Sustaining one's own health and wellness while supporting a stroke survivor: Spouses' and partners' perspectives

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgment is made in the acknowledgments.

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ABSTRACT

Utilising an interpretive descriptive approach, this qualitative study explores and identifies how spouses and partners of stroke survivors sustain their own health and wellness. Recent literature has mainly focused on identifying psychological coping strategies thought to assist in adapting to the caring role. As a consequence, there is limited knowledge regarding the experiences of how spouses and partners attend to their own health and well-being. This study aimed to explore how spouses and partners sustain their own health and wellness while supporting a stroke survivor. Purposive and theoretical sampling strategies were used to guide recruitment. Semi-structured interviews were carried out with seven spouses and partners who were living with, and supporting a stroke survivor.

A central theme with three sub-themes became apparent when examining spouses and partners' experiences. The theme of Meeting Needs connects the three sub-themes, in that spouses' and partners' health and wellness appeared to be influenced by and intertwined with attending to the stroke survivors' needs. The context of Being in a Relationship provided a rationale for prioritising the stroke survivors' needs and was the first sub-theme. Secondly, Living Both Lives explains how spouses/partners were busy thinking and attending primarily to the stroke survivor's daily requirements whilst also trying to attend their own needs. The third sub-theme, Uncertain Health encompasses how a spouse's and partner's well-being is connected to the stroke survivors' health and their future concerns about being able to provide care if they themselves become sick. Therefore, these circumstances shaped their ability to attend to their own health and well-being.

Whilst attending to the stroke survivor was at the forefront of their minds there were some strategies which spouses/partners utilised to support their own health and well-being. These were: creating time and space for themselves; talking with others; and comparing own lives against others who were seen to be worse or better off, in order to support their own emotional well-being.

This study found that the participants struggled to prioritise and attend to their own health and well-being, as most of them were busy primarily attending to the stroke survivor's needs. Overall, results suggest that exploring what spouses/partners think and do within the relationship could be valuable for health practitioners. Given that it is the intimate nature of being in a relationship that is the foundation for spouses/partners supporting the stroke survivor, it could also be important for services and health professionals to consider the well-being and needs of the couple, not just the stroke survivor.

KEY TO TRANSCRIPTIONS

The abbreviations and conventions given below are used throughout this thesis when excerpts from interview transcripts are quoted.

Italics   Indicates speech of participants

. . . .   Denotes material which has been deleted from the original text

[   ]   Indicates comments made by the researcher or words added to clarify

          certain aspects of transcripts

Chapter One: Introduction

The study aims to understand how spouses and partners sustain their own health and wellness while caring for their stroke survivor partners. This unique group of informal support people can provide extensive care to a stroke survivor for many years. Understanding how they maintain their own health and well-being in this situation is an essential step towards supporting caregivers who provide substantial ongoing care. This chapter will briefly introduce the background and context to the study, the focus taken, the assumptions underlying this positioning, and an overview of this thesis.

Background

Stroke is a major cause of chronic illness and disability in New Zealand and internationally (Stroke Foundation of New Zealand Inc, 2006; World Health Organization, 2003). The consequences of stroke can vary and include physical, emotional, psychological and financial impacts not only for the survivor, but can also extend to family. It is estimated that between 58-68% of people who are hospitalised for a stroke are discharged home and a large proportion of these are in need of ongoing support (Dorsey & Vaca, 1998; Fang, Alderman, Keenan, & Croft, 2007).

Spouses and partners are increasingly recognised as the main provider of support to the stroke survivor (Heaton, 1999; Jansson, Nordberg, & Grafstrom, 2001; Tennstedt, 1999; Wolff & Kasper, 2006). There are several reasons why there has been an increased reliance on spouses and partners to provide support when there is a chronic condition. Firstly, there have been changes in how families are structured (i.e. from extended to nuclear units, migration). As a result of these structural shifts, there is a

reduction in the number of family members can be drawn upon to provide support (Bittman & Pixley, 1997; Elliot, 1996; Twigg, Atkin, & Perring, 1990). Secondly, in today's current economic climate, women are expected to participate in the workforce. Historically, females have been, and to some extent still are, expected to provide informal support (Heaton, 1999). Thus, the availability of women to provide support has also declined (Bittman & Pixley, 1997; Elliot, 1996). Lastly, there is more demand for informal care after a stroke than ever before, as a consequence of an increasingly older population and advances in medical treatment. Therefore, people are more likely to survive the initial insult of stroke and to return to the community (Dorsey & Vaca, 1998; Tobias, Cheung, Carter, Anderson, & Feigin, 2007).

There is a wealth of literature looking at the impact on health outcomes for relatives and spouses when supporting people who experience a chronic condition. Until recently, the main focus has been on the detrimental impacts or the burden of caring for another. People who support those with chronic health conditions are at higher risk of depression, anxiety, insomnia, reduced psychological well-being, poorer health, injury and death (Borg & Hallberg, 2006; Draper & Brocklehurst, 2007; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Wilson, 1990). In contradiction, there is evidence to suggest that support people also experience benefits from caring, which can contribute to their well-being. These benefits can stem from maintaining a relationship, fulfilling a supportive role and personal growth (Braithwaite, 1996; Farran, 1997; Noonan, Teenstedt, & Rebelsky, 1996).

In order to promote the well-being of support people, research has focused on identifying coping strategies that are thought to assist with the adjustment to the daily tasks of caring for a person with a chronic condition (Chow, Wong, & Poon, 2007; Doland & Sims, 1996; King & Semik, 2006; Lazarus & Folkman, 1984; Low, Payne, &

Roderick, 1999; Tennstedt, 1999). However, this positioning of linking a support person's health and wellness solely to the caregiving role ignores the support person's pre-existing and on-going health conditions, their own health and lifestyle beliefs and behaviours, and the relationship with the person they support. Little research has been undertaken to explore the decisions and actions taken by spouses and partners in regards to their own health and well-being.

The majority of research on caregivers has focused on progressive conditions such as Dementia and Alzheimer's. However, the consequences of stroke may be different from these illnesses, in that the sudden occurrence of stroke can rapidly change the level of support a spouse/partner may provide, rather than being a gradual process. Therefore, the process of sustaining one's own welfare may differ for the stroke survivors' spouse or partner due to the abrupt nature of its onset.

New Zealand Context

Consistent with international trends, in New Zealand there has been a shift away from institutional care, to caring within the community for people who experience disability. In response to the growing reliance on support people, the New Zealand Government has recognised that informal carers play a significant role in providing care (Ministry of Social Development, 2007a, 2008). For care to continue, aiding support people's health and well-being is now considered essential. To facilitate this, *The New Zealand Carers' Strategy and Five-year Action Plan* was recently developed (Ministry of Social Development, 2007b). This policy endeavours to improve the lives of carers (Ministry of Social Development, 2008). Whilst policies such as these are important to guide funding, service development and research, they have been criticised as ensuring and maintaining informal carers as the main source of disability support (Heaton, 1999).

This maintenance results in less demand for health services, rather than genuinely attending to the well-being of the support person. *The New Zealand Carers' Strategy* is no exception.

Focus of Inquiry

This study uses a qualitative approach, specifically interpretive description, to investigate the question "How do spouses and partners sustain their own health and wellness while supporting a stroke survivor?" The approach taken is situated within the interpretive paradigm and focuses on discovering commonalities or patterns of action, in order to inform clinical practice (Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). Answering the question utilising this methodology was considered important because there was a dearth of qualitative research exploring the experiences of carers of stroke survivors. The focus of this inquiry concentrated on spouses and partners as stroke tends to occur in an older population (Tobias, Cheung, Carter, Anderson, & Feigin, 2007), and spouses and partners are likely to be of a similar age and consequently have a higher risk of ill health. This implies that spouses and partners of stroke survivors are more likely to have health issues of their own. In addition, because of the intimate relationship with the stroke survivor, spouses and partners are drawn into the caring role, and as I will discuss in Chapter Two being a carer can be difficult in itself. For the purpose of this study, a spouse is defined as the legal husband or wife, and the term partner is used when there is a de facto relationship.

The term health is commonly referred to as the general condition of the body, specifically in terms of soundness or vitality (Foreman, 1970). In more recent times, health has been described as encompassing not just bodily conditions but, "a state of

complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 2006, p. 1). Given the connotations associated with the word health, I have used the term wellness to ensure clarity about my holistic approach to spouses' and partners' overall health. Wellness has been described as "the optimal state of health .... the realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one's role expectations in the family, community, place of worship, workplace and other settings" (Smith, Tang, & Nutbeam, 2006, p. 344). Similarly, Ryff (1989a, 1989b) explored positive well-being in older adults and found six dimensions. These included: personal growth, purpose in life, autonomy, environmental mastery, positive relations with others, and self-acceptance. Both wellness and well-being are similar concepts in that they describe a broad view of an individual's welfare. Therefore, these terms have been used interchangeably throughout this thesis.

Assumptions and Pre-Understandings

Reflexivity is an important part of qualitative research in that it acknowledges and clarifies your own beliefs, values, and knowledge about the phenomenon (Strauss & Corbin, 1998). Existing knowledge, whether acquired by formal research or informal experience is the beginning point of the inquiry (Thorne et al., 1997). Prior to this study I had formed some of my own understandings about the phenomenon of sustaining one's own health and wellness while supporting another. This was shaped through my professional experiences in mental health, research in the field of stroke rehabilitation, and my own personal life role as a granddaughter who provides informal care to a grandparent. In order to become aware of my preconceptions and how they could influence the research process, I was interviewed by a third party prior to commencing interviews with participants. The following assumptions were indentified from this

process, that:

- Spouses/partners may tend to focus on the stroke survivor rather than themselves.

- The caring role can be a big part of the spouses/partners life.

- The spouse/partner can be supported by other people.

- Large amounts of energy (physical, emotional and mental) can go into supporting a stroke survivor.

Throughout the research process some of these preconceptions were challenged along the way. Thus, prior beliefs and knowledge provided a foundation, rather than an over-riding structure, to this study.

Structure of Thesis

This chapter has endeavoured to set the scene for this thesis by briefly describing the background for this study, in particular, the current New Zealand context and policies influencing this area. The latter half of this chapter defined key terms involved in this study, and identified my pre-conceptions, both of which have shaped the approach to this inquiry.

Chapter Two provides the reader with an overview of the current literature surrounding sustaining one's health and wellness whilst caring for a stroke survivor. Existing literature relevant to caregiver's health has been reviewed and critiqued.

Chapter Three outlines the selection and application of interpretive description as the methodology of choice and describes in full the study's research process. This

chapter also includes a discussion on the ethical considerations and strategies used for promoting rigour for this study.

In Chapters Four and Five, the findings from the analysis of the transcripts are presented. The main themes, strategies used by spouses and partners, and consideration of their overall experiences are discussed.

Chapter Six draws together the findings and discusses these in relation to existing knowledge. The implications and recommendations for practice, study limitations and suggestions for future research are explored.

Chapter Two: Literature Review

This chapter reviews the current literature exploring the health and well-being of support people. In line with the approach of Thorne et al. (1997; 2004), an initial search of the literature was undertaken prior to analysis in order to develop and refine the research question. To begin with, the literature was searched through Ovid, Scopus, EBSCO Health databases, using terms such as informal carer or support person, stroke or myocardial infarction, health, well-being or stress. This produced some broad areas of knowledge. Subsequently, further literature that was considered relevant to this topic was obtained from bibliographies and searching within particular journals (i.e. *Social Science and Medicine, and Sociology*). These specific journals were searched in order to include research from a variety of professional disciplines.

Within the literature various terms were used to refer to informal support people. These included; relatives, support people, carers, caregivers, and family. At times, these terms were used interchangeably within the literature, and the relational aspect of care was unknown as some studies did not describe their participant's relationship with the person they cared for. While the knowledge gained from these studies is valuable, the lack of identification of participants' relationship to the person they cared for is considered a limitation of a study. In this review I have used original authors' terminology when referring to their work. However, of the studies that did describe their population, the majority recruited participants who provided regular, unpaid support, and thus grouped a wide variation of social relationships (i.e. siblings, friends and spouses). Although this focus of inquiry specifically explores the experiences of spouses and partners of stroke survivors, it is also important to consider evidence from other types of relationships as there may be similarities for health and well-being.

Within the caring literature, two approaches featured strongly, a sociological and a psychological approach. The sociological approach critically examined how caring has been constructed within society, while the psychological literature examined individual consequences of being a support person. Research into caring has primarily explored the impact on support people's health and well-being, focused on burden and in more recent time the benefits of caring. In particular coping strategies, informed by stress-coping theories, have been identified and are thought to assist them in the caring role, thus potentially influencing their health outcomes. Lastly, in this chapter a critique of the literature and the connection to health and well-being will follow.

Sociological literature

From the 1970's there has been a major shift from institutional care to community care for people who experience disabilities. As a consequence, there has been an emphasis and expectation for family, friends and neighbours to provide community care (Heaton, 1999). The discourses surrounding informal carers reinforce a "natural" moral obligation for family to function as carers, and in particular call to females to take up this role (Heaton, 1999; Hughes, McKie, Hopkins, & Watson, 2005; Montgomery, 1999). Some argue that this is a result of social policies, which benefit from unpaid care being provided in the community (Heaton, 1999; Montgomery, 1999; Sevenhuijsen, 2000). Furthermore, feminists assert that this construct of caring exploits women and reinforces existing inequalities in the labour market (Elliot, 1996; Hughes et al., 2005; Watson, McKie, Hughes, Hopkins, & Gregory, 2004).

Heaton (1999) critically explored English social policies using Foucauldian discourse analysis and found that the informal care role had been normalised within policies but it did not give people a choice as to whether they wanted to take up the

caring role or not. She also identified the division between informal and formal support. The informal carer is defined as the primary provider who is unpaid and is motivated by love and/or piety. In comparison, formal care is paid support and viewed as a secondary source. An example of this is how formal carers are relied upon to support and relieve informal carers when they are struggling to provide ongoing care. Another indication of this hierarchy is the subtle shift from the distinction of being an informal carer to now being referred to as a carer (Heaton, 1999). The shift implies that informal carers are the standard source of support and formal support is drawn on infrequently (Heaton, 1999). Ironically, her conceptualisation of informal carers as users of services highlighted how social policies are used to sustain the caring relationship, thereby preventing or averting the need for formal care.

Another criticism made by Heaton (1999) is that carers may have needs which are at odds with continuing to care. The support person and the person who experiences a chronic health condition through policies and service provisions are considered autonomous and disconnected from each other (Chattoo & Ahmad, 2008; Lloyd, 2000; Winch, 2006). While assisting the well-being of both parties is considered important, at times there can be tensions between each persons' rights and needs (Lloyd, 2000; Watson et al., 2004; Winch, 2006). For instance, a support person may no longer want to, or be able to provide support due to ill health. Residential care may become the only option to provide ongoing support to the person with the chronic health condition. However, the person who receives support may not want to or may resist moving into residential care, regardless of the needs of the support person. Ultimately, it is the needs and rights of the person with the condition which are considered paramount (Winch, 2006). This precedence can at times create oppositional support needs within the caring relationship.

Chattoo and Ahmad (2008) assert that the practice of caring is based on a moral framework from norms or values associated with family or religion. Drawing on interviews with people who were receiving cancer treatment and family carers, the authors asserted that the meaning of caring is a part "of a moral orientation of an embodied self within a framework of relational autonomy" (Chattoo & Ahmad, 2008, p. 561). This positioning provides a useful way of conceptualising supporting another and acknowledges the complexity of the relationship between two relatives, however, limited demographic information about the family carers referred to in their study was provided. In summary, sociological literature has examined influential government policies which have contributed towards the reliance on informal support people; and the complexity of a caring relationship embedded in social and familiar roles. The remainder of this chapter discusses the health outcomes for those supporting a person with a chronic condition.

Health outcomes

Whilst there is debate as to the type and degree of the impact of caring (Pinquart & Sorensen, 2003; Taylor, Ford, & Dunbar, 1995), it is important to acknowledge that health and well-being outcomes are changeable, and have many possible contributory factors. The majority of literature exploring health outcomes for informal support people focuses on the burden or detrimental impacts of being a support person. However, this dominance has been recently challenged by some theories and research and now includes exploration of benefits or rewards associated with assisting a person with a chronic condition (Hunt, 2003; Kramer, 1997b). Thus, there has been a binary positioning of positive and negative health outcomes. Each will be discussed separately as they appear in the literature, yet it is argued that both burden and benefits could occur simultaneously (Farran, 1997).

Detrimental impacts

In my review of the caregiving literature it became apparent that assisting a person who has experienced a stroke can have a harmful impact on the health and well-being of the primary support person (Han & Haley, 1999; Low et al., 1999). This section will explore three outcomes dominant in the literature: depression, death and physical health. When exploring the relationship between the role of caring and the health of those who provide the support, the majority of research has focused on the prevalence and risk factors of detrimental health effects and, in particular, the psychological consequences (Han & Haley, 1999). Based on my evaluation of the literature this claim still seems to hold true. Support people are at higher risk of experiencing depression, anxiety, insomnia, reduced psychological well-being, poorer physical health and death (Draper & Brocklehurst, 2007; Forsberg-Warleby, Moller, & Blomstrand, 2001; Han & Haley, 1999; Low et al., 1999; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Schulz, Tompkins, & Rau, 1988; Smith et al., 2004b; Wade, Legh-Smith, & Hewer, 1986; Williams, 1993).

Overall, depression is the most frequently researched health condition when considering the impact of supporting a stroke survivor. Research to date suggests that support people have a higher rate of depression compared to that of the general population (Forsberg-Warleby et al., 2001; Han & Haley, 1999; Schulz et al., 1988). However, the factors that predict depression beyond the early stages of supporting a stroke survivor still remain unclear. The frequency of depression is estimated to range from 34% to 52% for stroke support people, in comparison to 12% to 16% for non-support people (Han & Haley, 1999). Nevertheless, it has been highlighted that the relationship between supporting another and depression is not straightforward or linear, and can change over time (King et al., 2001). Also it appears that predictive factors for

depression can also vary after a while (Han & Haley, 1999; Low et al., 1999). In the early stages of caring, the factors most associated with support person depression relate to stroke survivor variables such as: physical disability, depression, behaviour, and concern for their future care (Forsberg-Warleby et al., 2001; Han & Haley, 1999; Low et al., 1999; Schulz et al., 1988; Wade et al., 1986; Williams, 1993). Interestingly and in comparison, during the chronic stages of caring, demographic variables relating to the support person, such as age, health and their income, become more predictive of support person depression (Schulz et al., 1988).

Supporting another person can have other serious impacts on one's health. Schultz and Beach (1999) explored the relationship between caregiver demands among older spouses and their mortality rates. Spouses aged 65 years and over, who provided care to their disabled partner and experienced difficulties in meeting activities of daily living, had a 63% higher mortality risk within four years compared to those who did not have disabled partners. Christakis and Allison (2006) reported a much lower mortality risk when examining the relationship between a partner's hospitalisation due to illness and the risk of death for the spouse. Within a year, when a wife experienced a stroke, the husband's risk of death increased by 6%; and when a husband experienced a stroke, the wife's mortality risk increased by 5% (Christakis & Allison, 2006). There are two possible reasons for these varied rates of risk between the two studies. One explanation could be due to the different lengths of follow up time. Schultz and Beach followed spouses for four years, whereas Christakis and Allison had reported after one year. Another reason could be the difference in methodology and sample population. The Schultz and Beach study was a longitudinal design and followed spouses who lived and provided assistance to partners who had difficulty with daily living activities due to their health. Christakis and Allison's study was a retrospective design looking at hospital admissions to indicate illness and incidence of death of spouses. As a result,

Schultz and Beach's sample would have included spouses who required assistance because of their health, but may not have been admitted to hospital for their condition. Regardless of the amount of variation in the results, it has been demonstrated that supporting a person with a chronic illness can negatively contribute towards ones mortality.

Up until recently there has been little exploration of the impact of caring on a support person's physical health with respect to supporting a partner who has had a stroke (Han & Haley, 1999; Low et al., 1999). The literature that focuses on this relationship has used quantitative measures of physical health, with many studies using one item global scales or symptom checklists. In a meta-analysis, Pinquart and Sorensen (2003) explored the physical health and well-being of those who provided care for the elderly, and the difference between caregivers and non-caregivers. Overall, the authors reported a small but significant difference, with caregivers experiencing poorer health. In addition, this finding was consistent if changes in health were measured subjectively or objectively.

When Williams (1993) explored the physical health of stroke support people by asking them about health problems for which they had not sought medical attention, six participants subjectively identified health conditions (i.e. weight control, pain in face and teeth). Yet, when participants were rated by a health professional, thirteen people were identified as having health problems (i.e. hypertension, obesity). This study highlights considerable disparities between subjective and objective measures of physical health. Some of these measurement differences could be due to: the perceptions of what is considered to be a health issue; and/or the ability for oneself to diagnose certain health conditions (e.g. high blood pressure). In addition to how health can be measured, some outcome measures and the interpretation of them, may conceal

the extent of health change that has occurred. For instance, Williams (1993) reported that caregivers rated their health as moderate to good on the Cohen-Hoberman Inventory of Physical Symptoms. Despite this finding, caregivers' health was estimated to be significantly lower than before the stroke occurred. Whilst this study provides valuable knowledge, the findings must be interpreted with caution as the aim of the study was to pilot test questionnaires on a small sample (N= 29) and so generalisation is limited.

Two further studies did not find any significant changes in the physical health of carers within nine months of their partner's stroke. King et al. (2001) found that there was no change in the physical health of the primary support person of a stroke survivor from the time of admission to the time they arrived home (6-10 weeks post discharge). However, 16% reported new or aggravated health problems post discharge. In addition, Schulz and others (1988) found no change in health problems of primary support people seven to nine months after a stroke. Thus, it appears that current evidence is inconclusive about the impact of caring on support people's physical health. Reasons for the ambiguity could be due to the various ways in which carers' physical health is measured and the various lengths of time of follow up.

Beneficial impacts

Although the majority of the literature concentrates on the detrimental impacts, or the burden of caring, there are also positive aspects experienced by support people (Farran, 1997; Farran, Keane-Hegerty, Salloway, Kupferer, & Wilken, 1991; Hunt, 2003; Kinney, Stephens, Franks, & Norris, 1995; Kramer, 1997b; Noonan et al., 1996; Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007). There are a variety of terms such as satisfaction, gains, rewards, uplifts, enjoyment, and positive aspects used to

capture and measure these benefits (Hunt, 2003; Kramer, 1997b). Most of the terms characterise the extent to which the support person "appraises" the caregiving experience to be life enhancing (Kramer, 1997b). That is, providing care for another can improve or add to the support persons' life on an emotional, physical, mental or spiritual level.

When reviewing the research on the types of benefits caring for another person can have, I identified three broad themes. Firstly, benefits to the interpersonal relationship can be experienced from the interactions between the care receiver and caregiver. Some aspects of this include: love/intimacy (Braithwaite, 1996; Cohen, Colantonio, & Vernich, 2002; Cohen, Gold, Shulman, & Zucchero, 1994; Farran et al., 1991); companionship (Cohen et al., 2002; Noonan et al., 1996); and valuing the relationship (Farran et al., 1991; Noonan et al., 1996). Secondly, carers may benefit from fulfilling the caring role. Role fulfilment can consist of: finding meaning in caring (Farran et al., 1991; Potgieter & Heyns, 2006); experiencing mastery and accomplishment in caring tasks (Sanders, 2005); fulfilling a sense of duty (Cohen et al., 2002; Cohen et al., 1994; Noonan et al., 1996) and providing quality of life to the care receiver (Cohen et al., 2002; Cohen et al., 1994). Lastly, support people have described benefits that relate to their personal growth. This has been expressed as spirituality and faith (Farran et al., 1991; Noonan et al., 1996; Sanders, 2005) and enhanced purpose in life (Noonan et al., 1996; Sanders, 2005). Within research, the consequential benefits of caring for another have been primarily conceptualised as something that can be measured, counted, and offset against burden.

The majority of research in this area has looked at those who support the elderly or people who experience dementia. In comparison, there has been limited research specifically looking at stroke support people. While stroke and dementia present

differently (acute vs. progressive) and have unique sequelae, there are also some similarities between the conditions, such as memory loss, change in personality, and that both conditions are more likely to occur in older adults. Therefore, research in the area of dementia and caregiving may provide relevant information for people who support stroke survivors. Overall, it appears that relatives who support the elderly or those who experience chronic illness frequently report benefits of caring. For example, 81% of spouses and adult children experienced some sort of gain related to the caring role whilst supporting people with Alzheimer's and dementia (Sanders, 2005). Similarly, Braithwaite (1996) reported that 83% of carers believed that some personal benefits (such as companionship, having someone in the house, being useful and keeping busy) would be missed if their caring role ceased. Cohen, Gold, Shulman and Zucchero (1994), in developing a measure to quantify the benefits of caring, asked participants (57% of whom were spouses) to list what they thought were the enjoyable aspects of supporting a person with dementia. The majority (73%) identified at least one positive aspect, with companionship as the most frequent response (15%). Farran, Keane-Hegerty, Salloway, Kupferer and Wilken (1991) explored from an existentialist perspective the meaning of caring when supporting a person with Alzheimer's. Of the 94 participants interviewed (66% of whom were spouses), 90% reported valuing positive experiences of caregiving with the relational aspects, such as cherishing their relationship (63%) being the most frequently reported.

The research exploring the benefits of caring has mainly been limited to a positivist orientation with content analysis and qualitative descriptive being the preferred methodology. In addition, most of these studies have been cross-sectional, and analyses of findings have regularly informed pre-existing frameworks. The dominance of one epistemology, I suggest, has restricted how the beneficial aspects of caring have been conceptualised and measured. For example, Noonan, Teenstedt and

Rebelsky (1996) aimed to explore the benefits and the meaning of caregiver. The authors used content analysis and initially used "selective" coding strategies to identify themes which were derived from previous research. Although they also used "open" coding to explore additional themes, the lack of information about the interview procedures (i.e. what questions they asked participants) and their focus on responses to questions related to the burden of caring, suggests that data collection did not adequately serve the aims of their study. Whilst this approach to analysis is consistent with the research methodology, I propose that using a predetermined framework can constrain the possible interpretation of benefits.

In order to develop a measure, Cohen et al. (1994) investigated the positive and enjoyable aspects of caring for people who experienced dementia. Support people were asked to list what they found enjoyable. Content analysis revealed the following frequency of experiences: other (52%); no enjoyment (45%); having the company of the care receiver (15%); keeping the care receiver at home (15%); love (9%); and feeling a sense of duty (8%). It is interesting to note that approximately half of the participants reported aspects that were coded into the "other" category. Despite the lack of information about analysis, the authors did state that the "other" was heterogeneous and provided some examples of responses which fitted into this category (e.g seeing the care recipient happy, feeling good about oneself). Given that such a high proportion of participants responses were subsumed into the "other" category, further analysis of this could have yielded important findings for conceptual measurement development.

When specifically exploring supporting stroke survivors and utilising content analysis, Pierce et al. (2007) followed 73 caregivers for the first year after the survivor's stroke. They categorised the problems and successes of caring and analysed the findings based on Friedmann's framework of systemic organisation. This

framework purports that support people strive towards balance and their behaviour patterns can be viewed into four process dimensions: system maintenance, coherence, individuation, and system change. Three themes were attributed to successes: making it through and striving for independence (system maintenance); doing things together and seeing accomplishments in the other (coherence); and reaching a new sense of normal and finding balance (individuation and system maintenance). This longitudinal design and application of a family systems perspective provides a unique view on conceptualising the positive aspects of caring and acknowledges the dynamic nature of caring. However, the lack of evidence such as appropriate quotes to support the themes and a limited description of participant retention throughout the study, suggests caution should be taken when interpreting these findings.

Link between benefits and health

The rationale for focusing on the benefits of supporting another person is that positive aspects can mediate or counter the detrimental outcomes of caring (Kramer, 1997b; Rapp & Chao, 2000; Sanders, 2005). Reports of positive aspects of caring associated with well-being include: lower depression scores (Farran, 1997); higher scores on intimacy and love, which indicates that support people are more likely to experience positive effects, psychological well-being and fewer minor psychiatric symptoms (Braithwaite, 1996) and have better health (Cohen et al., 1994). However, the evidence is unclear about this counterbalance association. For example, Lawton, Moss, Kleban, Glicksman and Rovine (1991) tested a two-factor model of caregiver appraisal and psychological well-being with people who supported Alzheimer's patients. In this study, 'appraisal' was operationalised as satisfaction and burden, and the level of psychological well-being was quantified by measuring positive effects and depression. Analysis of 285 spouse's revealed satisfaction was significantly associated

with positive effect and burden was related to depression. However, satisfaction was not associated with lower levels of depression. Therefore, they did not find evidence to support the hypothesis that positive and negative appraisals of caregiving contribute to negative and positive aspects of psychological well-being. One possible reason for the limited evidence could be attributed to the lack of robust measurement development, particularly for capturing the positive appraisals such as satisfaction (Kramer, 1997b). The authors measured caregiver satisfaction using five items but also juxtaposed satisfaction next to ten burden items. Thus, satisfaction was conceptualised as the absence of burden. I propose that a restricted conceptual development of positive aspects of caring could continue to impede the exploration of how appraisals may mediate health outcomes for support people.

Overall, it appears that the current research exploring the impact of caring on the health and well-being of the support person is very limited. Notably, there is a restricted view of health and well-being which has been predetermined by researchers. As a result, in my view there has been inadequate exploration of the impact on physical, social and spiritual well-being of support people (Low et al., 1999). Additionally, the majority of studies have: focused on a relatively short time frame of caring (two to three years after stroke); been cross-sectional rather than longitudinal studies; used some measures which have not been well conceptually developed; and relied on small and convenient samples (Han & Haley, 1999; Kramer, 1997b). Also, it has been highlighted that self-appraisals of benefits or burden are not an either or, that is both can be experienced at the same time and, nor do they have clear simple links to psychological well-being (Farran, 1997). In the absence of clear evidence, one way that is believed to promote the support person's well-being is to reduce the burden of caring (Folkman & Moskowitz, 2004; Oyebode, 2003). Research has primarily explored this area by looking at how support people adapt or cope with the stress of the caring role, purposing

that different coping strategies can mediate negative and positive health outcomes.

Psychological literature

Coping strategies

The topics of coping and caregiving are predominantly located in the field of psychology. Knowledge about this area has focused on how support people appraise a stressful situation and their different responses to their caring role (Folkman & Moskowitz, 2004; Oyebode, 2003). This section will explore and critique how coping strategies have been conceptualised in recent research. Before examining the literature on how support people might cope with stressors of the caring role, the underlying beliefs as to how this could connect with health and well-being are discussed.

To date research into coping strategies has been influenced by stress-coping models (Folkman & Moskowitz, 2004; Nolan, Keady, & Grant, 1995; Oyebode, 2003; Pearlin, Mullan, Semple, & Skaff, 1990; Schulz & Williamson, 1993). These models emphasize an individual's appraisal of an event/situation which is believed to strongly influence the coping process and subsequent psychological well-being. Models tend to include stressors, appraisals, and resources which are believed to mediate outcomes, such as psychological well-being and quality of life (Kramer, 1997b; Lawton et al., 1991; Lazarus & Folkman, 1984; Oyebode, 2003; Pearlin et al., 1990; Rapp & Chao, 2000; Schulz & Williamson, 1993). Critiques of these models have emphasised that they do not account for the positive interpretation or gains of caregiving (Farran, 1997; Kramer, 1997b; Rapp & Chao, 2000). As a result a two-factor model of caregiving was developed to include the appraisal of gains as well as strains (Lawton et al., 1991; Rapp & Chao, 2000).

Lazarus and Folkman (1984) define coping as "the constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Thus, coping is seen as the support person's interpretation of, and reaction to a situation where their available resources, internal (i.e. problem-solving) or external (i.e. income, social support) are not sufficient to meet the demands of caring for another. Defining coping in this way, I suggest, constructs it as an individual reaction and response to a stressful situation and emphasizes remediation through support people's interpretation of their situation. This definition also restricts how support people are believed to 'cope', that is, if a support person can meet the demands of caregiving then they are perceived to be coping. However, managing the immediate external and internal demands could be potentially at the long-term expense of the support person's well-being. While it is valuable to identify how support people cope during stressful situations, it must be kept in mind that the bulk of the current literature is limited to stressful coping rather than successful coping.

As a consequence of these influential coping theories, research has seen coping strategies classified into two categories: (1) problem-focused coping; and (2) emotion-focused coping (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Wright, Lund, Caserta, & Pratt, 1991). Problem-focused coping strategies are aimed at addressing the source of stress (Folkman & Moskowitz, 2004). Whereas, emotion-focused coping strategies are used to regulate or ameliorate the emotions associated with the source of stress (Folkman & Moskowitz, 2004). To illustrate, Smith et. al (2004b) found that 90 carers (67% of whom were a partner/spouse) of stroke survivors, one year post-stroke reported that they frequently used emotional coping strategies such as: taking one day at a time (82%); diversion (82%); being positive about situation (80%); acceptance (77%); and using humour (69%). In another study which looked at

family carers for older adults in Finland (Kuuppelomaki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004), 290 carers, of whom 65% were husbands or wives, reported that the most helpful strategies were a combination of problem-solving and emotional-cognitive coping strategies. Strategies included: establishing their priorities and concentrating on these (86%); believing in oneself and the ability to handle stress (85%); taking one day at a time (85%); and being positive about the situation (83%).

For many years problem-focused strategies have been positively correlated with psychological adjustment and emotion-focused strategies have been associated with poor psychological adjustment (Folkman & Moskowitz, 2004; King et al., 2001; Kramer, 1997a; Lui, Ross, & Thompson, 2005). While there is some support for this, there is recent literature to suggest that the associations are not straightforward and are more complex than first thought (Kendall & Terry, 2008; Smith et al., 2004b). For example, Smith et al., (2004b) recruited 90 stroke survivors and their carers, of whom 69% were partners/spouses. Carers reported utilising problem-focused coping strategies; however this was not predictive of their health measured by depression, anxiety and general health, one year post-stroke. In addition, it has been proposed that support people could use both types of coping strategies at the same time, as one type of strategy may be more helpful in certain situations, or different genders may use one type over another (Folkman & Moskowitz, 2004; Kuuppelomaki et al., 2004).

In addition to the above two dimensions of coping, meaning-focused coping (i.e. creating or managing the meaning of a situation) and social-coping (i.e. seeking support) have also been identified as ways people adapt to stressful situations (Ekwall, Sivberg, & Hallberg, 2007; Folkman & Moskowitz, 2004; Kramer, 1997b; Nolan et al., 1995). Interestingly, when Wright et. al (1991) explored the concept of coping and subjected the Jalowiec Coping Scale to factor analysis in caregivers of people with

dementia, they found four groups of coping strategies: problem-orientated, avoidant-evasive, re-framing, and regressive. Each group appeared to be both independent but interrelated. However, I purpose that the concepts of these coping strategies and how they are measured needs to be further explored, as some of the data reported in this study appeared counter-intuitive. For example, the problem-orientated factor consisted of the item "try to find meaning". At first glance, the strategy of trying to find meaning does not appear to fit under problem-solving but rather re-framing category. Therefore, there is a lack of clarity as to how the items fit within the different groupings of coping strategies.

Kendall and Terry (2008), however, did not find evidence to support a variant (Goodness-of-Fit coping hypothesis) of Lazarus and Folkman's theory. In an effort to explain when a coping strategy is effective or not, the Goodness-of-Fit hypothesis suggests that the effectiveness of the strategy is influenced by the perceived controllability of the situation (Kendall & Terry, 2008). In this study, the authors wanted to explore if the Goodness-of-Fit hypothesis could: explain coping, and impact on emotional well-being and social-role functioning outcomes for traumatic brain injured (TBI) patients and their relatives. They reported that the model was not supported for the relatives in the short-term (two months post-discharge), and the only significant connection between coping strategies and outcomes was with role functioning. There was also a negative association with the use of escapism strategies and a positive association with minimization strategies. Interestingly, there were no connections between emotional well-being when the situation was perceived to be controllable in the short or long-term. While this information is valuable and there are similarities between the consequences of stroke and TBI, unfortunately no demographic details of the relatives were provided. Therefore, I cannot determine if this study population (relatives of TBI patients) has similar characteristics, such as age and gender,

to partners or spouses of stroke survivors. Characteristics such as gender may influence which coping strategies are more likely, or not likely to be utilised.

In contrast to hypothesized theory based research, another way to investigate coping strategies is to explore the experiences of support people using qualitative methodologies to inform or develop theories. With regards to carers of stroke survivors, O'Connell and Baker (2004) used an exploratory descriptive study to identify strategies used to manage the caring role by support people within three settings; in acute, rehabilitation wards, and community. Of the 37 carers, 57% were partners or spouses. The authors reported a range of coping strategies adopted by the carers which included: remaining positive, adapting to change, comparing with others who were worse off, changing their employment status, humour, switching off, and using family support. It is interesting to note that while participants valued support from family and friends, they also identified that it could also be a source of distress. This highlights how a strategy can often assist people with the caring role and their well-being, but at times it can also be detrimental. Although these authors did not use pre-determined categories for analysis, there was a lack of clarity in the process of analysis, such as how many researchers analysed the transcripts and how they came to the final findings. Furthermore, the findings presented were not the primary focus of the study, but a secondary aim of a larger project. Thus, a different data collection method (i.e. face-to-face interviews rather than via the telephone) could have allowed further identification or exploration of strategies if the study was designed with the sole aim of identifying carer strategies.

In a study exploring the ways in which 18 relatives managed the demands of caring for relatives with advanced dementia, a craft of caring was described (de la Cuesta, 2005). The term "craft" referred to how relatives invented ways to respond to

caring needs. This craft of caring consisted of: ruses of care – which meant relatives had to discover ways of dealing with difficult situations; developing a language to communicate with the dementia relative; creating space – this included redesigning the environment and the activities within; creating spaces and building tools – relatives created or reinvented objects to assist them with caring tasks. These strategies allow valuable insights into how relatives manage caring. However, when evaluating the applicability of the findings compared to spouses and partners of stroke survivors, it is important to bear in mind the following: participants were recruited from a pre-existing university research group (a convenience sample); the focus was on advanced dementia; and involved mainly parent-child relationships (55% were daughters).

It is interesting to note that utilising qualitative methodologies which did not use pre-conceived analytical frameworks has elicited information that would not have been otherwise considered. To illustrate, de la Cuesta (2005) identified that relatives created a language based on familiarity. Thus, a qualitative approach towards coping whilst supporting another allows creative and diverse strategies to be identified.

As a result of the dominance of stress-coping models, some interventions and services aimed to assist support people's well-being have been influenced by these theories. Yet, there is limited evidence to support the effectiveness of these strategies (Lui et al., 2005; Stoltz, Uden, & Willman, 2004). In a review of problem-solving interventions for family members of stroke survivors, Lui, Ross and Thompson (2005) reported that two studies showed a significant reduction in depression, preparedness, vitality and coping with stroke survivors' emotions. However, the majority of the studies that they reviewed did not show a significant improvement in support people's physical health, stress, or burden (Lui et al.). A shortage of conclusive evidence of intervention efficacy was attributed to: the wide diversity in the type of interventions

(i.e. skills taught, method of delivery, and intensity); small sample sizes; and lack of appropriate outcome measures (Lui et al.).

Critique of literature

When reviewing the literature, if studies had disclosed their theoretical foundation, for the most part they were informed by psychological models (Schulz & Williamson, 1993). While it is beneficial to have a theoretical foundation, there is some evidence to suggest that these pre-conceived models may not be reflective of support people's experiences (Kendall & Terry, 2008; Lawton et al., 1991). Hence, current theories may not include important factors that mediate support people's health and well-being. Furthermore, a restrictive approach towards this topic brings up limitations. A critical examination of the main aspects of these models, appraisals, resources and outcomes is discussed below.

Focusing on cognitive appraisals or the interpretation of a stressful situation/event assumes that caring for another is only stressful, however this is not always the case (Beach, Schulz, Yee, & Jackson, 2000; Farran, 1997). For instance, the thought of a loved one in an institution could be more stressful for some support people and, as shown above, there can be many benefits to caring. It is also important to note that concentrating on how caregiving is interpreted (via coping) locates the mediator of stress, the resources, and the solutions to address health outcomes within the individual. This approach neglects: how others can influence the carer and their interpretation (i.e. social interactions); the concrete demands placed on support people by others, such as the health care system, to continue to fulfil this role; and the social norms surrounding caring. By emphasising individual reactions to stress, it also suggests that to address outcomes, intervention strategies need to be aimed at changing cognitive and

behavioural factors. Whilst changes at an individual level can be valuable, ultimately this approach negates formal support (Heaton, 1999).

This leads to the second concept within these models – resources. The stress-coping models conceptualised resources to deal with stressful situations/events as either internal or external (Lazarus & Folkman, 1984). However, exploration into coping primarily focused on internal resources in order to address demands. This focus discreetly assumes that support people can cope, that they possess certain coping strategies, and that they are aware of them; rather than viewing responses as something that develop over time and with experience. It also presumes that there are no limitations to internal resources (Farran, 1997). As noted above, it is too simplistic to categorise how support people cope in complex situations and relationships by: categorising coping into two main types (emotion-focused or problem-solving); taking for granted that one type of strategy can be used at a time; and thinking that what works in one situation is consistently effective in others (Kendall & Terry, 2008). While there have been some developments in the coping field (Folkman & Moskowitz, 2004), in the end this approach depersonalises the support person, the relationship they have with the person they care for and the environment in which they live. This approach also neglects support people's needs, simplifies what they do, and ultimately views them as a resource (Heaton, 1999).

Lastly, it is assumed that altering how support people cognitively cope with the caring role, will influence their health outcomes. Overall, evidence to date has indicated that there are associations, rather than causal relationships with some health outcomes (Lui et al., 2005). At the same time, outcomes measured have focused on burden and adaptation to the caring role. Thus, the well-being of the support person has been constructed as the absence of psychological distress or burden. However, well-being

and burden could be different constructs and require distinct measures (Schneider, Murray, Banerjee, & Mann, 1999). Equally important is that support people may appear to be coping with a caring role, but that does not necessarily mean that they are attending to their own health and well-being.

In addition to the above critique, many others have also criticised overall research in this area on the basis of small sample sizes, cross-sectional research, convenience samples, lack of clarity and definition of the study population, and limited theoretical foundations (Folkman & Moskowitz, 2004; Han & Haley, 1999; Kramer, 1997b). These criticisms need to be attended to in order for knowledge to advance about caring for another and the consequences that it can have.

Therefore, current attention has explored coping with the caring role, rather than how support people maintain their own health and wellness. One way to begin to strengthen knowledge in order to assist a support person's health and well-being is to investigate from their perspective how they sustain their own welfare.

Summary

It is clear from the above that health, caring and coping are entities which appear to be connected. To date psychological discourses, in particular, stress-coping theories have dominated research in this area. Consequently, many intervention strategies have focused on assisting support people, by teaching skills and reinterpreting stressful events, with mixed results. Whilst knowledge gained from concentrating at this individual layer has been extremely important, it has many limitations.

Chapter Three: Methodology and Methods

This chapter outlines the methodology and methods used to answer the research question: "How do spouses and partners of stroke survivors sustain their own health and wellness?" Following on from this, ethical considerations, issues of rigour, and an explanation of how data was collected and analysed are discussed.

Methodology

Given that the existing literature concentrates on identifying, measuring, and predicting the link between health outcomes for support people, I believed it would be valuable to specifically explore what spouses and partners of stroke survivors think and do about their own health and well-being. The current theories and research exploring this topic primarily investigates how spouses and partners appraise their coping ability with regards to the caring role (Farran, 1997; Folkman & Moskowitz, 2004; Lawton et al., 1991; Lazarus & Folkman, 1984), rather than, considering health behaviours and the meanings attached to them within a caring environment. In addition, research in this area has been predominantly quantitative. Humans are social beings and therefore meanings about health and wellness can be shaped by social influences (Crotty, 1998). For these reasons I decided on a qualitative approach to this topic.

Most qualitative methodologies are founded on a constructivist approach towards knowledge (Caelli, Ray, & Mill, 2003). Constructionism asserts that there are multiple 'truths' and knowledge is constructed from the interaction between humans and their social world (Caelli et al., 2003; Crotty, 1998). This study adopts one of the methodologies founded on constructionism; interpretivism. Interpretivism stems from

sociology and is often associated with Max Weber who was concerned with understanding or *Verstehen* (Crotty, 1998; Schwandt, 2000). Thus, interpretivism is concerned about how we construct meaning (Crotty, 1998; Grant & Giddings, 2002; Schwandt, 1994, 2000). Crotty describes an interpretivist approach as, "looking for culturally derived and historically situated interpretations of the social life-world" (p. 67). Thus to understand an action such as sustaining health and wellness, one must understand the meanings that have been ascribed to that action (Grant & Giddings, 2002). In order to do so, one must interpret the meaning of that action.

Recently, there has been movement within qualitative research from theoretically bound designs to the employment of atheoretical methodologies (Caelli et al., 2003; Grant & Giddings, 2002; Sandelowski, 2000; Thorne et al., 1997; Thorne et al., 2004). These research approaches have been referred to as generic qualitative research (Caelli et al., 2003). Whilst other qualitative methodologies, for example phenomenology, have established theoretical associations or draw from combinations of them, generic qualitative research does not outwardly have a theoretical home (Caelli et al., 2003). With generic qualitative research's blurring of methodologies, methods, and lack of theoretical alliances, the ability to judge the quality of a study becomes more challenging. This has led to more debate on how to critique qualitative research (Caelli et al., 2003; Carter & Little, 2007; Grant & Giddings, 2002). Generic qualitative research is at the centre of the debate. It has also been argued that researchers who use a generic approach do not state their philosophical foundations, such as objectivism, and apply methods in a variable manner (Caelli et al., 2003). However, some have argued that it is more important for the research question, methodology and methods to be congruent, rather than for the philosophical foundations to be identified (Caelli et al., 2003; Carter & Little, 2007; Grant & Giddings, 2002). In order to address these concerns, this study utilises one approach under the generic qualitative research:

interpretive description.

Interpretive description, as described by Thorne et al. (1997), has recently developed from the nursing profession and concentrates on understanding action. The aim of interpretive description is to discover themes or patterns and generate findings that can inform clinical understanding (Thorne et al., 1997; Thorne et al., 2004). These authors assert that reality is subjective, contextual, complex and constructed. But while there is complexity, at the same time there are shared understandings of the world. Thus, interpretive description acknowledges subjectivism and at the same time allows for shared experiences of a phenomenon. Thorne et al. (2004) state that philosophical underpinnings of interpretive description are the recognition that:

- Health and illness experiences are comprised of complex interactions between psychosocial and biological phenomena;

- The researcher and the participant influence one another;

- Theory must emerge from the data, rather than be imposed.

This positioning requires taking a holistic view of the phenomenon by exploring the exchange and influence of social, psychological and biological aspects of experiences. Furthermore, it recognises that 'a reality' is created as a result of the interaction between the researcher and the participant (Guba & Lincoln, 1994). Therefore, the act of engaging with each other influences the experience of the phenomena. In addition, no a priori theories could encompass the subjective and complex experiences and hence the findings must be grounded in the data (Thorne et al., 1997; Thorne et al., 2004).

It is the holistic perspective and pragmatic approach that attracted me to interpretive description. Other qualitative research approaches to answer my research question were also considered. For instance, a qualitative descriptive approach was explored. The aim of this methodology is to provide a descriptive summary of the data, yet its analytical process for me would not encourage conceptualisation or explanation of findings. The opportunity to conceptualise how themes could relate to each other could provide unique and meaningful ways of considering the phenomena (Thorne et al., 2004).

Another approach which was considered was social constructionism. Social constructionism takes a critical stance towards knowledge, explores how reality is constructed, and asserts that understandings of a phenomena are culturally and historically situated (Burr, 2003). Employing this methodology would have resulted in findings looking at the positioning through social discourses for spouses and partners. Although this knowledge would be valuable, I wanted to particularly focus on participants' thoughts and actions whilst also considering the influential interactions of their social environment. For these reasons, interpretive description was considered the most appropriate methodology for the question "How do spouses and partners sustain their own health and wellness while supporting a stroke survivor?"

Interpretive description is an emergent research design and consequently the method of collecting data was refined as directed by ongoing analysis (Thorne et al., 1997). The sampling and analytical techniques are outlined in detail below.

Methods

In qualitative research there are some strategies which are constantly used across the different methodologies (Mays & Pope, 1995). Interpretive description is no exception and utilises many of these well known strategies. The strategies described by Thorne et al., (1997; 2004) are derived from grounded theory methods. The rationale for sampling, participant selection, data collection and data analysis are discussed below.

Sampling

Since the intention of this study was to gain an understanding of how spouses and partners of stroke survivors sustain their health and wellness, purposive and theoretical sampling was deemed more appropriate than probability sampling. The objective of these sampling strategies is to obtain maximum variation in the experiences of the phenomena of interest (Patton, 2002; Ritchie, Lewis, & Elam, 2003; Sandelowski, 2000; Strauss & Corbin, 1998; Thorne et al., 1997; Thorne et al., 2004). Initially, purposive sampling was used to recruit the first six participants and based on pre-selected variables of interest (Ritchie et al., 2003; Trost, 1986). These variables were: length of time since stroke, gender, and ethnicity. Length of time since their partner's stroke was an area of interest because it enabled exploration of how spouses and partners sustain their health and well-being over time. As discussed in Chapter Two, the majority of research has focused on a relatively short timeframe after stroke. Thus, exploring what happens over a longer period of time could provide useful insights. As carergivers are predominantly female (Ministry of Social Development, 2007a), a mix of men and women in the sample would allow a variety of gendered perspectives on health and well-being. Lastly, the experience of ethnic minorities, such

as, Māori and Pacific decent was another area of interest. This is because these ethnic groups tend to: experience a higher incidence of stroke; be younger in age at the time of stroke; and have a higher chance of being dependent one year post-stroke (Baskett & McNaughton, 2003). Furthermore, the whānau and how it functions and provides support after a stroke is likely to be different compared to New Zealand European whānau (Barnes & Tunks, 1996; Collins & Hickey, 2006). Therefore, including participants from these ethnicities could provide unique insights into how health and well-being are sustained in these groups.

Ongoing analysis of the first six interviews informed subsequent recruitment strategies. Therefore, as categories and themes began to be identified from the data, the sampling strategy changed to theoretical sampling where participants were recruited based on certain criteria in order to test out the emerging findings (Strauss & Corbin, 1998; Thorne et al., 1997). Theoretical sampling led to recruitment based on length of the relationship between the stroke survivor and their partner. After the fifth interview and comparing it with the previous interviews, I realised that the length of the relationship played an important role with regards to spouses' and partners' well-being. At that point, four of the five participants had been in their relationships for a lengthy period of time (between 41-55 years). As a consequence, I then sought to recruit spouses or partners who had been in a relationship for less than 10 years. Unfortunately due to the constraints of this study being a Master's thesis, I was only able to additionally recruit one participant who had been in a relationship for a shorter period of time. While this participant had a very different experience from the rest of the sample, in relation to the research question, analysis revealed that her experience fitted in with the overall findings. Thus, recruitment ceased when the decision was made that interviews revealed no new sub-themes. This is known as data saturation (Caelli et al., 2003; Strauss & Corbin, 1998). Therefore, while participant seven had a different

experience from the rest, analysis of the transcript revealed that it did not yield new themes or sub-themes that contributed towards answering the research question.

Participant selection

To be eligible for this study participants had to: be the spouse or partner of a stroke survivor; support them for six months or longer; and preferably be able to communicate verbally in conversational English with the researcher. However, family or other supports were invited to assist with communication to enable the participation of those for whom English is a second language. The lack of funding for this study precluded the use of interpreters and travel beyond the wider Auckland area.

A total of seven participants were recruited from two community-based organisations. One was a community-based stroke service (Stroke Foundation of New Zealand), and the second was an outpatient rehabilitation organisation (Laura Fergusson Trust). Organisation representatives initially contacted potential participants based on the eligibility criteria. People interested in taking part consented to their details being passed on to me. I then made contact and gave further explanation of the study. Following on from this, the information sheet (Appendix A) and consent form (Appendix B) were sent out, which enabled participants to read through the information at their leisure. Written consent was obtained prior to the interview commencing. Of the people referred to me, only one person declined to take part due to personal reasons. A summary of participants' demographic information is listed in Table 1.

Table 1: Participant Demographics

Demographic variables	Results
Age (range)	35-84 years

Gender
    Female
    Male
	
	5
	2

Ethnicity
    NZ European
    Maori
    Other
	
	3
	1
	3

Time since stroke survivor's stroke (range)	1-13 years
Length of relationship with stroke survivor (range)	4-56 years

Living situation
    With stroke survivor only
    With stroke survivor and another
	
	4
	3

In addition to the above demographics, participants also reported any health conditions they experienced since their partner's stroke and the services they used on a regular basis. This information is outlined in Table 2. This data was collected in order to provide valuable contextual information in which to interpret the thoughts and actions of spouses' and partners'.

Table 2: Background Information

Pseudonym	Reported health conditions	Regular service use
John	Past history of hernia	18 hours of home help and caregiver support per week and 28 days of respite per year
Rosie	Within the first 2 years post stroke, experienced stress and lack of sleep	None
Lisa	Recently experienced "artery problems", osteoporosis, high blood pressure and high cholesterol	2 hours home help per week
Judie	Recently experienced sore shoulders	8 hours of home help and caregiver support per week
Bob	None	1-2 hours of home help for house cleaning once a fortnight
Rachel	Endometriosis	None
Patricia	High blood pressure, chilblains, asthma	Regularly attends a carers' group and receives support from community field officer

Data collection

With qualitative research there are a variety of ways to collect data. The traditional techniques include: interviewing, observing, analysing documentation, or various combinations of these techniques (Jones, 2002). Interviews were deemed the most appropriate way of gathering data for this study. In-depth interviews allow first-hand knowledge about what it is like to experience a particular phenomenon. Moreover, a semi-structured interview permits the researcher to probe participants and clarify their lived experiences as the interview and the analysis progresses (Holstein & Gubrium, 2002; Thorne et al., 1997).

Interviews took place from June 2007 to June 2008. Participants could choose the interview location. All but one preferred to be interviewed within their home. Prior to the interview commencing, the following issues were attended to: time was spent building rapport with the participant; any questions about the study were answered; participants were asked if they were happy for me to audiotape the interview; and written consent was obtained. Depending on how at ease the participant appeared at the beginning of the interview, it was determined whether the demographic information sheet (Appendix C) was completed at the beginning or end. For one participant who struggled to open up with the initial interview question, filling in the demographic questions served as another way to open up the discussion. All but one demographic information sheet was completed at the end of the interview.

As the interviews were semi-structured, questions were developed that sought to tap into the area of interest. The opening question participants were asked was, "What has it been like for you since the stroke?" This focused the interview on the topic of interest, but gave the participant scope to discuss his or her experience. The semi-

structured format allowed me to use the questions as a guideline and also to explore areas of interest as they arose (Appendix D). As categories and themes emerged, new questions were asked to explore these concepts (Legard, Keegan, & Ward, 2003). All participants chose to be interviewed without the stroke survivor being present and interviews lasted between 30 and 80 minutes. Every interview was recorded and transcribed verbatim by me.

Data analysis

In line with most qualitative methodologies, an inductive approach to analysis was used. Inductive analysis is where findings are generated from the data, rather than imposing pre-determined structure of analysis (Guba & Lincoln, 1988; Strauss & Corbin, 1998; Thorne et al., 1997). Thorne et al. (2004) state that interpretive description can draw on analytical techniques from other qualitative methodologies; however analysis is about "comprehending, synthesizing meanings, theorizing relationships, and recontextualising data into findings" (p. 11). This was achieved through several strategies. Initial analysis began by listening to and repeatedly reading the interviews which enabled me to become familiar with the data (Thorne et al., 1997). Whilst listening and reading each transcript, thoughts about participant experiences and their meanings were jotted down. Next, line by line analysis was used to generate the initial categories. Each transcript was examined in detail to identify concepts that related to sustaining health and well-being. A combination of writing on the transcript and entering data into a qualitative analysis software package, NVivo7 (QSR, 2006), assisted in managing and coding the interview transcripts. At this stage, labels were assigned to reflect the meaning of each category and sub-theme, for example, focus of attention. When it was appropriate in this study, participants' words that captured the categories or sub-themes were used as the label. This is called 'in vivo codes'(Strauss

& Corbin, 1998).

The next stage of the analysis included continually checking the developing coding of categories and sub-themes against new and previously collected interviews. This is known as constant comparison and the aim is to ensure that the categories and sub-themes can explain the differing experiences between interviews (Thorne et al., 1997; Thorne et al., 2004). At the same time, comparing, contrasting and grouping the categories to develop common sub-themes occurred. Linkages between the sub-themes and analysis of participants' experiences were used to elicit the central theme. With analysis, Thorne et al. (2004) advises against excessive micro analysis (word or phrases) and argues the importance of an iterative approach (micro to macro view) to analysis. This was primarily developed through the use of questioning and asking the data "what is happening here?" (Thorne et al., 1997; Thorne et al., 2004). As the analysis evolved and in line with the research question, other questions such as "what are spouses and partners doing?" assisted analysis. To support with this, thoughts about the analysis were documented, which is otherwise known as memoing (Thorne et al., 1997).

Lastly, preliminary findings were presented to the participants (member checking) to see if the findings reflected their experiences and knowledge about this area (Thorne et al., 2004). In addition, my primary supervisor checked the coding of a transcript, supervision meetings were regularly held to discuss analysis, and early findings were presented to colleagues with experience in rehabilitation research. These strategies contributed towards ensuring that the findings were reflective of experiences.

Ethical considerations

Research involving human subjects needs to ensure that fundamental ethical principles are adhered to. To ensure that these are met, researchers are required to submit the study protocol to an independent and specially appointed ethical review committee (World Medical Association, 2004). This study obtained ethical approval from a regional ethics committee in New Zealand, the Northern Y Regional Ethics Committee, and AUT University Ethics Committee (See Appendix E, F). The Declaration of Helsinki provided ethical guidance for this study (World Medical Association, 2004). Principles include: voluntary participation, informed consent, anonymity and confidentiality, and nonmaleficence. These areas are discussed in more detail.

Voluntary participation

Participation in this study was voluntary. To begin with, potential participants were able to choose if they wanted to take part without any direct contact from myself. All initial contact was made by a staff member of the recruiting organisations, and I had no influence over the decision as to who would be individually contacted. In addition, participants could withdraw from the study at any time. This right was made clear to the participant in the Information Sheet and again at the beginning of the interview.

Informed consent

When potential participants indicated that they would like to take part, their contact details were forwarded to me. Once contact details were obtained, I telephoned potential participants to see if they were still interested in hearing more about the study.

I provided further information about the study and answered any questions. Then an Information Sheet and Consent Form (Appendix A and B) were posted to participants. Any further questions about the study were answered before or if they arose during the interview. Written consent was obtained prior to the interview commencing. This process facilitated participants having multiple opportunities to find out about the study and allowing time to make an informed decision.

Confidentiality

To ensure confidentiality: all interviews were transcribed by me; participants' names were replaced with pseudonyms in the transcripts; any identifying features such as area of residence or partner's name was edited out of the transcripts; the original recordings were stored in a locked cabinet at AUT University and separated from the consent forms; and information stored on computers had password protection and therefore were only accessible to me.

Nonmaleficence

It was anticipated that this study would not be harmful for the participant. However, in the unlikely event that an interview caused distress, the participant could stop the interview at any time. They could also access support from two community agencies, or counselling services provided by AUT University. The contact details for these agencies were included in the Information Sheet. Furthermore, throughout the interviews I monitored participants' reactions to questions. At times, one participant became tearful, but when offered the opportunity to stop chose to continue with the interview. Whilst the interview occasionally brought up emotions, some participants stated that they found the interview therapeutic and were thankful for the opportunity to

discuss their lives. In addition, none to my knowledge sought counselling.

When designing this study, it was expected that the majority of participants would be living with the stroke survivor and their time would be filled with caring responsibilities. Given the sensitive nature of this topic and in order to facilitate participation in this study, I offered participants several options as to where they would like to hold the interview and I fitted in with their schedule. There were several occasions where I interviewed the participant while the stroke survivor was having a rest or was not at home.

Strategies for promoting rigour

Currently, there is still debate as to how to evaluate qualitative research, in particular for qualitative approaches that are not underpinned by established research methodologies (Caelli et al., 2003; Carter & Little, 2007; Sandelowski & Barroso, 2002; Thorne & Darbyshire, 2005; Thorne et al., 1997). Regardless of the research design, being able to judge a research study's level of quality is important in order to decide how much the findings are valid and applicable. In qualitative research, several approaches have been purposed in order to evaluate the rigour of a study. For this study I drew on two approaches and their strategies.   Whilst there is some overlap, each approach emphasises different aspects when evaluating qualitative research. The first approach takes a macro perspective and examines the overall consistency of the methodology and methods used to answer the research question.   This approach has been specifically developed for generic qualitative research studies that do not align with an established methodology. The second approach takes a micro perspective and examines how the research was implemented, with particular attention to the analytical process.

Caelli et al. (2003) recommend that for generic qualitative studies to be credible they must address four areas: the theoretical positioning of the researcher; the congruence between methodology and methods; the analytic lens; and the strategies to establish rigour. Firstly in Chapter One, I have addressed my theoretical positioning by: exploring what has led me to the area of research; explaining how I came to the research question; and making my preconceptions explicit about the topic. Secondly, the rationale for qualitative interpretive description and its methods have been discussed earlier in this chapter. Thirdly, to make it apparent how I engaged with the data, I documented my thoughts and ideas throughout the analysis (memoing). Lastly, other appropriate and established strategies to ensure rigour are discussed below.

Guba and Lincoln (1988) suggest there are four areas in which qualitative research can demonstrate trustworthiness. The areas are credibility, transferability, dependability and confirmability.

Credibility

The credibility of a study looks at the truth value of information. Credibility is ensured when the findings adequately reflect the multiple experiences of the participants (Guba & Lincoln, 1988; Koch, 2006; Krefting, 1991). The credibility of this study has been ensured through two ways. The first was the use of participants' words when appropriate to develop categories and themes labels (Strauss & Corbin, 1998). The second was checking with participants (member checking) during the evolving analysis to find out if categories and themes reflected their experiences (Koch, 2006; Mays & Pope, 1995, 2000). When preliminary analysis was consolidated, two participants were approached to discuss the findings. Overall, these participants thought that the themes and categories adequately represented their experiences.

Transferability

The generalisability of findings is different for qualitative research than compared to quantitative. How transferable a study's findings are based on the sample and context is an important consideration (Koch, 2006; Mays & Pope, 2000). In particular, inferential generalisation is the amount of congruence between the context of the conducted research, and the context to which the information is to be applied to (Lewis & Ritchie, 2003). Guba and Lincoln (1988) argue that for transferability to be met, adequate information about the participants and their context is required in order to be able to judge whether it fits a similar context. This study has provided demographic information about the participants (see Table 1 and Table 2), and where appropriate, other contextual information has been included in the findings.

Dependability

Another aspect of trustworthiness is consistency of the data. With qualitative research, variation of a phenomena or experience is actively sought (Mays & Pope, 1995; Ritchie et al., 2003). Therefore, data that was considered different from the usual experience was closely examined and explanations were provided as to why it was different. Furthermore, supervisor examination of the categories and sub-themes has been comprehensive in order to check the consistency of the findings. This process included; my supervisor examining the coding of one transcript, meeting regularly to discuss the interpretation of transcripts and the development of categories and sub-themes, and presenting preliminarily findings to colleagues.

Confirmability

For qualitative inquiry no researcher is considered completely objective, therefore neutrality of the data rather than researcher objectivity becomes an important aspect of trustworthiness (Grant & Giddings, 2002; Guba & Lincoln, 1988; Krefting, 1991; Mays & Pope, 2000). The principal strategy to establish confirmability is to ensure an audit trail is kept. This is to provide a link between the findings and the data so that any independent person can make conclusions about the data (Guba & Lincoln; Mays & Pope, 2000). An audit trail was employed through several strategies. These included: identifying my preconceptions and theoretical positioning; detailing the decisions made at each stage of the research process; keeping memos outlining thoughts about analysis; discussing the interpretation of the coding and the corresponding evidence from interviews; and my supervisor examining the interpretation of the findings.

Summary

This chapter has presented an overview of the research process used to answer the question "How do spouses and partners of stroke survivors sustain their own health and wellness?" The rationale for using an interpretive description approach and its theoretical assumptions has been explained. In addition, the methods used to collect, analyse, ensure ethical conduct and rigour have also been described and justified. The findings of this research will now be presented in Chapters Four and Five.

Chapter Four: Findings I

Findings show that the ways in which spouses and partners sustained their own health and wellness whilst caring for a stroke survivor were complex. Participant's thoughts, emotions and actions were embedded in values and beliefs about caring, and their relationship with the stroke survivor. In turn these were influenced by changing circumstances. Data analysis revealed one theme and three connected sub-themes running through partners' and spouses' experiences. The central theme, which I have called meeting needs, and the three sub-themes are: being in a relationship; living both lives; and uncertain health. The theme and each of the sub-themes did not occur in isolation; rather they overlapped, and at times were spoken of as occurring simultaneously. These findings show how spouses and partners found it difficult to think about and attend to their own health and well-being as they were busy meeting needs that stemmed from living both their own and the stroke survivor life. Their own well-being was connected to the stroke survivor because of their being in an intimate relationship. In addition, partners' and spouses' health was influenced by the stroke survivor's fluctuating health needs and uncertainties.

Participants did not use terminology such as 'stroke survivor' or 'care recipient'; rather, they generally used relational terms such as wife, husband or partner. In keeping with participants' terminology and for ease of reference within the findings, those who have experienced stroke will be referred to as the partner. Spouses and partners will be referred to as the participant.

Meeting Needs

After talking to participants about what it had been like for them since the stroke, these sub-themes were elicited from the data: being in a relationship; living both lives; and uncertain health. They described the complexity of supporting a partner after a stroke. Hence, each participant's health and wellness was influenced by and intertwined with supporting their partner's everyday needs; the relationship with them; and the changing nature of their own and their partner's health. While examining each of the sub-themes and how they related to each other, the central theme of meeting needs became evident. Needs are referred to as things that are necessary or required. This section will focus on the various aspects of balancing needs which are: whose needs; changing needs; and attending to needs. Lastly, meeting needs in relation to all three sub-themes and in particular, how it shaped their ability to think about or attend to their own well-being will be discussed.

Many participants found it difficult to talk about their own health and well-being, rather they consistently referred instead to their partner's health. In addition, all participants prioritised their partner's needs above their own at various times, and for some, it took great effort during the interview to consider their own. It seemed that often the participant's own health and well-being needs were silenced, forgotten, or put aside as it was the partner who had suffered ill health and lost the ability to meet his/her own needs. Partners were then seen as the 'victim', in a less able position, and thus 'needing' support. In Rosie's case, her own physical health needs, such as staying fit, were neglected because she had been busy supporting her partner's physical rehabilitation.

> *You know, and it's been hard work for him because he was never a physical person so, having to learn to walk.... and do the physical side of things. So he's*

got fitter and I've probably got more unfit.... So because I used to be a physical person, you know like gyms and that sort of thing and I just haven't done any of that since he's had a stroke, which is four years I suppose. (Rosie)

Additionally, even if participants had serious health issues of their own, some still considered themselves healthy when compared to their partner. Since they viewed themselves as 'healthier', participants did not 'need' to predominantly attend to their own health needs. For example:

Interviewer: And there's this tendency, where wives and husbands have tended to prioritise their partner's health over their own health. Do you think that applies to you?
Judie: Well not really 'cause touch wood, umm I don't get sick, I mean that's terrible to say but you know, I mean I may do, but I'm in pretty good health. I can't remember the last time I've seen the doctor, which is really bad I know. But because there's nothing wrong with me.

Judie considered herself in good health as she did not think she had any recent health needs which required medical attention. Yet, later in the interview she identified that she experienced aches and pains caused by lifting her partner. While her condition was not a disease or major injury, Judie had health needs of her own, but continued to carry on and not access health services such as physiotherapy.

Whilst the majority of participants focused on their partner's health and well-being and not their own, some did talk about meeting their own needs. Those participants who did, revealed that they would like to (or did) spend time doing things they enjoyed. Many of the activities participants identified were connected to other life roles that they fulfilled. For instance, Bob enjoyed spending time researching and reading for a group that he belonged to, which was similar to his job prior to retirement. Judie enjoyed spending time with grandchildren and catching up with family and friends. Whereas, Rosie identified she would like a hobby that she could feel inspired by and passionate about.

I think especially at my age I think I've got to find something that's got a deeper

thing for me... with a deeper meaning or something that's beautiful or something that I think. That's why I thought maybe because I've always quite liked that sort of simplicity but stunning Japanese art work and things like that or floral arrangements.... because I think ohh that's so beautiful you know and I love it. Its feeling that passion for something. (Rosie)

The perception of what was 'needed' varied over time and between participants. To illustrate: needs varied with the amount of thinking or doing required for the husband or wife; relationship needs changed through the interactions with the partner; and needs fluctuated if one of the couple's health changed.

You know I suppose the relationship is changing the whole time, nothing is static you always responding to different circumstances. (Bob)

Whilst Bob was referring to the relationship he has with his wife, this concept of reacting to changing needs applies to the three sub-themes. To respond to varying needs requires attention, which takes time and energy and it also has the potential to disrupt daily routine, which then may reduce the opportunities for small snatches of self-care.

All participants talked about them being the sole caregiver for meeting the majority of their partner's everyday needs. A few participants explained that while they had received support from their adult children, but this was limited because their children had other responsibilities to attend to:

Interviewer: I'm just thinking in terms of other support you can draw on around you like family or friends?
Bob: The daughter sort of phones us up and things. Probably ahh once a fortnight we go we go over and she gives a meal and she comes here with one or two of the family and I give the meal.... but I mean she's got a full-time job so she can't spend that much time.

And it was then that the hospital offered me help with caregivers.... and that was the first help that I'd had. I'd always managed by myself you see, up until then. They never had, nobody had offered me any assistance..... We think it was four or five years ago, we're trying to work out the date. But it was this time of year but it was about four or five years ago and then I'd got some help. But up until then it was only me and I was working..... But it was a long time before we got any you know anyone in that, so maybe, you know extra help when someone first has a stroke could go a long way to, especially with a very, very heavy person.
(Judie)

These quotes highlight how the absence or limited availability of other forms of support reinforced participants' responsibility to meet their partner's needs. In Bob's situation, while he thought he was able to manage meeting his partner's needs he explained how he did get some informal support from a family member. On the other hand, Judie talked about the absence of formal support even though she needed assistance to meet her partner's needs. Overall, participants were constantly meeting their and their partner's everyday requirements largely by themselves. While one or two participants voiced their frustration about their situation, on the whole, during the interviews most participants talked about meeting their partners' needs as a usual part of everyday life.

Being in a Relationship

The first sub-theme to emerge from the data was being in a relationship. This sub-theme refers to the personal relationship, the dynamics between the couple, and the impact the relationship had on participant's health and well-being. For many participants, the nature of being in a relationship was the main reason why they subordinated their own needs and well-being. The picture of two people holding hands signifies the bond between the couple, and the influence one person can have on the other. The two categories that formed this sub-theme are: joined at the hip, and the partners' response.

Joined at the Hip

Joined at the hip encompasses the history of sharing one's life with their partner for so long. The years of being together and knowing a partner appeared to fuse individuals within the couple physically, emotionally, and socially.

> *Mind you, we've been married for so long ... the doctor we used to have down at the hospital reckoned that we were joined at the hip [laughing]. That's what it is. (Judie)*

Judie and her husband had been married for 48 years and "joined at the hip" was an expression used to describe their relationship. For most of these participants, having a shared history and being together for many years created an emotional and almost physical bond. The participants spoke about companionship, a sense of duty, and a reciprocal giving and taking between each other. Many identified that the reason they put their partner's health and well-being above their own is because of the emotional connection, the history and the nature of their relationship (e.g. being married). This category is about what participants gain or lose from being in the relationship.

> *Interviewer: What else do you think has helped made your life a bit easier? Judie: Well the fact that he's still here [laughing] to be quite honest. I mean, you know, that he can still talk and do things; he's still there for company. The fact that he can't move around doesn't make any difference, and I think his brain works a lot better than he [laughing] thinks.*
>
> *He's an extension of my life. I mean its well over 35 years...... Well you know that's and [pause] it's the best part of my life. (Patricia)*

Although the stroke has changed the couple's life, losing their loved one would be an even greater loss. For Judie, regardless of her husband's physical abilities (he is wheelchair bound); having him alive and involved provides her with companionship. Furthermore, Patricia identified that her husband is and has been, a significant part of her life and thus losing him would be like losing a part of herself. Hence, not having their partner around was perceived to be very distressing and lonely.

Some saw that supporting their loved one after a stroke was an opportunity to give back love, care and attention to their partner. This also involved a sense of duty because of their long and close marital relationship.

> *[After lengthy discussions about how Bob did not get sick or tired]*
> *Interviewer: I'm trying to understand how you manage so well and what's your secret?*
> *Bob: Umm I would suggest that we've had a very close, happy marriage for 56 years and so the close bonding. Ruth looked after me for most of that time, exceptionally well and I'm just giving a little in return. Not of the same quality, I don't see it as an imposition....... I suppose basically ahh 56 years ago I promised to look after her, that's it.*

Bob attributed his well-being to the bond and positive relationship he had with his wife. He identified that for many years his wife had cared for him and that now he was returning the caring. Thus, he was reciprocating the support she had given him in the past. Entwined in this was Bob's commitment to his wife based on their wedding vows which included the promise to care for her regardless of the situation (i.e. in sickness and in health). As a result, the dedication to each other founded on marriage vows, the quality of the relationship, the length of time they had been together, and the experience of being cared for by the partner, caused some participants to see caring as an opportunity to give back.

The Partner's Response

What became evident in the data was the significance of the partner's responses both to the stroke and to the participant. This category encapsulates the husband's or wife's reactions to their situation, the participants, and the couple's familiarity with each other. Various reactions included: the emotions shared between the couple; the partner's attitude towards their own recovery; and appreciation of the participant.

Many participants talked about the shared emotions between themselves and their partner. Some identified that making their partner feel happy, in turn made them feel happy and how important it was to have a laugh together.

> *Bob: The greatest happiness comes from making other people happy..... So I'm very happy.*
> *Interviewer: I'm just thinking in terms of when your wife's happy, what does that give for you?*
> *Bob: Umm, yes I think that gives me a feeling of contentment............*
> *Interviewer: What ways do you get satisfaction?*
> *Bob: [long pause] I suppose it comes again back to sensing their well-being if they are content, if they are happy, if they're getting enjoyment that's where I get my satisfaction yes*
> *Interviewer: And how do you tell that they're-?*
> *Bob: 56 years ahh you're able to sense in advance what ahh the reaction you should get and if you didn't get that reaction then that would be a worry.*

For Bob, he experienced satisfaction from caring. Making his wife happy contributed to his own happiness and well-being. Not only did Bob react to his wife's emotions but he also anticipated what would elicit this reaction. Anticipating and being aware of what made his wife happy was based on years of experience and knowledge of each other. Bob highlighted that if he did not get the reaction that he anticipated, he would be concerned for his wife. As a result, not being able to positively influence his wife's mood would negatively affect him.

Rosie and Rachel highlighted how both their husbands' attitudes towards their own recovery or mood could influence them.

> *It's terribly hard you know. I keep saying to Richard, I'm so proud of you because you've done so well and you've come such a long way and I know it's been really hard for you. And it was hard and it was totally discouraging for him because he lost a lot of friends that he associated with.....So it was a huge adjustment for him and I think that somehow or other you seemed to end up taking it on board a bit...It's hard to separate it because I mean you feel so sorry for them. (Rosie)*

> *He started just to like just progress each day, and that I guess started to lift my spirits around things. And you begin to see there is going to be a light at the end of the tunnel. And because he's a, he's a real determined person, perseveres everything, he pushed himself so hard. And with that my respect and my love grew for him even more and I guess that's how we got through really.... so it's*

just umm his drive and perseverance, was like a real motivator for me. And that enabled me to be able to give I guess a lot more support back to him. (Rachel)

Rosie explained how the consequences of her partner's stroke brought about many changes for him to adapt to. Rosie's empathy to her partner's situation and emotions resulted in her sharing his emotions. These emotions were so entwined that she found it hard to separate her own mood from his. A reason why a partner's attitude and mood could be beneficial to the participant is illustrated by Rachel. Rachel's husband had hope and determination to overcome the consequences of the stroke. Watching him work towards recovery gave her hope and enabled her to continue to support him and strengthened their relationship.

The participants also benefited from the reactions of their partner in their everyday interactions. For many participants, words of encouragement, appreciation, signs of affection and emotional support from their partner were important. Rosie explained what it is like to no longer receive affection.

*It was just the little things, and I used to say to Richard well you don't even give me a hug anymore. You've got one good arm why can't you give me a hug.... You know it's, it's just those sort of stupid little things. I mean they're stupid to everybody else but they were just important to me. It was just that sort of contact, I certainly wasn't **demanding** [Rosie's emphasis] anything from him in any way. But just something to show that you do care, like I care and I've gone through all this and you're not showing any response I suppose and so that was my anger if you like. (Rosie)*

You must appreciate it is a two way thing. I mean she's wondering how she can make life easier for me and she's always saying "why don't you go out and do this or do that?" (Bob)

For Rosie, signs of affection were an indication of her partner's affection and appreciation for her. While these signs could appear insignificant to others and go unnoticed, they were important to Rosie. She needed to know that she was still valued and cared for in some way. Even though Rosie requested affection, it appeared that her partner did not respond to this even though he had the ability to. Interestingly, during

the interview, Rosie found it difficult to describe their relationship in terms of a partnership and likened it more to friendship. As a consequence, she was looking for activities outside the relationship to fulfil her emotional needs. Therefore, Rosie continued to meet and consider her partner's needs, even though she acknowledged that their relationship no longer met her emotional needs or was likely to meet her future needs. On the other hand, Bob explained that his wife thought about his welfare. This exposes the idea that not only participants themselves have the ability to support their own health and well-being, but also that the partner can contribute towards this. Thus, I suggest the ability of a partner to recognise or respond to their participant's needs could have serious affects on the relationship.

Overall, this sub-theme reveals from a participant's perspective, the importance of being in a relationship and the commitment to their partner.

Living Both Lives

Living both lives describes how participant's lives changed after a stroke in that they needed to do what their partner no longer could. The hand and footprint above symbolises one person living both lives: the partner's life (solid black print) and the participant's life (outlined print). Judie explains what it means by living both lives.

> *You really are living two lives I think.....What I mean is you have to do everything twice. You have to get up, you have to get him up, you have to have two showers, you have to clean your teeth twice, you have to get ready to go out twice, you have to decide if it's warm enough or cold enough for a jacket, if you need your sunglasses. You have to do everything in life twice, which really fills the day up pretty much. (Judie)*

This sub-theme reveals the enormity of thinking and doing for their loved one and the pressure that it can sometimes create. Living both lives takes time and energy. The participant's everyday life is filled up with meeting the fundamental needs of not only themselves but also their partner's needs. Depending on their partner's abilities, the needs ranged from hygiene and safety, to planning how the day was spent. The way in which Judie listed all the needs she met in a day indicated the persistent and repetitive nature of living for oneself and another. Judie was constantly doing things for and thinking about her partner, to the point where she took on ownership of his body. Also, the repeated phrase "you have to" signifies obligation for participants to focus on and meet their partner's needs. Therefore, this sub-theme exposes how the participant's time and energy was directed and the tendency to prioritise their partner's health and well-being above their own. To describe this in more depth, the categories focus of attention and being immersed are discussed.

Focus of Attention

This category relates to whom participants, partners, and health professionals, concentrated on and prioritised in everyday life: the person who had experienced the stroke. At times, this had important repercussions for participants in thinking about and attending to their own health and well-being. In the interviews, I found that when asked to speak about their needs, and how they cared for themselves, it took determined questioning for participants to talk and focus on themselves. They continually referred back to their partner's needs, desires and health journey. For example:

> [When her husband had the stroke] From then on it was all [him], he was the
> main [one], so your own life takes [a] back seat. Am I doing alright talking
> about him? Cause its more supposed to be about me, I've gone off the subject
> haven't I?.... Well with me I found that I put him first for everything and I didn't
> realise that. (Patricia)

> *But I just think that I've wrapped my whole [world] around, my world became his. Or his world became mine if you like.   (Rosie)*

As these excerpts, show Patricia and Rosie, like all the other participants in this study talked about how their focus changed after their loved one experienced a stroke. Not only did their focus shift to their partner but it dominated their whole attention. Furthermore, the change in focus encouraged participants to prioritise their husband or wife over themselves and put their own life in the background. For some participants, their lives became so intertwined with their partners that it took great effort to separate thinking about their own needs and interests from their partners. Interestingly, it wasn't until years after the stroke that Patricia and Rosie said that they became aware of how they needed to shift their attention away from their partner. For example, four years after her partner's stroke Rosie contemplated taking up a hobby, and Patricia wanted to get a higher education three years after her husbands' stroke.

Thus, as a consequence of focusing on their partner, participants tended to overlook themselves. However, when they were able to, or had an opportunity to focus on themselves, it allowed a break from their partner and an ability to think about and/or attend to their own needs. Whilst the focus on the partner and participant are discussed separately and as sub-categories, it is important to note that participant's attention shifted between them.

Focus on Partner

All participants spent time focusing on their husband or wife. This included: considering and finding out their needs; meeting their needs; and monitoring their partner's health and well-being. Judie's words convey the amount of consideration that

she had for her husband's everyday welfare.

> *You're trying to think what they want and what they would like. I know they can think for themselves but maybe you think too much for them. But you're trying to make life as comfortable for them as possible. What would you like to do?*
> *(Judie)*

The act of thinking and second guessing what another person would like occupies time and energy. Not only did participants spend time physically meeting their partner's needs, but they also used mental energy considering and monitoring their needs. Like Judie, many of the other participants expressed the desire to make life easier for their partner and frequently considered what their partners would like to do with their time. In the process of considering how to make life easier, I suggest, participants had less time and energy to consider how they could make life easier for themselves.

Focusing on and prioritising the partner over the participant was also partly reinforced by other people (i.e. family members, and health professionals). As this excerpt highlights, other people place the responsibility of the husband's or wife's health and recovery on the participant. This emphasis on the partner creates an environment and expectation for participants to concentrate on and attend to their partner's needs. For example, Julie when talking about her husband's recent health problems said:

> *You don't, you don't really realise I think for awhile that there's something wrong. Just that he's not moving very well and of course everyone says "ohh you've got to exercise [him] more, you've got to do all this because when he has a check up with the doctor everything is good".   (Judie)*

> *Interviewer: What health problems have you had?*
> *Lisa: Well I've had artery problems.*
> *Interviewer: Is this while Ken was sick?*
> *Lisa: Well it started out before his stroke and they'd started to investigate it...and then once he had his stroke I just put it aside.*

Lisa put her own serious health condition to one side in order to focus on her husband. The sudden nature of stroke was a life threatening experience and directed the focus of attention onto the partner. All but one participant continued to prioritise their partner's needs long after the stroke and sometimes at the expense of their own health and well-being. Lisa's quote reveals how she suspended her own serious health needs in order to attend to her husband's. Not only were participants' health needs placed second, but also their own basic needs:

> *You know if you make somebody else's lunch and a drink and then you're gonna do something else. You don't always remember that you haven't eaten. Silly things like that. (Judie)*

Like Lisa, Judie highlighted how her attention was focused on meeting her husband's basic needs. Given that her concentration was elsewhere, Judie often forgot about her own basic and fundamental needs such as eating, and even played down the importance of her own needs. Although missing a meal may not seem significant for one's health, the occurrence of this over prolonged periods could lead to much more serious problems (Ennis, Saffel-Shrier, & Verson, 2001).

Focus on Self

Several participants spoke about experiencing a shift in attention from their partner to include themselves. A few participants identified that they realised it became essential to focus on their own needs. This had happened several years after their partner's stroke had occurred. They talked about how they actively tried to think about and attend to their own health needs. To illustrate:

> *I mean you sort of get caught up in it [her partner's recovery].....And it's understandable. I'm certainly not sorry about that. It's just I think, that I just need to somewhere along the line, I've got to take ....better care of my own health. (Rosie)*

Whilst recalling the events since her partner's stroke, Rosie acknowledged that her life had been taken over with her partner's recovery and while she didn't regret coming second, four years after the stroke she allowed herself to think of her own needs. This highlighted a shift in focus from thinking about her partner's, to also thinking about herself.

In comparison, Rachel described her experience of setting boundaries right from the beginning of her husband having a stroke in order to cope with the situation. Her husband's confused cognitive state and his desire for her to be with him all the time during his hospital admission distressed Rachel and led to continual telephone calls while she was at work. After one of these calls Rachel explained:

> *My friend at work said to me "ohh you should go and see him", and I said "no, no he needs to learn that I can't always just drop everything to be at his side all the time". So I did the kinda 'tough love' thing, instead of the 'I need him to know that I'm really there for him'. Which was a bit horrible but I guess that, in some respects, that's the way you cope sometimes. (Rachel)*

Although there was a desire to be a supportive spouse, Rachel talked about her need to set limits around the amount of support she could provide in order for her to be able to attend to her own grief. It is important to note, that while Rachel's experience refers to the acute stages after a stroke which was not the primary interest of this study, however, during the interviews many participants talked about both their early and current experiences.

It is also notable that Rachel described this boundary setting as emotionally difficult for her and she felt awful about implementing it. The term "tough love" is usually referred to when being strict with a loved one to encourage them to solve their own problems (HarperCollins Publishers, 2003). Similarly, a few other participants talked about at times encouraging their partner to become less reliant on them, and thus increasing the partner's own responsibility to attend to their own needs. For example:

I just say "do it yourself", it's not a hard thing for him to do. Some things he can't do, that's understandable but other things he needs to try and do you know, and I'm just sort of been stepping back a bit slowly...to focus that [her partner's] independence more. I mean the rehabilitation programme is good because that gives them independence as well..... probably [the programme has] given me a window of opportunity ....that I sort of think, I have got two hours now that I can use, that is not surrounding what he's doing, you know what I mean? (Rosie)

In Rosie's case, not only did she herself try to encourage her partner to be more independent in meeting his own needs, but also at the time her partner was involved in rehabilitation programme which provided an opportunity for her to focus on herself. Other situations which created opportunities for participants to focus on themselves included: changes in the dependency of the stroke survivor through improved health; encouragement and support from family or health professionals to take time out; and participants establishing ways of taking time and space to enjoy their own interests, for example, reading a book while their partner was asleep.

However, some participants identified difficulties with focusing on themselves while supporting their husband or wife. One reason for this was the perception that attending to their own needs could be perceived as being "selfish" by other people.

Interviewer: You mentioned the hospital offered some counselling. What made you take that up?
Rachel: Because I was desperate to talk to someone. I just felt like I wasn't coping, I just wanted to get into a corner and not come out. I think she just let me cry and talk and say exactly what I wanted to say. Whereas I don't think I could actually say exactly how I felt to like anyone else around.
Interviewer: Why do you think that is?
Rachel: Because possibly what I was saying was selfish.... because you're talking about how you feel as opposed to ohh poor Tom type thing. You're saying ohh I feel so trapped, I'm such a wreck what am I'm going to do? So I couldn't say anything to Tom's parents. You definitely couldn't share anything like that with Tom at that stage because you were there to support him, you couldn't expect him to try and even think about trying to support me.

In the early days after the stroke, Rachel wanted to express her thoughts and emotions, but felt she could not confide in the people who usually supported her for fear

that she would be seen as "selfish" as there was an external expectation for her to focus on her sick husband. Despite the fact that Rachel felt that she could not initially cope with the consequences of stroke, to the point that she experienced anxiety attacks, she still continued to support him by visiting him in hospital and giving him encouragement. Through counselling Rachel was given the opportunity to vent her thoughts and emotions.

Another difficulty was that a few participants experienced guilt for focusing on themselves. They described feeling guilty or blaming themselves for not thinking about or attending to all their partner's needs. Patricia related an incident:

> *Patricia: And they [physiotherapist] said it might have been him just stepping off one of the machines you know the walker or whatever [during the physiotherapist appointment]. But see he's got one side of his body is weak. So from then on I don't know why it's just automatic, it was my fault in my mind. I felt guilty that I had not gone in.........*
> *Interviewer: Can I ask you why do you feel guilty though?*
> *Patricia: Well because I was out there reading the paper when I could have been in there looking after him.*

Patricia tried to implement a strategy in order to take some time away from her husband. This consisted of using the time while her husband attended a physiotherapy appointment to do something that she would like, such as read the newspaper. During one of these visits, her husband damaged his foot and Patricia blamed herself for not being by his side to monitor him and prevent the injury. It is important to highlight that Patricia felt responsible for monitoring his welfare, even though he was under the care of the physiotherapist. Therefore, this section shows that for the participants there was an expectation, perceived to be both internal and external, to focus on and prioritise the stroke survivor over the participant.

<u>Being Immersed</u>

In many different ways thinking and doing for one's partner can be consuming. For many participants, their daily lives were absorbed and engrossed in meeting their partner's needs. This included: when and which type of activities need to be completed; when or if participants had time for leisure activities; and the environments in which they could access or spend time in. As a result, being immersed in another person's life could impact on the participant's well-being. As John and Patricia revealed, their partners' needs dictated both their routines and what they did with their time.

> *A convict in jail [laughing] has more freedom and rights than I have. You understand they have got a time to get up, to breakfast, to go to work, to shower, when they want to... Any time I am preparing food, [hand thumping the table] I must leave the food and go and help her onto the commode because she cannot do it by herself.....you cannot do what you want when you want. You cannot shave when you want to shave [laughing], you cannot wash when you want, you cannot go and shower when you want, you cannot go to the toilet when you want. I must always tell her I'm going to do this now, this now, and this now. You got no real freedom, you feel like a wild animal in a, in a box. You've seen those in the zoo, the animal that walks up and down, up and down, up and down the fence all day...You get the feeling you're cornered. (John)*

> *Everything is just like, you're a zombie you know, you do things, you just do it because it's got to be done. Like somebody said "what do you do for time out, or what do you do for time out?" You don't do anything. I don't do any activities I used to do. (Patricia)*

It is interesting to note that John compared his situation to that of a prisoner, in that his everyday liberties and ability to self-determine were removed as he was confined to his home space. As a result, John experienced a lack of control or "freedom" in his own life. Therefore, his routines and own needs were subjugated. With subjugation, control is held by another, and in this instance the partner's needs determined the participant's everyday life activities. In Patricia's experience, she talked about going through the motions and doing activities that 'needed' to be done. Her everyday life revolved around her husband and she no longer took time or did very little

for her own leisure.

While John mostly identified that his life was consumed in meeting his wife's needs, there were brief moments when he felt free:

> *Interviewer: You say listening to the church [service] and flicking through the circulars, do you get any other time to yourself?*
> *John: Not really. I do the dishes, prepare the food, do the washing, put the washing on the line, take them off bring them in (laughing...) more or less go out to the letterbox to see if there's any letters in the post. Just to get a bit of walking..... There when you felt you are corned.....when the humour comes out that disappears, you come out of the cage for awhile [thumping hands on table].*
> <div align="right">*(John)*</div>

Other participants talked about enjoying spending time connecting with family and friends, and doing activities that they enjoyed which were primarily based within the home (e.g. reading a book). For these participants, experiencing brief moments of enjoyment and laughter, or focusing on other people's lives interrupted the immersed feeling of living both lives. However, many of these moments were short-lived, infrequent and mostly took place within the confines of their home.

One exception was Rachel. She seemed to be able to maintain her own everyday activities and thus not be so immersed in living both lives. It appeared this was because she continued to work (giving her time, space and a focus away from her partner); her husband was not reliant on her in meeting his basic fundamental needs (i.e. cooking, showering); and she still maintained an active social network. In contrast to the rest of the participants, this appeared to be because Rachel and her husband were younger, he was less physically impaired by the stroke, and they did not have the same financial options (i.e. superannuation) available to them.

When the stroke occurred, its sudden nature not only resulted in a dramatic shift of everyday routine, activities and thus becoming immersed in their partner's life, it also changed the environment in which couples could spend their time. Husbands and wives

who had limited physical ability to access other settings spent the majority of their time at home and as a consequence so did many participants. In addition to the lack of mobility, the level of effort required for participant's to move their partner outside the house and the bulk of their routine activities revolving around the house, appeared to contribute towards staying at home.

> *Yeah, yeah now it's hard for me. I've been used to being a farmer. My job was outside. I know how to cook and [how to] prepare food and things like that but [being] in[side the] house cleaning it is so irritating for me. (John)*
> *I mean I could see that it would be fairly easy if you had a life which involved being outside, going everywhere, travelling, and you were suddenly tied to basically one room, that could be a big strain [hands thumping]. But for me it isn't because I'm doing what I've always done in the sense. The only extra is the cooking which billions of people are involved in, that's no hardship. (Bob)*

As John and Bob identify, being restricted to the house, after being used to moving from one environment to another, may be a difficult adjustment for some to make. John highlighted how his occupation prior to the stroke was primarily outside the home environment. It is possible that John was accustomed to spending time outside as a farmer and found being inside confining. On the other hand, two female participants reported that they were able to adjust to this change in lifestyle even though they had given up work to care for their partner. Therefore, becoming immersed in another's life (or difficulty with) as a result of a partner's health condition may have the potential to impact on their well-being and influences participants' ability to attend to themselves.

Carrying On

Several participants talked about carrying on during difficult stages, but at times some found it difficult to convey how they did this. However, one way they appeared to continue on was to put one foot in front of the other, or get on with each day. Interestingly, participants talked about carrying on even though they were told to slow down or stop because of health concerns. The drive to keep going, regardless of one's

health, was in order to meet their partner's needs. For instance, for Lisa to have time to recuperate from an operation support was organised for family and respite services to care for her husband. However, Lisa's story reveals that taking a break or stopping is not straightforward. Even though her husband had had a previous positive experience with a local rest home, the length of this stay was cut short. As the interview progressed, Lisa identified that he did not enjoy staying at the rest home because there were staffing issues.

> *Lisa: It [respite] was just really upsetting. So I brought him home after a month. [We] just sort of muddle along here together....you get there.*
> *Interviewer: How was that for you?*
> *Lisa: Not too bad, I just sort of paced myself.*
> *Interviewer: How did you do that?*
> *Lisa: Well I either had to shut my eyes to things that I couldn't do and just take my time, yeah that was all.*

Despite being unwell, when Lisa saw her husband in distress she decided to withdraw him from the rest home and instead try to cope at home. Given that participants focused and prioritised their partners' needs, carrying on for many was the only option. For Lisa, she was able to continue on caring, even in poor health, by confining herself to what she could do and doing it at a slower rate. Other participants like Rosie also carried on, even when they needed to slow down or stop.

> *I was going through nights where I wasn't sleeping. I was tossing and turning and thinking about things and so it was lack of sleep. It was pressure and there was lack of sleep, there was lack of lots of things......... She [doctor] said to me I needed a break. She said to me "you need to take breaks". She said, "you can't do it 7 days a week, 24 hours a day". But there weren't really any options, so it didn't happen. (Rosie)*

Rosie talked about how at one stage supporting her partner had impacted on her ability to relax and sleep. Yet, when she was advised by her doctor to take a break from caring, she felt there were no viable alternatives to support her to take a break. As a consequence, the only option she saw was to keep going and attend to her partner's needs in spite of her own needs. It is important to note that, as shown by Rosie, at times

family and health professionals had encouraged the participants to do something about their health and well-being. However, many participants often chose to carry on.

In summary, many years after the stroke, most participants continued to focus on their partner and subordinate their own needs. At times, some realised a need to include a focus on themselves for their own health and well-being, but found it hard to put into practice. This highlights the tension in balancing both their own and their partner's welfare after a stroke.

Uncertain Health

When describing their experiences, many participants talked about their own and their partner's health and well-being in terms of high and low points, or "ups and downs". Their partner's improvement was a high point, and their deterioration a low point. The unpredictable aspect of health was at times like an emotional roller coaster and for many guided where their attention needed to be and why their partner's needs needed to be met. The incident of a stroke was considered a major low point and started a very different journey. For example Rosie said:

> So you go through this up and down sort of stage. I think, once they start getting, certainly not better but better than they were, a lot better than they were ...... But it probably took me a year to adjust to that and I went through my ups and downs..... So anyway now I'm settled if you like, I've gone through all the [referring to ups and downs], Richard's gone through all his ups and downs.
> (Rosie)

Like many of the other participants, Rosie described periods of instability, which for Rosie lasted for over a year. Whilst there were periods of highs and lows, Rosie also noted that there were "settled" periods.   These calm stages were evident when both the

partner's and the participant's health were stable. In conjunction with living their own

and their partners' lives, their partners' unstable level of health affected participant's

perceptions of their own well-being. Many participants position themselves by their

partner's side and therefore shared each other's ups and downs. In addition, this sub-

theme also encompasses the uncertain journey ahead for the couple.

Connectedness of Both Partners

Several participants described a connection between their own health and well-

being to their partner's. As their stories unfolded, many participants referred to

instances and events in the partner's health journey that influenced their own physical,

psychological, and emotional well-being. This emphasises the interconnectedness of

health status between the partner and participant. Rosie captures the essence of the

connectedness between both partners in the quote below:

> *I'm not sure who the victim is, you know it's totally different obviously but you*
> *still become a victim if you like. A victim of the person, you become a victim in*
> *a different way because you haven't had the stroke, but you become a victim to*
> *everything that's touched them.......Just in every way I think it affects you, so*
> *there's a big adjustment you go though and it's an emotional one.   (Rosie)*

Whilst the person who experienced the stroke is considered the "victim",

participants like Rosie spoke of themselves as victims too as their lives have also been

affected. Her partner's stroke changed her whole life and Rosie had to make significant

adjustments. In particular, Rosie highlighted the emotional turmoil she experienced.

Like a stone creating ripples in water, the consequences and adjustment to stroke also

reached into the participant's life.

Not only do the physical and cognitive consequences of a stroke extend to the

participant, but also the day to day changes in their partner's health can have a bearing

on participant's health and well-being. For example, Judie talked about how a change

in her husband's health impacted on her own physical well-being:

> *Because I mean the difference after the last two or three months is incredible, it really is. So if you'd asked me last October, November and I'd tell you I couldn't manage (laughing) because he was so heavy [husband Jeff was ill during this time]....... You know, if you're trying to pull somebody up, or trying to lift them you don't actually damage anything but you do ache a bit. [Jeff is now better] Now I don't ache, I'm feeling a lot better about it [laughing]. It is awful if you go around and your back always hurts, or your shoulder always hurts. (Judie)*

The first part of the excerpt reveals the recent improvement in Jeff's health. During a low phase, Judie described that changes in her husband's physical condition had a detrimental impact on her. During this time she felt she "couldn't manage" and experienced physical discomfort from assisting him. Even though these symptoms may not be obvious to others, Judie emphasised the significant impact of these symptoms on her well-being. By doing for her husband what he could not do, Judie physically struggled to meet both her husband's and her own needs. In contrast, when Jeff's health improved (a 'high' phase) and was more capable of moving around, Judie explained that her well-being improved.

Many participants saw themselves in a more fortunate health position than compared to their partner because they had not experienced a stroke, and/or their own health was not compromised, or did not fluctuate as much as their partner's. This perception contributed towards and provided another reason for focusing on their partner's needs, prioritising them, and subordinating their own health needs. Rosie explained:

> *But you know and he forgets what he was like and even last year compared to this year there's a difference, I see a difference in all sorts of little ways you know, but he doesn't see that cause it's such a slow progress. But I think he's done so well.... and it hasn't been easy for him by a long shot, so who am I to bleat, Natasha. I'm the lucky one really you know because I have got my health. (Rosie)*

In this excerpt, Rosie considered that she still experienced good health while her partner did not. However, as discussed in the previous sub-theme, continuing to support him had at times been at the detriment of her emotional and physical health. On the whole, participant's health and well-being did not occur in isolation from their partner and provided a reason for focusing on their partner's needs. While for many, their partner's health was relatively stable when interviewed, participants talked about past experiences and future health concerns.

Uncertain Future

In the early days after the stroke, there was much uncertainty for the participant as to whether his/her loved one would survive. The suddenness and severe consequences of the stroke jolted participants into an awareness of their partner's mortality. Three years after the stroke, the shock of potentially losing her husband still resonated with Patricia.

> *They just gave him no hope, and they said look he if he doesn't cough he's gonna die. And so we spent about three hours trying to get him to cough. Well they were just so matter of fact. The doctor said "look he's had a massive stroke there, we don't think he's going to make it" and they keep telling us this. I don't know if they were trying to prepare us.... Because he's been knocking on the door. Like when this happened .... it hit me, you know?[close to tears].*
>
> *(Patricia)*

In the acute stage health professionals communicated the seriousness of the situation and tried to "prepare" Patricia for the worst. Patricia responded by doing all that she could to ensure her husband's survival. As I have described elements of this behaviour still remain in the chronic stages of stroke, for example; by focusing their attention on their partner, attending to their partner's needs, and feeling responsible for their partner's health. For the majority of couples, while a significant amount of time had passed since the stroke, some continued to be concerned about the future of their

partner's and their own health.

> *So your fear is that we're coasting along quite nicely thank you very much but you don't want to lose them, I guess.   (Lisa)*

> *Patricia: But he's had the stent removed. He's got an operation coming up in the very near future, like in the next month for his rotator cuff....*
> *Interviewer: With all these operations*
> *Patricia: That's this year those ones*
> *Interviewer: Yeah, how's life been for you?*
> *Patricia: Ohh terrible, but that's what I mean, you learn to block it out....[when talking about her husband's operation] I mean he's so impulsive which he was recuperating and he goes out and slips over because he wanted to go for a walk in the rain, on crutches. And you think ohh what next! And then that's why he's having this [operation], it's just so many things that needn't happen. But because he's impulsive it's compounded the problem, something else. Like I just think what next, what next?*

The excerpts above illustrate how a few participants worried about the ongoing health of their partner and an uncertain future. Participants revealed this through different ways and depending on whether their partner's health was stable or fluctuating. Lisa was afraid that future ill health for her husband may result in death although his current health was stable. Whereas the ongoing health threats to Patricia's husband's health were so stressful for Patricia that she tried to block it out. Later in the interview Patricia revealed how her husband's impulsive behaviour, which was a consequence of the stroke, contributed towards further injuries and health uncertainty. In addition to this, some participants were also concerned about their own health and how it affected their ability to care. For some, fluctuating health and an inability to support their partner in the future created stress and worry. Judie explained:

> *I haven't used respite care because I'm keeping it there as my insurance policy. I mean you get two weeks a year. You can have respite care but I mean, the agreement we've always had is, cause if I did get sick, the children with grandchildren in no way could look after Jeff [husband]. So I mean that is there if I got ill and he knows he will have to go into respite care. I mean I'm scared of twisting an ankle or hurting, you know breaking something. So I wear track shoes all the time [laughing], not very glamorous but they're quite steady if you're walking. (Judie)*

Thirteen years after the stroke, Judie identified that she had been purposefully saving her respite allocation in case she ever got sick and could not care for her husband. However, in New Zealand if the allocated respite is not used then it does not get accumulated. In addition, not using the yearly allowance of respite can be detrimental for participants as service providers equate not utilising respite, to respite not being needed (L. Hilsgen, personal communication, December 16, 2007). In addition, Judie and her husband had discussed and planned for future uncertainty as there was limited family support that could be provided, if or when the need arose. Although this couple had a plan, Judie still worried about having to use respite services and as a consequence, she did what she could with everyday tasks to minimise the risk of injury (i.e. wearing track shoes). Despite having family, Judie also drew attention to the limitations of family support as she felt that their children could not fully take on the caring role as they had their own responsibilities to attend to. Bob commented:

> *Bob: Obviously there are problems ahead if I get ill or something of that sort …. I think to have no backup, family backup would be quite stressful. It would sort of be a black hole you wouldn't know what happens the other side.*
> *Interviewer: Knowing you have family support, what does that mean for you?*
> *Bob: Umm [long pause] I think it means that you needn't worry that ahh if I get ill the family will take over in some form or other. Depending upon the exact circumstances… So in other words it's not a background worry.*

Like Judie, Bob also had a "backup" plan in case he was ever sick. However, for Bob, the family would be the ones who would make decisions and be responsible for ensuring his wife was cared for. Bob emphasised how stressful the unknown can be, and that having support, if needed, reduced this concern. Thus, some participants made future plans in case they ever got sick, which in turn alleviated some of their stress and concerns about an uncertain future.

Summary

To summarise, many participants found it difficult to talk about and focus on themselves. Analysis revealed that their health and wellness was enmeshed in what was going on around them and their relationship with their partner. The reason for attending to their partner needs and neglecting their own needs was because of the relationship with their partner, and the unpredictable nature of their partner's health.

The following chapter will discuss how participants met their own needs. Specifically, it will explore participants' experiences of meeting needs which were shaped by the three sub-themes. In addition, the ways in which participants managed to meet their own needs within this context will also be outlined.

Chapter Five: Findings II

In the previous chapter, I have shown that for the participants, attending to their partner was at the forefront of their minds; but how they sustained themselves was embedded in everyday life. Considering that there was a sense of responsibility for participants to care for their partner, how demanding and consuming the role of caring had the potential to be, and bearing in mind that there was uncertainty about their own or their partners' health, I believe that the participants did well to attend to their own needs with the opportunities they had. The first section of this chapter brings together how participants attended to meeting needs in relation to their own wellness. The second section focuses on the strategies that participants used to support their own wellness.

Overall, participants tried to meet all the needs that stemmed from the three contextual factors discussed in Chapter Four. I have represented them graphically in Figure 1. The hands symbolise the participant's reaction in attending to needs. The balls signify the participants own needs and those of their partner. Juggling these needs occurs within and is shaped by the circumstances of being in a relationship, living both lives and uncertain health.

While all the needs of the participant and the partner, and the sub-themes appear equal in size in Figure 1, over time one or more of these has the potential to dominate. To illustrate, when their partner first had their stroke, many participants spent time dealing with uncertainty and ensuring their partner's basic needs were met. It is important to note, that the times of stress for participants appeared to occur when one or more of these were out of balance.

Figure 1: Meeting Needs
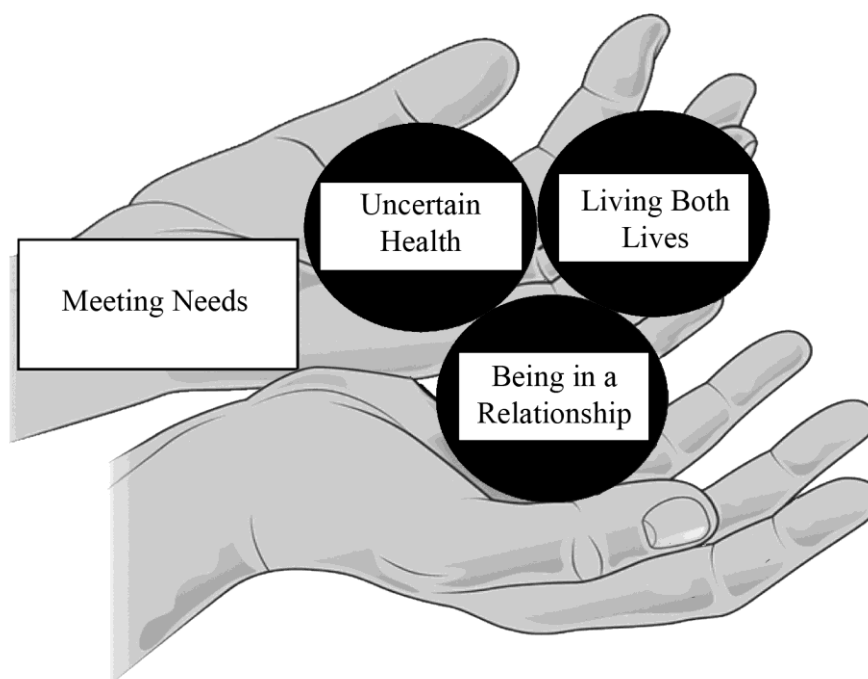
At the time of the interview, John found caring for his wife quite stressful as he was unable to freely attend to his own needs, which was signified by his analogy in Chapter Four of feeling "caged". Although he had been caring for his wife for four years, John had expressed how he was not used to being housebound and thus struggled to meet the demands of living both lives. He had very little opportunity to focus on himself or relax. In Rosie's experience, her life became particularly stressful when she was frustrated with the situation and her need for affection in the relationship was not being addressed. As illustrated in Chapter Four, Rosie waited until her partner's health was stable before she was then able to attend to her own emotional needs.

In the beginning when the stroke occurred, the dramatic change in health was stressful for all participants. In Chapter Four, Lisa talked about how hard it had been for her.   It appeared this was because both her and her husband's health had been so changeable and unstable over the years.   At one stage when they were both in a 'low' phase with their health, Lisa struggled even to attend to her own health needs, let alone

those of her husband. Thirteen years after the stroke, Judie's life appeared to be relatively balanced. However, when her husband experienced periods of ill health, she struggled to meet the physical demands of looking after her husband. Judie identified that when her husband's health was compromised, her well-being was also impacted on.

A year after the stroke, Bob appeared to be able to meet his wife's and his own needs although he attended to her everyday personal needs. He identified that his commitment to his wife and her happiness contributed to his well-being. As a result, he expressed concern about the future and being able to continue to meet his wife's needs.

Rachel's experience was very different from the others in that she and her husband were in their early thirties when her husband's stroke occurred. Therefore, they were very young compared to the rest of the participants and retirement was not an option, as it had been for other couples who were older. Furthermore, her partner had made a significant physically recovery and was relatively independent. As a result, he was able to contribute towards the running of the household and to support Rachel when she was ill. Three years after the stroke, it seemed Rachel was able to balance her own and her husband's needs as there were fewer caring demands. However, Rachel lived both lives to an extent in that she was the sole income earner for the couple, and thus met financial needs rather than physical needs. In addition, she identified that the first few months after the stroke were extremely difficult for her, especially when trying to meet her own emotional needs whilst still supporting her partner.

In contrast, Patricia who identified as Maori, talked about struggling to attend to her own needs. Since the stroke, Patricia's life became devoted to attending to her husband's needs, rather than her whānau members. This change in whose needs she attended to had created some tension within her whānau. During the interview, Patricia also talked about her husband's ongoing health issues which continued to be a source of

stress and worry for her. His uncertain health was the catalyst for thinking and planning about how she would financially manage in the future.

To summarise, the theme of meeting needs explains what participants did, where their energy was directed and how the three sub-themes are connected. It also depicts why these participants tended to overlook their own health and well-being.

Ways of Meeting One's Own Needs

While managing to address their partner's needs as well as their own, some participants demonstrated that they were active and skilful in the way in which they meet these needs. Even though these participants mainly focused on their partner's needs, some managed to attend to their well-being by taking small snatches when they could. A few participants talked about trying to find different solutions in order to respond to their own needs and to create a sense of balance in their lives. For two participants, Judie and Rachel, the ways in which they met their own needs had adapted over time and was embedded in everyday routine. The major strategies which participants utilised to support their own well-being were: creating time and space; talking with others; and comparing own lives against others.

Creating Time and Space

Since most of their time was spent caring for their husband or wife all day, every day, and within the home; many developed and established ways to take time and space for themselves. Judie explained a novel way of creating space for herself.

Judie: Now this bell is the bane of my life, I swear sometimes but it means that I can watch television or sit and talk to somebody with the door closed you see.... Well you see if I, if he wanted me I mean I can put the television on if I wanted to see a cooking programme or something in the afternoon....I can sit out here, put the television on, he can't hear me but I can hear the bell [laughing]. I just, I just thought it was a good idea, I don't know.
Interviewer: You've tuned your ears into it?
Judie: Yeah, ohh probably I have, yes [laughing]. But it is quite good because I mean if he needs me. Everybody's so used to it around here [laughing] of course, nobody, nobody thinks about it.... But if I want to, we've got a rumpus downstairs, if I want to go and do the washing or go downstairs or want to do anything and he does need something, I can hear the bell... I mean if you do know somebody [will] come and visit like you do and he's asleep, I don't have to go and see if he's okay or check if he wants me, he'll do that. I think we used to use telephones at one stage but it [bell] was easier.

As Judie's husband was unable to call out to her, they had developed a system which enabled her husband to signal her when he needed her. Judie had tuned her ears to the bell's ring and was vigilant in listening out for this sound. Despite the bell being a bane, it was also a boon. It allowed her to have privacy, time to herself, and the freedom to do what she wanted within the home, whilst still being able to attend to her husband's needs. In addition, this system of communication reduced the amount of energy that Judie spent monitoring his needs and her husband was able to signal to her when he actually needed her.

Bob: I'm doing what I've always done in the sense of..... I mean I used to work in the University, now I work up there you know [pointing to a study upstairs]. It's my little University room there.
Interviewer: And when you say it's a break, how do you mean it's a break?
Bob: Ahh well it's a totally different mental task from cleaning the house and cooking, I go up there and I'm reading... and it's a total break.

Like Judie, Bob was able to create space and time to engage in activities he enjoyed on a regular basis. Shifting his attention from household chores to intellectual tasks enabled him to feel like he had a rest from care-related activities.

On the other hand, Rosie used various strategies to create time and space when she experienced difficult times, rather than on a daily basis. Approximately a year after the stroke, Rosie described going through a difficult time of being angry with her partner. Even though she said she was unsure about what to do, Rosie explored several different options before finding one that helped her.

> *Interviewer: What do you think helped you to get through it?*
> *Rosie: Meditation [pause], amazingly enough. Umm I wasn't sure what to do and I'd read a book on meditation. So I went and took lessons in the morning. Six o'clock in the morning I went and did lessons on meditation.... And the guy that was running it he was a nice guy and.... he knew about Richard, well I told him and he said to me to meditate at night. Cause what it is, is you just take everything off your mind.... and he said to me I need you to do it for at least forty minutes and to do it first thing in the morning before I got up. So I did that, and I could feel like because you're actually aware of your body if you like. When you shut your mind out like and that's probably what I needed because my mind was wearing around and emotions were up and down.... He said to me just become aware of your body and I could feel like all this pressure, if you like all the blood running out of my brain and down my face and my nerves would and I thought ohh my god I really was wired to the wall if you like.....So through that I just calmed down.*
> *Interviewer: That helped you?*
> *Rosie: Yeah, well I put it down to that and I think because it calmed, because you go into that state of not thinking about anything and maybe in a way and they also teach you that even if you're angry with someone you put your love out to that person, and that sort of thing. So by doing that I probably just went through that accepting stage.*

Through meditation, Rosie became aware of the emotional turmoil she experienced as a result of the demands of supporting her partner. It had taken time and effort to find a suitable strategy to deal with her distress. Rosie had realised that she needed to attend to her own emotional needs and had found that meditation was a means of addressing them. She consequently made the time to ensure that she put it into practice. For instance, she created time by meditating early in the morning and late at night when her partner was asleep. It is important to note that this strategy did not intrude into her role or tasks when caring for her partner. The act of meditating also created the space for Rosie to concentrate on her own body and emotions. As a result, she felt that she was able to relax and transform her negative feelings into more positive

ones.

In the midst of the needs he had to meet, John found another way of creating time and space for himself.

> *Interviewer: Do you get any other time to yourself?*
> *John: Not really. I do the dishes, prepare the food, do the washing, put the washing on the line, take them off, and bring them in.*
> *Interviewer: Man you're a busy person*
> *John: More or less go out to the letterbox to see if there's any letters in the post, just to get a bit of a walk.*

However, in John's case fitting in time for himself was restricted to going to the letterbox or reading junk mail. Like many of the other participants, John had limited opportunities and strategies to take time or make space for himself and found small ways and snatched opportunities of time when he could do this.

Talking with Others

Another strategy that appeared significant for several participants was talking with other people. Friends and family were identified as being important people to talk to. This strategy appeared to support their well-being in two different ways. Firstly, in particular, female participants identified the importance of sharing their thoughts and feelings with other people:

> *I just went through all this emotional sort of [stage]. I was really lucky I had good friends... and girlfriends they came and talked to me. I mean nobody ever tried to solve it. It was just getting it off your chest to somebody really.*
> <div align="right">*(Rosie)*</div>

> *Interviewer: You mentioned that the hospital offered some counselling?*
> *Rachel: Yeah, the social worker*
> *Interviewer: What made you take that up?*
> *Rachel: Because I was desperate to talk to someone....I think she just let me cry and talk and say exactly what I wanted to say. Whereas I don't think I could actually say exactly how I felt to like anyone else around.*

When Rosie experienced a difficult emotional time, she was able to confide in friends. By sharing her thoughts and feelings with others, it gave her the space and opportunity to talk about her situation. For Rachel, she needed to talk to someone, but as discussed earlier was worried that the thoughts and emotions she wanted to share would be criticised by others. Several participants emphasised the significance of being able to share with someone they could trust and who would not criticise them. Therefore, Rachel's emotional need to vent her distress remained unmet until an opportunity was provided by hospital staff. Interestingly, even though Rachel had a supportive network to talk to, she did not consider them appropriate to talk to during this difficult time.

A few participants also described how conversing with friends and family was an enjoyable activity. Judie identified how talking with others keeps her cheerful.

> *Yeah well I get, I get phone calls from my girlfriend we can talk for a long time..... And I ring my son and his family on Friday nights, not all the time but every few weeks and I stick on the phone there for a long time too [laughing]...because we want to know everything they're doing and they want to tell us and ... it doesn't cost very much....Yeah because when your friends are moving, over the place, e-mail and the phone is really a great way to keep in touch cause we all still want to know who's doing what....and how the kids are going and how the grandkids are going and all growing up.* (Judie)

Since the majority of Judie's friends and family have moved away, and as she is unable to easily leave her husband alone and therefore leave their house, keeping in touch by phone is the main way she connects with the important people in her life. For Judie, this is the most effective and inexpensive way of maintaining these relationships and prevents her from becoming socially isolated. By phoning on a regular basis, Judie is able to keep up with what is happening and the changes in other people's lives. I also suggest that keeping in contact with what was happening in other's lives requires a shift in the participant's focus, which is neither on their partner or themselves. Thus, talking to and focusing on others about their lives enabled a 'break' away from thinking about

and doing for their partner.

It is important to highlight, that the first two strategies were used when they were not required to meet their partner's needs. Therefore, participant's took what little available time and space they could in-between caring for their partner.

Comparing Own Lives Against Others

At various stages following the stroke, some participants spoke about how they compared their own situation to that of other people. Comparing one's life with another was not an obvious strategy that a lot of participants identified using. Yet, for those who did they choose whom, and when they compared themselves against others. Overall, participants mainly evaluated themselves against people in worse situations as this allowed them to appreciate their own circumstances. Rosie and Bob illustrate this below:

> *Interviewer: How did you get into meditation? Like what prompted you to go?*
> *Rosie: I'd read some books and umm I read a book on this lady and I mean she'd ...I was sort of going through that stage of reading books of ladies, ohh people that had life experiences or things like that. And I basically did that to remind myself that mine's not too bad, people out there far worse off than you ever are and what they're living with you know. And I sort of did that to sort of remind myself that you know, what have I got to bleat about or you know be sorry for and things like that.*

> *Interviewer: I was wondering how's it been for you since the stroke?*
> *Bob: in the simplest terms busy, but I think we've managed it fairly well so far. I mean compared with the problems other people have its very, very simple really...And if you take role, sort of similar situation of families with handicap children, that I think is a whole step further in problems, I'm just caring for one person. (Bob)*

Rosie identified that when she was going through a low period, she actively sought comfort, through reading about other women's life experiences and comparing her life against theirs. Making comparisons may influence participants' well-being in several different ways. Firstly, seeking someone's life to compare against allows

identification and evaluation of other lives. For instance, Rosie chose women who had experienced traumatic life events and Bob chose other carers. This act of evaluating others people's lives can create a sense of reassurance in that one is not entirely alone with their experience, that their situation was not as bad as others and encourages a change in focus of attention. Consequently, participants were able to briefly focus on other people's lives, rather than themselves and their partner.

Secondly, contrasting one's own life to those less fortunate seemed to highlight the positive aspects of the situation, helping participants to accept the current situation. On the other hand, the distress that participants, like Rosie, experience can be put aside when one compares their own life against others. However, accepting the current situation may temporarily mediate participants' distress until they are in a position to address their concerns.

Making comparisons against those in worse situations was not used by all participants. One participant compared her situation with people whom she thought were better off.

> *'Cause I hadn't had that before [referring to anxiety attacks] .....A couple of days later she [a friend] managed to get me outside to go to the supermarket, I couldn't face going anywhere. And even like you walk into the hospital and you'd see all these people, and it sounds really horrible, I'd see people crying and I'd think what are you crying about, at least you can walk [slight laugh].... so I hated everybody around me, cause it was just so unfair.* (Rachel)

In the early days after the stroke, Rachel experienced emotional turmoil such as anxiety attacks, and she struggled to leave the house and be around people. As Rachel's experience highlighted, evaluating her life against those who had the abilities that her partner did not, reinforced what had been lost. Comparing herself to those more fortunate allowed Rachel an opportunity to acknowledge her loss and anger that resulted from the stroke. While this strategy was utilised during the acute stages of stroke by

Rachel, using this strategy in the chronic stages may also be of benefit as it could facilitate participants to express their emotions (Folkman & Moskowitz, 2004).

Overall, most participants compared their own lives with others in a way that appeared to support their well-being. Actively contrasting their own circumstances with others less fortunate, supported participants to accept their current situation, as opposed to comparing against those more fortunate, this in turn assisted the grief process.

Summary

To conclude, this chapter has drawn together the contextual factors and identified the strategies that emerged from the data when implementing an interpretive description approach. The findings have demonstrated that participants were constantly primarily meeting the needs of their partner and consequently had very limited opportunity, which fitted around their caregiving time and space, to attend to their own health and well-being. Even though these participants mainly focused on their partner's needs, some managed to attend to their well-being using various strategies. Creating time and space; talking with others; and comparing own lives against others were three small ways which participants sustained their own health and well-being. The following chapter investigates the central theme, sub-themes and strategies within the context of current literature, and the strengths and limitations of this study are explored.

Chapter Six: Discussion

The aim of this study has been to explore how spouses and partners sustain their own health and well-being while supporting a stroke survivor. The phenomenon has shown to be complex and dynamic. Findings suggest that the three sub-themes; being in a relationship, living both lives and uncertain health, shaped and were connected by the theme of meeting needs. Since participants felt commitment to their relationship with their partner, were busy thinking about and doing so much for their partner, and were concerned about their partner's fluctuating health, many participants focused on their partners needs. As a consequence of focusing on their partner, participants took snatches of time and space which were bounded by and embedded in everyday routine to attend to their own health and well-being.

This chapter considers the findings in relation to current literature and discusses the implications of the study. Firstly, the findings are considered in relation to existing literature by exploring the similarities and differences. Secondly, the strengths and weakness of the study are considered. The section concludes with the implications of the study for policy makers, service providers and health professionals, and suggests recommendations for future research.

Meeting Needs

The overall theme of meeting needs describes how most participants were busy meeting the stroke survivor's needs and therefore spoke more about this than how they sustained their own health and well-being. This notion is evident within recent research and the discussion pertaining to societal factors which have influenced whose needs should be met has been mentioned in the Chapter Two (Chattoo & Ahmad, 2008;

McKevitt, Redfern, Mold, & Wolfe, 2004).

This study found that many participants saw caregiving as part of their role of being a partner, and in keeping with their marriage vows to look after their husband/wife in sickness and in health. Thus, the nature of the relationship and moral obligations connected with this type of relationship contributed towards calling spouses and partners to become the primary caregivers and fulfil all the stroke survivor's needs. Whilst it appeared that meeting the stroke survivor's needs could contribute positively to the participants well-being, at times it appeared to detrimental. I define successfully meeting needs as when the demands of caring is not to the detriment of spouses' and partners' health and wellness. Embedded within the literature are some findings which relate to support people balancing multiple needs (Pierce et al., 2007; Silva-Smith, 2007). For instance, Pierce et al., (2007) when using a systems framework to identify the problems and successes of caring within a year after a stroke, found that meeting and balancing needs contributed towards problems and successes. Carers struggled with changes and looked for maintaining a sense of normality in caring. But carers also found that success came out of reaching a new sense of normal and finding balance in life. In addition, Silva-Smith (2007) found that during the acute stage after a stroke, family members reported that they had to restructure their lives and manage multiple roles, priorities, demands and added responsibilities. Several years after the stroke had occurred, many of Silva-Smith's participants were still trying to meet different demands from changing circumstances, and some were trying to finds ways to meet their own needs and the needs of caring.

What is not evident in the literature, but was found in this study, was the extraordinary level of energy that went into monitoring and thinking about the stroke survivor in addition to undertaking tasks. As identified in Chapter Four, participants'

everyday activities were focused around meeting the stroke survivors' needs. There is some evidence in the literature to suggest that spouses and partners assist with more caregiving activities than non-spouses (Finlayson & Cho, 2008). The current categorisation of caregiving tasks, such as activities of daily living, conceals the extent and scope of energy that spouses and partners employ in carrying out such tasks. Similar to that of other informal stroke carers, such as daughters, sons and other family members (Pierce et al., 2007; Silva-Smith, 2007), participants in this study had to also juggle meeting their own and the stroke survivor's needs.

Furthermore, as discussed in Chapter Four several participants in this study described having limited support (formal or informal) or resources to assist them in attending to the stroke survivor's needs. Many spouses and partners did not want to rely on other family members as they were considered to have their own responsibilities and lives. As I argued in Chapter Two, government policies and health services assume that there is informal support to draw on (Heaton, 1999). However, the decline of extended families, reliance on women in paid employment, and the encouragement of individualism (Fine, 2005; Heaton, 1999; Winch, 2006) could create disparity between what is needed and what resources are available to meet these needs.

Being in a Relationship

As identified and discussed in Chapter Four being in a relationship was for many participants the reason why they attended to their partner's needs and deferred or ignored their own needs. Their commitment was based on the history and the intimate nature of their relationship. The knowledge that other people can be influential on spouses' or partners' well-being is not new. In particular, some research has concentrated on whether there is a connection between the nature of the relationship in

adapting to the caring role and consequently on a support person's well-being (Farran et al., 1991; Lawton et al., 1991; Noonan et al., 1996; Sawatzky & Fowler-Kerry, 2003; Schulz et al., 1988; Silva-Smith, 2007). While there is acknowledgment that the personal relationship can contribute towards the well-being of the person who provides support (Lawton et al., 1991; Pearlin et al., 1990), the relationship has been conceptualised as a background influence, whereas the caregiving role is in the foreground. Although there is some merit to this, as discussed in Chapter Four, many participants in this study described it differently – their life partner's well-being and existence was important to their own well-being. As a result, caring was perceived to be a part of the role of being a spouse/partner. This highlights how the spousal relationship is unique. Through a shared history, commitment to each other through marriage vows, intimate knowledge of each other, and emotional connection, it became apparent how the relationship could contribute to a spouse's or partner's well-being.

One explanation which has been put forward is that caring for a partner is bound up in expectations about kinship ties and marital obligations (Lawton et al., 1991; McKevitt et al., 2004). In this study, there was support for this notion of relational obligation, yet it appeared that much more was occurring within the relationships. From the findings it is also interesting to note the significance of the partner's responses and the impact they had on the some participants. This has been alluded to previously in the literature but has been framed in terms of the caregiving role (e.g. stress related to care recipient's behaviour), rather than framed from a relational aspect (e.g. seeing a loved one in distress). For instance, Kinney et al., (1995) explored support people's well-being in terms of the hassles and uplifts of caring for a stroke survivor, and found that the most frequent reported uplifts were related to positive interactions with the stroke survivor (e.g. seeing the care-recipient calm). In addition, a stroke survivors' affect is thought to contribute towards caregiver adjustment and stress (Schulz & Williamson,

1993). These interactions have been regarded as stroke survivor attributes, rather than interpreting them as influential interactions between the stroke survivor and support person. To illustrate, Rachel's experience in Chapter Four highlighted how her husband's optimistic outlook on his situation and recovery could influence her and strengthen her commitment and support she provided to him. Of interest the lack of physical interaction, such as affection, between the couple and how it can impact on the relationship and the spouses' well-being is relatively unexplored within the caregiving literature.

The tendency for many participants in this study to put aside their own daily requirements or health issues in order to meet the stroke survivor's needs because of their commitment to the relationship, as exemplified by Lisa by not eating regular meals and not following up on her heart problems could be explained, I suggest, by a symbiotic perspective. Symbiosis describes a relationship where two beings function as one, for example a mother and an infant are intertwined physically and become reliant on each other (Tissaw, 2000). There appears to be some similarities between the initial stage of symbiosis and the mother/infant dyad, and these participants and their partners. For instance, Tissaw describes this stage to include helplessness and instrumentality. The incidence of stroke can create a sudden decline in a partner's functional ability and thus a degree of helplessness. Furthermore, the consequences of stroke can to some extent create a level of dependency on others in order to meet fundamental needs, which spouses/partners are instrumental in meeting. On the other hand, the stroke survivor could become fundamental to a spouse's or partner's well-being as they are seen as an extension of one's self as Judie and Patricia explained in Chapter Four. By focusing on how spouses and partners cope with providing care and overlooking the relationship that they have with the person that they care for, perpetuates gaps in knowledge regarding the complexity of existing relationships and, I suggest, misses a significant

link in how this contributes towards spouse's and partner's well-being.

Living Both Lives

Living both lives reflects the participants carrying out personal everyday activities for the stroke survivor and is deeply rooted in the literature especially through the carer-dependent paradigm. The term 'burden' is frequently referred to in the caring literature and thus perpetuates the representation of caring as onerous. Burden is defined as "that which is borne or carried" (Foreman, 1970, p. 74). Thus, people who experience a chronic condition, such as stroke, have been conceptualised as being dependent on others due to a lack of their physical ability (Charmaz, 1983; Hughes et al., 2005; Watson et al., 2004). In addition, it is also the reason behind why a significant proportion of research in the caregiving area has explored characteristics such as patient symptoms, degree of disability, and time spent caring; as the type and degree of burden is thought to play a part in moderating health outcomes for support people (Han & Haley, 1999; King et al., 2001; Smith et al., 2004b; White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). Interestingly, these aspects have concentrated on the spouse and partner in meeting the stroke survivors' fundamental needs, rather than meeting or attending to their own needs.

The discussed above, the expectation for a spouse or partner to care for a stroke survivor has been heavily influenced by economics, government policies, health professionals and the wider community (Caplan, Jennings, & Callahan, 1988; Charmaz, 1999; Fine, 2005; Heaton, 1999; Winch, 2006). Informal caring is seen as the primary source of support within the community. In a society when individualism and autonomy are valued at one level, it appears contradictory at another level, given that there is no choice whether or not a spouse/partner takes up the caring role (Chattoo &

Ahmad, 2008; Fine, 2005). It is only when spouses or partners can no longer sustain caring; either in a crisis or indefinitely, that formal care is then considered (Heaton, 1999). Therefore, spouses and partners are expected to support the stroke survivor at the expense of their own health and until they can do it no more.

The finding in this study of focusing on the stroke survivor's needs and putting second one's own can be reinforced through societal expectations. Heaton (1999) identifies that through the life course of informal care, family are implicated in not only the responsibility of monitoring themselves, but are also responsible for overseeing the health of those they care for. Yet, spouses and partners by default are expected to prioritise the stroke survivor's welfare because they are viewed as sick, weak and reliant on others. Charmaz (1999) suggests that chronic illnesses are deemed as legitimate suffering, and at times this suffering can elevate an individual's moral status. A sick person can make certain moral claims, such as being dependent and in need (Charmaz, 1999). In this study by living both lives and focusing on the stroke survivor, a moral status surfaced within the couple's relationship and resulted in participants privileging the stroke survivor's needs above their own. While it is important to identify and address the needs of the stroke survivor, it is also necessary to consider that the spouse or partner's needs have to be recognised as well.

Taking on a symbiotic role was consuming for many participants in this study. This finding is scattered throughout caregiving literature (Ohman & Soderberg, 2004; Sawatzky & Fowler-Kerry, 2003; Smith, Lawrence, Kerr, Langhorne, & Lees, 2004a). For example, Ohman and Soderberg (2004) explored with close relatives the meaning of living with a family member with a serious chronic illness. Relatives reported "a shrinking life" in that they were forced to alter their daily life and felt imprisoned (Ohman & Soderberg, 2004). On the other hand, Pierce et al., (2007) reported how this

changed within the first year of caring for stroke survivors. Initially, caregivers identified the "successes" of the caregiving in relation to the stroke survivors' recovery. At nine months, "successes" were more about caregivers resuming their own activities, thus, indicating a change over time and the importance of regaining one's own interests while caring. These findings were similar to Rosie's experience in that four years after the stroke and her life wrapped around partner's life, Rosie was exploring her own interests. As a result, current literature is preoccupied with focusing on how support people adapt to caring tasks, rather than how an illness can disrupt their roles and identity.

It is important to note that in this study, the things that appeared to contribute towards the participants' health and well-being were things that shifted their attention from their partner to themselves or others, such as creating time and space for themselves. This enabled participants to carry out activities that gave them enjoyment. It also highlights the tension in meeting both their own needs and their partners'. As mentioned above, spouses/partners are expected to care for the stroke survivor and care for themselves. When looking at how social workers could assess and develop strategies to promote caregiver self-care, Jones (2006) recommends examining the caregiver's physical, psychological and socio-cultural needs from an individual perspective. While the assessment is comprehensive, it still advocates the stance of sustaining the caring relationship. In particular, it does not ask or guide social workers to explore if the carer's health and well-being is being compromised in order to care. At times, to focus on oneself could be at the expense of the stroke survivor; whereas to focus on the stroke survivor could be at the expense of the carer. Therefore, there appears to be a contradiction between the self-care and carer ideals.

Uncertain Health

This study also revealed how some participants were pre-occupied with the stroke survivor's fluctuating health and concerns about their future ability to provide care. In the literature review I identified that this method of inquiry would allow acknowledgement and exploration of the thoughts and behaviours regarding spouses' and partners' well-being. Utilising this methodology has facilitated identifying the changeability and connectedness of the stroke survivor and spouse's/partner's health, which is an area that has yet to be addressed within the literature. Although there is some literature exploring the predictability of patient characteristics (i.e. patient physical recovery) on caregiver outcomes; this approach takes an individualistic view of the couple's well-being. During the interviews participants constantly referred to the stroke survivor's health when asked about their own. In Chapter Two, I identified the lack of background information about support people and a lack of information about the health and well-being of the person who experienced the stroke. Accordingly, current quantitative research approaches eliminates important information about the environment in which the support person's well-being operates. Thus, a reliance on quantitative studies in the caregiving literature, I suggest, has consequently contributed towards the dominant individualistic perspective, rather than a family systems approach to spouses and partners' health and wellness.

Years after the stroke, many participants in this study reported being concerned about future health of the stroke survivor and their own. As identified in Chapter Two qualitative studies have findings that differ with this finding (O'Connell & Baker, 2004; Silva-Smith, 2007). In particular, the results from O'Connell and Baker (2004) indicated that carers of stroke survivors felt that rather than being given a choice they were thrown into the caregiving role, whereas the spouses and partners in this study

appeared to be willing to take on the role of carer and expressed a concern about their ability to maintain this role. It may also be that during the interview the participants did not want to seem unwilling to be a carer.

In spite of the limited research exploring future uncertainty, new developments in the field of psychological coping have distinguished a 'future-orientated proactive coping' strategy (Folkman & Moskowitz, 2004). This is described as coping strategies which are implemented in advance, in order to reduce or prevent the impact of potential stressors (Folkman & Moskowitz, 2004). This description resonates with some of the participants' experiences. As discussed in Chapter Four some had backup plans in case they were no longer able to care for the stroke survivor, or engaged in preventative behaviours to minimise the risk of ill health.

In addition, some of the participants in this study had created ways to meet their own needs while still attending their partner's needs. On reflection, these strategies are more like snatched opportunities and indicate how marginalised spouses' and partners' needs can become.

Creating Time and Space

Several participants talked about creative ways in which they took time and space out for themselves during their everyday life. I described this sub-theme as creating time and space. In particular, these participants utilised the time when the stroke survivor was asleep or engaged in other activities. For example, participants went for a walk, read a book, or did meditation. Support people taking time out for themselves has been identified in previous research (Sawatzky & Fowler-Kerry, 2003) and is conceptualised as a coping or a self-care strategy. However, many participants in this study had limited time or space to engage in self-care strategies.

With regards to creating space, many participants found ways to create space within their homes for themselves and which were away from the stroke survivor. As discussed in Chapter Two there was one piece of qualitative research exploring strategies used by relatives when caring for a family member with advanced dementia (de la Cuesta, 2005). The study's findings highlighted how relatives "create spaces" which included redesigning their home and the activities they did within it (de la Cuesta, 2005). Even though participants in this study were able to make space for their own activities it was within the confines of their home.

Talking with Others

Most participants appeared to find it beneficial to express their thoughts and emotions with others. This finding has support within existing literature. Interestingly, during the consultation process for the *New Zealand Carers' Strategy*, carers identified that emotional support, such as talking to someone was important and an important need (Ministry of Social Development, 2007b). This document highlighted that services such as counselling and peer support could be useful (Ministry of Social Development, 2007b). However, a few participants in this study demonstrated that also talking to a range of formal and/or informal supports appeared important to their well-being.

In the literature, problem-focused coping has been viewed as the preferred strategy over emotion-focused (Folkman & Moskowitz, 2004; Kramer, 1997a; Kuuppelomaki et al., 2004). However, more recently, this belief has been challenged. It has been suggested that emotional strategies provide for the processing and expressing of emotions, and in turn talking to others has been linked with decreased depression and hostility (Folkman & Moskowitz, 2004). Similarly, some participants identified how important it was to share their thoughts and feelings with others.

However, the findings from this study highlighted how some participants considered who they could share their feelings without being criticised for focusing on themselves. In addition, for these participants talking with others was not only just a coping strategy but also an enjoyable activity. Conversing with others also appeared to enable a break, by focusing on someone else other than the stroke survivor and being immersed in attending to their needs.

Comparing Own Lives Against Others

Participants at times evaluated themselves against people in worse off situations. This appeared to facilitate emotions such as appreciation and grief. While there has been some indication of this in other research (see O'Connell & Baker, 2004), recent literature from the field of psychological coping could shed more light on this concept. It has been proposed that individuals can influence which emotions they have, when they have them, and how they experience and express them (Folkman & Moskowitz, 2004). This has been described as emotional regulation coping and is believed to diminish negative emotions and encourage positive emotions (Folkman & Moskowitz, 2004). This supports this study's finding in that by choosing with whom to compare with, participants were able to influence and regulate their own feelings. However, the concept of comparing with others differs from existing literature, given that evaluations were also made with people perceived to be in a more fortunate position during the acute stage of stroke. In this instance, being able to compare oneself with others appeared to assist in the expression of the loss experienced as a result of the stroke. Having considered how findings from this study contribute towards existing and new knowledge, the practical implications of these findings will be discussed.

Implications and Recommendations

Implications for Practice

The findings of this study reveal how during the interviews, participants tended to speak about their partner, rather than about how they attended to their own health and well-being. For most participants in this study, the ways in which they took the opportunity to attend to themselves were minor, as many of them were busy primarily attending to the stroke survivor's needs. Bearing in mind the population of this study, findings suggest that what spouses and partners may think and do within the couple could be useful information towards supporting other carers' health and well-being. For example, the intimate nature of the relationship was the foundation for most participants to support the stroke survivor, and their well-being was intertwined with their partners'. It could also be important for health/support services and health professionals to consider the well-being and needs of the couple, as well as the individual. Often spouses and partners of stroke survivors may be older and may have health issues of their own as shown in this population (see Table 1 and Table 2 in Chapter Three). Subsequently, health professionals such as general practitioners, nurses and stroke organisations could bear in mind that spouse's/partner's health and well-being can be just as fragile as the stroke survivors'. When implementing new treatments, strategies or services other potential applications could include:

- Assessing the level of resources and needs of the couple as well as on an individual basis. This could involve an exploration of how the stroke survivor could contribute towards meeting the needs and well-being of their spouse/partners, as well as both of them both as a couple.

- When designing interventions for either of the pair, consideration of how interventions and services may impact on the other person, and if the home environment is conducive to implementation of strategies.

- Taking into account the dynamic nature of health, there could be new or enduring spousal and couple needs which require formal support beyond the acute stage.

- Developing a routine during the early days of rehabilitation to include and support spouses/partners regularly taking time out, space for themselves, and resources to meet their own needs.

The current literature locates the solutions to health outcomes for the spouse or partner within the individual. But these results suggest that others may play a part in "coping", even the stroke survivor. In this study, many participants felt they had to carry on despite their own needs and health issues. This would suggest that strategies aimed at individual coping with the caring role may have limited application if other aspects, such as being in a relationship and the extent to which spouses or partners have to live both lives, are not acknowledged or addressed.

Implications for Policy Makers

In the recently developed *New Zealand Carers' Strategy* (Ministry of Social Development, 2008), one of the objectives of the strategy is to protect the health and well-being of caregivers. The current action plans to address this area by ensuring access to: learning, training, improvement of respite services; and encouraging the access of services for carers of people with mental illness or addiction. Whilst these are important areas to address, there is little evidence as to how best to directly support

carers' own health needs. This research provides some insights into and gives possible indications of how to assist carers' welfare. For instance, the findings from this study indicate that in order to support spouses' or partners' well-being, the relationship between them and the stroke survivor needs to be considered. In a critique of the 1999 British National Carers Strategy a similar finding was reported, which was that the attitude of the policy towards caring diminished the relationship between the carer and care recipient and its vital link to their well-being (Lloyd, 2000).

In addition, it is also important to recognise that stroke tends to occur in an older population, and most of the spouses in this study were above 40 years old. Not only does the current *New Zealand Carers' Strategy* (Ministry of Social Development, 2008) neglect the interpersonal relationship, but also assumes they will continue to care with minimal formal support. Thus, a shift in focus from viewing spouses/partners as resources to provide informal support, to one of sustaining the health and well-being of the couple may provide creative impetus in the effort to support spouses/partners.

Study Limitations and Suggestions for Future Research

This study provides some insights into the experience of seven spouses/partners who supported their partner after a stroke. As with any methodology and study, there are limitations. Firstly, the findings from this study are specific to the participants' experiences and as a result it is not possible to generalise beyond this population. However, there may be some commonalities and shared experiences of the phenomenon of sustaining one's own health and well-being while supporting a stroke survivor with spouses/partners in similar situations.

Secondly, it is possible that those who agreed to participate in this study did so because of personal characteristics or desire to talk about their experiences. Thus, potentially these spouses/partners could have tended to experience more social isolation. Furthermore, recruitment was primarily facilitated through the New Zealand Stroke Foundation. In the study's geographical area, when a person is hospitalised with stroke, they are approached by the New Zealand Stroke Foundation in order to see if they would like to become members. Although participants may have had contact with services, they may not have necessarily accessed them since the stroke occurred. From the demographic information collected, two spouses/partners did not use any services at all, and another two only received one to two hours of formal support per week.

Lastly, partially due to time constraints, the numbers in this study are small; however, this is congruent with the methodology (Thorne et al., 1997). Further theoretical sampling could have provided a more robust understanding of this phenomenon as I would have liked to recruit additional participants in order to explore some themes in more depth. Nonetheless, data saturation was reached for the categories and sub-themes that were of primary interest.

As mentioned above, there are other experiences which could be valuable to include when investigating how spouses/partners sustain their own health and well-being while supporting a stroke survivor that go beyond the scope of this study. For example, all the participants in this study resided with their partner and received low levels of formal support. Suggestions for future research include further exploration of the opportunities to focus oneself, the experiences of couples who do not reside together, other ethnic groups, or spouses/partners who have health conditions of their own which impede them from caring for their partner on a daily basis. In order to explore changes over time, it also would have been valuable to have had multiple

interviews with spouses/partners over a period of time. In general, when researching support people and their health and well-being, it could be important to consider collecting basic health information about the stroke survivor as it can contribute towards analysis.

These findings would benefit from further research; specifically it would be useful to see if they are valid in a larger population. Also, these findings highlight how for these participants, the current models which influence policy and service, underestimate the complexity and importance of couple dynamics on spouses/partners' well-being. Therefore, it could be important to undertake a critical review exploring a variety of professional disciplines and theoretical frameworks.

Summary

The study sought to answer the question "How do spouses and partners sustain their own health and wellness while supporting a stroke survivor?" It was striking how challenging it was for spouses/partners to talk about themselves, and how their health and well-being was intertwined with the stroke survivors. Interpretation of the interviews has generated three factors that shaped caregivers' role and their ability to attend to their own well-being: being in a relationship, living both lives, uncertain health; and one central theme, meeting needs. This described the circumstances in which their health and well-being operated in. Whilst spouses and partners were skilful in how they met the needs of the stroke survivor, most could only take small moments to meet their own needs due to the limited opportunities available to them as primary caregivers. The strategies in which they used to support their own health and well-being were through: creating time and space, talking with others, and comparing own lives against others. This study also highlights the importance of the interpersonal

relationship with the stroke survivor and the connection between their health and the spouses' and partners' health and well-being.

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Participant Information Sheet

Project Title
Sustaining one's own health and wellness when supporting a stroke survivor: Spouses' and partners perspectives.

Invitation
Kia ora, talofa lava and hello, you are invited to take part in a study to get a better understanding of what you do that impacts on your health and well-being. Please remember that:

- Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future care or treatment.
- If you do agree to take part you are free to withdraw at anytime, without having to give a reason and this will in no way affect the healthcare service that you or your partner receive.
- This information sheet explains the research study. Please feel free to ask about anything you do not understand or if you have questions at anytime.

What is the purpose of the study?
This study aims to identify what spouses and partners do that influences health and well-being while supporting a stroke survivor.

How are people chosen to be asked to be part of the study?
We are asking spouses and partners who have supported a stroke survivor for six months or longer to take part.

What happens in the study?
If you agree to participate, you will be interviewed for 40-60 minutes wherever you prefer (eg at home or at AUT). The interview will be recorded and transcribed. The focus of this interview is about your health and well-being and so we will not ask personal questions about your partner. Sometime after the interviews and if you agree, we may contact you to get your view on the early results.

What are the risks?

You may find answering some of the questions difficult due to the sensitive nature of some questions. If you find the interview upsetting you can stop the interview at any time. If you would like to discuss this with someone, then let the research team know so that we are able to refer you as appropriate.

How will this study help?

The information we gain will help us understand what spouses and partners do that impacts on health and well-being and how best to support you.

What are the costs of participating in the project?

There will not be any cost to you except your time. If interviews are held at a place you need to travel to, we will reimburse you by providing you with a petrol voucher.

How will my privacy be protected?

All information you give will be kept confidential and your name will not be known to anyone but the principal investigator. We will keep the information locked in a cabinet. Any reports will make sure that you cannot be identified.

What will happen with the results?

If you would like a copy of the findings or the original recording, it will be sent to you at the end of the study (about 6 months after the interview). Usually there is a long delay between collecting information and letting people know about the results. The results of this study will be published as a Master's thesis and we hope to also publish in a relevant health journal.

If you have any concerns or questions?

If you have any questions please feel free to contact:

Principal Investigator:	Natasha Moloczij (09) 921-9999 ext 7531
Supervisors:	Deborah Payne 921-9999 ext 7112
	John F Smith 921-9999 ext 7753

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate on 0800-555-050.

If this study brings up individual issues please do not hesitate to contact:

Citizens Advice Bureaux	0800-367-222
Lifeline 24 hours	09-522-2999
AUT Health Counselling and Wellbeing	09-921-9998

Statement of Approval

This study has been approved by the Y Ethics Committee

Appendix B

Consent Form

Sustaining one's own health and wellness when supporting a stroke survivor: Spouses' and partners perspectives.

Principal Investigator: Natasha Moloczij   Phone: 921-9731
Supervisors: Dr John F Smith   Phone: 921-9999 ext 7753
        Dr Lynne Giddings   Phone: 921-9999 ext 7013

- I understand the information provided and have read or had read to me the Information Sheet (dated 2 July 2007) for volunteers taking part in the study designed to identify what spouses and partners do that impacts on health and well-being while supporting a stroke survivor.

- I have had the chance to ask questions and to have them answered. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study. I am satisfied with the answers given.

- I understand my participation is entirely voluntary (my choice) and do not have to take part in this study, and it will not affect my healthcare or my partners healthcare.

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

- I understand that the interview will be stopped if it should appear harmful to me.

- This study has been approved by the Y Ethics Committee. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

                                                                    Please tick one

- I consent to my interview to be recorded and transcribed   Yes O No O

- I consent to being contacted about the early findings   Yes O No O

I wish to receive:

- a summary of the report from the findings   Yes O No O

- the original recording   Yes O No O

I, _____ (full name)
consent to take part in this study

_____   _____

Signed   Date

Participant Contact Details (if copy of report requested):

……………………………………………………………………………………

……………………………………………………………………………………

………..

_____   _____

Project explained by   Signed

Demographic Information

ID No	

Age	
Gender	Female / Male
Ethnicity	
Area reside in	
Do they live together?	Yes / No
How long have they been together?	Years before stroke Years after stroke
How long have they been supporting their partner since the stroke?	Months Years
Time spent caring per week	Hours per week
Health problems (Past and present health problems experienced while supporting partner)	
Use of support services (eg. Stroke Foundation, home-help)	
Other caring roles? (eg child or elderly parent)	

Interview Guideline

The semi-structured interview will be customised to each individual's situation. The questions below serve to examples of prompts to encourage the participant to talk about their own experiences and only some will be asked as required.

- Tell me about your health since your partner had their stroke?
- What do you do for your well-being?
- How do you sustain your health while supporting your partner?
- How do you feel about your well-being?
- What keeps you well?

**Health
and
Disability
Ethics
Committees**

13 September 2007

**Ms Natasha Moloczij
Rehabilitation & Occupation Studies
Auckland University of Technology
Private Bag 92006Auckland**

Dear Natasha

Sustaining one's own health and wellness when supporting a stroke survivor: A grounded theory of spouses' and partners perspectives.
Investigators: **Natasha Moloczij,** Dr John Smith, Dr Lynne Giddings.
Ethics ref: **NTY/07/07/080**
Locations: **Laura Fergusson Trust, Stroke Foundation, AUT University.**

The above study has been given ethical approval by the **Northern Y Regional** Ethics Committee.

Approved Documents
-Interview Guideline
-Information Sheet and Consent Form dated 17 August 2007
-Demographic Information

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until **30 September 2008**. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

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

Yours sincerely

**Amrita Kuruvilla
Northern Y Ethics Committee Administrator**

Email: amrita_kuruvilla@moh.govt.nz

M E M O R A N D U M
Auckland University of Technology Ethics Committee (AUTEC)

To: John F Smith
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 19 November 2007
Subject: Ethics Application Number 07/184 **Sustaining one's own health and wellness when supporting a stroke survivor: a grounded theory of spouses' and partners perspectives.**

Dear John

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application at their meeting on 12 November 2007. Your application is now approved for a period of three years until 12 November 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through *http://www.aut.ac.nz/about/ethics*, including when necessary a request for extension of the approval one month prior to its expiry on 12 November 2010;

- A brief report on the status of the project using form EA3, which is available online through *http://www.aut.ac.nz/about/ethics*. This report is to be submitted either when the approval expires on 12 November 2010 or on completion of the project, whichever comes sooner;

It is also a condition of approval that AUTEC is notified of any adverse events or if the research does not commence and that AUTEC approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTEC for approval before that change is implemented.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Natasha Moloczij nmolcij@aut.ac.nz

From the desk of
Madeline Banda
Executive Secretary
AUTEC

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New Zealand
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