiakiresearch@nzno.org.nz

Manuscripts should be submitted initially as PDF files; numbered figures and tables should be included in the PDF file in the first instance. To facilitate the reviewing process the submitted manuscript should be formatted with the body text in 12 point Times New Roman and line spacing of 1.5. Text should be left-aligned and surrounded by 3 cm margins. The formatting of text and headings will be removed during the production

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process and replaced with *Kai Tiaki Nursing Research* styles. Upon acceptance, a Word file of the manuscript will be required. High-quality figure files will be requested if necessary. For details see detailed guidelines, available on the web site. A signed Exclusive Licence Form will be required upon acceptance. Both forms are available on the NZNO web site. Provided these forms have been faxed to the Publications Office, it is sufficient to send the originals by regular mail.