

**Understanding the experiences of caring for someone after
stroke: A qualitative study of
caregivers and stroke survivors.**

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Declaration

This thesis contains no material that has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text of the thesis.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for photocopying and loan.

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Statement of Participation and Publication

My primary supervisor is Dr. Maree Hackett who is a Senior Research Fellow at the George Institute for International Health and a Senior Lecturer at Sydney Medical School at the University of Sydney. My Associate supervisor is Dr. Barbara Mullan who is a Senior Lecturer and co-ordinator of postgraduate health psychology studies at the School of Psychology at the University of Sydney.

The original conception for this project was developed by Dr. Maree Hackett. As chief investigator, I carried out work through all stages of this project from ethics applications, a literature review, generation of all forms and questionnaires, recruitment, data collection, analysis, write up, and poster and oral presentations. Both supervisors oversaw my work throughout these stages. Blake Dear was employed as a second independent coder and professional transcription services were utilised.

I carried out platform presentations at The School of Psychology Research Seminars and The Postgraduate Psychology Conferences at The University of Sydney from 2008-2009. I also gave a presentation at the Annual Community Stroke Forum held by the National Stroke Foundation at Canterbury RSL on September 14, 2009. In addition, a poster presentation was given at the 19th European Stroke Conference (ESC) during May 25-28 at Barcelona, Spain. The ESC was a large and highly prestigious international stroke conference with a very competitive process of acceptance. Attendance gave me the opportunity to network and liaise with leading researchers in the field, disseminate my findings to them as well as represent the University of Sydney and the School of Psychology in an international forum. This project has also been

accepted for a platform presentation at the 21st Stroke Society of Australasia Annual Scientific Meeting in Melbourne, September 1-3, 2010. Maree Hackett and Barbara Mullan were second and third authors in all presentations and posters and the official project title used in all settings was: Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors. Finally, I intend to publish one to two research papers following submission of my dissertation.

Yasmeen El Masry

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Abstract

The majority of stroke survivors live with a permanent disability, and require some form of caregiver support. Research into the nature of stroke caregiving however, remains limited. Current literature provides evidence that support services and interventions for caregivers, especially in relation to managing affective symptoms, are unsatisfactory (Hackett & Anderson, 2006). The main aim of this study, therefore, was to investigate stroke caregiver experiences and needs, and their evaluation of existing support services. Twenty informal caregivers participated in individual semi-structured qualitative interviews covering all aspects of caregiving. Ten stroke survivors were also interviewed (predominantly for triangulation purposes) to discuss their views on their caregiver's experiences. Data collection continued until, after at least three consecutive interviews, no new themes were identified. Data analysis and interpretation was primarily thematic, with the generation of an integrative set of themes. Five inter-related master themes with various subcategories emerged from the data: Relationships and Support; Caregiver Factors; Stroke Survivor Factors; External Stressors and Positive Outcomes. Caring for a stroke survivor involves a complex process of several different factors, all of which interact in different ways according to the individual. The study findings increase our understanding of caregiver experiences and needs, which in turn, should encourage healthcare professionals to develop improved and tailored support services and resources.

Chapter I: Literature Review

1.1 Overview

Stroke, the most common form of cerebrovascular disease, is a disabling medical condition that is particularly common in elderly populations. While there has been considerable research into the pervasive effects of stroke on survivors (National Stroke Foundation, 2005), relatively little attention has been paid to the experiences of the primary caregiver. More specifically, the psychosocial changes these caregivers experience and their individual needs are still poorly understood (e.g. Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Franzén-Dahlin et al., 2006; Mackenzie et al., 2007). The literature that is available on caregivers of stroke survivors provides evidence that caregiving is often challenging; affecting the physical and mental health of the caregiver (Berg, Palomäki, Lönnqvist, Lehtihalmes, & Kaste, 2005; Han & Haley, 1999). Caregivers also experience significant dissatisfaction with available support services because their experiences and needs are often overlooked (e.g. Kalra et al., 2004; Mackenzie et al., 2007). Unsurprisingly then, current research provides evidence that effective interventions for caregivers, especially in relation to managing emotional symptoms, remain inadequate (Hackett & Anderson, 2006).

While some investigators have used quantitative studies to measure the prevalence of and risk factors for caregiver burden following stroke (Visser-Meily, Post, Schepers & Lindeman, 2005a), many of these investigators report inconsistent findings and fail to comprehensively explain caregiver experiences. It is still uncertain what factors underlie a caregiver's psychosocial and physical health and which caregivers cope better than others, and why this is the case. The reasons behind satisfaction and dissatisfaction with support services are also poorly understood.

Qualitative research exploring the nature and reasons for the burden of caregivers of people with stroke, remains to be an under utilised method of inquiry warranting further attention (McKevitt, Redfern, Mold, & Wolfe, 2004). In addition, investigation of caregiver experiences from the stroke survivor's perspective has not been carried out to date in qualitative research. This kind of information would not only increase understanding of caregiver experiences and strain, but it would also serve to corroborate the information elicited from the caregiver themselves. This method of triangulating similar kinds of information gathered from different sources therefore increases the robustness and validity of the qualitative research technique.

The following review will begin with a description of stroke, followed by an overview of the subtypes, causes, signs, risk factors, epidemiology and course of stroke as well as a review of the long-term outcome of stroke on stroke survivors. Following this, the available quantitative and qualitative research on the impact of caring for someone with stroke, an evaluation of stroke and caregiver interventions, and directions for future research will be reviewed. Quantitative research methods and strategies including types of data collection, and analysis will be outlined. Finally, based on the information presented, the research questions and aims of the current study are described.

1.2 Stroke

Cardiovascular disease, the number one cause of death in Australia, includes all diseases and conditions of the heart (*cardio*) and blood vessels (*vascular*). This includes coronary heart disease (CHD) (disease of the blood vessels supplying the heart), peripheral arterial disease (disease of blood vessels supplying the arms and legs) and cerebrovascular disease (disease of the blood vessels supplying the brain) (Burke et al., 1995). A cerebrovascular accident (CVA), commonly known as stroke, is the most common form of cerebrovascular disease, particularly in people aged 65 years and older (Lezak, 2004).

A stroke is a disruption of normal blood flow to the brain via the obstruction of arteries due to a blood clot or plaque (an infarction), or, when an artery ruptures (i.e. a hemorrhage). This disruption stops the vital nutrients oxygen and glucose, from reaching brain cells, leading to irreversible tissue damage (Lezak, 2004). The effects of stroke lie on a continuum from rapid complete recovery to severe long term disability, or fatality, depending on the severity of the stroke and the brain region affected (Warlow, 1998). For the stroke survivors that do endure disability, a considerable amount of burden is usually placed on caregivers who are required to support the person who has had the stroke through the rehabilitation and recovery process.

The World Health Organisation (WHO) defines a stroke as “rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24 h or leading to death with no apparent cause other than of vascular origin” (Hatano, 1976, p.541). This definition of stroke has been used clinically for over 30 years, however, the use of modern brain imaging technology (e.g. Computer Tomography or Magnetic Resonance Imaging) has allowed stroke to be categorised into different types and sub-types. A stroke should be distinguished from a Transient Ischemic Attack (TIA) which is defined as a transient episode (symptoms persist for

<24 hours) of blood flow disturbance without resulting tissue death (Easton et al., 2009) or long-term impairment (Lezak, 2004). The two main types of stroke are: (i) Ischaemic stroke (approximately 80% of all cases) which are caused by blockages in arteries due to blood clots and (ii) Haemorrhagic stroke which is due to a bleed in the brain, i.e. when a blood vessel bursts open leaking into the brain (approximately 20% of all cases) (Warlow, Sudlow, Dennis, Wardlaw & Sandercock, 2003).

1.2.1 Ischaemic strokes

1.2.1.1 Embolic strokes

Embolic strokes occur when a mass (usually a blood clot from the heart) travels through blood vessels to the brain and causes a blockage when it reaches a blood vessel that is too narrow, becoming stuck (e.g. Adams et al., 1993; Lezak, 2004). This subtype accounts for about 16% of all stroke cases (Warlow et al., 2003).

1.2.1.2 Thrombotic strokes

Thrombotic strokes occur when plaque-like deposits of cholesterol build up and grow along the arterial walls causing arteries to narrow or become blocked, disrupting blood flow to the brain, especially via arteries in the neck to the brain (Adams et al., 1993; Lezak, 2004). This Atherogenic process leads to the condition called atherosclerosis, i.e., the condition of thickened arterial walls (Tegos, Kalodiki, Sabetai & Nicolaides, 2001). This subtype accounts for about 40% of all stroke cases. A further 20% are due to lacunar infarcts -blockages in small, cerebral arteries deep within the brain, while 4% of all stroke cases are caused by a variety of other vascular abnormalities (Warlow et al., 2003).

1.2.2 Haemorrhagic stroke

1.2.2.1 Subarachnoid haemorrhages

Subarachnoid haemorrhages occur when there is a bleed directly under the cerebral membrane (Donnan, Fisher, Macleod & Davis, 2008; Lezak, 2004). This subtype accounts for 5% of all stroke cases (Warlow et al., 2003).

1.2.2.2 Intracerebral strokes

Intracerebral strokes are caused by bleeding that takes place at a deeper level, within the brain region itself (Donnan et al., 2008; Lezak, 2004), accounting for 15% of all stroke cases (Warlow et al., 2003).

1.2.3 Signs

The signs of stroke depend on the brain region affected and can include the sudden onset of one or more of the following symptoms (i) weakness or paralysis of the face and limbs to either one or both sides of the body, (ii) difficulty speaking or understanding speech, (iii) dizziness or a loss of balance, (iv) severe and acute headaches or a notable change in the experience of headaches, (v) blurry or decreased vision to one or both eyes (vi) chest pain and, (v) shortness of breath (Pancioli et al., 1998).

Stroke symptoms require immediate medical attention to reduce the risk of death and improve the chances of best recovery (Lezak, 2004; Pancioli et al., 1998). It is recommended that patients go directly to hospital as soon as symptoms are noticed to enable treatment within the first three hours of stroke (Clark et al., 1999). In addition to the warning signs of stroke, there are important risk factors that need to be considered when understanding stroke.

1.2.4 Risk factors

There are several risk factors for stroke (Warlow et al., 2003). These include older age, poor diet (e.g. the over consumption of saturated fats, salty foods and alcohol), high blood pressure (hypertension), obesity, smoking cigarettes, drug use, high cholesterol, diabetes mellitus, a lack of exercise, a pre-existing heart condition/disturbance in blood flow such as myocardial infarction (heart attack), atrial fibrillation (irregular heart beat in the upper chambers of the heart) and possibly psychological stress (Boden-Albala & Sacco, 2000; Andersen, Olsen, Dehlendorff & Kammersgaard, 2009; Pancioli et al., 1998; Wood, 2005). These factors can contribute to the condition of atherosclerosis discussed earlier (Burke et al., 1995; Wood, 2005). Previous cases of a TIA or stroke are also risk factors for first time and recurrent stroke, respectively (Pendlebury & Rothwell, 2009). In terms of recurrent stroke, these risk factors tend to have the greatest influence soon after an initial stroke, especially within the first 7 days. While the impact of risk factors decrease over time, authors of follow up studies still report an association between these risk factors and a recurrent stroke up to 10 years following a first in a lifetime stroke (Mohan et al., 2009; Pendlebury & Rothwell, 2009).

It has been found that public awareness of the warning signs and risk factors for first time or recurrent stroke is less than desirable (Pancioli et al., 1998). The awareness of risk factors is important however, not only for reducing the burden on those individuals directly at risk, but also to alleviate the burden that would inadvertently be placed on their potential informal caregivers and the wider healthcare system.

1.2.5 Epidemiology

The public health burden of stroke is increasing internationally, particularly in nations with an ageing population and western lifestyles (Warlow et al., 2003). Stroke is the third most common cause of death worldwide, following heart disease and all forms of cancer (Warlow et al., 2003). The likelihood of having a stroke increases with age and is higher among people aged 65 years and older compared to people below 65 years of age, and is more common in men than women (Lezak, 2004). Following a first in a lifetime stroke, it has been estimated that 20% of individuals will die within the first month, 33% will die within a year, while between 40% and 90% of those who survive will live with a permanent functional disability or handicap (Anderson Linto, & Stewart-Wynne 1995; Sacco, Wolf, Kannel & McNamara, 1982), and become dependent on some type of informal caregiver to assist with functioning in daily life (Dewey et al., 2002; Thrift, Dewey, Macdonnell, McNeil, Donnan, 2000). It is also estimated that the numbers of stroke and mortality will double by 2020 due to aging populations, the effects of smoking in developing countries (Warlow et al., 2003), and more sensitive methods of diagnosis (Lezak, 2004). These statistics further indicate the increasing role that caregivers will continue to play in stroke recovery, on a global scale.

In Australia, stroke is the second largest cause of death after heart disease, and is a leading cause of disability in older adults (NSF, 2007b). Approximately 53,000 strokes occur in Australia per year, with at least 346,700 Australians having a stroke in their lifetime. Of those, 90% (312,030) will be living at home, and approximately, 80% (282,000) will have a permanent disability (NSF, 2007a). The life-time cost of stroke to the Australian healthcare system has been estimated to be \$A2 billion each year (Cadilhac, Carter, Thrift, & Dewey, 2009).

It has been suggested that the numbers of people surviving from stroke in Australia are likely to increase over the next 10 years, similar to the findings from other countries (Dewey et al., 2001). Reasons for this include the aging population of Australia and improvements in stroke treatment which means that more people are surviving strokes. Unfortunately this will mean more stroke survivors living with chronic disabilities, thus increasing the need for informal caregivers. This is especially so as the healthcare system attempts to reduce cost burden by discharging stroke survivors home rather than to government-owned formal care facilities (Berecki-Gisolf, Lucke, Hockey, & Dobson, 2008; Dewey et al., 2001).

Despite this significant burden to public health and increasing numbers of stroke survivors and caregivers, far less research funding is provided to stroke compared to heart disease or cancer (Warlow et al., 2003). This in turn contributes to gaps in our knowledge about several aspects of stroke, indicating the importance for further research in this area, especially in relation to the impact stroke has on caregivers.

1.2.6 Course of treatment and recovery

Stroke recovery can begin within hours. Medications that break down blood clots (i.e. thrombolytic agents) form a large component of stroke treatment in the immediate stages (Clark et al., 1999). Carotid endarterectomy is an early secondary prevention surgery that helps to remove plaque along the walls of the Carotid arteries, the major blood vessels in the neck that supply blood to the brain (Barnett et al., 1998).

Treatments that decrease the occurrence of blood clots such as antiplatelet (e.g. aspirin) and anticoagulation medications can also help to reduce further tissue damage, and lower the risk of future strokes in the long-term maintenance of stroke recovery (NSF, 2005). Risk factor

management, such as medication that lowers blood pressure is also commonly prescribed for stroke survivors (NSF, 2005).

Recovery also occurs via anatomical and neural plasticity, i.e., where neurons take on new functions to compensate for the loss of brain tissue (Johansson, 2000; Warlow et al., 2003). The re-acquisition of functional skills is also enhanced through rehabilitation training with the aid of health professionals such as physiotherapists and occupational therapists (Hochstenbach & Mulder, 1999; Warlow et al., 2003). Adjustments in the environment and the use of aids may also be implemented, helping stroke survivors enhance their daily functioning and independence (Warlow et al., 2003).

Apart from the implementation of the above treatment methods, the outcome of stroke can be affected by stroke survivor characteristics such as greater age at onset, level of disability (e.g. mobility) and aphasia (impairments in language expression and comprehension) at the time of discharge (NSF, 2005), as well as duration of hospital stay (Teasdale & Engber, 2005; Warlow et al., 2003). Gender (with men reporting lower levels of satisfaction with recovery than women), an unhealthy lifestyle (e.g. smoking, poor diet and exercise), poor pre-morbid family functioning, high levels of depression and unrealistic expectations of recovery are also risk factors for poorer stroke recovery (Young, Bogle & Forster, 2001). Stroke has also been associated with a greater risk of recurrent stroke, myocardial infarction and other vascular problems such as dementia (Han & Haley, 1999; Warlow et al., 2003).

Caregivers can be involved in all stages of stroke treatment, recovery and rehabilitation, for example they can assist with medication compliance, transport to and from support services, and with mobility and other every day activities. Caregivers can also have a large influence on many of the modifiable stroke risk factors outlined above such as encouraging exercise and a

healthier lifestyle. Furthermore, while a great deal of short-term recovery of function can occur following stroke, as discussed, long-term and often permanent disability remains for many, and caregivers are also often involved in the management of longer-term care.

1.3 Stroke survivors

Investigators of both quantitative and qualitative research have found that the short and long term consequences of stroke include changes in various areas of functioning. These impairments can be severe, highlighting the need for caregivers' assistance, as well as the large burden that may be placed on the caregiver when providing this assistance. In order to understand this strain that is placed on caregivers of stroke survivors these consequences of stroke will be described below.

1.3.1 Sensorimotor, physical/medical, and Activities of Daily Living (ADL) functioning

Following stroke, an array of sensorimotor impairments, physical disability and daily functioning complications can develop (NSF, 2005; Warlow et al., 2003). Common sensorimotor outcomes include Hemiplegia (paralysis of one side of the face and body) and Hemiparesis (weakness of one side of the face and body), both of which can lead to significant disability and consequent handicap due to restrictions in the environment (NSF, 2005). Loss of tactile and kinaesthetic sensations and spasticity (increased muscle tone reflexes) may also occur following a stroke. These conditions contribute to overall difficulties with joint mobility in different regions such as the shoulders, arms or hips. Secondary consequences of weakness and immobility can include pain (such as shoulder pain), swelling of extremities, increased falling and lowered cardiovascular health (NSF, 2005).

The main physical burden includes impairments in voluntary motor movements and motor control, such as Apraxia. More specifically, Apraxia is defined as “impaired planning and sequencing of movement, that is not due to weakness, in coordination, or sensory loss” (NSF, 2005, p.26). Apraxia can affect the ability to carry out functional activities such as walking, dressing and driving (NSF, 2007a). People with stroke can also experience other physical problems that affect their ability to function independently and carry out Activities of Daily Living (ADL henceforth). ADL can include community-based activities, e.g. organising financial matters, running errands, driving, shopping and “checking-up” on the stroke survivor, (Young, Murray & Forster, 2003); domestic activities, e.g. home maintenance, housework, meal preparation, medication supervision and assistance with walking outside the home (Dewey et al., 2002); and personal activities, e.g. standing, sitting, balance, eating, grooming, bathing, dressing, toilet use and movement around the house and stairs (Dewey et al., 2002; Hochstenbach & Mulder, 1999; Wade & Hewer, 1987).

Medical complications can also follow as a result of stroke, which place a larger burden on the caregiving role. These conditions can include urinary incontinence (Wade & Hewer, 1987) and bowel control problems, pain, sleep apnoea, seizures, pyrexia (fever), deep vein thrombosis, pulmonary embolism (PE), Dysphagia (problems swallowing), and general dehydration and malnutrition (NSF, 2005).

1.3.2 Cognitive sequelae

1.3.2.1 Communication, visuospatial and perceptual impairments

Aphasia is a common impairment following stroke and is characterised by difficulties in language and communication, including auditory comprehension and the formulation of

grammatical verbal messages (e.g. verbal fluency and naming) (Mukherjee, Levin & Heller., 2006). Reading and writing difficulties may also occur (Hochstenbach & Mulder, 1999). Aphasia is not, however, the same as the act of articulating speech sounds, although speech problems such as verbal dyspraxia which describes an inability to sequence and plan the movement of the muscles required for speech, or dysarthria, unclear speech due to actual impairments in the speech muscles, may also occur following stroke (NSF, 2005).

Other communication problems include expressing and understanding non-verbal language cues like facial expressions and gestures, intonation, understanding other peoples' emotional states and turn-taking (Hochstenbach & Mulder, 1999; NSF, 2005). Discourse skills such as narrative organisation and conveyance can also be affected (NSF, 2005).

Speech and language problems are found to be more prominent in left-sided stroke, whilst visuoperceptual deficits, including auditory and visual affect recognition (difficulties with understanding emotional and social cues such as gestures, tone and facial expressions), are more common with right-sided stroke lesions (Lezak, 2004; Mukherjee et al., 2006).

Other visual recognition problems include unilateral or hemispatial neglect. Hemispatial neglect affects either sensory or motor systems and is characterised by a failure to perceptually attend to or voluntarily move towards (e.g., limb akinesia) visual and auditory information in one side of the environment. This sensory or auditory information appears contralateral to the lesion location (i.e. usually in the left field of vision or part of the body following right-sided lesions), even though sensory processing abilities and muscle tone and strength remain intact (Hochstenbach & Mulder, 1999). Blindness in one side of each visual field (homonymous hemianopsia) may also occur following stroke, and it has been found to exacerbate the likelihood of developing neglect (Hochstenbach & Mulder, 1999).

Disorders of object recognition (visual agnosia) and prosopagnosia (an inability to recognise familiar faces) can also arise with some types of lesions, again, despite intact visual perception (Hochstenbach & Mulder, 1999). For example, visual agnosia has been characterised by difficulties evaluating distance, size, shape and the positioning of one's body or another's in the environment, and recognizing pictures, symbols, and numbers (Hochstenbach & Mulder, 1999). Agnosia does not only impair object, body part or facial recognition, but it can also hinder other sensory modalities such as olfaction and hearing (NSF, 2005); for example recognising the danger of smoke or a police siren. Defects of visual functioning can also result from a stroke and may include problems with visual scanning, double vision (diplopia) and hypersensitivity to light (NSF, 2005).

Any one of the above deficits serve to inhibit the stroke survivor's ability to function independently, affecting every day activities such as reading, writing, walking and staying safe in various situations such as in traffic (NSF, 2005). One of the roles of caregivers of stroke survivors is to help manage these deficits which can be stressful and time consuming for all concerned.

1.3.2.2 Attention, memory, executive functioning

Other cognitive deficits following stroke predominantly include difficulties with attention, memory (Madureira, Guerreiro & Ferro, 2001; Teasdale & Engberg, 2005) and executive (frontal lobe) functioning (Mukherjee et al., 2006). Visual-spatial ability has also been found to decline, however attention, memory and executive functioning are more significantly affected and researched (Knopman et al., 2009).

All forms of attention; selective, focused, divided and sustained attention can be compromised following stroke. This can inhibit a stroke survivor's ability to concentrate on tasks for a prolonged period, especially in the face of distractions or when needing to perform two tasks at the same time. Information processing speed can also be slowed, which leads one to think and act slowly. This can lead to social withdrawal and fatigue for a stroke survivor (Hochstenbach & Mulder, 1999). Memory can also be impaired in relation to both the storage and retrieval of information. Memory dysfunctions may impair a person's ability to recall or recognise episodic or semantic information, and can cause serious problems in the life of a stroke survivor (Hochstenbach & Mulder, 1999). For example, they may forget appointments, phone calls, or their medication. This forgetfulness can essentially affect their overall ability to learn skills and to function independently without a caregiver.

Executive functioning involves the integration of skills including the ability to control, organise, and monitor one's cognitive processes, emotions and behaviours, in a goal directed manner (Brookshire, Levin, Song, & Zhang, 2004; Kennedy et al., 2008). Executive functions therefore, can not only be applied to solving problems but also towards conforming to socially appropriate norms of behaviour (Brookshire et al., 2004). Deficits in executive functioning include problems in organising, planning and multitasking, poor problem solving, verbal tangentiality, poor verbal fluency (e.g. letter and category fluency) and emotion dysregulation (Cicerone & Tanenbaum, 1997; Kennedy et al., 2008; Lezak, 2004; Prigatano, 1992). Furthermore, executive dysfunctions can sometimes be misinterpreted by others as 'laziness' or a lack of motivation (Hochstenbach & Mulder, 1999). Executive dysfunction can also leave a stroke survivor seriously dependent on others and external structure and routine (Hochstenbach & Mulder, 1999). Dementia and mild cognitive impairment (MCI) have also been associated with

stroke (Knopman et al., 2009; Madureira et al., 2001). Anosognosia may also develop following stroke (Starkstein, Fedoroff, Price, Leiguarda & Robinson, 1992). Anosognosia is usually associated with right hemisphere stroke and involves a lack of self-awareness of one's own problems, affecting motivation to rehabilitate, engaging in safe behaviours and consequently interpersonal relationships (Cicerone & Tanenbaum, 1997; Lezak, 2004; Mukherjee et al., 2006; Prigatano, 1992).

1.3.3 Psychosocial functioning

Apart from the residual physical and cognitive impairments that occur following stroke recovery, disruptions in emotional wellbeing, health-related quality of life and other psychosocial outcomes can also arise, which impact upon the stroke survivor's recovery, and in turn their caregiver's wellbeing.

1.3.3.1 Emotional functioning, behavioural problems and health-related quality of life (HRQoL)

Emotional changes following a stroke have been well documented (Dennis et al., 1998). The most widely researched and commonly found emotional difficulties are depressive symptoms (e.g. Dennis et al., 1998; Hackett, Yapa, Parag & Anderson, 2005; Mackenzie et al., 2007; Young, Murray & Forster, 2003). Understanding the nature and incidence of this depression has been complicated by the inconsistent methods used across studies; this includes variability in defining and measuring depression and stroke, various time-points at which depression is measured, selection biases in sampling, the exclusion of stroke survivors with cognitive or physical impairments in some studies and the lack of control for extraneous variables that affect depression such as premorbid mental health or other risk factors (Johnson, Minarik, Nyström, Bautista &

Gorman, 2006). Correctly assessing depression in stroke survivors is thwart with more difficulty due to the nature of stroke symptoms, some of which can be confused with depression (Berg, Lönnqvist, Palomäki & Kaste, 2009).

According to the Diagnostic and Statistical Manual of Mental Disorders (*DSM-IV-TR*, American Psychiatric Association, 2000), depressive symptoms are characterised by low mood, feelings of sadness and/or the loss or reduction of interest, pleasure and engagement in previously enjoyed activities (APA, 2000). In addition, changes in appetite and sleep, low energy and motivation, poor concentration and memory, thoughts of hopelessness and worthlessness (including suicidal ideation) may also be exhibited (APA, 2000). In relation to the stroke survivor however, symptoms of depression can be confounded by other neurological and cognitive stroke symptoms (Hackett, Anderson, House & Xia, 2008), which may lead to over or under diagnosis of depression symptoms or a depressive disorder. For example, deficits in emotional expression (aprosody) due to brain injury as a result of stroke may be misinterpreted as depression (Hackett, Anderson, House & Xia, 2008). Furthermore, aphasic stroke survivors may not be able to express themselves and any difficulties they have (Johnson et al., 2006). Cognitive and somatic impairments that result from the stroke such as poor memory, concentration, motivation, sleep and fatigue also overlap with the diagnostic symptoms of depression, creating further difficulties with assessment (Berg et al., 2009).

Despite this, good quality research provides evidence that as many as one third of stroke survivors can experience significant depressive symptoms (Fuentes, Ortiz, SanJose, Frank, & Diez-Tejedor 2009; Hackett, Yapa, Parag & Anderson, 2005; Young et al., 2003). Furthermore, researchers suggest these depressive symptoms are quite prevalent during all stages of recovery, with approximately 33% of stroke survivors exhibiting depressive symptoms in the acute (first

month), medium (between one and six months) and long-term (six months or more) phases of stroke recovery (Hackett et al., 2005; Kotila, Numminen, Waltimo & Kaste, 1998; Teasdale & Engberg, 2005).

Depression in stroke survivors can either be a primary response from the amount of direct brain tissue damage and associated neural changes, or a secondary response that results from a reaction from the stroke survivor (and others) towards the stroke symptoms and consequences (Hochstenbach & Mulder, 1999). An extensive number of researchers have shown that the causes for depression following stroke are multifactorial with both these endogenous (biological), and exogenous (psychological environmental) attributes, in line with the biopsychosocial model of mental illness (Whyte & Mulsant, 2002). In terms of exogenous factors, stroke survivors often report feelings of grief and loss in association with changes in their own independent functioning, reporting a difficulty with accepting and adapting to life because they are no longer able to carry out activities or roles they previously could (Clarke & Black, 2005). Furthermore, changes in physical functioning can reduce the degree of social interaction engaged in, leading to social isolation and associated loneliness and depression (Haun, Rittman & Sberna, 2008; Young et al., 2001).

There are also particular demographic and various clinical factors that increase the risk of developing depressive symptoms after stroke which are outlined in Table 1 below. This is not an exhaustive list, but includes the variables predominantly reported in the literature.

Table 1.
Factors Associated with Depression in Stroke Survivors

Factor	Study
Gender (female)	Andersen, Vestergaard, Ingemann Nielsen & Lauritzen, (1995) Kotila et al., (1998) Sharpe et al., (1994)
Age (>65)	Kotila et al., (1998) Sharpe et al., (1994)
Premorbid depression	Anderson et al., (1995) (1995) Hackett & Anderson (2006)
Depressive symptoms in the acute phase of stroke recovery (within first 10 days)	Fuentes et al., (2009)
Stroke severity: e.g. greater lesion volume	Sharpe et al., (1994)
Stroke type (haemorrhage)	Van De Port, Kwakkel, Bruin & Lindeman (2007)
Physical/health disability/poor independent daily functioning (e.g. both personal and community activities)	Andersen et al., (1995) Hackett & Anderson (2006) Kotila et al., (1998) Sharpe et al., (1994) Suh et al., (2004) Van De Port et al., (2007) Whyte & Mulsant (2002)
Duration of unconsciousness	Hackett & Anderson (2006)
Cognitive impairment	Andersen et al., (1995) Whyte & Mulsant (2002)
Poorer social support and lack of employment	Anderson et al., (1995) Morris, Robinson, Raphael & Bishop (1991) Suh et al., (2004)
Caregiver depressive symptoms	Suh et al., (2004)

Anxiety and related emotional responses such as insecurity and distrust can also occur following stroke, and are often comorbid with depression (Hochstenbach & Mulder, 1999; Mineka, Watson & Clark, 1998). There has been considerably less research focus however investigating anxiety in stroke populations compared to depressive symptoms. Anxiety is generally associated with a perceived, future oriented threat that may or may not be realistic. Heightened physiological arousal is also associated with anxiety. Whether the perceived threat is realistic or not, anxiety can cause severe distress and impairment in everyday life, such as hindering decision making, concentration and participation in activities (APA, 2000; Wells, 2005). Stroke survivors have reported various anxious thoughts related to the consequences of stroke such as a fear that another stroke will occur (Clarke & Black, 2008), concern about the welfare of their caregiver (if applicable), apprehension around engaging in physical activities, negative evaluation from peers, interpersonal problems and a loss of control in their behaviour (NSF, 2007a).

Other emotional problems include general emotional lability characterised by outbursts of anger and irritability (Mukherjee et al., 2006; Teasdale & Engberg, 2005) or feelings of resentment towards other people or for the stroke occurring (Clarke & Black, 2005; Hochstenbach & Mulder, 1999). For example, stroke survivors may experience guilt or resentment towards their caregivers for assisting them (NSF, 2007a). Finally, changes in personality and behaviour can also occur, which are sometimes related to the cognitive impairments discussed above (particularly to executive dysfunction/frontal lobe damage). The stroke survivor can become more egocentric i.e. fail to respond appropriately to social cues, develop impulsive behaviour, and become agitated and impatient, especially in relation to change or unpredictability. Compulsive and inappropriate crying or laughing, or in contrast, emotional

bluntness and indifference can also occur (Hochstenbach & Mulder, 1999). Some researchers have argued that emotional reactivity has been associated with left-sided stroke whilst restricted affect expression is more likely to arise following right-sided stroke (Hochstenbach & Mulder, 1999; Lezak, 2004). However, these claims on stroke lesion location are debatable, and authors of an extensive systematic review in depression after stroke found no support for the claim that depression is influenced by the brain region in which the stroke damage occurred (Carson et al., 2000).

These emotional and behavioural changes can have a deleterious impact on stroke survivors' adjustment to, and recovery from stroke. Depressive symptoms in particular, have been associated with increased morbidity (House, Knapp, Bamford & Vail, 2001; Morris, Robinson, Andrzejewski, Samuels, & Price, 1993), reduced improvement in the physical functioning of everyday activities (Parikh et al., 1987) and reduced participation in meaningful activities (Van De Port et al., 2007). Finally, depression has also been found to be a significant predictor of poorer subjective health-related quality of life (HRQoL), (Hartman-Maeir, Soroker, Ring, Avni & Katz, 2007).

Quality of life refers to an individual's evaluation and satisfaction with various aspects of their life in the context of their goals and standards, while HRQoL refers to those areas that are affected by disease and illness (Sturm et al., 2004). HRQoL includes the domains of emotional and psychological health, independent functioning, physical health and social functioning (Pan, Song, Lee & Kwok, 2008). Like depression, poor HRQoL exists in a significant proportion of stroke survivors, with estimates of approximately 20 and 25% at 2 and 5 years, respectively, post stroke (Paul et al., 2005; Sturm et al., 2004). Depressive symptoms have in fact been associated with poorer scores in all domains of HRQoL at 16-months post stroke (Jönsson, Lindgren,

Hallström, Norrving & Lindgren., 2005) and up to two years post stroke (Sturm et al., 2004). Given that depression and HRQoL are highly correlated; many of the same factors outlined above for depression are also exhibited for HRQoL. Females, older stroke survivors (Sturm et al., 2004) and those with poorer functional status and social participation have been found to demonstrate poor HRQoL scores (Clarke & Black, 2005; Teasdale & Engberg, 2005). Other factors that have been associated with decreased HRQoL include anxiety, fatigue, cognitive impairments such as dementia (Visser-Meily, Rhebergen, Rinkel, van Zandvoort & Post, 2009b; Sturm et al., 2004), physical impairments and disability, institutionalisation, low socioeconomic status and markers of stroke severity such as neglect (Sturm et al., 2004). Improvements and deterioration in each of these HRQoL domains are not found to be consistent over time however. For example, some investigators have found that a stroke survivor's emotional and psychological health can improve over time, but physical functioning declines or is low (Jönsson et al., 2005; Patel et al., 2006), whilst others report the opposite (Visser-Meily et al., 2009b).

Understanding the effect of emotional and behavioural problems, as well as poor HRQoL on stroke recovery is required not only to inform and tailor effective rehabilitation programs (Visser-Meily et al., 2009b), but these pervasive consequences again underscore the importance of acknowledging the impact on caregivers who may be required to compensate for what may be less than optimal improvement in stroke survivors.

1.3.3.2 Activities, social isolation and interpersonal relationships

Investigators have shown that stroke survivors participate in drastically fewer recreation/leisure, social and family activities following their stroke (Teasdale & Engberg, 2005; Hommel et al., 2009; Young et al., 2003). These changes in social functioning can remain several months or

more since the time of stroke, and exist even in young stroke survivors with mild to moderate impairments (Hommel et al., 2009). In the elderly, activities are considerably more restricted compared to age-matched healthy populations (Hartman-Maeir et al., 2007). This reduction in activity can be due to various physical, psychosocial, and environmental factors (Young et al., 2003). That is, stroke survivors may have residual physical and motor disabilities which inhibit their ability to participate in activities previously enjoyed. In addition, emotional problems such as depression and anxiety or cognitive impairments such as executive problems may impede their motivation or capability to initiate action (Hommel et al., 2009).

Predominant activities that are compromised amongst stroke survivors are those associated with cognitive impairments (lack of concentration, aphasia, and memory deficits), such as employment. Many stroke survivors are unable to return to vocational work following a stroke or have to alter their schedule/workload, role complexity or work environment to accommodate for various residual disabilities. The literature on return to work rates with stroke survivors is inconsistent in relation to the methodologies used. The time point assessed since the stroke, the stroke population demographic information (such as age and stroke severity), as well as differences in the definitions used for “stroke” and “work” are evident. This has led to estimates of return to work rates to vary from 11% to 85% in stroke populations (Wozniak & Kittner, 2002). Although, investigators of a recent good quality population-based study found that approximately 47% of a sample of stroke survivors previously employed prior to the stroke had not resumed full-time work at 6 months post the stroke (Glozier, Hackett, Parag & Anderson, 2008). Several barriers to returning to work have been established in the research. The predominant factors include psychological problems experienced by the person with stroke such as depression, physical/medical problems (e.g. weakness, fatigue and diabetes) which not only

impeded practical abilities but also on self-confidence to carry out tasks, and increased stress levels at work (Alaszewski, Alaszewski, Potter & Penhale, 2007; Wozniak & Kittner, 2002). More specifically, job characteristics have included white collar vs. blue collar jobs, with stroke survivors in the former being more likely to return to employment (Wozniak & Kittner, 2002). Though not an exhaustive list, other stroke survivor characteristics that have been frequently posed as restrictions to returning to work include non-anglo-saxon ethnicity, engaging in part-time rather than full time employment before the stroke (Glozier et al., 2008), older age and a higher educational level (Wozniak & Kittner, 2002). In contrast, factors that facilitate an individual's return to work following stroke have been found to include a flexible work environment that allows for modifications in the job role, as well as supportive and understanding people in the stroke survivor's social network (e.g. employers), social interaction from work colleagues and financial responsibilities (Alaszewski et al., 2007). Other personal characteristics that have been found through more in-depth qualitative interviews, that serve as motivating factors to return to work include a resilient and stoic outlook on the situation, whereby the stroke survivor perceives returning to work as an indicator of recovery and returning to their pre-stroke level of functioning, and they refuse to allow the stroke to hinder their opportunity to work (Alaszewski et al., 2007).

The loss of employment activity and associated skills has been associated with a loss of personal identity (Alaszewski et al., 2007). This is due to the assertion that one's vocational position is essentially related to one's own sense of self and forms a large part of the role they play in their personal and social worlds (Mukherjee et al., 2006). Furthermore, feelings of boredom, and a loss of confidence, purpose and self-respect can also exist, because a large part of one's daily lifestyle and meaningful activity has been removed.

As a consequence of reduced or restricted activities, stroke survivors can feel isolated from social networks (Mukherjee et al., 2006; Haun et al., 2008; Young et al., 2003) and significantly dissatisfied with this aspect of their life (Hartman-Maeir et al., 2007). Such social isolation can lead to further negative effects on a stroke survivor's physical and mental health, and also presents the need for full time caregivers who can engage stroke survivors in activities and help improve their satisfaction and quality of life (Mayo, Wood-Dauphinee, Cote, Durcam, & Carlton, 2002).

Stroke survivors also experience changes in their relationships with those around them. These relationship shifts can occur as a result of factors already discussed above. Communication impairments, reduced participation in activities and social isolation can hinder already established relationships or the initiation of new relationships with people (Lamb, Buchanan, Godfrey, Harrison & Oakley, 2008; Mukherjee et al., 2006). There is also evidence that stroke survivors may feel discriminated against by other people in society or treated in a condescending way because of their medical condition (Mukherjee et al., 2006). This could then further distance them from engaging in fulfilling social relationships. Furthermore, medical problems that arise from a stroke can also impact on sexual relationships between the stroke survivor and their partner, who is often their caregiver (Young et al., 2001). Sex however has not received much attention in the stroke literature, perhaps because caregivers and stroke survivors may experience discomfort when interviewed about this topic (Hartman-Maeir et al., 2007).

Unfortunately the research into interpersonal changes following stroke has not been extensive, and there are inconsistencies in the findings. This is indicated by other research which has shown that stroke survivors reported becoming "closer" or more "connected" to their partner following the stroke (Haun et al., 2008), and that stroke survivors are highly satisfied with their

family and spousal relationships compared to other aspects of their life such as their vocational situation (Hartman-Maeir et al., 2007). Yet other investigators report relationships with family members did not significantly change over a 15-year period following stroke (Teasdale & Engberg, 2005).

Upon describing the long-term physical and functional, cognitive, and psychosocial consequences of stroke, and the difficulties many stroke survivors encounter in daily living, the extremely important and on-going role of caregivers is expressed, as they play a pivotal role in the long-term rehabilitation and recovery of stroke survivors (Anderson et al., 1995; Low, Payne & Roderick, 1999). This caregiving role can be quite stressful and it would be expected that such a role may place its own set of physical and psychosocial consequences on the stroke caregiver's wellbeing. Equally important then is understanding and exploring the impact of caregiving, not only because a caregiver's difficulties may influence the quality of care they are able to provide to the stroke survivor (Anderson et al., 1995), but because the numbers of stroke caregivers are large, and the associated personal difficulties are of utmost significance, from both a mental health and public health perspective.

1.4 Informal stroke caregivers

Although there has been an abundance of research focusing on the effects of stroke on survivors, relatively little attention has been paid to their primary informal caregivers (Han & Haley, 1999; Scolte op Reimer, de Haan, Rijinders, Limburg, & van den Bos, 1998; Smith, Lawrence, Kerr, Langhorne & Lees, 2004b). This is surprising given that an estimated 1 in 20 households across Australia contain an informal caregiver of some kind (Schofield, Herman, Bloch, Howe & 1997), and that caregivers play an important role in the welfare of the ill and

disabled (Al-Janabi, Coast & Flynn, 2008). In general though, it has been found that caregivers of people with various conditions undergo different types and levels of distress (Simon, Kumar & Kendrick, 2009).

As discussed earlier, the numbers of unpaid stroke caregivers, particularly for the care of older people, are expected to increase (Al-Janabi et al., 2008; Berecki-Gisolf et al., 2008). This is in addition to the increase in people having a stroke (and associated disability) due to aging western populations and government initiatives to move care into the community (Berecki-Gisolf et al., 2008; Dewey et al., 2001; NSF, 2007b) and the home, which will place increased responsibility on these informal caregivers (White, Lauzon, Yaffe & Wood-Dauphinee, 2004). Improvements in acute stroke treatment have also meant that there is a reduction in stroke mortality (Al-Janabi et al., 2008; Berecki-Gisolf et al., 2008), with the consequence being a larger proportion of people with stroke are indeed surviving, but with many of the residual disabilities discussed earlier, creating an even greater need for stroke caregivers.

Not only is the prevalence of stroke caregivers increasing, the great burden of caregiving following a stroke has been reported in some of the quantitative and qualitative stroke literature (e.g. Low et al., 1999). Stroke caregivers have been known to experience poorer emotional functioning compared to the general population (Low et al., 1999), middle-aged and elderly people (Han & Haley, 1999; Schulz, Tomkins & Rau, 1988; Simon et al., 2009), or caregivers of people suffering from other illnesses such as neurological disorders (Chow, Wong & Poon, 2007). Furthermore, stroke unlike some other health problems, occurs suddenly and is a long-term condition (Kerr & Smith, 2001; Simon et al., 2009), with potentially no certain end point for the caregiver. Arguably then, understanding the potentially unique experiences of stroke caregivers through further research is essential, rather than assuming all types of caregivers have

the same experiences. This will serve to not only help improve services for stroke survivors and their caregivers and decrease the need for long-term institutional care, but will also work towards reducing the physical and emotional burden placed on caregivers themselves through appropriate services.

While definitions of stroke caregivers can vary slightly across different research studies, for the purpose of this thesis an informal caregiver of someone with stroke, as based on previous literature (Dewey et al., 2002; Parag et al., 2008), is defined as someone who is:

- i. A spouse, child, other relative or friend of the stroke survivor
- ii. The primary unpaid caregiver
- iii. Caring for at least 3 months and,
- iv. Assisting this person with at least one major ADL.

Caregivers often enter into their roles unexpectedly, with little or no preparation (Kerr & Smith, 2001). Such responsibility can be very challenging, affecting the health and psychosocial functioning of the caregiver.

1.4.1 Psychosocial functioning

1.4.1.1 Emotional functioning and HRQoL

As with people who have experienced stroke, symptoms of depression, anxiety and other emotional problems are common in caregivers of stroke survivors, and are the most frequently researched of all emotional states (Hans & Haley, 1999). Depressive symptoms have also functioned as key indices of caregiver burden, distress and strain. The prevalence of caregiver depressive symptoms has been found to range from between 39-55% across various studies (Anderson et al., 1995; Berg et al., 2005; Dennis et al., 1998; Han & Haley, 1999; Kotila et al.,

1998). It has been suggested that caregivers of stroke survivors experience depressive symptoms during both the acute and chronic phases of stroke recovery (Han & Haley, 1999). Caregiver depression and distress during the acute phase of stroke recovery has been shown to predict continued depression and distress 6 (Schulz et al., 1988), 12 (Simon et al., 2009) and 18-months (Berg et al., 2005) post-stroke. Depressive symptoms are not only found to remain over the long-term but can also *increase* from 1 to 3 years after stroke (Visser-Meily et al., 2009b). This effect has been speculated to occur due to decreases in social contacts and relationship harmony with the stroke survivor (Visser-Meily et al., 2009b), although whether this is actually the case is uncertain. In addition, investigators of large scale longitudinal population-based studies have found significantly lower scores on measures of emotional wellbeing in caregivers compared to stroke survivors (Jönsson et al., 2005; Parag et al., 2008). Furthermore, these depressive symptoms can inadvertently influence the stroke survivor and their recovery process (Franzen-Dahlin et al., 2006; Mackenzie et al., 2007; Suh et al., 2005).

The reasons for this high prevalence of emotional difficulties is not sufficiently understood or explained in studies using quantitative methods. While there are several factors that have been associated with caregiver depression, few appear to be consistent across the literature. Although the physical, cognitive, emotional and behavioural state of stroke survivors has been fairly consistently associated with caregiver emotional wellbeing (e.g. Chow et al., 2007; Dennis et al., 1998; Haley et al., 2009; Kotila et al., 1998; van den Heuvel, de Witte, Schure, Sanderman & Meyboom-de Jong, 2001), other variables have been linked less reliably. See Table 2 below.

Table 2.
Factors Associated with Stroke Caregiver Depression Symptoms

Factor	Study
Greater or young age of the caregiver	Schulz et al., (1988); van den Heuvel et al., (2001), respectively
Greater age of the stroke survivor	Berg et al., (2005)
Female gender	Dennis et al.,(1998) Franzén-Dahlin et al.,(2006) van den Heuvel et al.,(2001)
Lower Socioeconomic Status	Han & Haley (1999) Schulz et al., (1988)
Poor caregiver-stroke survivor relationship	Han & Haley (1999)
Level of social interaction and support	Cumming, Cadilhac, Rubin, Crafti & Pearce (2008) Grant, Bartolucci, Elliot & Giger (2000) Grant, Weaver, Elliott, Bartolucci & Giger (2004 a & b) Han & Haley (1999) van den Heuvel et al., (2001)
Poor physical health status	Bugge, Alexander & Hagen (1999) Grant et al., (2000) Han & Haley., (1999) Schulz et al., (1988) van den Heuvel et al., (2001)
Greater time spent caregiving/amount of caregiving	Bugge et al., (1999) Han & Haley., (1999) Scolte op Reimer et al., (1998) Smith et al., (2004c)
Dissatisfaction with support services	Hodgson, Wood & Langton-Hewer (1996)
Poor problem solving/coping skills and preparedness	Grant et al., (2000) Haley et al., (2009) van den Heuvel et al., (2001) Visser-Meily et al., (2005b)

Other researchers have attempted to measure anxiety (Cumming, Cadilhac, Rubin, Crafti & Pearce, 2008). Authors of one population-based study found that approximately half their caregiver sample experienced feelings of anxiety (Anderson et al., 1995). Caregiver anxiety has been associated with the degree of the stroke survivor's physical and mental health (Chow et al., 2007; Schulz et al., 1988), and can involve a reluctance to leave the stroke survivor unattended in case they fall or have another stroke. Caregivers may also experience doubt in their own ability to cope with the physical constraints that caring for a stroke survivor entails (Anderson et al., 1995; Kerr & Smith, 2001; Schulz et al., 1988).

Unfortunately, the picture that is painted in the literature with regards to understanding emotional problems in caregivers is incomplete. First, there are few researchers investigating other emotional symptoms such as anger or irritability (Cumming et al., 2008). Second, and more importantly, an explanation for these symptoms, rather than a mere description and possible predictors of them, is lacking in the quantitative literature. Quantitative accounts can be considered overly simplistic when attempting to capture the rich experiences of stroke caregivers (Dowswell et al., 2000), and explanations underlying emotional functioning are arguably inconsistent and limited (Han & Haley, 1999; Low et al., 1999). Investigators of quantitative findings too often report the prevalence and predictors of particular symptoms as operationalised by scores on various scales. For example, take the case of the common finding that stroke survivor disability predicts poor caregiver emotional function (namely depression). There could be various different explanations for this association. Through qualitative interviews it may be found that the caregiver may be feeling depressed because they are empathising with the experienced loss of the stroke survivor, or because the disability has meant that the caregiver can no longer function in their usual activities which in turn impacts upon their own personal feelings

of inadequacy and social inclusion. There may be of course other major alternative explanations that could be uncovered within just this one example. Further, other researchers have found that females score higher on various outcomes such as caregiver burden (e.g. White, Mayo, Hanley & Wood-Dauphinee, 2003) and emotional and physical health compared to male caregivers (Dennis et al., 1998; Nieboer et al., 1998; Scolte, Richter, Frank & Wallesch, 2006). However, the reason why female stroke caregivers may cope differently from male caregivers is still unclear. These examples highlight the richness of data of personal stroke caregiver experiences that can be obtained when using qualitative studies.

Caregiver emotional problems have also been linked to poor satisfaction with life (Forstberg-Wärleby, Möller & Blomstrand, 2004; Gran et al., 2000; van den Heuvel et al., 2001; Visser-Meily, et al., 2005a) and low levels of QoL or HRQoL compared to normative data (e.g. Parag et al., 2008; White et al., 2004). As outlined in section 1.3, HRQoL is a broad term used to cover many domains in life that are affected by disease and is associated with stroke survivor characteristics such as disability and emotional/cognitive impairment (White et al., 2004) and age (McCullagh, Brigstocke, Donaldson, & Kalra, 2005); caregiver characteristics such as emotional functioning (White et al., 2004); age (Jönsson et al., 2005); gender-males being more satisfied than females (McCullagh et al., 2005); ability to use coping skills (Rochette, Bravo, Desrosiers, St-Cyr, & Bourget, 2007; Van Puymbroeck & Rittman, 2005; Visser-Meily et al., 2005a); confidence in caregiving ability (van den Heuvel et al., 2001; White et al., 2004); and level of caregiving burden (White et al., 2003). Other aspects such as changes in physical health, and environmental components which include employment status (where applicable), activities, social participation/support, interpersonal relationships and access and evaluation of health care

services (White et al., 2004) are also apparent. These physical and environmental characteristics will be outlined below.

1.4.1.2 Employment and financial strain

The caregiver role can lead to changes in employment as well as a substantial financial cost to the caregiver (Anderson et al., 1995; Brereton & Nolan, 2000; Dewey et al., 2002). It has been found in a recent large-scale longitudinal study surveying 9,857 mid-aged women in 2001 and 2004 that those providing care for someone ill, disabled or frail had reduced their participation in paid employment, after accounting for health and socio-economic status (Berecki et al., 2008). While there is some evidence for employment and financial problems for stroke survivors, there is a limited amount of research dedicated to their caregivers, despite poor income being associated with adverse caregiver outcomes such as depression (Schulz et al., 1988), an overall lower quality of life (White et al., 2004) and satisfaction (Forstberg-Wärleby et al., 2004). Nonetheless, it has been found that caregivers of stroke survivors experience financial stress, especially in circumstances when the stroke survivor was the primary wage earner (Anderson et al., 1995; White et al., 2004) or if they have to reduce their work hours or terminate employment, in order to take on the caregiver role (Anderson et al., 1995; Dewey et al., 2002).

Despite these findings, the way in which caregivers perceive these financial burdens and changes in employment, and how they impact on their emotional and psychosocial wellbeing, is still uncertain. It is not known whether employment changes and financial constraints, and ability to access formal services, affect the wellbeing and lifestyle of caregivers, their personal identity or the stroke survivor's recovery. Such insights are able to be uncovered via more open-ended lines of questioning.

1.4.1.3 Activities and social isolation

Caregivers can experience changes to various domestic, community, personal and leisure activities; predominantly leading to reduced social interaction and functioning (Anderson et al., 1995; Periard & Ames, 1993; Young et al., 2003), at levels significantly below age and sex matched norms (Scolte et al., 2006). Approximately 50% of caregivers of people with stroke report considerably less time for social or leisure activities such as holidays or outings with friends and family members (Parag et al., 2008). As well as reduced time, caregivers are either unable to or believe they cannot leave the stroke survivor home alone (Periard & Ames, 1993). Caregiver's dissatisfaction with their social contacts and leisure participation has also been found to remain at one year post stroke (Forstberg-Wärleby et al., 2004), as are reductions in the availability and quality of social support for the caregiver (Simon et al., 2009). Although, there is some evidence that this social functioning can improve by 18-months post-stroke (Parag et al., 2008), this finding is uncommon.

These changes in lifestyle, reduced social contact, and perceived decreases in the quality of social support have been linked with poor psychological and emotional health, such as symptoms of depression, anxiety, irritability and strain (Cumming et al., 2008; Simon et al., 2009). Feelings of isolation can also occur (Kerr & Smith, 2001; Schulz et al., 1988), as well as possible altered self-identity due to the suggestion that lifestyle and activities form a part of how individuals perceive themselves and their self worth (Periard & Ames, 1993). The themes of isolation and identity, however, are still quite underdeveloped within the stroke caregiver research, and the psychological and emotional impact of changes to lifestyle need to be examined further. In addition, older caregivers of stroke survivors, and males, may be more accepting of

these lifestyle changes than younger (Periard & Ames, 1993) or female caregivers (Parag et al., 2008), although, explanations for this are not yet known.

1.4.1.4 Interpersonal relationships

Caregivers have also reported less satisfaction with, and poor interpersonal relationships since becoming caregivers (e.g. Forstberg-Wärleby et al., 2004). Caregivers of spouses with a stroke report deterioration in the quality of the spousal relationship, experience reduced closeness, harmony and sexual intimacy, problems with conversation and communication, and report a lack of appreciation from their spouse for their efforts (Forstberg-Wärleby et al., 2004; Simon et al., 2009; White et al., 2004; Visser-Meily et al., 2005a/2009a). Caregivers can also experience a loss of companionship and support from the stroke survivor (White et al., 2004). A more harmonious relationship between the stroke survivor and their spousal caregiver has been associated with gender (being a male caregiver), not having young children, and caregiver support seeking and coping skills (active rather than a passive coping style) (Visser-Meily et al., 2005a/2009a). There is some evidence for improvements in spousal and family relationships (Schulz et al., 1988), but this finding is less common and will be discussed in section 1.4.3.

With regards to family functioning, conflict and tension with other family members may arise when the primary caregiver feels neglected and unsupported by other family members or alternatively, when other family members feel abandoned by the caregiver who may be focusing more of their attention on the stroke survivor (Anderson et al., 1995; Eaves, 2002; Periard & Ames, 1993). Caregivers may also inadvertently displace their anger and frustrations associated with caregiving onto other family members (Anderson et al., 1995). Caregivers have also

reported experiencing a distance between them and other family members, who visit them much less frequently than they did prior to taking on the caregiving role (Periard & Ames, 1993).

Stroke caregivers also report a more distant and less intimate relationship with friends, attending fewer social gatherings and receiving fewer visits (Periard & Ames, 1993), as well as no longer being able to discuss problems with confidants for fear of being a “burden” (Kerr & Smith, 2001; Schulz et al., 1988). With relation to the wider environment, problems between stroke caregivers and health professionals have also been reported (e.g. Eaves, 2002). More specifically, caregivers feel inadequately heard or supported by health professionals, often feeling isolated or that the focus is only on the stroke survivor’s health (Kerr & Smith, 2001). More detail regarding the efficacy of support services will be provided in section 1.5.

Notwithstanding the information outlined above, the determinants of stroke caregiver’s psychosocial functioning are still not completely understood, warranting the need for more exploratory, qualitative research (White et al., 2004). For example, while various factors have been associated with HRQoL as outlined earlier, the way in which these factors interact and affect each other is not always explained by quantitative research. One of these factors, social support, has a valuable effect on HRQoL but it is not clear if this is because it alleviates the caregiver’s emotional burden, gives the caregiver more time to focus on other tasks, or if there are other explanations (White et al, 2004).

1.4.2 Physical health

Relatively little is understood about the impact of caregiving for people with stroke on their physical health because very little research specifically elicits this information (Han & Haley, 1999). The impact of physical health on other emotional and psychosocial factors in the lives of caregivers of stroke survivors is also still unclear, given the lack of studies measuring the prevalence of physical health problems in stroke caregivers in comparison to a non caregiver control group (Han & Haley, 1999). This is likely to be important information, however, as the majority of caregivers are elderly partners of stroke survivors (Kerr, 2001; Smith et al., 2004c; Suh et al., 2005), who may in turn be suffering from chronic health conditions (Chow et al., 2007; Schulz et al., 1988). In addition, caregiving can place a physical burden on stroke caregivers (Kerr & Smith, 2001), as they are needed to undertake a greater amount of instrumental activity that was previously carried out by the stroke survivor. This can in turn potentially affect their self-reported physical health and ability to care.

The findings so far have been inconsistent, and the extent to which stroke caregiving leads to new medical problems or exacerbates pre-existing conditions prior to the stroke is uncertain. On the one hand, stroke caregiving has been associated with medical problems such as arthritis and interference with managing existing medical conditions (Anderson et al., 1995), and deterioration in self-reported physical health since becoming a caregiver (Chow et al., 2007) and over the course of a year post stroke (Scolte et al., 2006; Simon et al., 2009). Other researchers have also found that caregivers report having a lack of energy and vitality, sleep problems, headaches and fatigue even one to two years post stroke (Anderson et al., 1995; Kerr & Smith, 2001; Smith et al., 2004c; White et al., 2003), although to what extent these symptoms overlap with depression is not obvious. Authors of longitudinal studies suggest that the caregiver's

increasing age and depression levels predict their physical health status (Chow et al., 2007). Poor physical health has in turn been associated with increased rates of long-term depressive symptoms (Schulz et al., 1988) and may pose as one risk factor for long-term general wellbeing, although this finding was reported in only one study, with a small sample size (Hodgson et al., 1996).

Conversely, other researchers suggest little or no detrimental changes to physical health in association with caregiving (Parag et al., 2008; Smith et al., 2004c), that physical symptoms are not as problematic as emotional problems such as depression and anxiety (Williams, 1993), and that caregivers' physical health does not decline over time (Chow et al., 2007). Finally, in a recent study comparing stroke caregivers to matched non-caregivers, no significant differences in health status were found (Simon et al., 2009). Further exploration of caregivers' physical health is therefore warranted.

1.4.3 Positive caregiving experiences

Quantitative research has predominantly focused on the negative impact of caregiving following a stroke (e.g. Parag et al., 2008), usually neglecting the benefits of the caregiving role. Nevertheless, the experience of caregiving is very complex and varies across individuals. Some investigators demonstrate the benefits of caring for someone with a medical illness in general (Brouwer, Van Exel, Van Den Berg, Van Den Bos, & Koopmanscap, 2005), and more specifically with stroke (Johnson, 1998). Experiencing positive outcomes and enjoyment from the process of caregiving can be influenced by the individual's appraisal of the caregiving situation as well as the amount of objective burden, i.e. the number of hours spent caregiving (Hilgeman, Allen, DeCoster & Burgio, 2007). Lower anxiety, perceived difficulty with the

changes in the care recipient's behaviour and lower socioeconomic status have also been connected with increased positive subjective associations with caregiving for people with Alzheimer's disease (Roff et al., 2004).

With particular regard to stroke caregivers, there is evidence of caregiver satisfaction with life and positive feelings about their role as a caregiver (Han & Haley, 1999; Parag et al., 2008). For example, as stated earlier, interpersonal relationships between caregivers and the stroke survivor (predominantly the marital relationship) can improve following a stroke, whereby the caregiver and stroke survivor become closer (Schulz et al., 1988; Parag et al., 2008 Periard & Ames, 1993). This may occur following increased time spent together (Schulz et al., 1988). Relationships with other family members may also become closer (White et al., 2004). In addition, caregiving can allow individuals to value life and its meaning more, feel appreciated, and have a greater level of self-esteem (e.g. feeling more confident and useful) (Haley et al., 2009).

If factors associated with a positive outlook on caregiving are identified, they could be incorporated into caregiver intervention programs (Roff et al., 2004). Becoming aware of the benefits of caregiving and adopting a less negative perspective on the situation is argued to be a potentially valuable coping tool (Haley et al., 2009).

1.4.4 Qualitative findings of stroke caregivers

A meagre amount of research has been conducted using qualitative methods to explore in a more in-depth manner, the nature and themes associated with caregivers' emotional and psychological experiences following a family member's stroke. The main findings outlined in the available literature centre around three main areas.

1. Preparation and professional support.

“I mean they just put him out of the hospital and that was it more or less...no one seemed to care how we were getting on” (Kerr & Smith, 2001, p.433)

Caregivers have reported a lack of confidence when carrying out the caregiver role. Caregivers often feel ill-prepared and inadequately informed and supported by health and financial services, following the stroke survivor’s hospital discharge. Caregivers frequently felt they lacked the information needed to understand the nature and prognosis of stroke (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002; Brereton & Nolan, 2000), claiming that they have to persist, often “go it alone”, and take the initiative to find their own resources and services (Smith et al., 2004b). Caregivers have also expressed fear that they are not sufficiently trained to care for the stroke survivor in the home effectively, and that as a result negative consequences such as a future stroke or falls may occur (Bakas et al., 2002; Kerr & Smith, 2001).

2. Adjustments to changes in the caregiver’s life and personal self.

“It’s like a life sentence with no remission, that’s how bad it is” (Kerr & Smith, 2001, p.433).

Caregivers have reported an emotional and physical toll when observing the changes in their loved one and with managing the ongoing nature of caregiving which can include an array of appointments, transport and home care (Bakas et al., 2002; Smith et al., 2004b). Problems managing anxiety and depressive symptoms and associated somatic problems such as poor sleep

are often conveyed, and feelings of guilt may also arise when the caregiver has to divide their limited time between the caregiver and other commitments such as children or paid employment (Kerr & Smith, 2001). The theme of loss is often highlighted in interviews; this loss is usually in relation to loss of their healthy partner/family member, future retirement dreams, independence with leisure/recreation activities or social relationships (Dowswell et al., 2000). Finally, struggles with balancing all their demands (Pierce, Steiner, Hicks, & Holzaepfel, 2006) and the changes in roles were also an issue for caregivers, whereby caregivers took on new roles and additional responsibilities (Smith et al., 2004b).

3. Adjustments to changes in the stroke survivor

“We’ve got to watch him. He’s told us that he just doesn’t want to live like this. I don’t know how else to say it. It’s horrible. He cried. My dad don’t cry” (Bakas et al., 2002, p.247).

Caregivers have also reported concerns and problems when dealing with the changed behaviour, emotional functioning (e.g. lability), personality (e.g. becoming short-tempered) and altered health of the stroke survivor. Caregivers can feel helpless and often need guidance in how to manage these changes (Bakas et al., 2002). Conflict can arise when dealing with the stroke survivor’s lack of appreciation and motivation for participating in physical and social activities, their anger outbursts, and large amounts of sleeping, particularly because these behaviours were viewed as either the stroke survivor’s fault or indications of “laziness” (Bakas et al., 2002; Smith et al., 2004b). In addition, similar to the quantitative research findings, caregivers express concerns that if stroke survivors are not participating in physical and speech therapy adequately,

their health may worsen (e.g. continued seizures or a recurrent stroke) (Bakas et al., 2002; Pierce et al., 2006). Difficulties dealing with the stroke survivor's diminished communication, mobility, confidence, tolerance of noise and crowds, and refusal to leave the house can also develop (Bakas et al., 2002; Smith et al., 2004b). Problems managing the physical and instrumental (e.g. managing finances or organising transport) care of the stroke survivor are also prevalent (Bakas et al., 2002). Finally, caregivers felt their spouse was a completely different person who could no longer provide them with emotional support (Smith et al., 2004b).

Unfortunately, qualitative findings result from a very small body of literature. The investigators of these studies usually list themes without providing great detail or explanation of each theme. A theme is defined as something that captures an essential and meaningful pattern of responses found within and across data sets (Braun & Clark, 2006). The title of themes are conceptual and typically utilise psychological terminology (Willig, 2001), such as the theme 'loss' (Dowswell et al., 2000). In addition, the applicability of the available findings to the stroke caregiver population is questionable. Some studies use what even by quantitative research standards would be considered small samples (e.g. N=9) (Bakas et al., 2002; Dowswell et al., 2000; Pierce et al., 2006), while others recruit convenience samples of caregivers of mostly anglo-saxon origin or who were already participating in a caregiver education and support intervention (Pierce et al., 2006). One study (Smith et al., 2004b) that did use a very large sample size (N=90), conducted the caregiver interviews in the presence of the stroke survivor which may have influenced the caregivers' responses. Personal and emotional changes for the caregiver were also not specifically targeted in this study, limiting the understanding of caregivers' personal needs and beliefs. Further, most studies have limited sample populations, for instance, Bakas et al., (2002) focused on spousal caregivers only who were all female from either an African

American or anglo-saxon background, who were all from a low SES and caregiving in the short-term (6 months).

Finally, the investigators of all the qualitative stroke caregiver studies reviewed fail to detail their method of qualitative data saturation, merely reporting that interviews continued until themes were saturated, i.e. no new information was generated (e.g. Bakas et al., 2002). Therefore, it is unclear whether the whole representation of caregiver experiences has indeed been captured. The reliability of the findings may also be questioned given that most of the investigators did not consistently use the same interviewer across their study.

Understanding caregivers' needs and beliefs is necessary if effective interventions are to be implemented for caregivers (Bakas et al., 2002). Furthermore, future researchers need to recruit caregivers from different ethnic and cultural backgrounds, and over longer time periods as opposed to just the initial months of caregiving (Pierce et al., 2006). So, any conclusive statements about caregivers' personal experiences, general themes and the relationship between these themes at this point in time cannot be made.

1.5 Support services and interventions

The significant cognitive, physical and psychosocial effects of stroke, on both survivors and their caregivers, have been described. It is known that stroke survivors and caregivers can affect each other in terms of adjustment and wellbeing (Suh et al., 2005). Therefore, services that assist stroke survivors and their caregivers are essential and would also generate optimal stroke recovery (Han & Haley, 1999). Evaluating such support services has been an important area of the stroke caregiver research.

Support services can be categorised into four broad categories (Visser-Meily et al., 2005b):

- i. The provision of tangible specialist stroke services such as stroke nursing care, physiotherapy, occupational therapy, speech pathology, aids, and respite care
- ii. Information about the nature of stroke, risk factors, the available community services and caregiver instrumental stroke care training
- iii. Supportive counselling and psychological services
- iv. Group social support

1.5.1 Specialist stroke services

The provision of instrumental support, such as occupational therapy, physiotherapy, and nursing stroke care workers, has been perceived as beneficial by stroke survivors, as they encourage returning to activities and functioning that were lost following stroke (Clarke & Black, 2005), and can even lower caregiver depression symptoms (Kotila et al., 1998). Services which provide families with a paid stroke support worker have been found to increase knowledge of how to care for someone with stroke and facilitate satisfaction with that knowledge and the care provided, but do not necessarily improve the health status and psychosocial functioning of caregivers (e.g. mood, levels of strain and independence with daily activities) (Dennis et al., 1998; Mant, Carter, Wade & Winner, 2000; Lincoln, Francis, Liley, Sharma & Summerfield, 2003; Rodgers et al., 1999). In another trial providing nursing care (Forster & Young, 1996), no significant differences between the intervention and control group on stroke survivor functional ability, health status, social activity, or caregiver stress on a battery of measures were found. Investigators therefore highlight the need to address other dimensions of support such as information, psychological, and social provisions (Young et al., 2003).

1.5.2 Information provision and training

RCTs evaluating stroke information programs have generated mixed results. Information programs can include knowledge about stroke, the effects of a stroke, how to reduce stroke recurrence and increase awareness of available services (e.g. Lee, Soeken & Picot, 2007). Investigators of one RCT found no significant difference between the intervention and control group on stroke recovery or emotional functioning for caregivers at 6-month follow up (Rodgers et al., 1999). Further, while the caregivers in the intervention group felt more informed and satisfied with the information provided (Rodgers et al., 1999) and scored higher on social functioning measures than controls, the effects were small (Rodgers et al., 1999). In contrast, other researchers did not find a difference in caregiver or stroke survivor satisfaction with information received, between intervention and control groups (Mant et al., 1998). Increased knowledge has also been cited to help reduce anxiety symptoms in stroke survivors (Smith, Forster & Young, 2004a). Overall though, increased knowledge does not in itself improve the emotional, social or physical wellbeing of caregivers and stroke survivors, or the recovery of stroke survivors (Forster et al., 2001; Kalra et al., 2004; Mant et al., 1998; Smith et al., 2004a).

Providing stroke education and training to caregivers in the form of face-to-face contact has been found to be more helpful than written materials (Bhogal, Teasell, Foley & Speechley, 2003; Forster et al., 2001). Training caregivers in nursing and personal stroke care techniques (e.g. lifting and handling of the stroke patient) prior to hospital discharge has reduced caregiver and stroke survivor anxiety and depression, and improved quality of life. At the same time public health costs were lowered in the long term (Kalra et al., 2004), though, effects were only modest.

1.5.3 Psychological services

Counselling and psychological programs, which focus on teaching psychological coping strategies such as relaxation, cognitive restructuring and problem solving to reduce distress, have demonstrated some promising results (King, Hartke & Denby, 2007; Visser-Meily et al., 2005b). Depression, anxiety and caregiver preparedness levels have been shown to improve in some studies (e.g. King et al., 2007), but unfortunately the research in this area is very limited and inconclusive. For example, one RCT combined a stroke information package with three counselling sessions over a 6-month period and authors found improvements in family functioning for stroke survivors and caregivers, and functional status in stroke survivors compared to the control group. However, there were no significant differences in caregiver or stroke survivor depression, anxiety or health levels (Clark, Rubenach & Winsor, 2003). Further, such multidimensional approaches make it difficult to ascertain which component is responsible for the observed outcomes.

Community services tend to focus on physical care for the stroke survivor and overlook the caregiver's need for support and education around managing the behavioural and emotional problems of the stroke survivor, or their own emotional, social and relationship difficulties (Anderson et al., 1995; Simon, Kumar & Kendrick, 2008). This is unfortunate as help managing the emotional and behavioural changes in the stroke survivor has been cited as one of the most important and frequent needs raised by caregivers (e.g. Bakas et al., 2002). The situation is made more problematic for the caregiver as they may not always initiate support from family, friends or their General Practitioner, for fear of burdening them or appearing incompetent (Anderson et al., 1995).

1.5.4 Support groups

Virtually no researchers have investigated the effect of support groups on improving the wellbeing of caregivers (Visser-Meily et al., 2005b). In one study it was found that whilst involvement in a stroke club was said to provide some friendship and emotional support for caregivers, there were no significant differences on outcome measures of caregiver burden and emotional functioning compared to caregivers not involved in the stroke club (Printz-Feddersen, 1990). Given the association between social support and positive caregiver outcomes (e.g. Cumming et al., 2008), this is an avenue that merits further study.

Investigators of a small number of studies have reported positive intervention outcomes in some domains such as knowledge about stroke, caregiver emotional functioning, and stroke survivor functional status. There is also some evidence that stroke survivors and caregivers are satisfied with the support services and interventions accessed (e.g., Clarke & Black, 2005; Simon et al., 2008; van der Smagt-Duijnste, Hamers, Abu-Saad & Zuidhof, 2001; Young et al., 2003), for example in terms of increasing instrumental daily functioning in stroke survivors via occupational therapy (Clarke & Black, 2005).

In summary, the majority of investigators evaluating interventions for caregivers and stroke survivors have found unpromising results, and a significant proportion of caregivers feel dissatisfied with the amount of preparation and lack of assessment of their competence before hospital discharge (Smith et al., 2004a). As previously stated, communication between caregiver and health professionals has also been cited as inadequate (Tyson & Turner, 2000). Information about stroke and access to appropriate community support services has also been insufficient, and discontent with the quality, quantity, and the timing of services that are received has been expressed (Eaves, 2002; Kerr & Smith, 2001; Smith et al., 2004a). More specifically, information

about the general nature, consequences and prognosis of stroke, and access to practical stroke support and home respite care, where the caregiver can abrogate their caregiving responsibility to someone else for a period of time, appear to be lacking (Greveson & James, 1991; Kerr & Smith, 2001; Mackenzie et al., 2007; McKeivitt et al., 2004; Rodgers, Francis, Brittain & Robinson., 2007; Smith et al., 2004a; Simon & Kendrick, 2002; Wellwood, Dennis & Warlow, 1995). Even a large proportion of stroke health professionals in one study reported that they rarely provided information to stroke survivors and caregivers, and that when the information was provided, it was usually insufficient (Hoffman, McKenna, Herd & Wearing, 2007). Caregivers consequently report feeling unheard by health professionals, and experience isolation and abandonment post-discharge (Smith et al., 2004b).

Insufficient financial or emotional support has also been reported (Kerr & Smith, 2001). It has been argued that addressing the psychological and emotional needs of stroke survivors and their caregivers is necessary for other services (such as respite, rehabilitation services and information provision) to have a positive impact (Carnwath & Johnson, 1987; Han & Haley, 1999). Unfortunately, as stated earlier the provision of many services is based on the physical and cognitive functioning of the stroke survivor (Anderson et al., 1995; McCullagh et al., 2005), and so psychological support to help improve the emotional functioning and quality of life for caregivers is scarce (Simon et al., 2008). Additionally, most stroke survivors and caregivers suffering from depression and distress rarely access or seek any treatment (Hackett et al., 2008; Kotila et al., 1998; Young et al., 2003), demonstrating the need for health professionals to be more pro-active in promoting such participation in these services. When services are received, this is often only following the request and persistence of the caregiver (Brereton & Nolan, 2000; Smith et al., 2004b), and there is often a delay in the provision of services such as aids for the

home, leading to decreased stroke survivor independence and increased caregiver burden (Kerr & Smith, 2001).

So, it is clear that to date, there is inconsistent evidence regarding the efficacy of available services with investigators showing that stroke survivors and their caregivers exhibit both positive but predominantly negative perceptions and experiences (e.g. Lamb et al., 2008; Visser-Meily et al., 2005b). Furthermore, the factors that comprise effective interventions for caregivers, especially in relation to managing affective symptoms, remain elusive (Dennis et al., 1998; Forster & Young, 1996; Hackett & Anderson, 2006; Low et al., 1999; Parag et al., 2008). Therefore, before any of these types of premature recommendations can be implemented and assessed, gauging the lived experiences of caregivers, and more thoroughly addressing caregiver factors such as their needs, concerns, emotional functioning and HRQoL is required via qualitative research (White et al., 2004), and will assist in better understanding caregivers, improve discharge planning and service provision, and reduce their level of burden (Bugge et al., 1999; Dennis et al., 1998; Franzen-Dahlin et al., 2006; Han & Haley, 1999; Lui, Ross & Thompson, 2005; Parag et al., 2008; Scolte op Reimer et al., 1998). The necessity for this research has been highlighted several times in the existing caregiver literature (e.g. McCullagh et al., 2005; Visser-Meily et al., 2005b), and is one of the key priorities outlined by the NSF's clinical guidelines for stroke rehabilitation and recovery (NSF, 2005). Unfortunately, the qualitative research available is parsimonious; that is, information is only gathered from caregivers when exploring perceptions, needs and evaluations of support (Kerr & Smith, 2001). Hence, conducting qualitative research that uses the method of triangulation, which entails eliciting the same information from multiple sources, by also interviewing stroke survivors'

views of their caregivers' experiences, would serve as a valuable contribution to the existing research base.

In addition, as previously discussed, the current body of evidence is still predominantly quantitative in nature, and the summarised criticisms concluded that:

- Most standardised measures fail to capture the multidimensional nature and complexity that comprises caregiver experiences and,
- Quantitative methods may also be biased towards only measuring particular dependent variables that relate to the author's pre-existing hypotheses and assumptions, thus potentially missing other important information about caregivers (Dowswell et al., 2000).

1.6 Qualitative Research

Qualitative research complements quantitative research, and is an effective method of achieving a rich understanding of caregiver needs and experiences. Qualitative research allows caregivers to elaborate on their experiences and shed light onto the underlying processes and reasons behind dissatisfaction and perceived needs (Clarke & Black, 2005; Kerr & Smith, 2001; McKeivitt et al., 2004; Simon et al., 2008). This is particularly essential, given the established inadequacies of stroke caregiver support services and interventions, and the relative neglect of incorporating caregiver needs when developing health services (Kerr & Smith, 2001; Simon et al., 2008).

In general, qualitative research is used in psychology when investigating human phenomenon which are still poorly understood, and is an important first step towards the generation of particular theories or models (Strauss & Corbin, 1990). Qualitative research allows

a rich in-depth exploration of the complex and multifaceted issues that underlie human experiences and actions, how people understand and what they think about their subjective experiences, as well as their related behaviours and interactions with others (e.g. Banister, Parker, Taylor & Tindall, 1994; Creswell, 1998). Qualitative methods generate data within “natural settings” using *open-ended questioning* techniques. Words, themes and concepts, rather than numbers, are analysed in various ways (Priest, Roberts & Woods, 2002). In this way, qualitative research generally generates hypotheses rather than testing them. When the understanding of a particular phenomenon increases, more specific questions, hypotheses and theories can *then* be formulated. These can then be tested using quantitative methods (Leedy & Ormrod, 2005).

1.6.1 Types of qualitative research methods

There are various forms of qualitative research approaches. Some of the most common include:

1. Case studies, which focus on understanding the experiences of a very small number of people, collecting data via interviews, observation or other material and categorising data into common themes that emerge. A case study could involve tracking the experiences of an individual who has had a stroke. However, this method lacks the sample size, even for qualitative standards, to make complex conclusions about a particular group of people.
2. Ethnography, which focuses on behaviours within a particular culture and group, collects data via interviews, observations, other documents or artefacts found within the natural setting. Data are then used to identify norms, beliefs, social patterns and structure within the defined group. An ethnographic study could be as complex as investigating a large cultural group or as specific as observing the intravenous drug errors made by nurses

(Taxis & Barber, 2003). This approach hence lends itself to analysing social settings and processes as opposed to the psychological experiences of individuals.

3. Phenomenological studies investigate different peoples' perceptions of their experiences of a particular phenomenon via in-depth semi or unstructured interviews with a purposively selected group of individuals, i.e. participants are intentionally selected who share a common characteristic of research interest (Bowling, 2002). Data from these multiple perspectives are then consolidated and used to convey the various perspectives among and between individuals within this particular group. Information is synthesised into categories and common themes to convey a general description of peoples' "typical" experiences (Leedy & Ormrod, 2005; Willig, 2001). For instance, studying the experiences and cognitions of people caring for someone with a chronic illness is a form of phenomenological inquiry.
4. Grounded theory constructs a theory about the process of a particular topic, such as an individual's experiences of undergoing medical treatment for illnesses such as cancer (Schou & Hewison, 1998). This method is different to the phenomenological approach as it involves conducting research with relatively little or no knowledge of the research area in question prior to data collection (Straus & Corbin, 1990). The analysis of data, however, is very similar to the phenomenological approach. Data are categorised into themes in an ongoing manner based on interview or other material collected about peoples' perspectives on the process itself.
5. Content analysis of data sets involves coding predetermined characteristics when analysing different types of human communication (e.g. analysing verbal and visual material and documents such as newspaper articles). These coded items within the

material are then analysed using descriptive or inferential statistics, whereby the frequency of particular statements are counted (Leedy & Ormord, 2005; Priest et al., 2002). This method of analysis can be applied to various types of written material, such as understanding the ways in which nurses report helping patients quit smoking (Woods, Priest & Roberts, 2002). Content analysis however, serves to quantify the frequency of comments made within data, rather than exploring the relationships between themes and issues with the data.

6. Narrative analysis involves interpreting individual transcripts in terms of a respondent's 'story'. This story or narrative explains an event with a temporal sequence that contains a beginning, middle and end (Woods et al., 2002). The interviewer's comments and other unnecessary words are deleted and themes/subplots are then identified (Woods et al., 2002). One difficulty with narrative analysis is that it is open to numerous interpretations in relation to the structure and meaning of stories. This is compounded by the fact that story structure and grammar vary across cultures. The credibility of narrative analysis as a psychological research method has therefore been questioned (Woods et al., 2002). In addition, narratives are usually associated with unstructured interviews (Priest et al., 2002) and recall external events that a respondent has experienced (Eaves, 2002), as opposed to focusing on the psychological internal experiences.

Upon consideration of the different types of qualitative methods above, the phenomenological approach was considered to be the most appropriate for this study. One example of this approach is known as Interpretive Phenomenological Analysis (IPA; Braun & Clarke, 2006; Giorgi & Giorgi, 2003; Willig, 2001). IPA is an effective form of qualitative analysis technique developed over a decade ago, which uses the method of thematic analysis to

interpret data (Braun & Clarke, 2006), and is commonly used in the field of health psychology (Smith, Flowers & Osborn, 1997; Willig, 2001). IPA is derived from the Grounded Theory method of qualitative research (Willig, 2001). Grounded Theory and IPA are similar in that they both involve the systematic analysis of data to evaluate a person and group's views on particular phenomena by identifying different levels of themes and categories that emerge from the data. The main difference between the two methods, however, is that IPA was established as a specifically psychologically-oriented research method that serves to explore peoples' psychological and cognitive worlds, whereas Grounded Theory has traditionally been geared towards exploring social processes within the field of social sciences (Willig, 2001). In addition, while Grounded Theory is older and better known than IPA, to date, the technique has been fraught with much debate as to how it is to be conducted, with different versions emerging, and no one version confirmed (e.g. Glaser, 1992; Straus & Corbin, 1990; Willig, 2001). IPA, on the other hand, has managed to avoid such problems (Willig, 2001). Furthermore, in order to conduct Straus & Corbin's traditional Grounded Theory the researcher needs to begin the research in a significantly barren field of inquiry, enter such investigation with virtually no knowledge of any relevant literature (if this literature is available), and devote a large amount of time and potential participant sample pool in order to continue data collection and saturate every possible dimension of information at the specific category level until a theory is developed. This saturation may also involve collecting data from the same participant at different time points. This type of extensive research and theory development, however, was beyond the scope of the current study and was possibly unnecessary as there is an existing, albeit limited, body of knowledge. Moreover, while many researchers claim they are conducting Grounded Theory, upon careful consideration of their methodology it is usually found that they are actually conducting thematic analysis

techniques similar to IPA. For example, Haun et al., (2008) comprehensively examined stroke survivors' feelings of isolation and social connection. However, they claimed to use the Grounded Theory approach, but did not specify which version they used, nor did they interview participants at multiple times, selectively sample participants to complete gaps in the concepts and categories, or develop a theory, as outlined by Straus & Corbin's (1990) version of Grounded Theory.

1.6.2 Data collection methods

Data collection through qualitative interviews is either carried out via individual or focus group face-to-face interviews that can be unstructured or semi-structured. Unstructured interviews contain no fixed questions or precodes. In this way, they are different from what is generally found in a questionnaire or self report measure. On the other hand, semi-structured interviews are typically used when more specific information is required. Using this method, the interviewer guides the interview on the topic of interest through the use of specific, open-ended questions that strongly tie into the research questions or aims (Bowling, 2002). Including carefully formulated open-ended questions in the interview guide rather than mere topic headings is important for maintaining an open and less directive line of questioning, in keeping with the nature of qualitative methodology (Willig, 2001). Further, these interview questions should be used flexibly, and where appropriate, the language style of the interviewee adopted, and their own comments re-stated and incorporated into further questioning. This serves to increase rapport in interviews, check for understanding of the interviewees' responses and maintain flow (Banister et al., 1994; Willig, 2001).

Both unstructured and semi structured interviews enable researchers to gather in-depth, meaning-rich information, in a more objective, unbiased and explorative way compared to structured questionnaires (Bowling, 2002). Semi-structured interviews, however, are argued to be the most adequate form of data collection in scientific research as they ensure a level of consistency while at the same time permitting participants to discuss the concerns and experiences that are important and relevant to them (Atkin, Twigg & Perring, 1990). This type of valuable information may be overlooked in standard, pre-coded questionnaires that ask people to rate their experiences. Not only can complex issues be investigated, respondents' answers can be clarified at the time of collection, and the informal atmosphere may serve to facilitate openness to sensitive issues. This format may also serendipitously identify important issues and themes that have not previously been highlighted in the literature (Bowling, 2002).

1.6.3 Data analysis methods

Data analysis can be carried out via manual coding procedures or computer packages such as NVivo (QSR, 2008). Manual approaches are usually appropriate with small data sets and usually involve the cutting and pasting of sections of text into Microsoft Excel or Word files which are then filed into particular categories (Bowling, 2002), often by tabulating the information. Within computer software programs, raw transcripts are entered from an associated word processing file. The data are then stored and categorised using short labels into "nodes" which are akin to theme names. Following this marking of themes, analysis is then carried out by the program using a series of queries, searches and other operations. The operations that are carried out by manual and computer programs are the same and therefore either method is

satisfactory. Although manual procedures take longer, they allow the researcher to be “closer” and more interactive with their data (Bowling, 2002).

There are two main types of coding; inductive, bottom-up coding and theoretical/deductive, top-down coding. Inductive coding refers to coding data without attempting to fit that data into a pre-existing coding system that is based on an existing theoretical framework. This approach is data-driven and is similar to grounded theory data analysis approaches (e.g. Strauss & Corbin, 1990). In contrast, theoretical coding refers to purposely coding and identifying data that are specific to the research questions, and is more heavily based on the researcher’s theoretical interests than an inductive approach (Braun & Clarke, 2006).

In terms of writing up results after coding, there are several important constituents that form a phenomenon/research topic. In phenomenological analysis the essential factors and themes are summarised to portray the general structure of the research topic, in this case the typical experiences of stroke caregivers. The relationship between these constituents is also reported (Braun & Clarke, 2006; Giorgi & Giorgi, 2003).

1.6.4 Assessing qualitative research

Qualitative research can be assessed on various dimensions including:

- Theoretical rigour: Clarification and justification
- Procedural rigour
- Representativeness
- Interpretative rigour
- Reflexivity and evaluative rigour
- Transferability and conceptual generalisability

Theoretical rigour refers to the appropriate choice of research methods that best answer the research questions. Therefore, there is a need to clearly outline the research questions and aims, while also providing an adequate explanation of why qualitative research in general, and the particular research design more specifically, were chosen (Kitto, Chesters & Grbich, 2008).

Procedural rigour is shown by clearly describing and making transparent the techniques of data collection and analysis including how participants were chosen, the duration of interviews and questions asked and how data were recorded and subsequently coded (Kitto et al., 2008).

Representativeness involves utilising sampling techniques that ensure conceptual generalisability (relevance and transferability) of the results to wider research and practical contexts. Sampling refers to the method by which data sources (usually people) are selected, and is predominantly nonrandom in qualitative research (Leedy & Ormrod, 2005). Sampling techniques that ensure conceptual generalisability can include ‘maximum variation sampling’ which involves recruiting participants with diverse characteristics in order to generate information that comprehensively covers the research topic, or ‘purposive sampling’ that selects a homogenous group of individuals who share a particular characteristic that is imperative to the research question, for example, caregivers of stroke survivors (Bowling, 2002; Kitto et al., 2008). Also, ‘theoretical sampling’ involves the continuation of sampling in conjunction with ongoing coding and analysis until no new issues or themes emerge from the data. In this way, the exact number of participants depends upon when the *saturation* of themes are established (Bowling, 2002). This process of saturation will be discussed in more detail in section 2.4.

Interpretive rigour relates to the quality and comprehensiveness of the information reported and usually refers to the concepts of validity and reliability. Validity relates to how accurately the findings reported actually represent the phenomena under investigation (e.g.

Silverman & Marvasti, 2008). A comprehensive and systematic analysis of data is also required to ensure good validity (Silverman & Marvasti, 2008). This is shown by analysing all data line by line ensuring no important information is overlooked. The constant comparative method can also be used (Silverman & Marvasti, 2008; Strauss & Corbin, 1990). This refers to analysing the same data several times in an iterative process, ensuring that all data transcripts and seemingly conflicting findings or deviant cases are acknowledged and accounted for. Including verbatim accounts of caregivers' and stroke survivors' experiences is also another way of enhancing the validity of inferences and conclusions made. Finally, 'data and theoretical triangulation' are important factors that enhance the validity and credibility of the research findings. 'Data triangulation' involves investigating the same issue from a variety of perspectives by comparing "multiple data sources in search of common themes" (Leedy & Ormrod, 2005, p.100). 'Theoretical triangulation' relates to formulating a conceptual understanding of the data by applying different theories and models to the research findings which can increase the comprehensive understanding of the research topic in question (Kitto et al., 2008).

Reliability relates to the level of consistency of findings generated across different time points or observers (Silverman & Marvasti, 2008). Reliability can be obtained by using an independent coder or re-interviewing participants, if feasible (Silverman & Marvasti, 2008).

Reflexivity and evaluative rigour involve acknowledging the effect the researcher's own biases and research method may have on the findings, and the ethical issues associated with the research process. Discussing the transferability and clinical and practical implications of the findings to the wider research field, policy and practice is also an essential element of qualitative research methods (Green & Thorogood, 2004).

1.7 Overall summary

Stroke is a serious illness that leaves one third of survivors with permanent physical and cognitive disabilities and often many psychosocial problems. It appears that caring for someone following stroke can have a predominantly negative impact on the caregiver. In addition, the number of stroke survivors and caregivers is likely to increase. Providing caregivers with effective support would be important in improving their quality of life as well as that of the stroke survivor. Unfortunately, present interventions and support programs have been found to be suboptimal, and caregivers often feel unheard and dissatisfied with the support they receive (if any) following the stroke survivor's discharge from hospital. This is because stroke and caregiving is a multifaceted and complicated process whereby physical and psychosocial factors are inter-related. The relationships between these factors are still not clearly delineated (Dowswell et al., 2000) and there still appears to be a gap in understanding the full range of caregiver experiences, needs and evaluations of services. Selecting appropriate and sensitive measures and methods that explore these relationships is also difficult (Dowswell et al., 2000).

Based on the current literature, important topics for research in the stroke caregiver field are:

1. Encouraging caregivers to report on all areas of life that occur following stroke. Much of the stroke caregiver research has focused on depressive functioning with relatively little investigation into other important areas such as anxiety and anger, physical functioning and psychosocial aspects such as the effects of employment changes on the caregiver's subjective wellbeing (Low et al., 1999). The positive effects of informal caregiving are also less commonly explored (Hans & Haley, 1999).

2. Understanding the different ways men and women respond. Some literature provides evidence that women experience greater caregiver burden (e.g. depression and anxiety) than men (Dennis et al., 1998; Franzen-Dahlin et al., 2006; Hirst, 2005). However, this evidence is descriptive; that is, it merely states that there is a significant difference between men and women as manifested in scores from standardised measures. The explanation for this difference is still insufficient. Indeed, it would be helpful to explore why distress levels are higher for women than men, and the different themes that may emerge from both groups of caregivers.
3. Acknowledging the impact of caring for a stroke survivor with aphasia, which has to date, not been covered in the research (Han & Haley, 1999). This is possibly because, as mentioned earlier in the stroke outcome section, many authors exclude aphasic patients. However, caring for someone with communication problems may pose unique effects that are as yet undetected (Han & Haley, 1999).

Methodologically, future researchers need to:

1. Utilise a more representative sample of caregivers (rather than convenience samples), that are not just spousal caregivers, but also children and other relatives, from different cultural and socioeconomic backgrounds.
2. Elicit the experiences from long-term periods of caregiving (Bakas et al., 2002; Visser-Meily et al., 2009a).
3. Investigate caregiver needs from the stroke survivor's perspective, which to date has not been carried out, but could prove very insightful.
4. Implement sound qualitative methods that thoroughly explain "data saturation" and therefore justify the sample size used.

1.8 Research questions and aims

Based on the above review of the relevant literature, this study will determine**:

1. What are the various experiences and needs of caregivers and stroke survivors?
2. Have these needs been met through support services, why or why not?
3. Do different caregivers have different experiences, and
4. Do stroke survivors' beliefs about caregiver experiences and needs differ from those revealed by caregivers?

** Qualitative hypothesis-generating research involves collecting interview data from research participants and then using what they say in order to develop hypotheses. It uses the two principles of (1) questioning rather than measuring and (2) generating hypotheses using inductive and theoretical coding. Hence, no hypotheses are provided above.

Following from this, the specific aims of this study are:

1. To explore caregiver experiences, concerns and needs when dealing with the effects of looking after someone following stroke.
2. To identify caregivers' evaluations and use of available support services.
3. To compare and contrast the themes elicited from semi-structured interviews between male and female caregivers.
4. To compare and contrast the themes elicited from semi-structured interviews between caregivers and stroke survivors.

2.1 Overview and design

Based on the reviewed literature, the qualitative research approach of Interpretive Phenomenological Analysis (IPA; Braun & Clarke, 2006; Giorgi & Giorgi, 2003; Willig, 2001) was chosen and data were gathered via in-depth semi-structured interviews with caregivers and stroke survivors, at various time points across stroke recovery. Data were then analysed via thematic analysis techniques (Braun & Clarke, 2006; Willig, 2001).

2.1.1 Sampling

The types of sampling used in this study include purposive/homogenous, maximum variation and theoretical sampling. Purposive sampling was ensured in that specific inclusion and exclusion criteria were applied for participation in the study. Furthermore, caregivers and stroke survivors with a variety of demographic characteristics were sampled (see Table 4, section 3.1). Theoretical sampling involves the saturation of themes. This process of saturation will be discussed in more detail in the data analysis section.

2.2 Participants

Participants were caregivers of stroke survivors admitted to the Royal Prince Alfred Hospital (RPAH) stroke unit between the years 2007 to 2009 inclusive. A sample of stroke survivors also participated. Other sites included the Speech Pathology Department at RPAH and Balmain Rehabilitation Hospital. The inclusion and exclusion criteria were as follows:

2.2.1 Inclusion and exclusion criteria

For the purposes of this study a caregiver was defined as:

- Being the primary unpaid caregiver for someone with stroke for at least 3 months
- A spouse, child, other relative or friend of the stroke survivor
- 18 years of age or older
- Assisting the stroke survivor with at least one major ADL (see Chapter 1, section 1.3.1 for the definition of an ADL)

For the purposes of this study a stroke survivor was defined as someone who:

- Had experienced a stroke (as identified from hospital records) at least 3 months prior to the interview
- Was admitted to RPAH, Balmain Rehabilitation Hospital or the Speech Pathology Stroke Outreach Service at RPAH
- Was 18 years or older
- Required care in at least one ADL
- Was able to consent, and had a caregiver participating in the study

Exclusion criteria included:

- Caregivers and stroke survivors who were unable to comprehend and express English proficiently enough to verbally communicate in interviews. In the case of caregivers or stroke survivors who were able to participate, but who had difficulty reading, the researcher explained the information and consent form to them and answered any questions to ensure full informed consent could be given.
- Patients who suffered a TIA (see Chapter 1, section 1.2 for definition) were excluded from the study due to the acute nature of their symptoms and recovery.

2.3 Procedure

2.3.1 Recruitment

The recruitment process began following ethics approval from the RPAH Ethics Review Committee (Protocol No X08-0051/HREC Ref.08/RPAH/89) and The University of Sydney Human Research Ethics Committee. Minor emendations were made over the course of the study (see Appendix A for copies of ethics approval letters). Recruitment adopted an arm's length approach whereby a Stroke Case Manager in the RPAH Department of Neurology (not directly associated with the study) identified appropriate stroke survivors who had been discharged from the hospital within the last 3 years due to the convenient accessibility of these records.

Identified caregivers and stroke survivors were either mailed (if post-discharge), or handed (by the Stroke Case Manager) upon discharge, a cover letter signed by the Head of Neurology inviting them to consider participation in the study, an information sheet, and a consent form (see Appendix B for copies of cover letters, participant information sheets and consent forms). Caregivers and stroke survivors consenting to participate were instructed to return the consent form in the reply-paid envelope provided, to the hospital. Contact details of consenting stroke survivors were then provided to the researcher. Individuals also had the option of contacting the researcher directly.

Following this, the researcher then telephoned individuals to answer any questions, ensure they met inclusion criteria for the study, and to organise an interview time and venue. Following several ethics amendments and liaison with various staff and sites, other recruitment sites were approached half way through data collection to ensure an adequate sample size was available. These sites included Balmain Rehabilitation Hospital and the RPAH Speech Pathology Department. Only 2 caregivers, however, were recruited from these sites. In the later stages of

data collection reminder letters about the study were mailed to patients from 2008-2009 RPAH patient lists (see Appendix B for a copy of the reminder letter).

The RPAH Cardiovascular, Physiotherapy and Dietician Departments, Concord Hospital and The George Institute Cardiovascular Clinic were approached but did not take part in the study. A flowchart of the recruitment stages is illustrated in Figure 2, section 3.1.

2.3.2 Development of the interview guide

All semi-structured interviews were conducted with the assistance of two interview guides, one for caregivers and one for stroke survivors. Prior to conducting interviews, a practice session was piloted with another qualitative researcher not involved in the study, using a draft interview guide to obtain practice and feedback on the process and content of the interview. The original versions included topics that strongly tied in with the research questions outlined earlier, which is essential in qualitative research (Leedy & Ormrod, 2005), and both covered the same topics to ensure consistency of themes. The main topics for both guides included:

- The various psychosocial changes that may have occurred in various areas such as emotional and social functioning, and over different time points including the acute hospital and rehabilitation stay, the first weeks following discharge and the months following the stroke.
- Access and evaluation of formal support services over the course of stroke recovery and caregiving.
- Previous and current needs of the caregiver.

This pilot interview lasted 60 minutes with the independent researcher playing the role of the caregiver while the chief researcher of this project was the interviewer. Following the insights and feedback that emerged from this pilot session modifications to the interview guide included:

- Making questions more specific and open ended than solely topic headings in order to facilitate flow and transition during interviews. For example in the case of the topic heading “relationship/closeness”, the original sentence was “How has life changed for you (if at all) since the stroke? Specifically changes in your relationship with the stroke survivor?” This latter question was adapted to a more detailed question: “What about changes in closeness or getting along (appreciation, liking)?”
- Reducing the number of questions/areas within the interview guide to 10 to ensure all the important areas were covered and that the duration of interviews was within 30-60 minutes.

Importantly though, the interview questions were used flexibly throughout this study, and at times the caregivers’ and stroke survivors’ own language styles were adopted, and their own comments re-stated and incorporated into further questioning, e.g. “And you also mentioned you don’t see your friends as much, have your friendships changed?” In addition to the main interview questions used which initiated and guided conversation, were probe and follow up questions (e.g. “Tell me more about that” or “You mentioned earlier some emotional difficulties, can you tell me more about that?”) which clarified responses and encouraged elaboration (Bowling, 2002). Key topics that were not mentioned spontaneously by caregivers and stroke survivors but central to the research aims were probed for by the interviewer, for example, asking open-ended questions about any changes in social activities or emotional functioning that had

occurred since stroke-related caregiving had begun (see Appendix C for copies of the final interview guides used in this study).

2.3.3 The interview process

Once caregivers were approached and informed consent obtained, individual interviews took place and were audio recorded. The duration of interviews ranged from 30 minutes to 2 hours in length, with an average time of 60 minutes per interview. Each caregiver was interviewed once, and caregivers were free to stop the interview at any time. Interviews for caregivers occurred in appropriate meeting rooms either within RPAH, The George Institute for International Health, The University of Sydney or at the caregivers' home following stringent safety procedures outlined within the RPAH and University of Sydney ethics protocols (see Appendix C for a copy of this home interview protocol). Interviews were completed separately, with caregiver interviews conducted prior to interviews with the stroke survivor.

Interviews with stroke survivors followed the same procedure as caregivers with the exception that the interviews lasted for a shorter period, on average for 30 minutes, and on two occasions were conducted within a nursing home.

All interviews were guided by the interview schedule but for the most part, were directed by the participant, who was allowed to concentrate on issues that they found most important. At the very end of each interview, standardised demographic information was gathered such as age, gender, marital status, relationship to stroke survivor/caregiver, ethnic background and type of caregiving duties (see Appendix C for a copy of the demographic forms used for caregivers and stroke survivors, respectively). Audio recording continued during this phase of the interview session to capture any further information that may have been revealed. Each caregiver and stroke

survivor who participated was reimbursed with a \$20 shopping/petrol voucher at the end of the interview. Immediately following each interview, some fieldnotes were taken by the interviewer (Leedy & Ormrod, 2005). These fieldnotes described any notable features of the surrounding environment such as noise or interruptions, rapport between the researcher and participant, any key themes or interpretations that emerged such as ‘emotional functioning’, and important nonverbal and behavioural responses made by the participant, such as if they were tearful or had a depressed affect.

2.4 Data analysis

Data analyses were conducted manually. Reasons for choosing a manual approach as opposed to the assistance of computer software included:

- Manual approaches are ideal for small data sets such as that of the present study, and can be used to conduct the exact same operations as computer software, albeit at a slower rate (Bowling, 2002).
- Manual approaches allow the researcher to work more closely with their data, helping to facilitate interpretation and theme development (Bowling, 2002). Given the primary researcher did not transcribe most of the data set the need to work more closely to the data was deemed even more important.
- Although manual approaches can be more time consuming in some cases in comparison to computer approaches, it is estimated that this extra time would equate to the length of time that would be taken to learn how to use a qualitative computer package.

See Figure 1 below for an illustration of the three stages of data analysis.

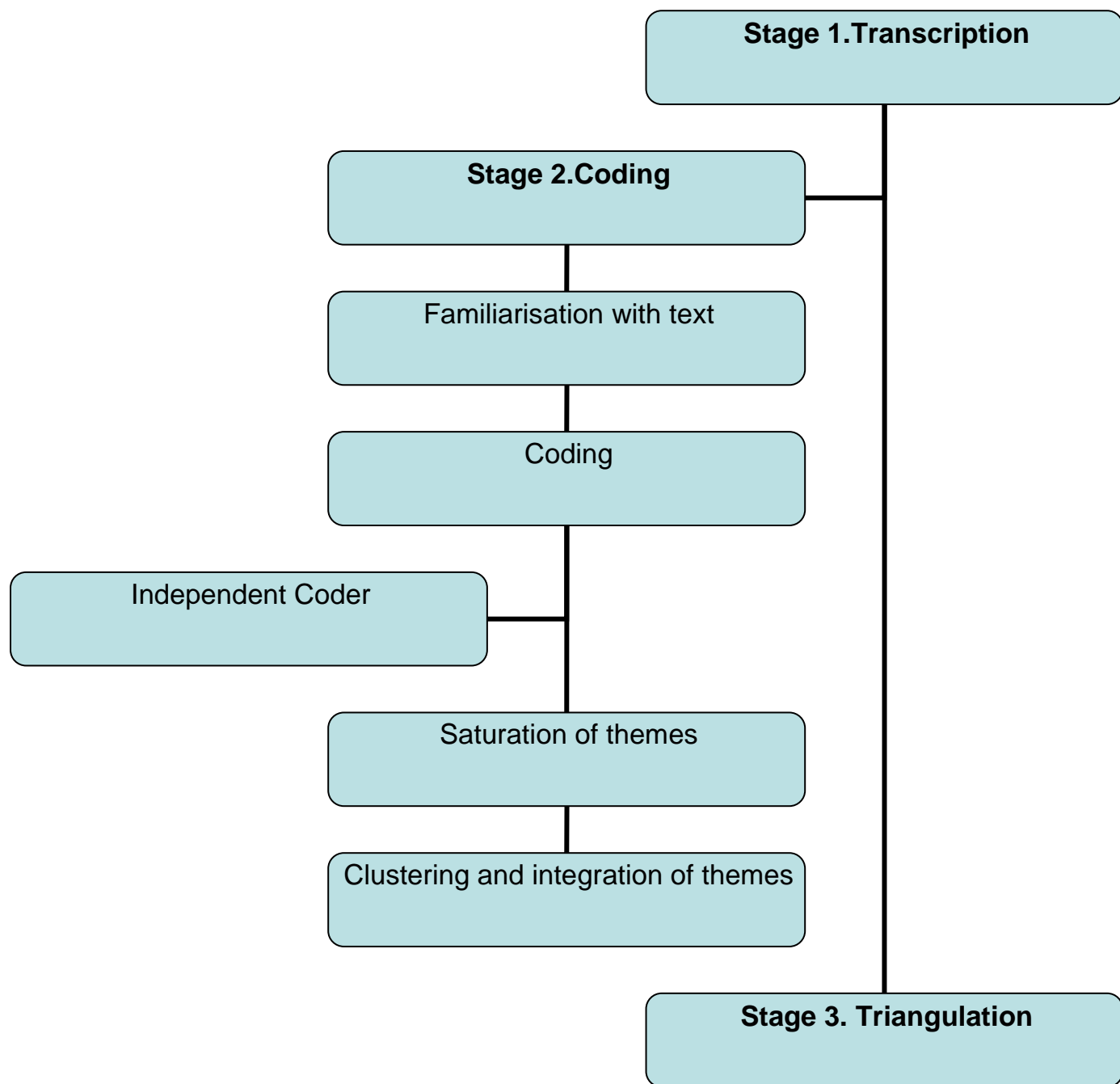


Figure 1. Stages of data analysis, adapted from Willig (2001).

2.4.1 Transcription

Each recorded interview was transcribed verbatim prior to coding and thematic analysis procedures. The first 60 minute interview recording was transcribed by the chief researcher, taking 10 hours to complete. This was conducted in order for the researcher to become immersed in the data. The remaining interviews were transcribed by a hired transcriptionist service.

2.4.2 Coding

Interpretive Phenomenological Analysis (IPA; Braun & Clarke, 2006; Giorgi & Giorgi, 2003; Willig, 2001) was adopted as the method of choice for coding and analysis. The following stages of IPA were used:

1. Familiarisation with the text. Each individual transcript was entered into a Microsoft Word file, printed in hard copy and read over twice, to obtain an overall sense of the data. Broad notes were made in the right hand margin of the text while the researcher reflected on the content of the text.
2. Identification of themes. Inductive and deductive coding of raw data transcripts were conducted in an iterative manner after each interview was completed. More specifically, using Word file documents which were all merged into one Word file, transcripts were read line by line, section by section. During this process, the identification and organisation of information into categories, and broader subthemes and major master themes was carried out using descriptive labels. These short thematic labels and descriptions were entered in the right hand margin of the word file as a 'Comment'. These labels often corresponded to the topics outlined in the interview guide or psychological concepts such as support, emotional functioning and loss that reflect the

‘psychological meanings’ that are explicitly or implicitly articulated by caregivers and stroke survivors (Giorgi & Giorgi, 2003).

To ensure the reduction of subjective biases in analyses, coding was carried out by the investigator and an independent experienced qualitative coder, and occurred at different phases across data collection. The independent researcher coded ten interviews all together, with the first 6 interviews of the study coded initially, developing a list of broad themes. The investigator (who also coded the first six interviews) and independent coder then met to discuss and compare their independent findings and resolve any disparities in themes/definitions generated. Ninety percent agreement in themes was initially found (although sometimes different labels were given by the two coders) before the remaining discrepancies were then resolved until a common theme list was constructed. Coding was also conducted by the independent researcher during the middle (two interviews) and final phases of data collection (two interviews), and compared with any new themes found by the chief investigator to ensure consistency and that no important information was overlooked (see Appendix D for the original two theme lists generated by the qualitative coders).

Master themes, subthemes and categories were then recorded in a working Microsoft Excel spreadsheet summary table. This summary table also contained key descriptive labels, brief quotes and the corresponding source (see Appendix E for a copy of the final excel spreadsheet used by the chief investigator and the final theme list generated by the independent coder). In conjunction with this summary table, constant organising/re-assignment, comparison and refining of coded data were carried out in a cyclical manner. This was done by comparing emerging master themes, subthemes and

categories that were being coded in new interviews with existing themes in a back and forth movement between raw data and the thematic summary table. This ensured only new independent master themes were added to the overall summary theme list, and that emerging subordinate sub-themes and categories were systematically integrated under these master themes.

3. Data Saturation. As previously discussed, qualitative data collection is generally said to end when no new theoretical insights emerge that would further develop a conceptual theme (Bowling, 2002; Strauss & Corbin, 1990). Unfortunately, most if not all of the qualitative literature in this area does not actually specify the process and criteria by which saturation of data are reached (Francis et al., 2009). In response to this gap, Francis and colleagues recommended procedures by which saturation of themes could indeed be systematically conducted and reported, and hence sample size more adequately justified. In accordance with these procedures, once an initial sample size of 10 was reached, analysis of saturation using the coding summary/paradigm outlined above and in Appendix E was carried out. A stopping criterion of 3 was initially set; that is, data collection was planned to stop when no master themes emerged from the data after three consecutive interviews. However, because the recruitment and data collection was slow in the earlier stages and fast at the later stages, the coding of an interview was not always completed before the next consecutive interview took place. Therefore, the stopping criterion of three was sometimes exceeded (see Appendix E for the saturation of themes table which illustrates this process). Although the stopping criterion could not strictly be adhered to, what is clear and of greater importance is that the sample size is sufficient for the saturation of themes.

4. Clustering of themes. Master themes, subthemes and where applicable, categories, were then clustered and refined into five broad master themes with respective subthemes:

- Relationships and Support
 - Caregiver-Stroke Survivor Relationship
 - Informal Support
 - Social Functioning
 - Formal Support and Access to Services
 - Evaluation of Services and Unmet Needs
 - Messages from Health Professionals
- Caregiver Factors
 - Emotional Functioning
 - Social Functioning and Independence
 - Resilience
 - Caregiver's Physical Health
 - Caregiver's Characteristics
- Stroke Survivor Factors
 - Cognitive and Behavioural Changes
 - Stroke Survivor Emotional Functioning
 - Stroke Severity and General Physical Health
- External Stressors
 - Employment and Financial Strain
- Positive Outcomes
 - Enhanced Relationships and Perspective on Life

5. Integration of themes. Integration of themes was then carried out within and between each individual interview transcript. This was done by copying and pasting the direct quotation extracts of all common master, subtheme and category labels ('Comments') into individual word files that corresponded to each of the five master themes. See Table 3 below for the layout of the first master theme file: Relationships and Support. This was completed for all interviews until there were five major Microsoft Word documents for each of the five main master themes.

Table 3.
Layout of Master Theme File for Relationships and Support

Master Theme: Relationships and Support
Interview 1
Subtheme 1: Caregiver-Stroke Survivor Relationship
Extracts
E.g. "Yea...sex has gone out the window..."
Subtheme 2: Informal Support
Extracts
E.g. "Yes...but it's something I can handle...It's not a problem. And my kids are great, they say mum if you want to go out or something we'll look after dad while you're gone...cause' two of them are still living at home...yea"
Cont. for all subthemes and categories of this master theme
Interview 2
As above, and onwards for the remaining transcripts

2.4.3 Triangulation of caregiver and stroke survivor material

This stage involved comparing and contrasting caregiver and stroke survivor themes for the purposes of triangulation and consistency. This was made possible as both stroke survivor and caregiver data transcripts were coded in a similar fashion.

Once themes were completely refined, the phenomenon of stroke caregiver experiences was essentially defined, and this process is presented in Chapter 3. The relationship between the different categories, subthemes and master themes were then interpreted and explained (Braun & Clarke, 2006; Creswell, 1998), and this is presented in Chapter 4.

2.5 Quality of methods

The present study demonstrates sound methodological rigour as shown by the procedural, interpretive and evaluative rigour and representativeness of the study.

2.5.1 Procedural rigour

Procedural rigour was shown by:

- Guaranteeing that the techniques of data collection and analysis are clearly described and made transparent. The nature and selection of the participants, the interview process, questions asked, and method of coding and analysis have all been made explicit.

2.5.2 Representativeness

Representativeness was shown by:

- Using the sampling techniques of purposive, maximum variation and theoretical sampling which increase the transferability or conceptual generalisability of the findings to wider research and clinical contexts.

2.5.3 Interpretive rigour: Validity and reliability

Adequate validity was demonstrated by:

- A comprehensive and systematic analysis of data, as all data were analysed line by line ensuring no important information was overlooked.
- The use of the constant comparative method (Silverman & Marvasti, 2008; Strauss & Corbin, 1990), as the same data were read and coded several times in a back and forth manner, ensuring that all data transcripts and seemingly conflicting findings or deviant cases were identified.
- Providing verbatim accounts of caregiver and stroke survivor responses as evidence to support the themes generated (see Chapter 3).
- Implementation of data and theoretical triangulation via the collection of information about caregiver experiences from stroke survivors, and the application of existing theories and models (see Chapters 3 and 4, respectively).

Adequate reliability was ensured by:

- Establishing inter-coder agreement, whereby an independent coder was utilised who was blind to specific research questions and expectations.

2.5.4 Evaluative rigour

Evaluative rigour was established by:

- Obtaining ethics approval and acknowledging important ethical issues such as the researcher's need to demonstrate a non-coercive and 'arm's length' approach to recruitment, ensuring informed consent from participants and considering their wellbeing during the interview process.

Other important criteria that establish high quality qualitative research, and which were demonstrated in this study include theoretical rigour, conceptual interpretation, and transferability, which will be discussed in Chapter 4.

3.1 Recruitment and demographics

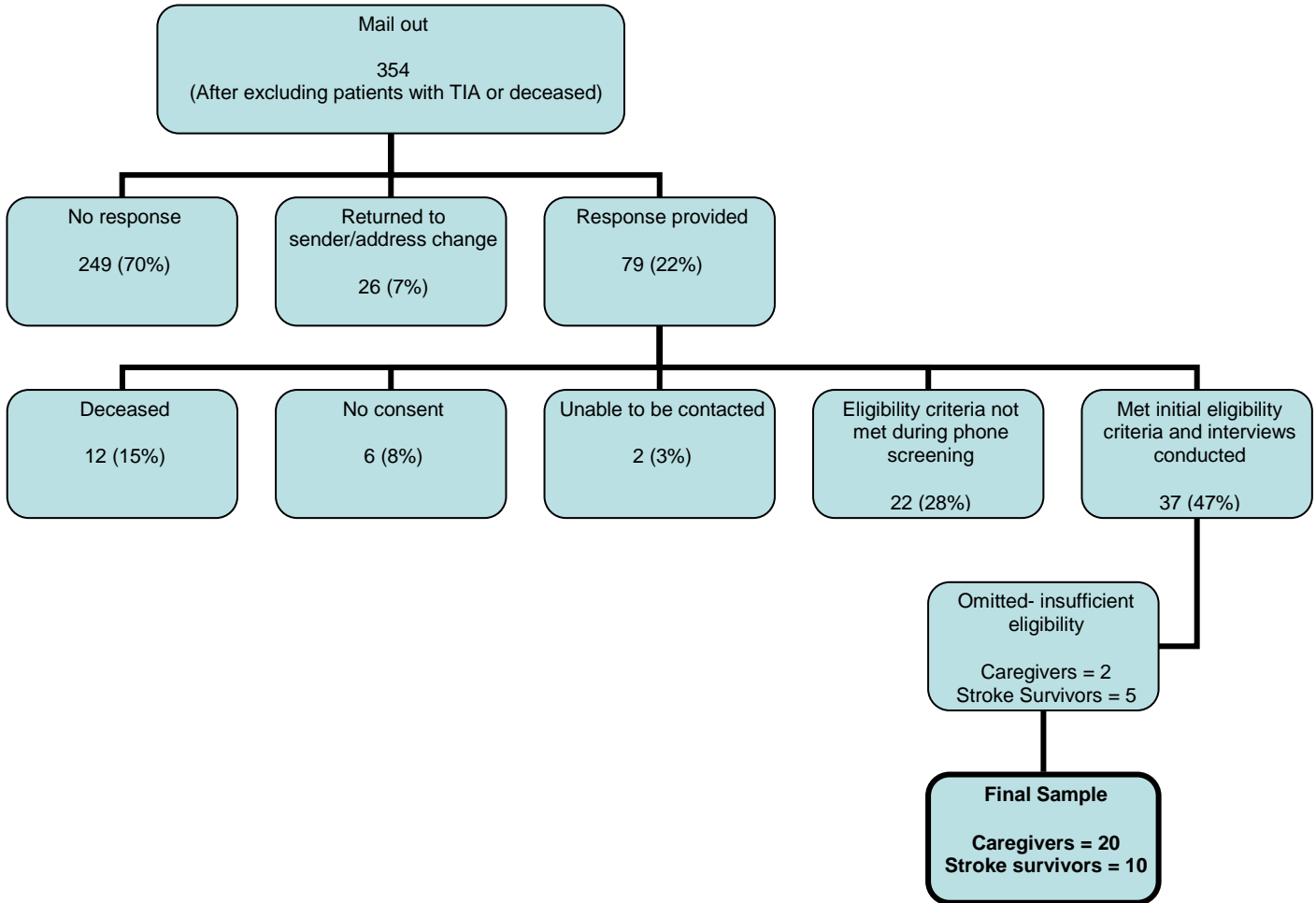


Figure 2. The recruitment process

Overall, approximately 350 stroke survivors were invited by mail to participate across all sites. Of those, 249 did not reply. Of those who responded, 12 were reported as deceased by family members, 6 did not consent, 2 were unable to be contacted and approximately 22 were ineligible for the study, as the stroke survivor was functioning independently and did not have an informal caregiver. A further 2 caregivers and 5 stroke survivors were omitted following interviews, as it was found the caregiver did not meet the eligibility criteria for being a caregiver or the stroke survivor's aphasia (previously minimised or not reported by their caregiver) was too extensive to verbally communicate, respectively.

See Table 4 below for the demographic characteristics of caregivers and stroke survivors in the study. Of note was the large proportion of female caregivers which is consistent with the composition found in most of the stroke caregiver literature (e.g. Anderson et al., 1995; Dennis et al., 1998). Caregivers providing a range and quantity of care, and stroke survivors demonstrating varying levels of functional impairment and disability, were included. See Table 5 below for the type and intensity of activities caregivers carried out.

Table 4.
Demographic Characteristics of Caregivers and Stroke Survivors

		Caregivers (n=20)	Stroke Survivors (n=10)
Age		Frequency	Frequency
	31-40	2	0
	41-50	2	2
	51-60	3	0
	61-70	5	4
	71-80	5	3
	81-90	3	1
Gender			
	Male	4	8
	Female	16	2
Marital status			
	Single	1	1
	Married	16	9
	Living with partner	1	0
	Widowed	2	0
Caregiver-stroke survivor relationship			
	Spouse	15	8
	Sibling	3	2
	Child	2	0
Duration of caregiving			
	< 12 months	4	
	1-2 years	10	
	>2 years	6	
Ethnic background			
	Anglo-Australian	9	10
	European (English speaking country)	2	0
	European (Non English speaking country)	7	0
	South American	1	0
	South East Asian	1	0

Table 5.
Type and Intensity of Caregiver Activities

Caregivers (n=20)	
Activity	Frequency
Personal	
Standing	1
Eating	2
Grooming/Hygiene	7
Bathing	6
Dressing	8
Toilet use	3
Movement around house	1
Monitoring	10
Domestic	
Home maintenance	2
Housework	8
Meal preparation	9
Medication supervision	8
Community	
Organising financial matters	8
Making appointments	7
Completing errands	5
Driving/transport	12
Shopping	10
Assistance with walking/movement outside the home/stairs	8
Help with rehabilitation (Speech and Physiotherapy homework)	2
Caregiving Intensity	
Low (1-2 ADL ¹)	3
Medium (3-4 ADL)	4
High (4+ ADL)	13

3.2 Themes

Five master themes emerged from the data and they are: Support and Relationships, Caregiver Factors, Stroke Survivor Factors, External Stressors and Positive Outcomes. See Figure 3 below for a representation of each of these inter-relating master themes and their corresponding subthemes. As seen in Appendix E no new subthemes for any of the broad master themes were generated after interview 15. Therefore, all master themes were saturated by interview 15.

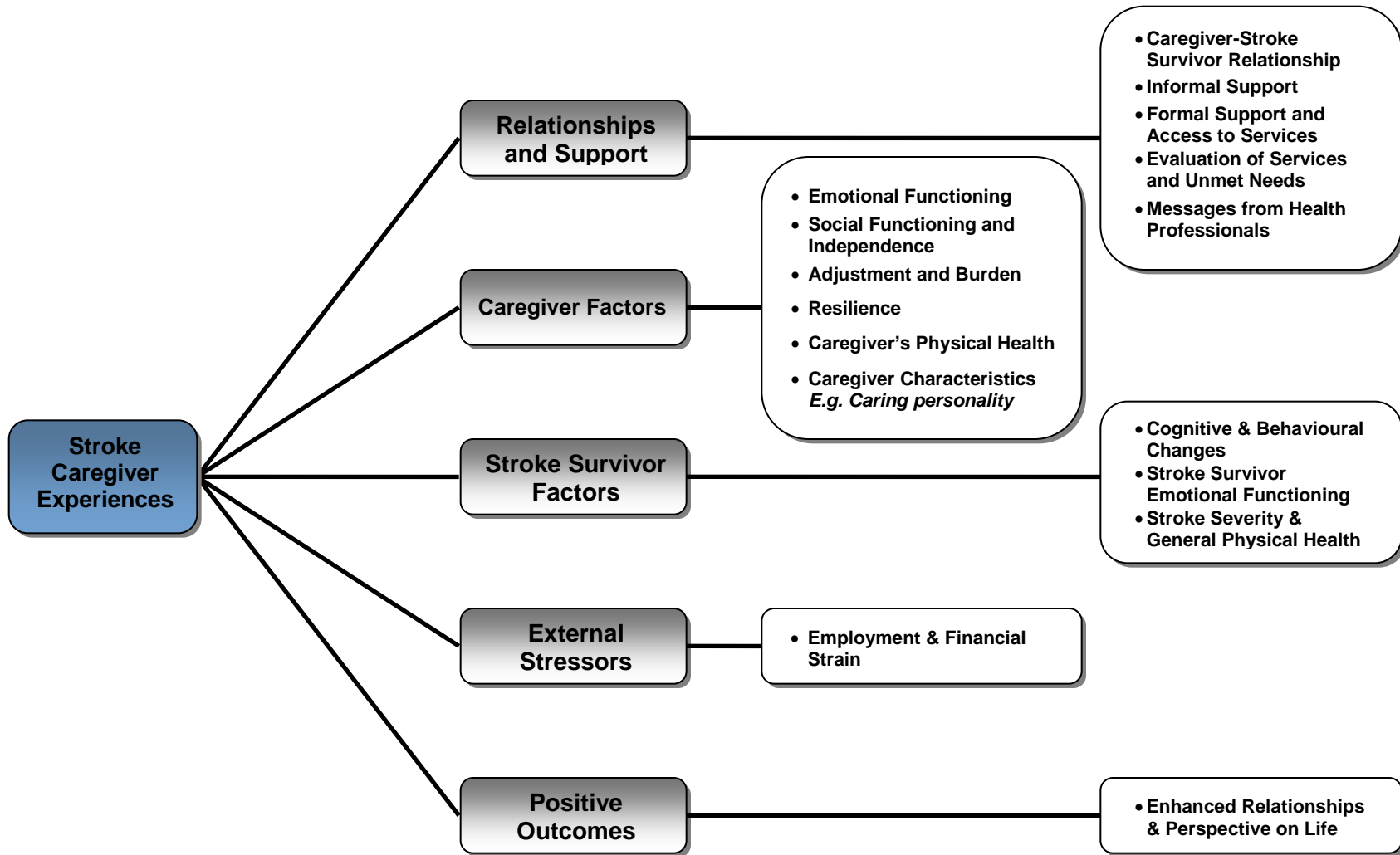


Figure 3. The emergent themes of caregiver experiences

3.2.1 Relationships and support

3.2.1.1. Caregiver-stroke survivor relationship

Thirteen of the twenty caregivers (65%) interviewed reported changes in their relationship with the stroke survivor since the time of the stroke. The relationship was either said by some to become more distant or strained (7 caregivers) or closer and more enriched (6 caregivers). The shift in relationship dynamics on the distance-closeness continuum seemed to partly depend on the quality of relationship prior to the stroke.

For couples who had experienced interpersonal problems before the stroke, the impact of the stroke served to exacerbate conflicts and add further distance and stress to the relationship. Overall, some caregivers often stated that the stroke survivor made unreasonable demands, failed to support and appreciate them adequately and that less quality time, conversation and shared activities were had together.

“If I don’t make it, he’s angry and screaming something like ‘bring me coffee, what’s wrong with you, you know I’m sick’. ‘You’re a sick man, but you have to do something, you can’t sit there and say you’re a sick man because you had a stroke – I work with sick people and they’re going to the toilet all by themselves, they ask for a shower”. (C11: Spouse)

“Yeah he’s very controlling because he can’t do things himself he has to give all the orders and get it all done his way which really gives em to me. He’s not, don’t know, he’s not a compassionate man, not towards me. He expects me to be strong. I resent that sometimes”. (C3: Spouse)

Conflicts or distance also arose out of incongruence in concerns and priorities between the caregiver and stroke survivor, or a lack of understanding and empathy towards each other. For example, some caregivers disclosed that they wished their spouse would behave differently, such as persist further with their physical and rehabilitation exercises, whereas the stroke survivor did not want to or was unable to. These caregivers usually considered such behaviour as 'lazy' rather than also considering that the lack of behaviour was possibly due to an inability as a consequence of stroke impairment, depression or poor executive functioning.

"Sometimes getting along and sometimes arguing, arguing just because he doesn't want to do these exercises like I tell him like yesterday I do all the jobs, he can help me hang the clothes outside and I say come on you help me hang the clothes and he doesn't want to do it he just sits there and I say come on let's go let's get up let's do something, off your bum...so that's why I keep whinging" do stuff do stuff" and I feel so frustrated sometimes and I get angry and that's what we argue about...". (C32: Spouse)

Sexual activity and intimacy was also reduced in many of the spousal relationships. However, most of the caregivers were more disappointed by the loss of intimacy, quality time together and lack of support and appreciation rather than the reduction in coital relations. The category of loss will be discussed in section 3.2.2.

"I guess our, from my perspective probably the friendship that is most lacking is the friendship with him. That's, now I'm teary sorry, it doesn't exist. No it's, I have become nothing more than a carer, you know - the secretary that sits at the computer typing, doing his emails, reading everything to him, telling him about everything that happens. But that's all there is to it".

"So your relationship with him has changed"?

“Dramatically yeah, that is the hardest part. To me that is the hardest part...the husband/wife relationship, and I’m not talking the sexual relationship, that’s been non-existent for a long time because of, he hasn’t been very well for a long time..Honestly just to have him come in from his bowls this afternoon, put his arm around me and say “How was your afternoon darling?” would be so nice, but he would no more do that, he will walk in, he will sit in that chair and pick up the remote control and turn on the telly before he’ll even say hello, and you think “Oh!”. (C22: Spouse)

Finally, the caregiving role in some cases was perceived as obligatory; because there was no one else available to care for the stroke survivor and nursing homes were deemed inappropriate or inadequate, which placed further strain and burden on the caregiver.

“I’m just wondering what is it that keeps you wanting to help her, if the relationship wasn’t...”

“If I’m not around, then nobody will do it”.

“So it’s obligation, partly”?

“Obligation totally. Yeah. It would not happen. I mean, as I say, I love my kids dearly, but there’s no way in the world that they’d be managing her healthcare or her social life as well. Yeah”. (C23: Spouse)

Caregivers and stroke survivors who were functioning well and were mutually close and supportive of each other prior to the stroke usually maintained this closeness with a sound understanding of each other’s concerns.

“I think you learn a lot about yourself when you go through not just a stroke but if you go through any type of trauma. You learn what capacity you have to deal with things. You learn how much strength you’ve got. You learn how much resilience you’ve got and you learn how much you become solid with this other individual that needs you, because I think if anyone - somebody asked me the other day: given

that you were newlyweds when Trevor had the stroke, has this made you stronger or has it made it harder for you to have a relationship? I said: we're unbreakable". (C24: Spouse)

This closeness was also enhanced by the increased time spent together due to the stroke resulting in the stroke survivor being home more often, and becoming more dependent on their caregiver.

"It's, we sort of, yeah, it's probably, might be a little bit closer now if anything.

Why do you think it's closer now?

I spend more time with her. I guess we have something in common now, which is trying to get her as well as, her recovery, yeah, yeah". (C23: Spouse)

Furthermore, caregiver attributes (to be detailed in section 3.2.2.6), such as openly communicating with the stroke survivor, demonstrating patience, compassion and maintaining a sense of humour were reported in these more harmonious relationships.

"I've always talked to him, I feel that it's better that I run it by him and I tell him this is what's happening and whatever and even though I know Tim's not happy with it, if he's not happy with it I can see it on his face". (C7: Sibling)

"I think that even though Patrick's stroke has been devastating, it really does bring him down to earth with a big thud. I mean I've got a fetish for shoes, I've got about fifty pairs of shoes (laughs). And Patrick pokes fun at me about that, that's great, that's great that he can poke fun at me". (C1: Spouse)

"...I suppose what they are is that that world is smaller now, because we just don't do that many things, but our time together is still that big if you know what I mean. It's just that those little unique events every

day don't necessarily happen but that doesn't stop us trying to do those special things and enjoying them when they do happen but I still have time with Harriet which is really important so I don't care if she doesn't sit with Jason and I, her father, to have dinner and she feels easier sitting up in a chair...I'm very happy to accommodate anything that she wants because I'm okay, you know, she's the one that's got the difficulty" (C20: Spouse).

A perception of commitment to care rather than an obligation per se, also reinforced this closeness.

"Sorry. If anything happened to her, as long as I was capable of looking after her I would. I would never put her into a nursing home" (C13: Child)

"...There'd be no way that I would neglect my sister to satisfy a husband that was still capable of doing things. Yes I'm afraid that's the way it would have gone". (C15: Sibling)

Other factors pertaining to the caregiver (such as emotional functioning) and the stroke survivor (such as the severity of the stroke/subsequent stroke survivor disability and personality changes) also impacted upon the caregiver-stroke survivor relationship. These factors will be discussed in sections 3.2.2 and 3.2.3, respectively. For those caregivers that reported enhanced relationships, it was usually in the context of positive outcomes of stroke and so this information will be reported later in section 3.2.5.

3.2.1.2 Informal support

Caregiver responses in relation to informal support highlighted experiences that lay on a continuum between adequate support from friends, family and occupational colleagues and

interpersonal and social disconnect which manifested as a lack of understanding from others or offers of support. An adequate level of support served to in turn impact on caregiver factors such as emotional functioning, and caregiver adjustment and burden. Caregivers continually highlighted their appreciation of the support of other people and for some caregivers being able to reach out and talk to friends or colleagues was helpful in managing emotional difficulties.

"I've got a couple of good friends that I can unload on, this one particular girl is a...very good listener".

(C1: Spouse)

"...A girlfriend of mine is a sister, is very calm and logical... I've got great friends, I have got absolutely wonderful friends, and I don't know what I would have done without them" (C3: Spouse)

Practical support from family and friends allowed the caregiver to take a required break, or provided an opportunity to complete other tasks. Given caregiver personality characteristics (detailed further in 3.2.2) that included a history of taking care of others and not wanting to burden others, some caregivers commented that mere passive offers of support were not always sufficient, and an active provision of support was required by others in order for the caregiver to accept the offer.

"All my friends have been fantastic: so nice. They took me out to lunch last Thursday, one of them wants to buy me a day at a spa, and I said, if I only had the time: you know little things like that. They've just been incredibly supportive, and loving, and offering to help us out in any way they can. When John was in hospital, and I had both of the kids, and was going a bit nuts, people would cook things for us, and bring us dishes: you know, without even asking. They just did it, and said here's this: enjoy, or sometimes, I had someone come over, and say, I'm coming to take care of the kids. You get out of the house, and you

go and do something, and I so appreciated that! Because this is very helpful for your study: no matter how many offers you have, from really nice people, I have a hard time asking for help. I have a hard time saying, yes, that would be great. I would love it. I never ask: I just love it when people just say, "I'm coming. You do this: you get out", and you need that: I needed that". (C16: Spouse)

Motivational and emotional encouragement of the stroke survivor by friends and family was also deemed as valuable by caregivers.

"So every day because he was literally down the road from the XXX Ambulance Station, every day his colleagues were dropping in with a coffee or dropping in to see him. Trevor actually celebrated his birthday when we were there and we actually organised a surprise party, a barbeque with all the ambo's so they literally - about 30 of them turned up...He was just blown away by that, all the support from his colleagues. It just really made him really emotional that day. After they'd gone he was like holding it together. It was really nice to see the level of support that was constantly coming in. So every day he was coming in and I was able at that point with - that's at the point that I started to transition back into work part-time, which was great. That was the best outcome in terms of the location for us because all family and friends and all of his ambo colleagues were regularly going in to see him so it just kept him regularly entertained and focused on, everyone was looking out for him whereas if he'd been at XXX he would have been in complete isolation so it's a bit different". (C24: Spouse)

Flexible and accommodating employers allowed caregivers to adjust their work schedule to fit around their stroke survivor care responsibilities whilst minimising the degree of financial strain incurred.

“But the company was very good. They gave me three months off with pay and then let me stay in Australia for a while after that, so I could actually keep my job, although my initial thought was I thought I was going to have to give up my job”. (C23: Spouse)

A lack of even passive offers of support seemed to have a large effect on some caregivers. Some caregivers felt disappointed and resentful of the negligence of other family members and friends, especially from people they would have expected to assist.

“... I’m so disappointed with peoples’ behaviour. These places, these doctors, these ladies I go to up here. Tim’s known them for many, many years. They’ve never made one suggestion”. (C7: Sibling)

Some caregivers reported a lack of support from others (e.g. their children) but seemed to accept this without bitterness, acknowledging that these individuals were already pre-occupied with several other demands and responsibilities.

“He’s very helpful, but he’s a young person, he’s studying, he’s working, he’s a musician, he’s doing hundred things. I cannot depend on him, or ask him too much”. (C18: Spouse)

Finally, at times, conflict or interpersonal problems with other family members who did not offer support to the caregiver or stroke survivor or who challenged/blocked the caregiver’s decisions was said to occur, placing further stress on the caregiver.

“Well it’s just sort of hitting your head against a brick wall basically, because I did say to her husband ‘ring ACAT, see if you can get an assessor to come in, look at your house, see what we can do about doing

that'. He's done nothing...But yes, it's not solely hospital and ACAT... I've got a problem with him (stroke survivor/sibling's husband) as well". (C15: Sibling)

3.2.1.3 Formal support and access to services

All caregivers reported utilising at least one kind of formal stroke support service or resource for the stroke survivor either prior to or at the time of the interview. The major areas included assistance from:

- The family G.P
- Home Care nurses
- Rehabilitation for the stroke survivor-predominantly physiotherapy and speech pathology
- Stroke support groups
- Respite care
- Centrelink financial assistance

Other services outlined include psychological help, live-in carers and volunteer companions for stroke survivors, though these were only accessed by a very small proportion of caregivers. A small number of caregivers were satisfied with both the *accessibility* and *quality* of these services. The accessibility of services pertained to how easily services were to identify and gain access to, while the quality of services referred to how satisfied caregivers were with the standard of services that were accessed. Evaluation of the *quality* of services and resources will be detailed in the next section.

"Yes. You think about somebody who's living in rural Australia, a: Trevor wouldn't probably have survived because he wouldn't have got to hospital in time and he would have kept bleeding out; and you don't

have - that's the thing, the thing is now you just realise that you're in an environment where you've got the access to the facilities at the hospital. We're only down the road. It literally only took 20 minutes to get Trevor there. And you've got all your family and friends and you've got the constant access with the Stroke Outreach team, the doctors. We saw the rehab doctor last week. Well, the last time we saw was a year ago, but we're still tapping in to see him and he's really impressed with the news about the walking progress. It's great". (C24: Spouse)

"We have a temporary Home Care Help Assistance program: they come to help give John a shower Mondays, Wednesdays, and Fridays, three days a week. Then fortnightly, they help to clean the house. It's a huge help, and I look forward to those days, because it's a little bit less that I need to do, but we still have to do the daily stuff." (C16: Spouse)

Difficulty with access to appropriate services and resources was continually raised as a concern in caregiver interviews. Caregivers stated that they felt neglected by health professionals and lacked access to health services, especially following hospital discharge of the stroke survivor. There was a degree of expressed uncertainty for caregivers as to what specific services and resources were available and what to expect in terms of recovery. Caregivers stated they were often not provided with the appropriate information about rehabilitation services in the area, the nature of stroke, prognosis and risks factors for recurrent stroke or other valuable support services such as stroke support groups, Home Care or Centrelink Carer Allowance.

"And has your dad been the main person?

At the moment yeah, yeah he takes her everywhere, doctors, everywhere, rehab. We finally found some rehab. It's very hard when you're under 50 when you don't have financial backing to find a rehab place because that's what stroke people need, facilities. Apparently there was one opened four years ago but nobody tells you. There's no GPs, no doctors, nobody tells you there is a place that you can go for rehab

which is, the facilities are excellent and it's only \$150 for six months and it's just nothing really, even if you pay \$200 or \$300 for six months". (C 14: Sibling)

"No one sort of suggested either a cancer support group or a stroke one" (C3: Spouse)

"...I mean they were fantastic in terms of the acute care, et cetera, but they weren't that helpful in terms of the follow-up of what to do. I think that the social work department could actually improve in that area because people just don't know what to do: where to go, what sorts of services are available. We had to find all of that out ourselves and it's just through my sister's diligence and my diligence that we were able to access the different resources. So I think that at that end, the social work department could improve in terms of, "These are the resources that are available to you... a list of numbers to say, "Look, these are some of the nursing homes you could – or nursing homes, speech therapists, physiotherapists, et cetera". That would have been really helpful but we had to do all of that ourselves as well as deal with the fact that our mother was – had had a profound stroke. Yeah, so that could have been a little bit better in terms of "where to from here?". (C28: Child)

Therefore, caregivers had to adopt a level of initiative to advocate for the stroke survivor and conduct their own research to determine which services were available. Further, it was found that the ongoing persistence of the caregiver was required in order for services to be received in a timely fashion, or received at all. Some caregivers even disclosed that they had to challenge the hospital or rehabilitation facilities to keep their family member admitted for a longer period.

"No. You have to fight to get anything at the moment but if you tell people the truth you don't get anything but you have to go and see everybody to get anywhere... we only got rehab at XXX and that's because my sister (secondary carer) begged everybody. She even saw politicians, members of parliament, for her just to go into rehab, and that's why my sister's walking". (C 14: Sibling)

"Then, these are the little hitches I was going to say. When I phoned to say like he's ready to go in, his hips healed and he's ready to go into rehab, I phoned XXX Hospital and they said "No, you can't just bring him here". I said "But that was the arrangement that that's what would happen", "No, no he has to go through and see our doctors and see what's going on". So I phoned the doctor that was dealing with him at Prince Alfred and she was home and they put me through to her home and I told her, I said "Look he's ready to go in there and you told me that when he was ready he could go in" and she said "Leave it to me". Anyway the next day they had an ambulance there to take him and put him in. But I mean there's little...and if I hadn't of pushed it to phone her, I would have had him stuck there for a lot longer". (C31: Spouse).

The second major problem recalled by caregivers was that even when services and resources were known, access to them was sometimes restricted. Various problems were voiced with gaining access to services including respite services that would accept the stroke survivor or were appropriate in length of stay, Centrelink financial assistance, rehabilitation services or transport assistance.

"Well, that (respite) was offered as a possibility for like a weekend or a few days, yeah, but within a very limited period". (C31: Spouse)

"So anyhow, when I go to get it again (respite facility for stroke survivor), I can't get the place. Oh why is that? Well because they're inundated". (C7: Spouse)

"Home Care took about two months to get back to me and then told me that they're totally short staffed and can't help me out. A few other associations that I rang up they just couldn't help me. I think it was because I was the one needing the help directly, not my parents. I'm not quite sure why because I explained that I needed someone to be with them for the three hours or two hours while I went off and they couldn't help me. One actually said it wasn't a major emergency, but the thing is if it's an emergency

I have to ring them at the last minute, well they're not going to be able to organise something so I had to always organise to make sure that my brother was down, so yeah...". (C 13: Child)

"It wasn't easy for me to get the carer's pension either, by the way. She (Occupational Therapist) had to really push things because she filled in the form and so I think they were a bit reluctant to give it, but however I did get it and, probably the thing that bothers me most is the fact that it's not, I feel it's not always easy to get the transport I want to go up to these medical appointments...They've always got to have a roster for at least a fortnight and sometimes there mightn't be a carer who could take us to this appointment". (C34: Spouse)

"...Because she was just dismissed from rehab, she didn't qualify for rehabilitation...they wouldn't refer her because she couldn't sit up, and they needed the bed so they pushed us out. So thank God we found the XXX and we went to so many different places. So if – that was really difficult because she was – she's not going to make progress, but where do you go? What do you do...". (C28: Child)

"One of the things that I was very sad about, and once Gary was discharged from hospital we could no longer do anything about, was the fact that if I had gone and seen the social worker early in the piece, Gary would have had a disabled – I know this sounds ridiculous – again it would have made his life and mine easy as a result, a disabled thing for taxis – so we get half price taxis...". (C22: Spouse)

The caregivers that did receive the best access to formal support services such as ongoing rehabilitation, in-home carers and where relevant, high quality nursing homes, were those that were generally younger, currently employed, and could afford private and relatively high-cost support. Some caregivers also expressed stress around finances and employment, but while this stress is related to the access of services, it is not exclusive to this, and so these external stressors will be covered further in section 3.2.4.

“Well, Yasmeen, it’s something you could consider is the fact that we’ve got private health cover and if Erick hadn’t had that, he couldn’t, well, we would have had to pay at XXX Rehab. The alternative was to send him to YYY Rehab, which is public, and probably not as good. That’s what they told us at the hospital. Therefore, going to the XXX, they put us on the right track, particularly the occupational therapist; she said, “You’re going to need help when Erick comes home, so we’re going to arrange that for you” and then automatically after those three months of transitional care, then we went onto the aged care, which is very similar”. (C34: Spouse)

“...There’s a constant succession of people coming in. There’s a, I’ve got a New Zealand lady that takes her shopping; she comes once or twice a week. Lucy (speech therapist) comes a couple of times a week and then my daughters pop in now and again and that kind of thing...I’ve not got too much of a support network. I mean, I’ve built one up, but basically I pay for it”. (C23: Spouse).

“Exactly right. It’s a catch 22, yeah. So that was a real challenge but then I managed to – I think that was the saving grace for us is that we had money; without money, I don’t know what we would have done, to tell you the truth. Because we looked at some nursing homes and we just sort of, there’s no way and there’s no services in them, these poor old people crammed in, it’s like a kennel, just so awful”. (C28: Child)

3.2.1.4 Evaluation of formal services and unmet needs

While the previous section discussed the process of attaining or attempting to attain access to services, two other important themes that arose were caregivers’ evaluation of services and resources that were accessed, and their unmet needs. When services were provided to a sufficient degree, caregivers were satisfied with the available services, resources and stroke-related care. Of note was the high regard for the work of physiotherapists and their ability to improve the stroke survivor’s mobility.

“He made her walk and he was determined to do it for her and then sometimes he’d do it in his lunch hour because after six weeks or something you have to go then from there as well but he kind of kept her ongoing... and it’s very hard trying to find people like that, but he was very, very good. And then he got a transfer after two years but at least he got her up, he was the only one that got her up walking. Everybody thought she’s not going to, she’s just a veggie, she’s not going to walk or anything” (C14: Sibling).

Other beneficial services mentioned were: speech pathology, respite care, Home Care, the acute hospital stay, stroke support groups and companionship volunteers who spent time with the stroke survivor or took them out for recreational activities, and parking, taxi and disability permits/allowances. Some of these services were also helpful in reducing the caregivers’ everyday burden.

“It’s a big help (homecare) because showering him is a good half-hour process, and it’s not only showering him: it’s cleaning the bathroom afterwards, putting up the towels, doing a load of washing, whatever. It’s very helpful” (C16: Spouse).

Dissatisfaction rather than satisfaction with services was however more often voiced. In relation to quality, the most significantly criticised service was nursing homes which were said to be short-staffed and provided an inadequate level of care for their loved one.

“They say nursing homes are quite capable of looking after people like that but they’ve never been to a nursing home themselves to actually see the nursing home. And my sister and myself, well she checked out more than me, 52 nursing homes, and most of them you wouldn’t put a dog in there, not a loved one, especially a young one”. (C14: Sibling).

Criticism of hospital health care professionals (e.g. doctors, nurses and social workers) during admission in the acute and rehabilitation hospitals was related to their neglect or poor communication style with the caregiver and the stroke survivor (doctor communication will be covered further in section 3.2.1.5).

“He was choking and he was in that fixed position and she’d walked away (nurse), but it didn’t click with me, I just thought that he, something had happened to him til I seen it again.” (C31: Spouse)

Overall, it was found that when services were actually received they were found to be helpful and the satisfaction with the standard of quality was mostly high. The pertinent issue for caregivers was that formal support was not provided with enough continuity and that there was a lack of ongoing support and follow-up appointments after hospital discharge.

“No, it was part of the hospital, the public system, an absolute godsend (physiotherapy), I think. Because Trevor now doesn’t really do much with (hospital) at all I think - he hasn’t been discharged per se from the Stroke XXX but because he’s sort of, I guess, a mature patient as opposed to - there’s always new patients coming through the intensive level of care, ... and initially needing that intensity because they’ve only recently had a stroke. So last year it got down to physiotherapy once a month and that’s really not enough”. (C24: Spouse)

“So as it turned out I did get back to them, they reassessed her from the nursing home, and she was able to have three weeks of rehab at this hospital which was great, because at the end of that three weeks she was actually pulling herself up out of the wheelchair without any help from us and standing up. Then of course she goes back to the nursing home...But because you haven’t got that constant...there’s no one to encourage her. Well they have got a full time physio there, but they’ve got ninety six patients, so you can’t

expect one person to be doing that. And of course once again while the staff is very good, the medical side is excellent...You can't, yes you can't get that consistency and continuation." (C15: Sibling)

Caregivers appreciated regular, ongoing support, which at times helped to improve the stroke survivors' motivation to continue rehabilitation exercises.

"Sometimes, they go to the park across the street. The other physio guy had to put his hand above his head, which he hadn't been able to do before. So its huge stuff, and the fact that they say, you're doing so well, or, look at how far you've come along since we started, and all this, and it's extremely helpful, and motivating, and hopeful" (C16: Spouse)

Caregivers were found to appreciate the regular check-ups and sometimes participated in clinical trials as a way of attaining this.

"Yes they're good. I never have to say nothing wrong, the community is very good here in XXX. And he has to go twice for one month to see a doctor to the community centre, talk to him, which is good". (C11: Spouse)

"Well we go to hospital every month, you know....We have to check the blood, we are under the Rocket Scheme". (C9: Spouse)

An absence of education about the nature of stroke, risk factors for recurrent stroke, and the stroke survivor's prognosis were also revealed.

"The only thing I would like to have known was more about what had happened to him and what could happen to him". (C3: Spouse)

It was acknowledged by some caregivers that brochures and pamphlets were provided during the acute hospital stay but that this information was not always read due to the overwhelming nature of the acute phase or difficulty carrying out the required paperwork, and that the best mode for delivering this information was in a face-to-face format with the caregiver and appropriate hospital staff present.

“I know I have to go to talk to the social worker sometime but I'm not really good talking to people like they gave me this is phone number like this is the phone number you should ring to find out what is ... I hate to do that”. (C32: Spouse)

Closely related to the personal assessment of services and resources shared by caregivers was their corresponding outstanding unmet needs. There were four broad areas of needs.

- Independence
- Stroke education/knowledge
- Formal support
- A healthy and recovered stroke survivor

In terms of independence, caregivers revealed that at times they required respite away from their caregiving role where they could: have time to carry out other responsibilities, participate and enjoy separate recreational and holiday activities away from the stroke survivor and outside the home, or just be alone.

“I think we've been terribly deserted. I think that there should be something that I should be able to ring somebody and say look can you come and just spend two days here. Just while I go out and do whatever I wanted to do”. (C7: Sibling)

Caregivers also expressed a desire for the stroke survivor to be more independent which could be achieved through physical mobility aids and other services that assisted people with disabilities such as transport services.

“We’ve gone away with our friends up to XXX XXX for a week earlier this year and we hired a - on arrival at the house that we were staying at I’d actually hired in for the week a mobility scooter because we were sort of a kilometre from the main part of XXX XXX. Well, it was great because the rest of us, seven of us would walk, Trevor would hop on the mobility scooter and he had complete independence and he could take the - it was one of those travel ones that are really compact mobility scooters so we could go into restaurants and cafes”. (C24: Spouse)

In relation to stroke education and knowledge, calls for education about the nature of stroke and how to manage risk factors of stroke were made. Many caregivers stated they were not informed about the basics of stroke signs and risk factors and only those with drive and initiative sought this information through their own research. Awareness about the types of services and support groups available was also another key area of need for caregivers. A list of types of resources was said to be helpful, although less so than face-to-face education and hands on assistance, i.e. actually having a health care staff member help the caregiver complete appropriate forms or make phone calls. It was evident that such face-to-face assistance was invaluable as caregivers were usually in shock, unprepared and had very little or no previous awareness about stroke or available services in the early stages of the stroke.

“But when the second stroke happened, that was... And I was unaware of it. This is something I think sometimes people should be made more aware of things and I wasn’t... Maybe, maybe

somebody would have said "Look your husband's had one stroke, it's possible there could be more, this is what you've got to look out for", that would have been great but never got that. And I think that would have been...". (C31: Spouse)

Formal and informal support was also said to be necessary in reducing caregiver distress and burden. In relation to informal support, caregivers desired more practical assistance from family and friends such as offers to sit with the stroke survivor while the caregiver attended to other duties. A desire for an emotional outlet to talk about concerns and feelings with friends or a mental health professional was also raised. However, these were secondary to the need for caregiver respite or formal stroke services such as ongoing rehabilitation, medical services and financial assistance that facilitate recovery and the stroke survivor's motivation to engage in rehabilitation exercises. The most predominantly needed formal services cited are shown in Table 6 below.

"Yeah work with him, sit down with him doing his exercises or doing stuff with him because he doesn't want to listen to me anymore so it's better other people talk to him and then he might listen, that's what I need." (C32: Spouse)

"He was in the XXX Rehab for six weeks. Whilst he was there a lot of the nurses who I knew were very supportive of me and tried to encourage me to go and see the social worker and get what support I could get, but being the know-all and be-all I felt, "No I'm right, I know what's going on". I eventually did talk to a social worker there, a little late in the piece, but none the less, he was quite supportive and I realised that there were benefits in talking to other people, not in taking it all on your own plate". (C22: Spouse)

Table 6.
Formal Services and Resources Valuable to Caregivers

Services and Resources
Home Care nursing assistance for personal stroke survivor care
Home-based respite
Assistance with domestic duties: cleaning and meal preparation
Follow-up doctor appointments and check-ups
Low cost services: <ul style="list-style-type: none">RehabilitationPhysiotherapySpeech therapy
Regular and ongoing rehabilitation
Adequate nursing homes (environment and activities tailored to the stroke survivor's needs)

Ultimately, all the above needs contributed towards achieving the caregivers' greatest desire which was to see their family member reach a full recovery, return home (if in a nursing home), and return to the person they were before the stroke.

"To get him back, in thought: he thinks differently now, to how he was with his kids, having a sense of feeling and belonging and need to the world, and to us. There are times when he thought he was useless to us, and he's not... That's when I would like a magic wand: just get him back, or get him working again".

(C16: Spouse)

This involved the restoration of the stroke survivor's mobility, language abilities, cognitive functioning, pre-stroke personality and the loving and/or mutually supportive relationship that existed prior to the stroke.

3.2.1.5 Prognosis messages from health professionals

An issue that was highlighted in several caregiver interviews was the prognosis messages that were conveyed by health professionals, particularly during acute hospital admission. In all instances that this subtheme was raised, one factor was consistent, that the messages were considered to convey a negative outlook on the stroke survivor's prognosis. These messages included feedback that: prognosis and a chance of a good recovery was meagre, that there was no hope for the stroke survivor to walk again and that the only option available for the stroke survivor was a nursing home. Indeed, most caregivers reported that instilling hope (however slim the odds were) would be a far more valuable tool for a health care professional to use. The stroke survivor was also sometimes affected by such messages which may have consciously or unconsciously contributed to their mood.

"Yeah, that's right, and they kept on saying to us, "Put him in a nursing home. Put him in a nursing home" and I said, "No..." That's right. Oh well, she (doctor) said it to us, "He will never get better." "What you see is what you get. That's what you'll get from him." And even I said to her, "You're a very negative doctor." I go to her, because the negativity rubs off on your patients, first of all. If you're going to turn around and say something, move out of the room, because every time he'd see the doctor, he used to cry. Like, I know that's part of the stroke, but he used to have this fear of seeing her all the time...No hope, and they said, "We can't tell you that he will. What if he doesn't?" It was just like, well, you know what, maybe these people need a bit of hope. Just give them a bit of hope...If there is a slight improvement, you know that there was some kind of, something did come through. The littlest things, but

they just, the negativity in those doctors are unbelievable...But we're not asking you, "Is he going to get better? We're just asking is there hope of him having some kind of movement?" (C37: Spouse).

While some caregivers acknowledged that the pessimistic view of doctors may have been a way for them to think 'realistically', such messages were deemed to have an impact on the caregiver and wider support system. Other family members were said to be influenced by the negative prognosis, manifesting in their poor efforts at assisting with the stroke survivor's rehabilitation, possibly due to a sense of futility. In all instances caregivers acknowledged that the stroke survivor had made improvements beyond the doctors' expectations.

"They were mostly very good (Health-care professionals), apart from one particular sort of doctor who, any time I took my wife to visit him I just came out feeling just totally depressed, because of this whole thing about you can, the first six months is going to be recovery, but after that, that's going to be about as good as it gets and it's going to be plateau, and I thought, and Lisa after six months was in a pretty bad way and I just thought, this is, I just came out feeling depressed, depressed for her, depressed for me, and whatever. Although I'm basically, I'm a glass half full person". (C23: Spouse)

"...For the first three days we were just simply told that there was nothing that could be done for her, she would basically be a vegetable for the rest of her life and that was that....she has a husband... he was told right from the beginning that he would be unable to care for her, which immediately put that into his mind. So therefore he said "no, no, no I can't care for her". But I just didn't think that was quite appropriate to put before somebody anyway. And when we had our family meetings I must admit that I stood up and said that everything was too negative, they needed to be more positive. I even told the Doctor that. He said oh well I don't mean to be. But it is. It's one of those things where...I mean they say you've got to address reality, but how do you know where reality is if you don't give people a chance of doing it? And if

you tell somebody often enough that you can't do something, they're going to believe it aren't they?"

(C15: Sibling)

"Yeah, well once she was stable, they knew that she wasn't going to die, they had a bit of an attitude of, "Well, this is as good as it gets" and it wasn't. I would actually like to take my mother back to them and say, "This is actually how – this is as good as it'll get". I mean, look, she can't speak and she can't walk but they put her down to be vegetative and we said, "There's no bloody way our mother's going to be a vegetable"... I think that what would have been really helpful was for the doctors or whoever to say, "Look, there's a range of outcomes" because, at the end of the day, they actually don't know what the outcome for that person's going to be because strokes are just so unusual, et cetera. Having a pessimistic prognosis when you're so outside of yourself, I don't think is helpful but it's also got to be realistic so like, "Your mum could either be – could go from here to here and what would be helpful is for her to experience some physiotherapy, some speech therapy, et cetera". (C28: Child)

3.2.2 Caregiver factors

3.2.2.1 Emotional functioning

A broad range of emotional difficulties occurred in association with being a caregiver of someone with stroke, or which were exacerbated by the stress of the caregiver role. Caregivers experienced feelings of shock, sadness, guilt, anger, irritability, resentment, frustration and anxiety. Shock was reported to occur in the early stages of the stroke as caregivers faced the stroke without any preparation.

"It was a shock yes, because she's the driver, I don't drive...". (C29: Spouse)

Emotions that centered on depression and anger (sadness, guilt, anger, irritability, resentment and frustration) were more long-standing and explained by elements of loss and grief.

Loss of independence and spontaneity, lifestyle (which included enjoyable and social activities) and disruption of and inability to make future plans (such as overseas trips), were associated with feelings of disappointment and at times possibly resentment towards the stroke survivor or the situation in general.

“That’s probably the main issue for me, and as I said it’s this constant treadmill of appointments that doesn’t allow me to have something where I can go and say well Wednesday afternoon is supposed to be my own time but last week he didn’t go to bowls because he didn’t feel like it, the week before he didn’t go because he was sick with the flu, today he rings me up as soon as I get out to do something to tell me he’s coming home. So you can’t really say the afternoon is yours, you’re sitting there waiting for a phone call all the time. So it isn’t easy...” (C22: Spouse)

Caregivers also experienced a feeling of loss of the person they once had in terms of both personality/behaviour and physical health. That is, adjustment to the change in a loved one without any certainty whether they would return to pre-stroke functioning brought sadness and hopelessness to some caregivers.

“When I used to go out to visit him and he’d be sitting out the front in his wheel chair...ahhh...heart wrenching honestly...and he’d been sitting there just about all day waiting for me to come (starts crying)...It’s just not fair...why did it happen to him, this is what I get angry about, you know it shouldn’t have happened to him...should have happened to some bastard”. (C1: Spouse)

“... I don’t think the tears ever go away, as – God; I think what it is, is the loss of the person that you had. There’s this person who looks like my mother but it’s not the person that – like I can remember my mother used to stand in that corner, because every morning she’d get up to make me coffee on the way out to work, et cetera. She’d stand in the corner and she’d take so bloody long to make the coffee. I’d say, “Ma,

make the coffee, I've got to go". I would do anything to get her back (tearful). No, it's all right. It just never goes away. No, no, it's all right, this is the hard part". (C28: Child)

In addition, caregivers were also dealing with other stressors such as the loss of other family members and friends, and grief and loss became more prevalent, the older and more infirm people became around them.

"A friend I had we used to work in Thailand, he died just recently he was 90...

We used to ring one another a couple of times a week. Now there's no one". (C29: Spouse)

As previously discussed, the caregiver-stroke survivor relationship, and relationships with the caregivers' wider network such as those with other family members or health professionals were sometimes strained, and fraught with disagreements or a lack of support and understanding for the caregiver. Consequently, anger, irritability and frustration developed. Also related to the caregiver-stroke survivor dyad were feelings of guilt and anxiety on behalf of the caregiver if they left the stroke survivor home alone and engaged in their own leisure and recreational activities. The guilt was centered around the belief that the stroke survivor was no longer independent enough to engage in many previous social and personally enjoyable activities while the caregiver still could.

"Points of conflict that really do create a lot, but I'd like the, and I feel that, I have to say that every time I go out and leave him, and I do occasionally go out and leave him by the, when I say go out and leave him I mean to go and have some fun myself – very rarely but occasionally – I feel very guilty about it because I'm leaving him at home, he can't go anywhere but stay at home". (C22: Spouse).

Caregiver anxiety stemmed from fears that something detrimental may happen to the stroke survivor when left alone. Caregivers also demonstrated other anxious concerns fuelled by uncertainty around the stroke survivor's health (e.g. worries about a recurrent stroke, falls and overall future prognosis), the duration of caregiving and the caregiver's own health and who would care for the stroke survivor if they became unwell.

"But I think the worst part for me after it happened was, after the shock sort of settled was just living with the fear that it was going to happen again". (C33: Spouse)

"So you're tied to something, and too tired because you're mentally, "oh what happens if I go and something is wrong, what can I do, I have to come back"? And maybe this happened because I'm not here and maybe he's more stressed because I've left.... So I have to stop, for my sake and for his, because what happens when I get sick, who is going to look after us?". (C11: Spouse)

3.2.2.2 Social functioning and independence

Caregivers disclosed changes and reductions in the quality and amount of friendships they previously had and the social and recreational activities they once engaged in. Sometimes the isolation occurred as a general consequence of the stroke and the associated caregiver burden where there was less free time for the caregiver to interact socially with other people.

"Well before you know, ...every Friday I go and I leave her alone and I go there – up to 12 o'clock you know, the day – and play cards...there was all these people from the same country, the same age and you know, we had jokes...yeah so that was something psychologically very healthy and now I have to give it up, you know. Of course, you meet friends, "Are you coming Saturday at the XXX?" – "No thank

you". "Come on"... you know, we went there as I say, with a lot of friends, so we finish up... more isolated". (C9: Spouse)

"Socially, yeah, I mean, what social life?... I don't have one... I worked quite long hours, but then basically I'd, say, go down to the foreign correspondents' club, have my dinner, meet my friends, we'd maybe go and listen to a band or something, and basically I led a pretty, well, not a mad social life, but I had a pretty, I used to go, I mean, I loved hiking and that's sort of gone out the window...obviously I'm not in contact with close friends as I used to be. But I can handle it, yeah". (C23: Spouse)

Friends also appeared to invite caregivers out to gatherings less often or gatherings were restricted to the caregiver's home.

"I've lost friendships and that's basically definitely over this. That's definitely over this. Me not being able to because you know, go over to Manly and stay the night, wouldn't come home until 2 o'clock in the afternoon". (C7: Sibling)

"I think friendships with people have been limited because of my inability to reciprocate and I spend a lot of time entertaining here, trying to get people to come to dinner or whatever". (C22: Spouse)

Further, social isolation was sometimes a result of the caregiver's lack of independence, which concerned caregivers, due to the dependence of the stroke survivor on them for a variety of personal, domestic and community-based activities. Caregivers also found that the lifestyle they once had was now reduced. It was more difficult to plan holidays or weekly hobbies as the stroke survivor often could not be left alone or did not want to be left alone.

“Yes he doesn’t want to particularly go out, I mean I suppose the only time we go out is if we get asked and that’s not that often”. (C3: Spouse)

“He’s real dependent on me. I find that quite heavy, sometimes. He’s probably better now than he used to be, but when he has these days when he’s feeling a bit off and dizzy and so on. He doesn’t like to sort of lose sight of me”. (C3: Spouse)

Not only was there a reduction in social and leisure activities that the caregiver could participate in with or separately from the stroke survivor, but there was a general lack of time to enjoy one’s self and complete other tasks or activities outside of caring for the stroke survivor.

“Well you know, I cannot do anything myself, you know. Before I was in real estate and I was going out and just talking with the people to do some business. Now I can’t leave”. (C9: Spouse)

“Oh, yeah. I don’t do anything for myself any more, whereas I used to. I like to run: I like to exercise quite a bit, and I can’t do that at the moment”. (C16: Spouse)

Caregivers also found themselves restricted (not always intentionally) by the stroke survivor, who sometimes lacked confidence to do things on their own (despite physically being able to) or a desire to leave the home and engage in activities with others.

“Am I sad? Oh if ever I start, I am so sad. But I’ve got a two and a half year old grandson that truly it’s such a big deal for me to get there. You have no idea what a big deal it is. I have other grandchildren. I can never go, like one of my children lives on the central coast. “Tim let’s go to the central coast. Hop in the car, it’s an hour away.” He doesn’t want to go” (C7: Sibling).

It was stated in section 3.2.2.1 caregivers experienced guilt or anxiety if they left the stroke survivor home alone (who was often dependent on them to do many things), and so opportunities to engage in their own desired activities were further restricted. As stated earlier, independence was also restricted because formal (via respite) and informal support were non-accessible.

Caregivers who experienced the most restraint on their freedom, were those who already had pre-existing relationship problems with the stroke survivor. These caregivers felt obligated rather than committed to providing the stroke survivor with care (as outlined in 3.2.1.1 Caregiver-stroke survivor relationship) because there was no one else available to care for the stroke survivor.

3.2.2.3 Adjustment and burden

Caregivers reported various life adjustments as a result of taking on their caregiving role. It was found that household and relationship roles for caregivers had shifted over the course of caregiving. The caregiver would sometimes adopt duties previously attended to or shared with the stroke survivor such as managing the finances and driving (female carers) or domestic duties like cooking evening meals and grocery shopping (male caregivers).

“Pushing the trolley is so hard for me, I’m not very strong. He used to do everything for me. I was even a little bit spoilt, and suddenly I am the one who have (sic) to do everything, and take decisions...” (C18:

Spouse)

“But the problem is when I come from work I have to prepare his medication, prepare his lunch, his breakfast, because sometimes when I fall asleep he’s waiting for me to give him lunch...And sometimes I’m feeling sorry for myself, which I’m not supposed to probably, but that’s how I’m feeling, what a life.

What were you feeling sorry about, do you want to tell me more about that? All the decisions, the shopping, the cooking, the bills, everything is on my head, which before we'd sort of talk, and now he doesn't care". (C11: Spouse)

Essentially, the caregiver's daily 'to-do list' increased as a result of taking on the caregiving role, leading to burden and strain as many caregivers were responsible for assisting the stroke survivor with various personal, domestic and community ADL such as grooming, medication, and organising appointments.

"The hardest thing is we have always been very equal in everything that we do: you know everything that we do in the household. We've always been fifty-fifty in parenting, in our ideas, and things. I'm doing about ninety-five per cent of everything at the moment. So it's been really hard, that we hadn't planned it this way, because you never plan: things don't always go according to plan. To parent, two little babies by yourself, is very hard, and then to have him around and to not be able to do anything is very, very hard. Also, all the house stuff: cooking is a three-tier thing, because I have to do something for the baby. Making meals in the evening: last night was a perfect example. I had to give her a bottle first, get dinner ready for Joey, get our dinner ready, then feed A her solids after she had the bottle, so it was really hard to sort of balance all of that out". (C16: Spouse)

As will be discussed in the caregiver factors of physical health, this burden and strain manifested itself through feelings of tiredness, and physical and psychological stress including depression and frustration.

3.2.2.4 Resilience

Although not deliberately probed for in the qualitative interviews, it was found that caregivers exhibited an array of cognitive and behavioural coping strategies to manage the

emotional distress and strain associated with their caregiving role. Table 7 below lists the various strategies that were evident. Caregiver resilience and coping will be discussed in further detail in Chapter 4.

Table 7.
Caregiver Coping Strategies

Caregiver Coping Strategies	
Cognitive Strategies	Behavioural Strategies
Perspective and priorities	Activity scheduling (e.g. pleasant events)
Acceptance	Support seeking (emotional, spiritual, psychological)
Social comparison	Distraction (staying busy)
Searching for meaning	Physical activity/ exercise
Living in the present	Goal setting
	Problem solving
	Interpersonal communication skills
	Utilising prior nursing training skills
	Riding out stressful moments
	Boundary setting

Perspective and Priorities: *“It’s amazing how you can handle these things. You look at how other people who’ve got problems and you think, gee I couldn’t handle that. But when it comes down to it you just do it. You just pull the unimportant stuff out of the way”.* (C1: Spouse)

Living in the present: *“I’ve got Harriet as a living example that you can get slowly better, I’ve never had a timeframe for her recovery, I’m happy to live with it day by day... I just don’t ever think it’s worth living in the future or in a fantasy because I could be hit by a car tomorrow, I mean we’re all worried about Harriet, we’re all worried about her Dad being overweight but I could go tomorrow, so I don’t understand it, so I don’t have any need for a counsellor, I’m not stressed, I’m quite philosophical about life and I’ve become much more appreciative of its fragility and how important the present is, making the most of every single day. So that’s where I sort of come from”.* (C20: Spouse)

Activity scheduling and support seeking: *“And it’s just a great way - I found it a really good way of just letting it all go. It’s just that hour I can say anything and everything and no one’s going to judge me for how I say it, what I say, I just go blob, and it’s great. It’s just the best way because without that you’ve just got this pressure cooker building up in your head and it’s got to come out somewhere. So I saw her quite a lot when Trevor was going through that horrible return to work thing and that was a godsend. I tend to care - because I know that the nurses...they were always saying: “you’ve got to look after number one”. Without looking after yourself you can’t look after Trevor. Again, logical, but makes complete sense, so I tend to still have a night off with the girls, as it were, go out with a girlfriend or even just for a meal or a coffee or something, have regular facials and massages once a month, so just doing - tending to just do logical things just to relax. I’ve still yet to take up yoga but I am thinking, we’ve got a new yoga centre that’s just opened up across the road so I’m thinking: that’ll be good”.* (C24: Spouse)

Boundary Setting: *“Earlier on...I was trying to spend so much time with him I just, I don’t know I was a mess I’d say for quite a while. And then I decided that I would say have the mornings to myself and do whatever I wanted to do and go in the afternoon”.* (C 31: Spouse)

3.2.2.5 Caregiver physical health

Caregivers at times experienced changes to their physical health. Regardless of whether providing care directly contributed to physical health changes for them or not, a greater amount of burden was placed on the caregiver as they also had to manage the stroke survivor’s health. A subset of caregivers (particularly those over 50) reported having their own medical conditions that they also had to manage such as psoriasis, hip and back problems, low vision, hypertension, stomach ulcers, heart problems, skin cancers and even mild stroke.

“Well it (the uncertainty of stroke prognosis) certainly affected my psoriasis, I sort of come out in things like that”. (C3: Spouse)

"I had a cancer cut out on my leg there the other day" (C29: Spouse)

"And I suppose how, when you say it's frustrating, what's the most frustrating part about him just not remembering things day to day, on you?"

"Well because of my blindness, it's twice as difficult for me to find things. Puts the cutlery in the wrong sections, and I'm scratching around trying to find it, or oh just probably unimportant things, but frustrating for me because of my lack of vision". (C34: Spouse).

However, concerns and difficulties with managing these physical health problems were not raised as a predominant issue by caregivers beyond the need to monitor their own health, especially since the stroke survivor was dependent on them to be healthy.

"No, well I suppose having the heart attack makes you sit up and think well how much can I do and what have you. So I guess to a certain extent I've got to watch what I do...Well if anything happens to me, what's going to happen to her? This is the situation, I mean to say I get upset about it all, and I sort of think oh god what if I have a stroke, where do we go from there". (C15: Sibling)

In contrast, it was found that many caregivers experienced poor sleep quality or a lack of sleep, and low energy levels which were at times associated with a large quantity of caregiving responsibilities.

"..Sometimes when I'm going out I'm completely worn out by the time I hop in the car because I've had to write this out, I've had to tell him about this. We've got an alarm system here, I've had to tell him, "Tim don't forget", I've got to put a warning thing on the door so he remembers I'm not here. Then I've got to leave the food. Then I've got to be ready because I've got to give him his dinner.... So I've got to run back in here to give him his dinner. So by the time I get into that car I think oh my god. I do sometimes I think oh I'm totally bugged..." (C7: Sibling)

"When I have got that very rare break, I take full advantage of it, and I try to take a rest, because I am so tired". (C16: Spouse)

"The more I think of it, I think that is the most frustrating thing (trying to communicate with husband who has aphasia and speech problems)...because that brings more exertion, physical and mental. Tiredness". (C18: Spouse)

"I guess my sleep is probably more disrupted these days than it used to be." (C24: Spouse)

3.2.2.6 Caregiver characteristics

Caregivers were also found to possess particular personality and behavioural characteristics which may have affected other factors such as their relationship with the stroke survivor and others, and their overall distress levels and ability to cope. Characteristics include caring and nurturing qualities which were found across many caregivers. A proportion of caregivers showed a history of caring for others who were ill such as parents, aunts or uncles or worked in the caring professions (at least 25% of caregivers revealed employment in nursing, social work, or mediation).

"I think I've been put on this earth to care for people". (C13: Child)

Caregivers also reported a commitment and/or obligation, determination and persistence to care for the stroke survivor.

“But in my point of view, I know he’s a sick man, and I am the person that will never leave him, because how can you leave a sick person? He can probably do something very bad to himself or to your family, to children, you never know. So I care about him a lot, no matter what” (C11: Spouse).

Although, elements of over-protectiveness and over-accommodating for the stroke survivor in the provision of care, were also evident.

“I let him do that (withdraw from social interaction) so he completely started to withdraw...”. (C7: Sibling)

As discussed, many caregivers demonstrated their own coping strategies to manage stress and caregiver burden, and there did not seem to be an over-reliance on turning to others to talk about their thoughts and feelings for emotional support.

“Yeah and I just roll, as you say with the punches, and Harriet’s the barometer, however Harriet feels today is what I come up to, if she needs more support I double my support, if she’s doing okay and she wants to cook Christmas cakes which she did two days ago and this morning then I’m either there to help or she can handle it, she’s quite okay to handle it, I’ll do something else. I just sort of sit there and watch to see exactly what’s going to be important, what’s the best thing for me to do today to help her with her bucket of energy”. (C20: Spouse)

“Yeah, I’m hugely positive but I’ve always been that way and even if I’m not feeling positive, to portray that to my mother, if she was a little bit – well, she was a stress bucket, that’s why she had the stroke. She worries about me because she knows that I’m busy, et cetera, so I always have a happy face, even if I’m feeling tired or whatever. But, yeah, it’s a natural – it’s part of my personality, which is what I think gets me through”. (C28: Child)

This was found either because this was their personal way of coping independently or they did not want to ask for help and ‘burden’ others. There was also sometimes a belief that psychological help would not be beneficial and was less important compared to practical-based services.

“But then again, I don’t like to impose on them... I wouldn’t feel right doing that at home, people would get too concerned. They’d get worried”. (C1: Spouse)

“I’ve more or less got through a lot of things on my own. And I think sometimes you can nut things out and know how to deal with it. Maybe it is nice to get help from somebody but at this stage I don’t really, I think I can deal with things myself”. (C32: Spouse)

“There’s a psychologist in mum’s GP practice. It’s actually one of the doctor’s daughters. If I really needed them what are they going to tell me? I’m going to tell them exactly I know what the answer’s going to be, I just have to put myself above it. I know I have to free up my time even though my mother, the other trouble is my mother always wants me to be there”. (C13: Child)

3.2.3 Stroke survivor factors

Specific stroke survivor factors that contribute to caregiver experiences and outcomes were also found.

3.2.3.1 Cognitive and behavioural changes

Caregivers were shown to be affected by the the cognitive changes experienced by stroke survivors such as memory deficits, and a lack of motivation and action. A significant cognitive impairment for caregivers was the stroke survivor’s aphasia. The inability of the stroke survivor to effectively express themselves, be understood and understand others created sadness, distress

and frustration for the caregiver and stroke survivor. At times, the stroke survivor would become irritable when they felt misunderstood by their caregiver.

“Every activity. He’s paralysed on the right. The arm doesn’t work at all. He moves the leg a little bit, he can walk a little bit, but with help. And he cannot talk. That’s the worse... I think the hardest is his frustration, and not being able to tell me what he wants, or what - and my frustration sometimes not that I know. In his mind he thinks he’s talking to me, because sometimes he makes sounds...he thinks he’s telling me something. So he gets sort of angry, because I don’t understand what he means”.

(C18: Spouse)

Stroke survivors with aphasia were also less able to communicate their needs to others, including hospital staff, with some evidence that this resulted in less than optimal hospital care.

“Well, Mum has got acute dyspraxia and aphasia so she’s lost her speech and, our family, we’re women of chatterboxes and if you think I can speak - and I’m a lecturer - you should have met her beforehand. So to not be able to speak is the worst because she’s completely lucid. We’ve had cognitive functioning tests done, et cetera.

But she can’t get it out?

She can’t get it out, and she’s now wheelchair-bound, she’s lost the use of her right arm; and she’s a fabulous cook so she can’t cook. So all those things that defined her as a person, like her capacity to engage with people, to have conversations... it’s actually the loss of speech has been the hardest in all facets: you can’t advocate for yourself, you can’t communicate, your needs get overlooked, you’re dismissed, you’re ostracised socially - as well as professionally to a certain extent - unless you’ve got an advocate, and then it puts an amazing pressure on the advocate because you’ve got to be there as much as you can, et cetera...”. (C28: Child)

Aphasia also appeared to isolate the stroke survivor from their friends and other social and recreational networks, as many people found it difficult or awkward to deal with them and include them in group activities. This exclusion had a psychological impact on the stroke survivor and the caregiver, who reported feeling distressed by the lack of support and understanding of others.

"I think he's also a bit angry with them because they've stopped coming to visit (Rotary Colleagues)...But trying to get him to admit to that (why he no longer wants to go to the Rotary Club meetings) is something else again. But anyway so he, we've joined the XXX Group, but again I said to him last month after we'd come home from a meeting, "Now that was an interesting night wasn't it?" and he said "No." I said "Why not?" He said "Nobody talked to me". (C22: Spouse)

There were also accounts of behavioural and personality changes in the stroke survivor, affecting the harmony of the caregiver-stroke survivor relationship. Some stroke survivors were described as being more irritable, angry, obnoxious, obsessional (e.g. becoming more frugal about electricity use and spending money) and acting in an immature and childish manner.

"It has changed a little...he's umm...sometimes he just says silly things that would be funny for a 12year old but not really funny for an adult". (C1: Spouse)

Other caregivers however, noted that the stroke survivor had in fact softened and become more personable and affectionate since the stroke.

"Yes because he'd softened a bit and instead of firing at me, he would say something and then he'd say: "But I don't want to argue with you" so he sort of mellowed a bit that way and that was

something, yeah” (C31: Spouse).

3.2.3.2 Stroke survivor emotional functioning

Caregivers also expressed concerns with the emotional changes exhibited by their family member. These included symptoms of depression such as low mood, irritability, poor motivation and social withdrawal. Of these symptoms social withdrawal appeared to be the most prominent whereby, as previously discussed, the stroke survivor’s desire to leave the home or engage in social activities had significantly reduced since their stroke.

“Yea there has...we used to go out down the street to visit a friend of ours every couple of weeks to call in for coffee...we haven’t been there for months because um.....well.....I don’t really know the reason...but Patrick would prefer to stay home and watch Television”. (C1: Spouse)

On a few occasions stroke survivors were also reported by caregivers to dislike and refuse to stay in temporary respite care facilities.

“...we went up to the Presbyterian homes in XXX Street which is, the old building was demolished and this has been rebuilt, opened in July, absolutely beautiful, took us round showed us the rooms, showed us everything, Foxtel in every room, big TV’s, lovely lounge rooms everywhere and outdoor settings, and they take eighty five percent of your pension whilst you’re guests there, and I said to Erik, ‘How would you like to come and stay here for two weeks like a holiday?’ ‘No thank you’. I know what he would do, he’d come home and he’d be pottering around underneath the house with all his tools and what not, and come back for meals and have a sleep”. (C35: Spouse)

As outlined in section 3.2.2.2 on social functioning and independence, this in turn impacted on their caregiver who was no longer able to enjoy regular activities, social events and

sometimes holidays. In addition, a lack of motivation, volition and confidence of stroke survivors to attempt certain activities again (such as driving or assisting with domestic activities) was also reported by some caregivers.

"...Harriet doesn't drive anymore, because she's fearful of driving". (C20: Spouse)

Some caregivers were also concerned by the stroke survivor's reported compliance issues with a regular exercise regime for stroke rehabilitation (usually physiotherapy homework) or medication.

"What Trevor lacks is self-motivation to do the practice because all he wants is for the speech to be better.

He doesn't want to go through all that practice. It's boring. That's his attitude". (C24: Spouse)

"I have, in recent times, I don't know if I could call it resentment, but I have or recent times had to pull him up on a few occasions because he seems to think that I've had this stroke and so I don't have to do loads of stuff, he doesn't have to. Unless I make Tim do something in his day he wouldn't do anything at all. He

wouldn't get out of bed. He wouldn't eat. He wouldn't do anything". (C7: Sibling)

"Because we have a problem with him not taking medication". (C11: Spouse)

Finally, stroke survivors were reported to demonstrate various frustrations, bitterness and anger when they were no longer able to do things they once could such as participate in the workforce, communicate effectively with people, walk or drive. These feelings were then sometimes displaced onto the caregiver, thus causing caregiver-stroke survivor relational tension.

“We have the most terrible time in the car with him getting very, very angry with me because I’m not doing it the way he wants it done, and he perceives that he can drive better than me because he knows the area, and that’s a lot of the frustration from him I think, which is exacerbating him”. (C22: Spouse)

3.2.3.3 Stroke severity and general physical health

Overall, it was found that the greater the level of stroke severity, disability and reduction in general health, the greater the impact on caregivers’ psychosocial functioning and burden. Caregivers of stroke survivors who had physical impairments such as immobility, incontinence, aphasia, other speech problems such as dyspraxia or dysarthria or cognitive difficulties, expressed a great amount of changes to their life, burden and unmet needs from informal and formal support networks.

“The stroke’s really rattled him, I mean the cancer he never whinged about the cancer, never said why me or the prognosis wasn’t good and they misdiagnosed it in the beginning and so he had it for six months until it was really bad. As Frank (GP) said to me the other day when I managed to get up there by myself, he said he’s lucky to be alive. This tiredness and everything that he’s got, is just a progression of the disease. So we’re sort of lucky to have him and he’s sort of accepted cancer, but the stroke was just out of leftfield, and to destroy his intellect and all that really has made him quite, probably bitter really about it”. (C3: Spouse)

In contrast, caregivers of stroke survivors with relatively mild impairments or who had made an almost full recovery noted minimal changes to their life and had adjusted quite well; acknowledging that had the stroke survivor’s impairments been more severe their level of coping and difficulties may have also been greater.

“Yes, that’s right. As I said, we’ve managed. We’ve got through this and I think, as I’ve told you, I think Tim is a lot better than what he was, but it’s for the people who have got other big disabilities that’s really badly whatever, stroked. Like I mean if Tim couldn’t go to the toilet here, or couldn’t do something like that, I’d be in big trouble because we have an outside toilet. This house is well over 100 years old. Also if anything happens to Tim’s legs there’s stairs here”. (C7: Sibling)

3.2.4 External stressors

Other stressors outside the caregiver-stroke survivor system and the outer network of family, friends and formal support were also found to contribute to caregiver outcomes and burden. These included employment changes and financial strain that occurred as a result of the demanding caregiving role and the increased costs associated with stroke care (e.g. medications, rehabilitation, respite, transport, and adjustments to the home).

3.2.4.1 Employment and financial strain

Although half of the caregivers in this study had already retired at the time of the stroke, the remaining half were still engaged in paid work at that time. For these caregivers, changes to employment status as a result of the stroke situation were evident. These changes included: reduction in hours and work load, modified job roles, job relocation, or even termination of employment/early retirement. At times, a reduction of work hours was required in order to obtain the Centrelink Carers’ Allowance. Termination of employment or the prospects of termination appeared to have a large impact on some caregivers. Further, financial pressure and strain was found to exist for a number of caregivers regardless of their employment status and level of income.

“I’m not working and I’m on a carer’s pension. A major, major change. That’s probably also another major. It comes I think probably on equal footing with the social, if not a little bit above...It’s not like I’m walking around in rags or anything and I still can afford to buy things from time to time but it’s not quite the same freedom that you have when you’re getting a fortnightly pay packet”. (C13: Child)

“...I think she thought that I would just stop work and I think my kids did too, and then I just thought, I can’t do that. If I give up my job, then I’ve got really nothing, and luckily 2½ years later I’ve managed to juggle the two. As I say, I’m 60, I don’t really (need to work), I just feel I want to, I just get a lot out of my job”.

(C23: Spouse)

“ (We) rent this place, since he had the stroke we have more expenses... Before I used to work six or seven hours but now I have to work only five hours because of the carer allowance”. (C32: Spouse)

“Umm..we had to go and buy another car cause’ Patrick had trouble getting in and out of the one we had, and ah that’s a big thing, um we bought one that’s suitable but at the same time we need to adjust the seat to go back a bit further cause’ his legs were a bit cramped, but that was a big thing buying a new car, not new, second hand of course”. (C1: Spouse).

Reported financial strain, however, was more prevalent for those caregivers who were not in paid employment prior to the stroke, experienced a reduction in employment hours or termination to undertake the caregiver role or receive the Carers’ Allowance, or in the case where the stroke survivor had provided the main source of income. Caregivers who were retired or living off the income provided by the Aged Pension stated that they struggled to pay for all the stroke care costs in addition to the usual costs of living.

“Well now it’s more the financial than emotion, before you know, I was working in the real estate, you know, sometimes there was good money coming in and now...\$10,000 and you buy a better suit and

better shoes and take her somewhere, now with all these things gone, we have to live with the pension, can you imagine \$2-300 a week?". (C9: Spouse)

"...and also the cost factor, like if I put Tim into XXX, I can't remember how much the pension is, but if I put Tim into XXX that's 200 and something dollars for the week, which in all fairness is not a lot of money but it's because you've got that there and you're trying to keep this here and I'm trying to go on a holiday too, do you know what I mean?". (C7: Sibling)

It was acknowledged by those caregivers who were still employed at the time of the interview and on high incomes or those who were able to afford private health care, that they appreciated their relative financial security which allowed them the freedom to choose and access adequate formal support services and resources, rather than rely solely on government services or to manage the caregiver role without any formal support.

"I think that was the saving grace for us is that we had money; without money, I don't know what we would have done, to tell you the truth. Because we looked at some nursing homes and we just sort of, "There's no way" and there's no services in them, these poor old people crammed in, it's like a kennel, just so awful". (C28: Child)

"Well, Yasmeen, it's something you could consider is the fact that we've got private health cover and if Erik hadn't had that, he couldn't, well, we would have had to pay at XXX Rehab. The alternative was to send him to YYY Rehab, which is public, and probably not as good. That's what they told us at the hospital. Therefore, going to the XXX, they put us on the right track, particularly the occupational therapist; she said, "You're going to need help when Erik comes home, so we're going to arrange that for you" and then automatically after those three months of transitional care, then we went onto the aged care, which is very similar". (C34: Spouse)

3.2.5 Positive outcomes

3.2.5.1 Enhanced relationships and perspective on life

When asked if there were any positive aspects that had arisen as a result of the stroke and being a caregiver, two main subthemes were generated:

- The enhancement and affirmation of relationships with the stroke survivor, family and friends and,
- Changes in their perspective on life.

Some caregivers confirmed that their relationship with their partner was indeed strong and that mutual support for one another existed. These caregivers reported an increased intimacy with their partner who had become more affectionate and appreciative of what they did for them since having the stroke. As outlined in section 3.2.1.1, time spent between spouses sometimes also increased which was deemed to be a positive outcome for some caregivers.

“He’s become very affectionate...which is really nice...”. (C1: Spouse)

“He probably respects me more, for what I do during the day: he probably had no idea before, and now he can see I’m non-stop, I hope. I think that that might be a positive. We’ve learnt so much about strokes. We’ve learnt the signs to look for.” (C16: Spouse).

In addition, as previously discussed, stroke survivors sometimes underwent shifts in their behaviour and personality. For some caregivers this was in some ways a positive outcome when there was a reduction in some of the stroke survivor’s qualities that were not always healthy, such as alcoholism, aggression, dominance, and over-working. Some spousal caregivers noted that

although it was not something they would necessarily disclose to their partner, they were glad that their partner was more “controllable” and generally kinder and more personable.

“Well one thing we are happy about, this may be cruel to say, but before the stroke sometimes he’d just walk out and go and buy some drink or something, but now he can’t – this is cruel, and God forgive me to think, I don’t mean nothing bad. But at least we know we can control him”. (C11: Spouse)

This apparent affirmation was not only in relation to the caregiver-stroke survivor relationship, but also amongst the wider relationship and support networks of other family members and friends. A subset of caregivers found that their family had become more cohesive and closer, uniting to support one another in emotional and practical ways in relation to the care of the stroke survivor. In some cases, friends were found to show their support and even increase the amount of contact they had with the caregiver and family on a regular basis. Overall, these confirmations of support and meaningful relationships increased caregivers’ appreciation of the importance of such family relationships and friendships in their life, forming a realisation of whom specifically supported the caregiver.

“I suppose that’s another positive because the kids have been marvellous too. You sort of, you don’t really know how your children are going to react in certain situations, and sometimes they disappoint you greatly but they have been wonderful”. (C3: Spouse)

“As a family and the outer family has gone closer. I think that’s what’s made the stroke, I mean, it’s a bad thing to happen and a bad way to get together, but I think that’s just brought the family a lot closer.... I think we’ve got more time for each other” (C37: Spouse)

“And of course it changes your opinion perhaps of people as well, their attitudes, because it either brings out the best or the worst. And we’ve found this over a period of time, you know where people stand as to who your real friends are and who people are that are just users”. (C15: Sibling)

Some caregivers re-evaluated and appreciated life more, and prioritised what was indeed important and what was not.

“Oh you know, I always thought that going on, well very hedonistic, going on holidays, buying clothes and things like that to look good in and whatever wasn’t really important or things that you needed. Not materialistic, but just things that you probably wouldn’t have needed so much that I could afford to just buy without even thinking if I necessarily, if I sort of saw it, I wanted it, I’d buy it. I just thought well no I don’t really need that. I don’t really need as much clothes. I don’t need to be always going out for lunches or dinners. Again it was the quality of the friendships that formed once mum had had her stroke. So it was the people who stuck around after that who it didn’t bother them that I couldn’t go out or I couldn’t get out with them as much. Basically those sort of things. I think probably my faith came into it as well. I became, I’m a catholic. Sorry (tearful)”. (C13: Child)

3.3 Stroke survivor findings

The stroke survivor data were found to generate and validate all 5 master and 18 subthemes that were elicited by caregivers (see Table 3), substantiating the caregiver findings. What was notable from the stroke survivor data however, was the evidence of additional insights at the category level in the areas of the caregiver-stroke survivor relationship, caregiver needs, and the caregiver factor of emotional functioning.

In relation to the caregiver-stroke survivor relationship, some stroke survivors asserted that their caregiver did not always seem to understand the extent of their disability and that there was an associated disparity in concerns between the two where for example, the caregiver

interpreted the stroke survivor's behaviour negatively (e.g. 'lazy') while the stroke survivor reported that their behaviour was a consequence of their disability.

"What do you anticipate would have been the benefit of having, if she had that? (Education about stroke)

Wouldn't be in the state of guessing.

She wouldn't have been guessing?

Yes to what's going to happen. And why is he behaving like that, why is he angry?

Okay so what would have that meant for the relationship...

Why is he sleeping so much? Because he's recovering.

So it would have made her more understanding of you?

Yeah, yeah instead of oh all you do is get up and sleep...". (SS33: Spouse)

Alternatively, the caregiver and stroke survivor were found to have different perspectives and concerns about caregiving related issues.

"I think she needs a break now and then, but she doesn't leave me on my own. She seems to think I can't be left on my own". (SS8: Sibling).

When asked about caregiver needs, the importance of financial assistance and friendships was highlighted.

"I just think there should be some consideration given to, if you had what they call a disability they should give you some avenue to, not get extra money, but have enough money to pay for the support, taxis and things like that". (SS17: Spouse).

“but yeah I’m sure if she had someone who just dropped in and had a talk she’d be happy with it”. (SS2: Spouse).

Finally, in terms of caregiver factors, another important insight was into the caregivers’ emotional and physical functioning. For example, one stroke survivor was able to acknowledge that his wife no longer exhibited the same level of energy and motivation than in the past. This information was not in fact disclosed by the caregiver herself.

“...she’d rather watch television for six or eight hours or play a game on the computer rather than do something...the only change is she probably doesn’t feel like doing anything much at home now ...People talk about their retirement, like do painting or needlework or something, she just would like to watch TV”. (SS2: Spouse)

3.4 Summary

In summary, stroke caregiver psychosocial experiences and quality of life are influenced by five broad areas, relationships and support (e.g. caregiver-stroke survivor relationship and informal/formal support); caregiver factors (e.g. emotional functioning, resilience, physical health and personality characteristics); stroke survivor factors (e.g. cognitive and behavioural changes and stroke severity); external stressors (employment and financial strain); and positive factors (enhanced relationships and perspective on life). These five master themes, and the subthemes within them, do not exist in isolation however (see Figure 4). Subthemes overlap with each other and master themes influence each other dynamically. For example, on the subtheme level, within caregiver factors, a caregiver’s physical health overlaps with their emotional functioning (e.g. low energy). Further, a caregiver’s emotional functioning can be moderated by

the types of coping strategies they use (resilience), as well as predisposing factors like personality characteristics. On the master theme level for example, the quality of relationship and support was associated with caregivers' reported emotional difficulties and perceptions of burden.

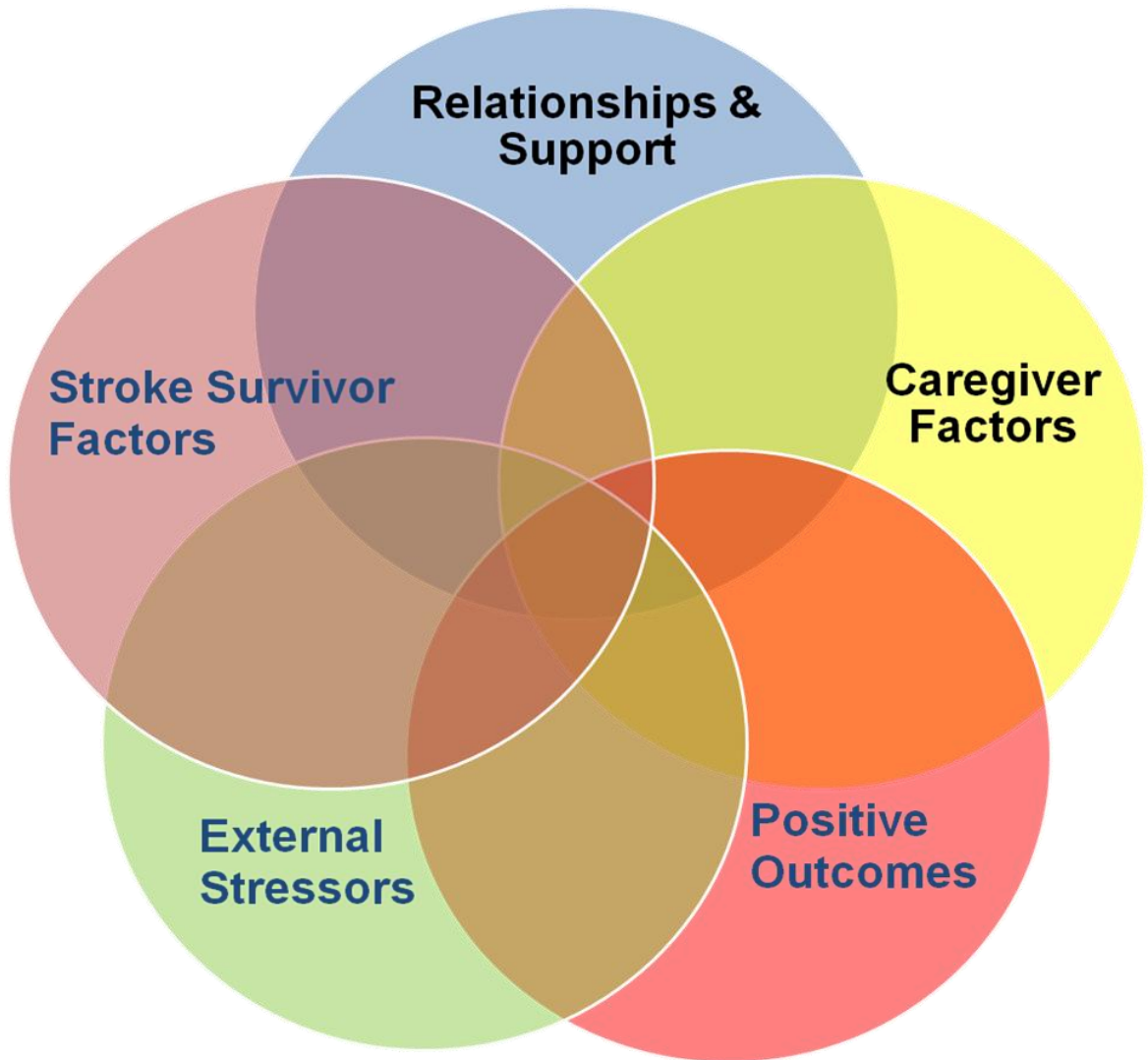


Figure 4. Components of stroke-caregiver experiences.

4.1 Summary of major outcomes

Overall, data indicated that stroke caregivers underwent a series of psychological, emotional, interpersonal, social, health and occupational changes as a result of undertaking their role. More specifically, the experience of caregiving can be grouped into five inter-related domains. The first being relationships and support in association with family, friends, work colleagues and health care providers. Second, caregivers' personal attributes and predisposing factors including their emotional functioning, level of social interaction and independence, coping styles and personality affected their overall adjustment. Third, changes related to the stroke survivor were also detrimental to caregivers' experiences. Fourth, external stressors related to employment and financial strain placed further burden on caregivers. Finally, although to a large extent the changes were unfavorable, some positive outcomes were found. One such outcome was the consolidation of interpersonal relationships. Each of these major themes will be explained in the next section in the context of existing literature and theory and in relation to the research questions and aims of this study.

There are three important aspects to the information generated from this study. First, the findings corroborated information found in previous literature while at the same time addressing the research questions of this study. Second, novel and unexpected findings were evident, these included caregivers' issues around doctor-patient communication and coping strategies. Third, the data identified some areas that did not appear significant to this group of caregivers despite being noted in the pre-existing literature.

4.2 Validation of existing literature and research questions

Changes in relationships with other people, particularly with the stroke survivor was an important subtheme of this study. The quality of the caregiver-stroke survivor relationship was found to shift along the spectrum between distance/tension to closeness. Sixteen of the twenty caregivers interviewed reported changes in their relationship with the stroke survivor since the time of the stroke. Relationships were reported to either become more distant and conflictual, or stronger and more supportive, depending on the status of the relationship prior to the stroke. Caregivers with more stable relationships with the stroke survivor seemed to care out of a sense of commitment and choice, whereas those with problematic premorbid relationships experienced more distress, and felt obligated to be caregivers as there was no one else available to undertake the role.

Similarly, caregivers asserted that informal support from family, friends and work colleagues also had a major impact on relationships, overall burden, ability to cope and emotional functioning. More specifically, caregivers became disappointed when family members or friends were not supportive enough, which sometimes led to relational tension, consistent with previous research findings (e.g. Eaves, 2002). Unsurprisingly, caregivers greatly appreciated pro-active offers of support (especially given their tendency to not want to burden others and ask for help). Caregivers' tendency to prefer receiving help without having to request it has also been previously found (Kerr & Smith, 2001; Schulz et al., 1988) and highlights the necessity for caregivers to become more assertive about their needs. Caregivers were also detrimentally affected by a lack of independence and changes in social relationships and friendships since undertaking the caregiver role. Caregivers' social functioning and level of interaction with friends had also reduced, either because the caregiver now had less time to engage in such activities, the

stroke survivor did not want to leave home as often, or friends made less effort to invite them to gatherings, in line with other results (e.g. Anderson et al., 1995; Periard & Ames, 1993; Young et al., 2003).

Another major theme pertained to factors that specifically related to caregivers' personal thoughts, feelings and behaviours. The first subtheme was caregiver emotional functioning which was primarily conveyed through feelings associated with depression, irritability, frustration, anxiety and stress. The depressive emotional patterns were usually explained by elements of grief and loss of a healthy partner/family member, personal independence and previous lifestyle (which included social relationships and specific roles once played). Also related to this depressive affect was internalised guilt that occurred if the caregiver left the stroke survivor alone or participated in their own separate leisure activities. This experience of loss was also associated with irritability and frustration, often due to changes in the strokes survivor's personality and behaviour. Finally, uncertainty around the stroke survivor's recovery created feelings of hopelessness and in particular, worried cognitions that something potentially detrimental was going to occur in the future, such as another stroke. There is a large body of evidence that supports stroke caregivers' experiences of depression (e.g. Han & Haley, 1999), and to a lesser extent, guilt (Kerr & Smith, 2001), irritability, and anxiety (e.g. Cumming et al., 2008). Nevertheless, only one known study thus far has highlighted the theme of loss amongst stroke caregiver experiences (Dowswell et al., 2000). The present study, therefore, is one of the first to provide in-depth explanations for such affective experiences rather than merely reporting prevalence rates and variables associated with low mood.

Caregivers also reported stress, usually as a consequence of managing and adjusting to the increased burden that occurred as a result of their competing demands and responsibilities, as

well as the changed roles within and outside the home. The experience of juggling various demands (Bakas et al., 2002; Pierce et al., 2006) and the changes in caregiver roles and identity (Dowswell et al., 2000) has also be touched on in previous qualitative studies, however these studies were small, and so the present findings help to strengthen this evidence base.

Caregivers were also seriously affected by difficulties with the stroke survivors' memory, communication, mood, motivation and personality (possibly as a result of poor executive functioning and anosognosia). All of these have previously been shown to contribute to caregiver-stroke survivor relational tension and conflict (Bakas et al., 2002; Smith et al., 2004b). These changes in stroke survivors have also been consistently found to affect caregivers' emotional functioning (e.g. Chow et al., 2007; Dennis et al., 1998; Haley et al., 2009; Kotila et al., 1998; van den Heuvel et al., 2001). It is possible that stroke survivors' poor intrinsic motivation, confidence and outlook on their prognosis and recovery may have sometimes caused poor compliance with rehabilitation regimes placing further burden and strain on the caregiver, who in turn, struggled to increase the stroke survivor's drive to recover. There is strong evidence for the emotional difficulties experienced by stroke survivors (e.g. Dennis et al., 1998), and based on the present findings the importance for stroke services to incorporate psychological and emotional support in addition to aspects of physical rehabilitation is highlighted.

Stressors outside the relational and support networks have also been found to impinge on caregivers' adjustment and wellbeing, such as employment changes and the financial cost of caring for someone with a stroke (Anderson et al., 1995; Brereton & Nolan, 2000; Dewey et al., 2002; Eaves, 2002; White et al., 2004). In the present study, those employed at the time of their family member's stroke experienced changes in their employment role or reductions in workload. In addition, financial strain was experienced for all caregivers due to the various costs associated

with caring for a stroke survivor. This financial strain was greater and reported more often for retired caregivers and those living on a pension, and their access to high quality stroke and rehabilitation services was also restricted. This in turn impacted upon caregivers' emotional functioning and burden as well as the stroke survivors' recovery trajectory because ongoing rehabilitation was inadequate or absent. Finally, financial strain meant that caregivers had to significantly reduce social and recreational activities that brought them enjoyment.

All caregivers had used or were currently using stroke services and resources. Some caregivers were found to appreciate the regular check-ups as a way of receiving reassurance that their family member was being looked after, this was partly indicated by their participation in clinical trials or other research studies that required ongoing visits to the hospital. Caregivers also stated that regular and ongoing rehabilitation was essential for stroke survivor recovery to continue, especially when intrinsic motivation was an issue for some stroke survivors. Most caregivers, however, reported dissatisfaction with access to services and resources, stating that appropriate services were either unavailable or access to them was restricted or declined. Furthermore, formal support that was accessed was not always of a high standard, regular or ongoing. Caregivers felt neglected by health care providers, particularly following hospital discharge of the stroke survivor, and expressed a level of uncertainty about what services and resources actually existed, and about the nature of stroke and the prognosis for their family member. Many caregivers also stated that their own proactive research and treatment planning and continual persistence was required to receive any formal support in a timely fashion. These concerns and issues have been expressed in a small amount of previous studies (e.g. Bakas et al., 2002; Brereton & Nolan, 2000; Eaves, 2002; Kerr & Smith, 2001; Smith et al., 2004b), and therefore provide further compelling evidence whilst also building on the developing knowledge.

Caregivers also reported dissatisfaction with the quality of services, particularly nursing home care and doctor-patient communication (the latter of which will be discussed in sections 4.3 and 4.6). It can also be suggested by the current findings that caregivers who rated services highly in terms of access and quality were generally younger, employed and able to utilise private or high-cost services. For the most part however, when services and resources were received, satisfaction was quite high. So, the main issue for caregivers was the discontinuity of care rather than the quality of care. Caregivers also reported that the best way of delivering stroke related information was in a face-to-face format, rather than simply providing brochures to caregivers at discharge. This is consistent with other studies which have found face-to-face education and training for caregivers to be more efficacious than the provision of written materials (Bhogal et al., 2003; Forster et al., 2001).

The main needs caregivers highlighted were: Independence, education and knowledge, improved formal and informal support and a healthy and recovered stroke survivor. Caregivers reported that their needs for independence would primarily be met through informal offers of support from family and friends and through access to respite services. Respite services were said to be difficult to access however, and often inappropriate as they were not home based, had a non-stimulating environment for the stroke survivor, or were too limited in duration. Apart from respite care, stroke education provision and other forms of formal support were also deemed insufficient for caregivers. It appears then, that caregiver needs, which were strongly tied to the stroke survivors' ability to access quality services and resources, were in general, not met.

In terms of the positive aspects of caregiving, two main subthemes that emerged were the affirmation of interpersonal relationships with the stroke survivor and other people, and an increased appreciation of life which involved a change in perspective and priorities. Some

caregivers reported a closer, more intimate and supportive relationship with the stroke survivor as well as a more cohesive family unit that banded together to help care for the stroke survivor. At times, friends also provided valuable support, through regular visits, emotional assistance and encouragement, and by providing practical help. These findings are also seen in the existing literature (Haley et al., 2009; Parag et al., 2008; Schulz et al., 1988; White et al., 2004), and could be interpreted in terms of the Response Shift Theory (Sprangers & Schwarz, 1999) which describes a change in an individual's internal standards and values when faced with illness, reprioritizing what is important and modifying life goals. In turn, a satisfactory QoL can be ensured despite the stressful situation. Although this phenomenon usually refers to people with medical illnesses, rather than caregivers, it could be usefully applied to caregivers of stroke survivors.

The themes that stroke survivors generated overlapped with the ones generated by their caregivers. Unsurprisingly, this congruence was found amongst strong caregiver-stroke survivor relationships. It was interesting however, that the concerns and priorities of some stroke survivors were different from those of the caregiver. In such instances the stroke survivor felt misunderstood by the caregiver, for example, they noted that they were not in fact lazy or incapable as their caregiver assumed, but depressed, fatigued and not functioning well. In turn, some stroke survivors found it extremely difficult to empathise with their caregivers' experiences or reflect on the issues that might be facing them. These findings provide evidence for the necessity of promoting a healthy caregiver-stroke survivor relationship, particularly a mutually open, assertive and compassionate one where each person's views are shared and made known to the other, while at the same time, acknowledging that there will be differences in opinions and perspectives on the same issues.

4.3 Novel findings

Patient-doctor communication

During interviews, the issues pertaining to patient-doctor communication and coping strategies were not probed for specifically as they had not emerged from the review of the existing literature. However, some compelling evidence for caregivers' dissatisfaction with the quality of services and resources and in particular the novel finding of their concern with health professionals' communication style was generated. One major pattern shown was that caregivers found messages about the stroke survivors' initial prognosis unnecessarily negative and disheartening, a feeling which may have been compounded further by the existing stress of having a loved one suffer an almost fatal stroke. Caregivers reported that such 'hopeless' messages may also impact the stroke survivors' motivation to recover as well as other family members who may internalise such messages and consequently reduce their efforts and actions towards encouraging stroke survivor recovery, creating a negative self-fulfilling prophecy. However, other caregivers were able to draw upon their personal resilience and coping skills to overcome such comments. Their positive thinking style and perspective, ability to channel feelings of anger to be assertive, and their strong commitment to the stroke survivors' recovery appeared to enable them to prevail over such comments. This concern about the communication style of the health care providers is novel in the stroke caregiver literature, but has been documented in the wider health psychology literature (Ong, De Haes, Hoos & Lammes, 1995).

Caregiver coping strategies

Caregivers also exhibited several different cognitive and behavioural coping strategies to help manage their situation. Cognitive strategies included perspective taking (the particular

interpretation of people, situations, and life) which was shown to be an important coping mechanism used by stroke caregivers. Particular attributions of the stroke survivors' emotional, personality and behavioural changes allowed caregivers to better adjust to the changes in their life since the stroke, as well as understand the stroke survivors' experiences, and in turn, maintain a solid relationship. For example, attributing the stroke survivor's changes in personality, specifically their increased levels of irritability, to the stroke and stroke-related medical conditions such as diabetes and hypoglycemia facilitated the caregiver's empathy for the stroke survivor. In turn, the caregiver was able to manage outbursts of anger with less disappointment and hurt because the behaviour was not personalised. Another beneficial attribution caregivers made was reminding themselves that the stroke survivor has suffered changes to their body and brain, and therefore does not have the same level of motivation or energy to do as much within the home and socially as previously. Some caregivers also focused on realistic (rational/factual) and even positive aspects of their situation in an objective, balanced way, rather than filtering negative information or worrying about potential detrimental events. Accepting the changed circumstances, comparing the stroke survivor's situation to other stroke survivors who were less fortunate, and focusing on the present moment rather than dwelling on the past or future were also valuable perspective taking strategies utilised by some caregivers. Caregivers also re-evaluated their priorities and what was important in life. Issues that may have upset them in the past were no longer 'important' and the fact that their loved one was still alive was what predominantly mattered to them. This was more evident in the cases where the stroke was mild and where the quality of the caregiver-stroke survivor relationship was high.

This information is important and extends on previous (albeit sparse) stroke caregiver literature which provided evidence that caregivers of people with stroke use different types of

cognitive coping strategies (e.g. Visser-Meily et al., 2009a), these include realistic (and at times positive) appraisals of the caring situation, focusing on one day at a time, acceptance of the situation, maintaining humour, and benefit finding (Smith et al., 2004c). It has also been found in the general caregiver literature that caregivers' positive appraisals of their situation and lower anxiety levels are associated with greater positive experiences of caregiving (Hilgeman et al., 2007; Roff et al., 2004).

There is empirical support for the use of these strategies in the field of clinical and health psychology. Effective cognitive and behavioural coping strategies have been found to improve emotional problems such as anxiety, depression and stress for people with a range of psychological disorders (Barlow, 2001). For example, acceptance of particular situations in life that cannot be changed, and Mindfulness training which involves focusing one's attention to internal experiences and external stimuli in the present moment, without engaging in judgmental thoughts or interpretations, are both helpful skills used in various therapeutic modalities for the treatment of psychological disorders (Baer, 2003; Harris, 2007; Linehan, 1993). These cognitive processes such as changes in perspective taking, benefit finding and making social comparisons towards more seriously affected individuals, have also been found to improve adjustment for people suffering various medical and life-threatening illnesses (Sharpe & Curran, 2006).

Behavioural techniques that caregivers engaged in included setting boundaries of personal self care by making sure to take time out for one's self and engage in regular pleasant and enjoyable activities, exercise (e.g. walking) and actively seeking the support of others (usually through friends, church, work colleagues, social groups or in one case professional psychological support). Expressing emotion and turning to spirituality have also been documented in the stroke caregiver literature (Pierce, 2001; Pierce, Steiner, Havens & Tormoehlen, 2008). Staying busy

was also said to help some caregivers avoid rumination regarding their stressful circumstance or concerns, and there is evidence in the depression literature that using distraction techniques can significantly reduce low mood (Noel-hoeksema & Morrow, 1993). Actively setting short and long-term goals gave caregivers hope and purpose, whilst solution-focused problem solving was also beneficial. Problem solving involved making phone calls to identify respite care facilities or searching the internet for stroke support groups that the stroke survivor could take advantage of. Drawing on one's strengths by applying previous nursing skills was also helpful and practical as it minimised the physical and emotional burden of providing personal care to the stroke survivor because the caregiver knew the most efficient way of completing such tasks and was more familiar and less daunted by them. Relying on one's own experience has also been previously found amongst stroke caregivers (Smith et al., 2004c), whilst actively confronting problems (van den Heuvel et al., 2001) and expressing emotions (Visser-Meily et al., 2009a) have been argued to improve caregiver strain and burden compared to passive strategies such as avoidance (Visser-Meily et al., 2005a), although this finding is not always consistently found (Visser-Meily et al., 2009a). In one study it was found that male caregivers of people with stroke experienced less burden and stress than their female counterparts (Tiegs et al., 2006). Though the reasons for this were unclear, the authors speculated that men tended to use more instrumental and solution-focused ways of managing their difficulties, such as utilising support from the external environment. Finally, being able to 'soldier on' and ride out stressful moments through patience, persistence, distraction or other cognitive and behavioural strategies mentioned was an essential aspect of caregiver resilience, and psychological techniques that help individuals 'ride out' stressful and uncomfortable urges and sensations such as anxiety, panic and high levels of distress have been shown to be effective in the treatment of some psychological and behavioural

problems like drug and alcohol abuse (Lamplugh, Berle, Milicevic & Starcevic, 2008; Linehan, 1993).

There is also a rich body of general psychological theory and literature to support the different cognitive and behavioural coping strategies found in this study. The work of Lazarus and Folkman and their theory of coping conceptualises coping as either problem-focused coping (attempts to alter the relationship between the person and the environment causing stress) and emotion-focused coping (regulating emotions) (Folkman & Lazarus, 1980). Furthermore, eight different styles of problem-focused and emotion-focused coping were developed (confrontive, distancing, self-control, seeking social support, accepting responsibility, escape-avoidance, planful and positive re-appraisal) which incorporate either avoidant or active approaches to stressful situations (e.g. Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). While there is some evidence that certain types are more adaptive than others such as planful problem-solving and positive re-appraisal compared to confrontive (aggressive attempts to alter a situation) and distancing, it should be noted that no one style in isolation is necessarily adaptive and that the context of the situation should be acknowledged (Folkman, Lazarus, Gruen & DeLongis, 1986).

Overall, both cognitive and behavioural coping strategies appeared beneficial in this study. Caregivers who used active coping strategies such as thinking in a realistic and positive way and who re-evaluated their priorities in life tended to be those who reported a strong relationship with the stroke survivor and an enhanced appreciation of life. One theory in relation to managing trauma argues that personality characteristics such as optimism and 'hardiness' are associated with positive evaluations of the trauma situation and hence better adjustment (Tedeschi & Calhoun, 1995). Further, the results of the present study suggest that individuals

who care for stroke survivors with moderate to minimal impairments were those who were more likely to disclose positive features of caregiving within their personal narratives. This finding was notable given that it has been suggested that the objective level of burden (i.e. operationalised as hours spent caregiving) can affect a stroke caregiver's positive experiences of their role (Hilgeman et al., 2007). So, promoting healthy coping strategies, especially those associated with one's cognitive appraisals of their situation, and problem solving ways to reduce caregiver burden appear to be promising aspects that can be incorporated into future intervention programs.

Relationship and personality factors

While relationship problems have also been found in previous literature (Forstberg-Wärleby et al., 2004, Simon et al., 2009; White et al., 2004; Visser-Meily et al., 2009a), the present findings expand the previous research, however, by suggesting that this shift is largely dependent on the quality of the relationship prior to the stroke. Similarly, the literature on complicated grief and bereavement may be applicable here. While the definitions of 'normal' and complicated grief are still unclear (Bonanno & Kaltman, 2001), complicated grief can be generally associated with chronic and more intense symptoms and reactions of mourning compared to common grieving, and it may be diagnosed as part of a psychological disorder (Bonanno & Kaltman, 2001). It has been argued by several theorists that there are various factors that make an individual particularly susceptible to experiencing complicated grief, one of which is "a premorbid relationship with the deceased which has been markedly angry or ambivalent or markedly dependent..." (Rando, 1992, p. 47).

Caregiver's personality traits and interpersonal communication styles may have also affected the relationship with the stroke survivor and caregiver wellbeing. These included

commitment to the stroke survivor, patience, hard work and persistence, and other inter-personal skills such as empathy, understanding and open communication. Elements of over-protectiveness and over-accommodating for the stroke survivor were sometimes found to result in the caregiver inadvertently reinforcing the stroke survivor's withdrawal, lack of motivation and dependence. Caregivers were also found to exhibit resilience and strength (as shown through the use of coping strategies described above), and were also generally self-dependent as exhibited by their autonomous ways of coping. Information into the nature of stroke caregiver personality traits is scarce in the stroke caregiver literature, but may prove beneficial for identifying factors that may improve caregiver burden.

4.4 Conventional wisdom challenged

In relation to caregiver burden, managing medical health problems was also pertinent. Older caregivers expressed health problems more often than younger caregivers which appeared to pose yet another responsibility to juggle, further exacerbating the degree of burden. However, it was unclear whether these 'physical health' problems stemmed from a somatic response to emotional stress, from the objective level of burden, the caregiver's existing medical problems or the aging process. For example, some caregivers experienced poor sleep because they worried and ruminated about caregiving-related issues, while others were mentally and physically exhausted from the day-to-day frustration and efforts of caregiving. There is limited information on stroke caregiver physical health and the effects on overall wellbeing (Hans & Haley, 1999). Considering caregivers' physical health in research is also important because most stroke caregivers are elderly and suffering from some form of medical condition (Chow et al., 2007; Kerr & Smith, 2001). At the same time however, physical health was one of the less prevalent

subthemes in this study, indicating that this issue is not a high priority or of large concern for most caregivers.

Interestingly, the present study found that the most detrimental stroke survivor impairments for caregivers were aphasia, social withdrawal, irritability and lack of motivation. What was further evident from the qualitative findings was that for caregivers of stroke survivors with relatively severe communication and mobility impairments, caregiver burden and distress was generally greater than for those caring for stroke survivors with less severe impairments. So while the stroke survivor literature has continuously provided evidence for the significant impact of stroke on the emotional wellbeing of stroke survivors (e.g. Anderson et al., 1995; Bakas et al., 2002; Simon et al., 2008), this study has shown that the physical disability of stroke survivors remains as important to caregivers as their emotional and behavioural functioning. It could be speculated that the reason for this notable finding in the present study is that caregivers of people with aphasia or those living in nursing home care (i.e. those with severe physical impairments) were included in the study, while previous investigators tended to omit stroke survivors with aphasia or caregivers of stroke survivors residing in nursing homes, in their studies (Han & Haley, 1999). Therefore, the need to include caregivers of very severely impaired stroke survivors (such as those with aphasia) in future research studies is great.

4.5 Methodological strengths and limitations of study

The present study recruited a diverse sample of caregivers with differing characteristics, this included a cross section of caregivers across age, ethnicity, socioeconomic status, duration and intensity of caregiving, and stroke survivor disability. Although the concepts of external validity and generalisability are not relevant in qualitative research, a homogenous sample can

lead to spurious and premature data saturation (Francis et al., 2009), and it is important to have a representative sample of stroke caregivers from various situations and backgrounds. The variability of caregiving duration in this study from 3 months to several years after stroke also helps to aid the understanding of long-term consequences of caregiving. A further strength is that similar experiences were found across this diverse group of caregivers and stroke survivors.

A second major strength of this study is its methodological rigor. To the author's knowledge, this study is the first to triangulate stroke survivor's responses as a tool for validating caregiver experiences and providing more thematic depth. Another major finding generated from this triangulation process was the difficulty stroke survivors' had empathising with their caregiver and perceiving issues from their perspective. This finding highlights the importance of understanding the nature of the caregiver-stroke survivor relationship in more depth. Further to ensuring validity, the reliability of the study findings was also demonstrated through the use of an independent coder. Finally, many investigators fail to be transparent with their data analysis techniques, begging the question of how credible the results are. In contrast, the present study used a systematic method of data saturation following the seminal work of Francis et al., (2009) and other important quantitative researchers in health and psychology (e.g. Braun & Clarke, 2006; Willig, 2001). The sample size was justified and the quality, reliability and transferability of the results as a representation of general stroke caregiver experiences and outcomes appear to have been established.

In relation to theoretical contributions to the literature the present study broadens the knowledge base and understanding of caregivers of stroke survivors. This study adopted openness to its inquiry, allowing all aspects of the caregiver experience to be shared and reported, while at the same time ensuring prompting for any key areas not spontaneously reported. Not

only did this study corroborate theory and evidence in the existing literature, certain gaps in the area were addressed and novel unexpected findings generated. These novel findings are important for better understanding caregivers' needs and how to improve their quality of life following their family member's stroke. The implications of such generated themes and insights will be discussed in the next section.

There are some limitations to this study that should be noted. First, one of the original research aims was to compare and contrast themes elicited between male and female caregivers. Sufficient numbers of male caregivers were not recruited. Nevertheless, the ratio of female to male caregivers in this study is consistent with the ratio found in most stroke caregiver studies (e.g. Anderson et al., 1995; Dennis et al., 1998) and therefore most likely in the stroke caregiver population at large. Second, stroke survivor data were only available for 10 stroke survivors, all of whom came from anglo-saxon and English speaking ethnic backgrounds. The remaining 10 stroke survivors were unable to participate due to language comprehension and expression difficulties. Third, the sample of caregivers in the present study consisted of a small percentage of people who were invited to participate in the study. It is therefore possible that the caregivers who volunteered to participate may be different in some way to those that did not participate. Selection bias, however, is a common limitation across many research studies. In future, adopting more direct methods of recruitment may optimise the number of people that respond to an invitation to participate in research.

4.6 Future directions, clinical implications and theoretical insights

Cognitive Behaviour Therapy and stroke caregivers

Due to the complex nature of caregiver experiences which vary across individuals, no one intervention will ever meet all caregivers' needs, and interventions will be required to have several different aspects that should be specifically tailored on a case by case basis. The current themes incorporated caregivers' cognitions (attitudes, perceptions) and behaviours. It can be argued, therefore, that the framework of Cognitive Behaviour Therapy (CBT) can be applied to caregivers of people with stroke via individualised treatment plans to target relevant unhelpful and unrealistic/negative beliefs and assumptions, as well as promoting cognitive and behavioural coping strategies. The main principle of the CBT approach states that the way people think and interpret the world, themselves and others affects their emotions and behaviour. Therefore, when such thoughts, underlying assumptions and core beliefs are maladaptive, they need to be challenged and consequently modified into more realistic cognitions (Beck, 1976; Ellis, 1962). In addition, CBT targets maladaptive behaviours that maintain difficulties through continual practice of adaptive behaviours (Wells, 2005). CBT is an effective approach for a variety of psychological problems such as depression, anxiety, chronic pain and eating disorders (e.g. Beck, 1995; Butler, Chapman, Forman & Beck, 2006; Clark, 1999; Leahy, 2006; Wells, 2005), and different types of CBT based intervention programs incorporating the insights generated from this study can be conducted with comparison to a waiting list control group. Findings from such studies will provide evidence of whether the needs and concerns of caregivers can be addressed in practice, which particular components of interventions are most efficient in reducing caregiver emotional burden and distress, and the most cost effective frequency, intensity, time and duration of CBT. In summary, particular components for future intervention studies include:

- Providing psychoeducation about the nature of stroke and how to maintain a healthy lifestyle to reduce the risk of recurrent stroke.
- Targeting relationship counselling between the caregiver and stroke survivor.
- Addressing stroke survivor emotional difficulties as well as facilitating successful access to adequate formal support including stroke rehabilitation services like physiotherapy and speech pathology.
- Providing training in effective coping strategies such as the ones demonstrated in this study, based on a CBT framework.

Health care providers and stroke caregivers

Another advantageous avenue for future research would be to conduct a focus group with health care providers (such as stroke nurses, neurologists and rehabilitation staff). Considering health professionals' perspectives, especially on doctor-patient communication, for example, would provide more information on ways to improve the relationship between caregivers and health professionals, inform future intervention programs and thus help to improve caregiver evaluation of these services and in turn, caregiver outcomes. Although the relationship and communication styles of health professionals have not been explored with stroke patients, let alone their caregivers, doctor-patient communication has been extensively researched in other health fields such as oncology (Ong et al., 1995). In fact, researchers have shown that there are particular communication and interpersonal skills that doctors can use to help patients and families better adjust to medical illnesses in terms of treatment adherence, psychological and emotional problems and satisfaction with formal care. Doctors are also found to be more satisfied with their work when utilising these skills (Maguire & Pitceathly, 2002). Some strategies include:

- Showing an interest in the patients' psychosocial functioning.
- Demonstrating honesty, compassion and empathy and,
- Exhibiting an open willingness to provide time, information, and answer questions (Juraskova, Butow, Sharpe & Campion, 2007; Klitzman, 2006; Maguire & Pitceathly, 2002).

Arguments have also been made that suggest providing an optimistic perspective on the illness and prognosis may even help patients cope better (O'Rourke, Barrett, Jones, Featherstone & Hughes, 2001), although this speculation awaits further examination. Therefore, this study has highlighted the importance of ongoing communication training for health professionals to be more cognisant of their communication style with stroke patients and family members. Such work has been shown to be effective for other medical conditions and hence may prove beneficial in the area of stroke.

Finally, the findings support the need for increased funding to enhance access to quality services and resources for caregivers and their families, including more thorough and systematic discharge planning. Prioritising funds in the area of community caregiving may potentially reduce the government health care cost burden in the long-term that will otherwise occur as a result of providing nursing home and other government funded facilities for stroke survivors and their caregivers, if caregivers' needs are not met.

Theoretical implications

In terms of theoretical implications, the themes proposed in this study are quite comprehensive and adequately represent the multi-dimensional nature of caregiving. White et al., (2004) attempted to develop a similar thematic model that represented multiple factors

influencing stroke caregivers' QoL. Their themes however, were based on a review of the literature rather than an empirically conducted research study. Moreover, their model merely speculated relationships, and included gaps and sometimes vague descriptions of factors. Specifically, the model did not include any information on caregiver coping strategies or positive outcomes, and there was a minimal amount of information about the psychological experiences, cognitions and concerns of caregivers. Extending White et al's (2004) conclusions, the present study can more confidently confirm the complex nature of caregiving experiences, which include various factors related not only to the stroke survivor, but also caregiver factors such as personality characteristics, the social environment, and the health care system. All of which interacted in different ways according to the individual idiosyncratic profile. Hypotheses regarding the relationships between the themes generated in this study have also been developed and theoretically inform the examination of these relationships using statistical analyses in future quantitative studies.

4.7 Conclusion

The present study has determined that caregiver experiences involve a complicated and sometimes unpredictable interplay of multiple processes. These processes occurred both within the individual, as well as in the external environment such interpersonal relationships with the stroke survivor and friends, the health care system, and financial stressors. Furthermore, the present study has delineated pertinent themes that arise in the lives of stroke caregivers, confirms the inadequacies of formal support services and resources, while at the same time highlighting what caregivers need and find beneficial. Future research is warranted to further test the proposed

relationships between these factors through the use of relevant measures and in specific clinical and psychological interventions.

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Appendices

Appendix A: Ethics approval forms

<p>ADDRESS FOR ALL CORRESPONDENCE RESEARCH DEVELOPMENT OFFICE LEVEL 8, BUILDING 14 ROYAL PRINCE ALFRED HOSPITAL CAMPERDOWN NSW 2050</p> <p>TELEPHONE: (02) 9515 6766 FACSIMILE: (02) 9515 7176 EMAIL: lesley.townsend@email.cs.nsw.gov.au REFERENCE: X08-0051/HREC Ref. 08/RPAH/89</p> <p>3 April 2008</p> <p>Dr M Hackett George Institute for International Health Level 10, Building 13 Royal Prince Alfred Hospital</p> <p>Dear Dr Hackett,</p> <p>Re: Protocol No X08-0051/HREC Ref. 08/RPAH/89 - "Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers, stroke survivors and health professionals"</p> <p>The Executive of the Ethics Review Committee, at its meeting of 27 March 2008, considered Ms Y Masry's correspondence of 26 March 2008. In accordance with the decision made by the Ethics Review Committee, at its meeting of 12 March 2008, approval is now granted to proceed.</p> <p>This approval includes the following:</p> <ul style="list-style-type: none">• Home Interview Protocol (Version 1, 26 March 2008)• Flyer (stroke participants) (Version 1, 27 February 2008)• Letter to stroke participants from doctor (Version 2, 26 March 2008)• Information for Participants (stroke participants) (Version 2, 26 March 2008)• Participant Consent Form (Stroke Survivors) (Version 2, 26 March 2008)• Flyer (caregivers) (Version 1, 27 February 2008)• Letter to caregiver from doctor (Version 2, 26 March 2008)• Information for Participants (caregivers) (Version 2, 26 March 2008)• Participant Consent Form (caregivers of stroke survivors) (Version 2, 26 March 2008)	<p>SYDNEY SOUTH WEST AREA HEALTH SERVICE NSW HEALTH</p>
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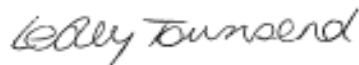
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- Flyer (stroke-related health professionals) (Version 2, 26 March 2008)
- Information for Participants (stroke-related health professionals) (Version 2, 26 March 2008)
- Participant Consent Form (stroke-related health professionals) (Version 2, 26 March 2008)

You are asked to note the following:

- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in April 2009.
- You are responsible for the following:
 - arranging an identity pass for any researcher who is not employed by the Sydney South West Area Health Service. You should contact the Ethics Officer on 02 9515 7899 for advice on this matter, and
 - if appropriate, informing the study sponsor that the membership and procedures of the SSWAHS Ethics Review Committee (RPAH Zone) comply with the National Statement on Ethical Conduct in Human Research.
- If you or any of your co-investigators are University of Sydney employees or have a conjoint appointment, you are responsible for informing the University's Risk Management Office of this approval, so that you can be appropriately indemnified.
- Where appropriate, the Committee recommends that you consult with your Medical Defence Union to ensure that you are adequately covered for the purposes of conducting this study.

Yours sincerely,



Lesley Townsend
Executive Officer
Ethics Review Committee (RPAH Zone)

Research Governance Officer
SSWAHS (RPAH Zone)

HERC/EXCOR08-04

ADDRESS FOR ALL CORRESPONDENCE
RESEARCH DEVELOPMENT OFFICE
LEVEL 3, BUILDING 92
ROYAL PRINCE ALFRED HOSPITAL
CAMPERDOWN NSW 2050

SYDNEY SOUTH WEST
AREA HEALTH SERVICE
NSW HEALTH

TELEPHONE: (02) 9515 6766
FACSIMILE: (02) 9515 7176
EMAIL: lesley.townsend@email.cs.nsw.gov.au
REFERENCE: X08-0051

15 September 2009

Dr M Hackett
George Institute for International Health
Level 10, Building 13
Royal Prince Alfred Hospital

Dear Dr Hackett,

Re: Protocol No X08-0051 - "Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers, stroke survivors and health professionals"

HREC/ 08/RPAH/89

BALMAIN SSA/08/RPAH/434

Thank you for submitting a Site Specific Assessment Form for this study. I am pleased to inform you that authorisation has been granted for it to be undertaken at the Balmain Hospital.

The approved information and consent documents for use at this site are:

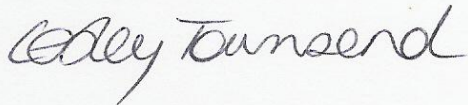
- Information for Participants – Stroke Survivor (Balmain Hospital Version 1, 31 August 2009)
- Participant Consent Form – Stroke Survivor (Balmain Hospital Version 1, 31 August 2009)
- Information for Participants – Caregiver (Balmain Hospital Version 1, 31 August 2009)
- Participant Consent Form – Caregiver of Stroke Survivor (Balmain Hospital Version 1, 31 August 2009)
- Reminder Letter (Balmain Hospital Version 1, 31 August 2009)

The following conditions apply to this research study. These are additional to those conditions imposed by the human research ethics committee (HREC) that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the study and which are submitted to the lead HREC for review, must be copied to me.
2. Proposed amendments to the research protocol or conduct of the research, which may affect the ongoing site acceptability of the study, must be submitted to me.

I wish you every success in your research.

Yours sincerely,

A handwritten signature in black ink that reads "Lesley Townsend". The signature is written in a cursive, flowing style.

Lesley Townsend
Research Governance Officer
SSWAHS (RPAH Zone)

RGO - Lesley\CORRES\X08-0051-Balmain

ADDRESS FOR ALL CORRESPONDENCE
RESEARCH DEVELOPMENT OFFICE
LEVEL 3, BUILDING 92
ROYAL PRINCE ALFRED HOSPITAL
CAMPERDOWN NSW 2050

SYDNEY SOUTH WEST
AREA HEALTH SERVICE
NSW HEALTH

TELEPHONE: (02) 9515 6766
FACSIMILE: (02) 9515 7176
EMAIL: lesley.townsend@email.cs.nsw.gov.au
REFERENCE: X08-0051

15 September 2009

Dr M Hackett
George Institute for International Health
Level 10, Building 13
Royal Prince Alfred Hospital

Dear Dr Hackett,

Re: Protocol No X08-0051 - "Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers, stroke survivors and health professionals"

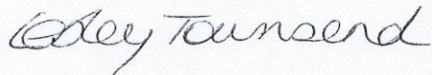
HREC/08/RPAH/89

SSA/08/RPAH/90

I refer to Ms Y El Masry's correspondence of 20 July 2009 concerning an amendment to the above study. Authorisation is given for the following:

- The addition of the Stroke Outreach Service as a study recruitment site.
- The inclusion of Ms Kate Schuj, Speech Pathologist - Stroke Outreach Service, as an associate investigator.

Yours sincerely,



Lesley Townsend
Research Governance Officer
SSWAHS (RPAH Zone)

RGO - Lesley\CORRES\X08-0051



The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee

www.usyd.edu.au/ethics/human

Senior Ethics Officer:

Gail Briody

Telephone: (02) 9351 4811

Facsimile: (02) 9351 6706

Email: gbriody@usyd.edu.au

Room 313, Level 3, Old Teachers College –A22

Human Secretariat

Telephone: (02) 9036 9309

(02) 9036 9308

Facsimile: (02) 9036 9310

13 May 2008

Dr Maree Hackett
Neurological and Mental Health Division
The George Institute for International Health
Level 10, Building 13
Royal Prince Alfred Hospital – C39

Dear Dr Hackett

Title: *Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers, stroke survivors and health professionals (Ref. No. 10988)*

PhD Student: *Ms Yasmeen El Masry*

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so has ratified your study to include the PhD student – Ms Yasmeen El Masry.

The Executive Committee acknowledges your right to proceed under the authority of the *Sydney South West Area Health Service Ethics Review Committee (RPAH Zone)*

Please note, this ratification has been given only in respect of the ethical content of the study.

Any modifications to the study must be approved by the *Sydney South West Area Health Service Ethics Review Committee (RPAH Zone)* before submission to the University of Sydney Human Research Ethics Committee.

Yours sincerely

Gail Briody
Senior Ethics Officer
Ethics Administration

Appendix B: Doctor cover letters, participant information and consent forms



The University of Sydney

School of Psychology

Faculty of Science

Dear Sir/Madam,

I am writing to let you know about a study that is being undertaken by The Royal Prince Alfred Hospital, The George Institute for International Health and The University of Sydney. The purpose of the study is to learn about the experiences and needs expressed by caregivers of stroke survivors, and the kinds of support they have had in the past. In addition, we are interested in talking to stroke survivors about the experiences and needs they believe their caregivers have.

Some information about the study can be found in the enclosed flyer and Information Sheet, but in brief, the study will involve participating in a 60-90 minute interview discussing the experiences of life after stroke.

If you would like to participate, please complete the consent form, and return it to **Nadia Schweizer, Stroke Case Manager at The Department of Neurology, Stroke Unit in the reply-paid envelope provided. Alternatively, you can contact the student researcher, Yasmeen El Masry directly at yasmeene@psych.usyd.edu.au or on 0401 235 287.** We will pass on to the study team only the names and contact details of those families who have indicated that they wish to participate.

Thank you for considering this study.

Yours Sincerely,

Professor Craig Anderson
Head of the Stroke Unit
Department of Neurology
Royal Prince Alfred's Hospital

Nadia Schweizer
Stroke Case Manager
Neurosciences Ambulatory Care
Royal Prince Alfred's Hospital



1 July 2009

Dear Sir/Madam,

This is just a courtesy reminder about the study being run by the University of Sydney in association with Royal Prince Alfred Hospital and The George Institute for International Health, titled: Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors.

The purpose of the study is to learn about the experiences and needs expressed by caregivers of stroke survivors, and the kinds of support they have had in the past. In addition, we are interested in talking to stroke survivors about the experiences and needs they believe their caregivers have. Caregiving may involve providing assistance with some type of activity (such as driving or walking), even if this is only occasional. This caregiving may be provided by a spouse, another family member, or friend of the person who has had a stroke.

Participation in the study will involve taking part in an informal interview talking about the experiences of life after stroke. If you choose to participate, you will be reimbursed with a \$20 shopping or petrol voucher, and interviews may take place either within a meeting room at RPAH or at your home if this is more convenient.

If you are interested in participating and have any questions you may contact the student researcher, Yasmee El Masry on yasmeene@psych.usyd.edu.au or phone her on 0401 235 287. Alternatively, a reply paid envelope has been enclosed where you can send the attached consent form to Nadia Schweizer, Stroke Case Manager.

Thank you for considering this study.

Yours sincerely,

Professor Craig Anderson
Head of the Stroke Unit
Department of Neurology
Royal Prince Alfred Hospital

Nadia Schweizer
Stroke Case Manager
Neurosciences Ambulatory Care
Royal Prince Alfred Hospital



Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors.

INFORMATION FOR PARTICIPANTS (Caregiver)

Introduction

You are invited to take part in a research study which will explore the experiences and needs of caregivers of people who have had a stroke, and the kinds of support they have had in the past. This study is important as the information will help us understand issues that are important to caregivers and stroke survivors.

The study is being conducted by

1. Dr. Maree Hackett, Senior Research Fellow, Neurological and Mental Health Division, The George Institute for International Health (Affiliated with The University of Sydney).
2. Miss Yasmeen El Masry, Doctorate of Clinical Psychology/Master of Science student, School of Psychology, The University of Sydney.
3. Dr. Barbara Mullan, Lecturer in Health Psychology, School of Psychology, The University of Sydney.

Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked, at a mutually convenient time, to take part in face to face interview with Miss Yasmeen El Masry. This interview will seek information on your own thoughts, feelings and general experiences as a caregiver of a stroke survivor. You may also be asked about any services or resources you have accessed in the past, whether they have been helpful and why, or why they have not been helpful, as well as your current needs as a caregiver. The interview is likely to take about 60 minutes but may take up to 90 minutes for some participants, and will be audiotaped and transcribed by a professional transcription service. The interviews may take place in a meeting room either within RPAH or The University of Sydney at a mutually convenient time. A more suitable location to carry out the interview may also be arranged if these places are inconvenient for you.

Risks

The risks of participating in this study are minimal. Most people will benefit from talking about and sharing their experiences, however some people may experience distress while doing so. It is not estimated that this distress will be severe in nature, nor last for long after the interview, however, if participants require assistance with any issues that arise from the interview they are welcome to contact The University of Sydney Psychology Clinic on: (02) 9351 4066, in confidence.

Benefits

This study gives you the opportunity to express your experiences as a caregiver of someone who has had a stroke. In addition, we intend that this research study will further knowledge about the experiences and needs of caregivers of stroke survivors and in turn may help to improve support services for families in the future.

Costs

Participation in this study will not cost you anything, you will be reimbursed with a \$20 shopping or petrol voucher for your time.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect your relationship with RPAH, The George Institute for International Health or The University of Sydney. Only the researchers named above, and the nursing staff member or doctor who gave you the initial letter and pamphlet will be aware of your participation or non-participation.

Confidentiality

All the information collected from you for the study will be treated confidentially. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Further Information

When you have read this information, Yasmeen El Masry will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 0401 235 287 or email yasmeene@psych.usyd.edu.au.

This information sheet is for you to keep.

Ethics Approval

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X08-0051.



Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors.

PARTICIPANT CONSENT FORM (caregivers of stroke survivors)

I, [caregiver]

of

.....[address]

..... [phone number]

have read and understood the Information for Participants on the above named research study and have discussed the study with Yasmeen El Masry (Ph: 0401 235 287, Email: yasmeene@psych.usyd.edu.au).

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I understand that the interview will be audiotaped, and I agree to this.

I hereby agree to participate in this research study.

NAME:

SIGNATURE:

DATE:



Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors.

INFORMATION FOR PARTICIPANTS (Stroke Survivor)

Introduction

You are invited to take part in a research study which will explore the experiences and needs of caregivers of people who have had a stroke. This study is important as the information will help us understand issues that are important to caregivers and stroke survivors.

The study is being conducted by

1. Dr. Maree Hackett, Senior Research Fellow, Neurological and Mental Health Division, The George Institute for International Health (Affiliated with The University of Sydney).
2. Miss Yasmeen El Masry, Doctorate of Clinical Psychology/Master of Science student, School of Psychology, The University of Sydney.
3. Dr. Barbara Mullan, Lecturer in Health Psychology, School of Psychology, The University of Sydney.

Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked, at a mutually convenient time, to take part in a face to face interview with Miss Yasmeen El Masry. This interview will seek information on your beliefs about the experiences and needs of your caregiver. Other research has looked at the experiences of those with stroke, but little research has been done to understand the experiences of caregivers, who are an important part of the rehabilitation process. The interview is likely to take about 60 minutes but may take up to 90 minutes for some participants, and will be audiotaped and transcribed by a professional transcription service. The interviews may take place in a meeting room either within RPAH or The University of Sydney at a mutually convenient time. A more suitable location to carry out the interview may also be arranged if these places are inconvenient for you.

Risks

The risks of participating in this study are minimal. Most people will benefit from talking about and sharing their experiences, however some people may experience distress while doing so. It is not estimated that this distress will be severe in nature, nor last for long after the interview, however, if participants require assistance with any issues that arise from the interview they are welcome to contact The University of Sydney Psychology Clinic on: (02) 9351 4066, in confidence.

Benefits

This study gives you the opportunity to express your experiences as a caregiver of someone who has had a stroke. In addition, we intend that this research study will further knowledge about the experiences and needs of caregivers of stroke survivors and in turn may help to improve support services for families in the future.

Costs

Participation in this study will not cost you anything, you will be reimbursed with a \$20 shopping or petrol voucher for your time.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect your relationship with RPAH, The George Institute for International Health or The University of Sydney. Only the researchers named above, and the nursing staff member or doctor who gave you the initial letter and pamphlet will be aware of your participation or non-participation.

Confidentiality

All the information collected from you for the study will be treated confidentially. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Further Information

When you have read this information, Yasmeen El Masry will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 0401 235 287 or email yasmeene@psych.usyd.edu.au.

This information sheet is for you to keep.

Ethics Approval

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X08-0051.



Understanding the experiences of caring for someone after stroke: A qualitative study of caregivers and stroke survivors.

PARTICIPANT CONSENT FORM (stroke survivors)

I, *[person who has experienced a stroke]*

of

.....*[address]*

..... *[phone number]*

have read and understood the Information for Participants on the above named research study

and have discussed the study with Yasmeen El Masry (Ph: 0401 235 287, Email: yasmeene@psych.usyd.edu.au).

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I understand that the interview will be audiotaped and I agree to this

I hereby agree to participate in this research study.

NAME:

SIGNATURE:

DATE:

Appendix C: Interview guides, home interview protocol and demographics forms

Caregiver Interview Guide

- **Start recording-test sound before interview. End recording after demographic info completed.**
- **Introductory spiel:** E.g. Non-judgmental environment, confidentiality, why audiotaping is required and how the data will be used, please be open and truthful, participant's own words, no wrong or right answers.

Questions

1. Can you tell me about your experiences of caregiving following []'s stroke?
2. How has life changed for you (if at all) since the stroke? Specifically changes in:
 - your emotions
 - social activities
 - friendships
 - family functioning
 - family activities
 - your physical health
 - finances
 - employment
 - the setting of the house, living arrangements (environment)
 - independence
 - Your relationship with [stroke survivor]? (interpersonal)
 - What about changes in sex/intimacy?
 - What about changes in closeness or getting along (appreciation, liking)
3. Have there been any good things or positive changes that have come out since the stroke? If yes, can you tell more about this?
4. You mentioned earlier some emotional difficulties, can you tell me more about what these are?
5. What do you make of these emotional difficulties you have?
6. Have there been any other changes that we haven't talked about?
(CHECK AUDIO & TIME)
7. Since you have been caring for [] what access to support services (if any) have you received? If not, why?
8. How have you found these services to be in meeting your needs?
9. I would like to know a bit more about your needs as a caregiver. Has there been any other kinds of help or services that you have needed now or in the past? Did you receive this help? If not, why? If yes, how did you find this?
(E.g. factual info about stroke and rehab, counselling, follow-up calls, house visits, support groups, comprehensive discharge planning, assistance with communication, mobility, caregiver training, knowledge about community services).
10. What about the timing of help, when would this help have been most useful?
11. **Demographic info:** Ok now I have a brief list of straight forward questions and I will write answers down.
12. Check in and thank

Stroke Survivor Interviews Guide

- **Start recording-test sound before interview. End recording after demographic info completed.**
- **Introductory spiel:** E.g. Non-judgmental environment, confidentiality, why audiotaping is required and how the data will be used, please be open and truthful.

1. What do you think ['s] experiences have been as your caregiver?
2. How do you think their life has changed (if at all) since the stroke? Specifically changes in:
 - their emotions
 - social activities
 - friendships
 - family functioning
 - family activities
 - their physical health
 - finances
 - employment
 - the setting of the house, living arrangements (environment)
 - independence
 - Their relationship with you? (interpersonal)
 - What about changes in sex/intimacy
 - What about changes in closeness or getting along (appreciation, liking)
3. In your opinion, have there been any good things or positive changes for them that have come out since the stroke? If yes, can you tell more about this?
4. Have there been any other changes for them that we haven't talked about?
(CHECK AUDIO & TIME)
5. In your opinion, what are the reasons for these changes or difficulties for [caregiver's name?]
6. What do you think their needs have been since the stroke, previously and currently?
7. What access to support services have they received, if any, if not, why?
(E.g. factual info about stroke and rehab, counselling, follow-up calls, house visits, support groups, comprehensive discharge planning, assistance with communication, mobility, caregiver training, knowledge about community services).
8. How do you think they have found these services?
9. Has there been any other kinds of help or services that you think they have needed now or in the past? Did they receive this help? If not, why? If yes, how do you think they found this?
10. What about the timing of help, when would this help have been most useful for them?
11. **Demographic info:** Ok now I have a brief list of straight forward questions and I will write answers down.
12. Check in and thank

Home interview protocol

The following is a guide for a safety protocol:

- There will be no interviewing after dark or before sunrise.
- The interviewer will wear photo identification with a University of Sydney Psychology Department, RPAH and George Institute logo.
- The interviewer will be dressed appropriately.
- The interviewer will practice the interview, the introduction and conclusion, before doing it in the field.
- Another member of the research team will be available for immediate contact while interviews are being conducted.
- The interviewer will carry a mobile phone and always let a third party (e.g. another research team member) know the time and location of each interview and the expected finish time. The interviewer will contact (e.g. via a phone message) the third party on arrival and again at the completion of the interview once they have left the interviewee's home.
- The interviewer will carry a spare mobile phone battery and make sure the phone always has sufficient credit before leaving for an interview, and/or, should they be unable to use their mobile phone for any reason they will make every effort to contact the third party.
- If the third party does not receive notification from the interviewer then they are to call her mobile as the first line of action. If the interviewer does not answer, the third party may then decide to contact the participants or in the unlikely event that there is evidence of harm, the police.
- If at any time the interviewer feels unsafe before or during an interview, the interview will be immediately cancelled or terminated and they will leave the premises.
- Finally, every effort will be made to hold the interview in a public location (university or hospital rooms) and home interviews will be a last resort.

- No change
- Took leave
- Reduced hours
- Rearranged schedule
- Ceased work

Reason for lack of employment:

- Caring for stroke survivor
- Retirement due to age
- Retirement due to own illness/disability
- Home duties/child care
- Other _____

7. Financial assistance: Yes No

Type:

- Centrelink disability pension
- Other

8. Relation to stroke survivor:

- Spouse
- De-facto
- Child of stroke survivor
- Parent of stroke survivor
- Grandchild of stroke survivor
- Friend
- Other _____

9. Type of caregiving before stroke:

Community-based activities:

- Checking up on patient
- Financial matters
- Completing errands
- Transport
- Shopping
- Other _____

Domestic Activities:

- Home maintenance
- Heavy housework: e.g. vacuuming, laundry, cleaning
- Light housework: e.g. washing up
- Meal preparation
- Medication supervision
- Assistance with walking outside
- Other _____

Personal activities of daily living:

Barthel index:

- Feeding
- Bathing
- Grooming
- Dressing
- Bowels
- Bladder
- Toilet use
- Moving from bed to chair
- Walking inside the house (level surfaces)

- Stairs
- Other _____

After stroke:

Community-based activities:

- Checking up on patient
- Financial matters
- Completing errands
- Transport
- Shopping
- Other _____

Domestic Activities:

- Home maintenance
- Heavy housework: e.g. vacuuming, laundry, cleaning
- Light housework: e.g. washing up
- Meal preparation
- Medication supervision
- Assistance with walking outside
- Other _____

Personal activities of daily living:

Barthel index:

- Feeding
- Bathing
- Grooming
- Dressing

- Bowels
- Bladder
- Toilet use
- Moving from bed to chair
- Walking inside the house (level surfaces)
- Stairs
- Other _____

10. Daily amount of care each week:¹

	Community Activities	Domestic Activities	Personal Activities	(C+D+P) x 7
	Hrs per day	Hrs per day	Hrs per day	Hrs per wk total
Pre-stroke				
Currently				

11. Secondary carers and support:

- Other family members
- Friends
- Health Professionals
- Health Services
- Other _____

12. Type of care provided by secondary caregivers:

- Community activities
- Domestic activities

¹ It was found very early in the interview process that people were often taking very crude estimates, were unsure or stated that they were caregiving 24 hours a day. Due to the non-systematic nature of peoples' responses to this question, it was discarded.

Personal activities

Other _____

Amount:²

	Community Activities Hrs per day	Domestic Activities Hrs per day	Personal Activities Hrs per day	(C+D+P) x 7 Hrs per wk total
Pre-stroke				
Currently				

13. Stroke survivor participating in study? Yes No

Adapted from:

ARCOS (Auckland Regional Community Stroke Study forms)

Dewey, H. M., Thrift, A.G., Mihalopoulos, Carter, R., Macdonell, R.A.L., McNeil, J.J, Donnan, G.A. (2002). Informal Care for Stroke Survivors (Results From the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*, 33, 1028-1033. (Following definition and demographic guidelines)

Mahoney, F.I., & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Maryland State Med Journal*, 14, 56-61.

Post-interview comments:

e.g. feelings about interview, disruptions, rapport, insights, ideas on categories and themes etc.

² See footnote 1 above.

DEMOGRAPHIC FORM 1.2: Stroke survivors

Date: _____

Location: _____

1. Gender of stroke survivor: Male Female
2. Age of stroke survivor: 25-35 36-45 45-55 55-65 >65

3. Ethnicity:

Anglo-Australian

New Zealander

Maori

Anglo-New Zealander

European

Greek

Italian

English

Other _____

Middle Eastern

Lebanese

Other _____

Asian

Chinese

Indian

Other _____

4. Time since stroke:

___ months, ___ years

5. Number of strokes:

1

2

>2

6. Paid employment:

Before stroke Yes No

After stroke Yes No

Change in employment:

No change

Took leave

Reduced hours

Rearranged schedule

Ceased work

Reason for lack of employment:

Retirement due to age

Retirement due to own stroke

Home duties/child care

Other _____

7. Type of caregiving before stroke

Community-based activities:

Checking up on patient

Financial matters

Completing errands

Transport

Shopping

Other _____

Domestic Activities:

- Home maintenance
- Heavy housework: e.g. vacuuming, laundry, cleaning
- Light housework: e.g. washing up
- Meal preparation
- Medication supervision
- Assistance with walking outside
- Other _____

Personal activities of daily living:

- Barthel index:
- Eating; grooming
 - Bathing; dressing
 - Toilet use
 - Incontinence management
 - Moving from bed to chair
 - Walking inside the house, including stairs
 - Other _____

After stroke:

Community-based activities:

- Checking up on patient
- Financial matters
- Completing errands
- Transport
- Shopping
- Other _____

Domestic Activities:

- Home maintenance
- Heavy housework: vacuuming, laundry, cleaning
- Light housework: e.g. washing up
- Meal preparation
- Medication supervision
- Assistance with walking outside
- Other _____

Personal activities of daily living:

- Barthel index:
- Eating; grooming
 - Bathing; dressing
 - Toilet use
 - Incontinence management
 - Moving from bed to chair
 - Walking inside the house, including stairs
 - Other _____

8. Daily amount of care each week:³

	Community Activities Hrs per day	Domestic Activities Hrs per day	Personal Activities Hrs per day	(C +D+P) x 7 Hrs per wk total
Pre-stroke				
Current				

³ See footnote 1 above.

9. Living arrangements for stroke survivor:

Before stroke:

Living alone

With caregiver

With others

After stroke:

Living alone

With caregiver

With others

10. Caregiver name (to match data) _____

Adapted from:

ARCOS (Auckland Regional Community Stroke Study forms)

Dewey, H. M., Thrift, A.G., Mihalopoulos, Carter, R., Macdonell, R.A.L., McNeil, J.J, Donnan, G.A. (2002). Informal Care for Stroke Survivors (Results From the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*, 33, 1028-1033. (Following definition and demographic guidelines)

Mahoney, F.I., & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Maryland State Med Journal*, 14, 56-61.

Post-interview comments:

e.g. feelings about interview, disruptions, rapport, insights, ideas on categories and themes etc.

Appendix D: Original theme lists

Themes summary: Chief Investigator

Master theme name 1: Independence				
	Subtheme name	Category name	quote/keyword	page/line nos
	SS Independence	Difficulty caring	SS resists care SS "obnoxious"	
		Difficulty caring	Obnoxious	
	Caregiver's Independence	Reduction in separate social/leisure activities Less time to laugh/enjoy self Dominated by SS-e.g. SS lacks confidence to do things on own so dependent on caregiver and will not appear to be improving. Or SS does not want to go out anymore		Interviews 3, 7 & 9.

Master theme name 2: Emotion				
	Subtheme name	Category name	quote/keyword	page/line nos
	Anger/ Irritability	Loss of future plans	"trips"	
	Frustration	Loss of independence		
	Identity/personality??			
	Shock			
	Anxiety/uncertainty	Fears anger/personality changes Recurrent stroke Concerns for SS's physical health and prognosis The duration of caregiving.	More of a concern than other illness (e.g. cancer).	(Interview 3)
	Loss and Grief	Caregiver's loss of healthy partner and personality changes		

		Caregiver's loss of future plans Identity and roles Spontaneity		
	Fairness/Injustice			
	Depression			
	Overwhelmed with stressful events.			
	Resentment			
	Rumination			
	Isolation			
	SS Motivation			
	SS Withdraws			

Master theme name 3: SS-caregiver relationship				
	Subtheme name	Category name	quote/keyword	page/line nos
	Sexual activity/intimacy	Reduction		
	Close and supportive	Good relationship to begin –stayed close Sense of humour together Support each other (caregiver Int. 5-not used)		
	Caregiver attributes	Caring and patient		
	Differences in concerns between them			
	Conflicts exacerbated			
	Conflicts reduced			

Master theme name 4: Resilience				
	Subtheme name	Category name	quote/keyword	page/line nos
	Caregiver coping strategies			
		Attributions- personality changes to medical conditions=easier to cope and empathise.		
		Priorities/perspective	e.g. caregiver reminds herself SS is not well to cope	Interview 1
		Acceptance		
		Social comparison with other stroke survivors		
		Planning pleasant activity scheduling	e.g. walking	
		Spiritual beliefs/faith		
	SS resilience			
		Attitude		
		Past adversity builds strength (caregiver Int. 5-not used)		

Master theme name 5: Support				
	Subtheme name	Category name	quote/keyword	page/line nos
	Informal Support	Positive family Support/Family cohesion in caring		Int 2 (ss)
		Support at work		
		Social/Friends (ventilation)		Int 4. (ss)
		Spirituality		
		Lack of offers of support	“These places, these doctor’s these ladies I go to up here. Terry’s known them for many, many years. They’ve never made one suggestion”.	Page 12, Int7
	Formal support/Services	G.P		

Master theme name 6: Financial/Employment strain				
	Subtheme name	Category name	quote/keyword	page/line nos
	Work schedule	Changes in hours		
	Financial costs	Increased costs due to disability, e.g., house adaptation, physio, speech pathology, gym, transport, homecare, medication, wheelchair and other aids		
	Loss of self-efficacy/identity			
	Loss of things could afford prior to the stroke			

Master theme name 7: Cognitive Changes				
	Subtheme name	Category name	quote/keyword	page/line nos
	SS-Memory			
	Caregiver-memory			
	SS Personality Changes	More obsessional-e.g. about the environment SS-Sense of humour-more childish SS more angry and irritable		
	SS comprehension Aphasia			

Master theme name 8: Physical environment				
	Subtheme name	Category name	quote/keyword	page/line nos
	House structure	Adaptations	Interview 1..”The boys built a rail and he can get up and down the stairs”	
	Literally moving closer to services		Int. 2..”So I’ve pushed steps that way. I think we sort of probably need to be a bit closer to hospital and RPA maybe, because if we, he has to have treatment down the track we really...”	

Master theme name 9: Social functioning				
	Subtheme name	Category name	quote/keyword	page/line nos
	Social Isolation	Reduction in social activities and friendships		

Master theme name 10: Physical health				
	Subtheme name	Category name	quote/keyword	page/line nos
	Carer's physical health	Poor sleep (emotional/medical cause?) Low energy (emotional/medical cause?) Medical conditions, e.g., Psoriasis	"Worn out"	

Master theme name 11: Positive Changes				
	Subtheme name	Category name	quote/keyword	page/line nos
	Enhanced relationships	More time together		
		More affectionate		
		Enhanced appreciation of friendships		
		Family pulls together/cohesion/unites		
	Resources access	Government/Centrelink bonus scheme		

Master theme name 12: Needs				
	Subtheme name	Category name	quote/keyword	page/line nos
	Physical			
	Independence	Alone time/respice Holidays Separate activities- especially outside the home		
	Education/knowledge	About nature of stroke and prognosis Types of support services or groups		
	Support	Emotional-to talk Practical-home based respice and Home Care to go out more/be independent Face to face tailored home Ax of SS situation and needs Formal home- based carers	"As I say, I'm so disappointed with people's..."	Int 7. page 12

	Medical services	Equal attention to stroke as other medical problems		
	Low cost services			
	Adequate nursing homes	With activities for SS and tailored to their levels		

Master theme name 13: Adjustment				
	Subtheme name	Category name	quote/keyword	page/line nos
	Household roles Increase in other responsibilities	E.g. Driving the SS to places		

Master theme name 14: Severity of stroke/disability				
	Subtheme name	Category name	quote/keyword	page/line nos
	Exacerbates effect of current medical conditions	E.g. Energy levels		

Master theme name 15: Caregiver characteristics	Subtheme name	Category name	quote/keyword	page/line nos
	Caring personality and history of looking after people	<p>“Over-accommodating” for SS and reinforce and maintain SS withdrawal and lack of motivation.</p> <p>Acceptance of carer role</p> <p>Belief will burden others of ask for help</p>		

Master theme name 16: Access to services/resources	Subtheme name	Category name	quote/keyword	page/line nos
	Neglect and Uncertainty re. post-discharge services	<p>Left without support post-discharge-uncertain of what to expect</p> <p>Unaware of available support</p>		
	Lack of appropriate resources and access to them	E.g. Respite care that will accept SS difficult-rejected by facilities-“too far away”		

Master theme name : 17 Evaluation of services and resources				
	Subtheme name	Category name	quote/keyword	page/line nos
	Neglect/ lack of communication	Dissatisfaction with centrelink		
	Physios	Helpful but not regular		
	Rehab	Dissatisfaction		
	Education	Lack of education re. stroke and prognosis		
	Neurology	Lack of follow-up appointments		
	Exercise clubs			From Int. 5 but not being used.
	Appropriate timing of access			
	Reassurance and regular check ups	Acute hospital stay	Pharmacotherapy helpful Clinical trial	
	Parking permit	Helpful		
	Respite care	Dissatisfaction- Nurse did not attend scheduled home visits-SS left home alone		

Themes summary: Independent coder

Themes	Theme components	Examples
Independence v. dependence	Caree's independence affects carer's provision of care	Interview 1a: "It's very hard to care for Patrick; he's very independent".
	Carer's independence affects requests for support	Interview 1a: "But then again I don't like to impose on them".
	Caree concern regarding carer's perceptions of dependence	Interview 1b: "sort of thing so I think she, she sort of looks, the changes that she's thinking I'm an invalid and she's looking after an invalid a bit and she's got to look after some things or do some things..."
	Mismatch between perceptions of dependence	Interview 1b: "So but when I think of her as a carer I don't think she fully understands what's wrong with me right and she has a picture of what she thinks I should do and she doesn't listen to my side or doesn't absorb what I say..."
	Drive for independence and acceptance of environmental changes	Interview 1a: "we organised the house to suit him more. We changed my bedroom to the down chairs...we had our bedroom upstairs...and when he came home he didn't like being in the downstairs one so we had to change back".
	Carer's resentment at loss of independence	Interview 2a: "Hmm, that's what I resent that, I do resent not having independence". Interview 2a: "His real dependence on me. I find that quite heavy, sometimes".
Experience of caree	Caree's difficulties in accepting caree role	Interview 2b: "Whereas previously, I'd never been sick in my life. For me, that was probably the worst part, I'd never been sick in my life. I sort of broke my elbow when I was a kid, falling off my bike, and that was really it. So I wasn't used to being, having things wrong with me".
	Concern for caring role affect QoL	Interview 1b: "but I wouldn't like to think it's oh, restricting or inhibiting particularly my wife right and I don't think it is but I worry that she doesn't seem to have any ambition that's all and whether that's something to do with me..."
	Misunderstanding of needs	Interview 1b: "I go down the shopping centre and that if there's tiles along the floor I'm following the line of the tiles, that keeps me in a straight line and that so I don't think she fully recognises it, she thinks the problems are physical."

	Uncertainty about the future	Interview 1b: " Some of the things that might have been critical or knocked you off or something have been fixed in a temporary way so maybe those problems have been solved and you hope they don't come up in another problem that's all".
	Adjustment	Interview 2a: "So we're sort of lucky to have him and he's sort of accepted cancer, but the stroke was just out of leftfield, and to destroy his intellect and all that he really has made him quite, probably bitter really about it."
	Concern for carer	Interview 2b: "While I was in hospital, I was thinking, what's going to happen now, what will Jane do?".
Experience of carer	Multiple carer roles	Interview 1a: Caring for daughter with schizophrenia as well.
	Frustration at ongoing health problems	Interview 1a: "Ongoing things, Patrick's diabetes and his stroke, mmmm, he had bypass heart surgery as well".
	Need for time out	Interview 1a: "But I do need to have a little bit of time to myself occasionally. And ahh...sometimes I go and sit in the park for a while and think of nothing". Interview 2a: "Because of where we are, we're sort of together all the time, and it's, I think..."
	Concern expressing difficulties with carer role	Interview 1a: "I wouldn't feel right doing that at home, people would get too concerned".
	Fear of recurrence	Interview 2a: "But I think the worst part for me after it happened was, after the shock sort of settled was just living with the fear that it was going to happen again, and coming home from the hospital and sleeping in the same bed and thinking are you alright..."
	Concern regarding ability to care if things worsen	Interview 2a: "I mean because there's no way in the world I could look after him at home if he was worse".
Familial and social support	Family support	Interview 1b: "Now I'm lucky because me son one of them lives at home and the other one only lives a few blocks away and so any sudden thing they'll jump in and do something". Interview 2b: "I suppose that's another positive because the kids have been marvelous..."
	Sharing of the caring role	Interview 1a: "And my kids are great, they say mum if you want to go out or something we'll look after dad while you're gone".

	Family assume roles based on skills	Interview 1a: "My daughter, my daughter Sharon is brilliant, she has taken over all of that stuff because she is..I think she worked in Tafe for a little while or something...she knows the system so she's working on it".
	Support of friends	Interview 1a: "I've got a couple of good friends that I can unload on, this one particular girl is a...very good listener". Interview 2b: "The girlfriends she has, she's still got. She's probably a bit more dependent on them now."
Relationship	Changed sexual relationship	Interview 1a: "sex has gone out the window". Interview 2a: "he sort of can't feel properly anymore so sort of making loves different". Interview 2a: "Yeah I don't feel the same; his touch isn't the same on me either."
	Change in intimacy	Interview 1a "He's become very affectionate...which is really nice".
	Exacerbation of existing problems	Interview 2b: "To me, the things that used to annoy Jane got worse. So her life was harder in that sense, that the things that she capable of, dealt with before became harder because they were all, to me not grossly different, but just, I don't know, things just got harder for her". Interview 2b: "So I think that's sort of, I mean, we've always been a bit like that and that's exacerbated that, I think. We've now got to the point where it's annoying her immensely, I would think. So I think that things we may have had some issues with have sort of just got worse, a bit worse, but not, you know, we still laugh about it".
	Increased strain	Interview 2b: "She's a bit more, cold is not the word, because she's very caring. We argue a bit more, well, we speak harsher. I swear a lot more than I ever. I suppose my temper's probably, and hers reacts to it, I think."
Occupational and recreational	Effects on carer's work	Interview 1a: "I've had to arrange at work that I get off about two or three so that I can go and get him from the factory".
	Restriction of recreational activities	Interview 1a: "I'm sort of tied down to him more than I was...I would get in the car and go where I wanted to go". Interview 1a: "yes we go out less... the kids have bought me a computer and I'll play scrabble". Interview 2b: She probably hasn't got as much time".
Stroke-related behaviour	Anger/frustration/etc.	Interview 1a: "And he does sometime he is just like his father was...it's scary". Interview 1a: "Oh I could cry just thinking about it, because it's not my P". Interview 2b: "I mean, she sees that probably my personality has changed in the sense that I'm much harder on, maybe pick on her about things she does and things like that".

	Caree's awareness	Interview: 2b: "I mean, she sees that probably my personality has changed in the sense that I'm much harder on, maybe pick on her about things she does and things like that".
Adjustment	Questioning fairness of stroke	Interview 1a: "why did it happen to him, this is what I get angry about, you know it shouldn't have happened to him... should have happened to some bastard".
	Acknowledgement of need to accept	Interview 1a: "Yeah, it is. I mean I've put it behind me, that's just crazy to do that, to think that way all the time, and I don't do it all the time".
	Difficulty adjusting to caree's disability	Interview 1a: "watching him walk around the table was tearful stuff and just seeing him so inadequate wasn't right".
	Change of goals	Interview 2a: "And I called packing up your dreams because you can't do them any more".
Environmental changes	Rearrangements to home	Interview 1a: "The boys built a rail and he can get up and down the stairs".
	Moving closer to services	Interview 2a: "so I've sort of pushed steps that way. I think we sort of probably need to be a bit closer to hospital and RPA maybe, because if we, he has to have treatment down the track we really' Interview 1b: "only that it sort of confirms that you're, you can do things together, one will look after the other"
		Interview 1a: "You realise what is important and what is not important. I mean it's not important if Patrick leaves the butter out of the fridge and it goes off does it? Who cares...".
Positive outcomes	Change of perspective	Interview 1a "He's become very affectionate...which is really nice".
	Increased intimacy Affirmation of relationship	Interview 2a: "Maybe the positive is just the friendships, how wonderful, you realise just how important they are and how wonderful people can be."
	Affirmation of friendships	Interview 2b: "I don't think anything particularly good came out of it, except she used to always say to me that, after I sort of didn't, her perception I didn't really support her while she had chronic fatigue, that she was never going to look after me... Yeah, at the time. That never came true".
	Affirmation of caring	
Support services	Financial concerns	Interview 1b: "So there's little things that come up all the time and instead of my wife having to take it out of her money". Interview 2b: "

Insufficient information

Interview 1b: "Now when the doctor found I had it, it was a bit like putting a sticker on the wall on the chart saying I found another one. He didn't actually tell me what the outcomes might be and where you started to fix it".

Insufficient support

Interview 2b: "Well, I think the aftermath of the whole thing was we didn't get, and I don't know whether it was our fault or what, we were really left on our own".

Appendix E: Final theme lists and saturation table

Chief Investigator: Final Theme List

Themes	Subtheme Components	Category	Extracts/Keywords and Sources
Independence	SS Independence	Difficulty caring	SS resists care SS "obnoxious"
	Caregiver's Independence	Reduction in separate social/leisure activities Less time to laugh/enjoy self/do things Restricted by SS e.g. SS lacks confidence to do things on own so dependent on caregiver and will not appear to be improving. Or SS does not want to go out anymore	Interviews 1, 3, 7 & 9.
Emotional Functioning	Anger/Irritability Frustration Identity/personality?? Shock Anxiety/Uncertainty	Loss of future plans Loss of independence	"Trips"
	Loss and Grief	Recurrent stroke Concerns for duration of caregiving Concerns for SS's physical health Falls Prognosis If caregiver becomes unwell/caregiver's health Caregiver's loss of future plans Caregiver's loss of the person they once had	More of a concern than other illness (e.g. cancer), Interview 3 Healthy partner/relative and personality/behavioural changes/relationship
		Identity and roles Spontaneity Independence Activities	

Friendships/relationships

Fairness/Injustice
Depression/sadness
Guilt

Domestic chores reduced due to lack of energy/motivation

Caregiver Motivation
Overwhelmed with stressful events (and other losses)
Resentment
Rumination
SS Motivation
SS Withdraws
SS Confidence
SS Depression
SS Shock
SS Uncertainty (re. Prognosis)
SS Bitter
SS Dignity
SS Anxiety

Int. 7
Panic attack, Int.20

SS-caregiver relationship

Sexual activity/intimacy
Close and supportive

Reduction
Good relationship to begin—stayed close
Relationship had prior difficulties
Sense of humour together

Int. 5 (omitted)

Caregiver attributes

Support each other
Caring and patient
Open communication
Commitment/obligation

Conflicts

Exacerbated
Differences in concerns between the two
Reduced

Distance

Less conversation and less quality time together
Less support from SS
Lack of understanding of each other and incongruence
Demands from SS

	Closer	Feels unappreciated More time together	
Resilience	Caregiver coping strategies	Attributions Priorities/perspective Ride out stressful moments Acceptance Social comparison with other stroke survivors Spiritual beliefs/faith Planning pleasant activities/activity scheduling Keeping busy/distraction Searching for meaning Goal-setting Prior nursing training Living in the present Problem solving Interpersonal communication and boundary setting	Personality changes to medical conditions: easier to cope and empathise, Int. 1 E.g. Caregiver reminds herself SS is not well to cope, Int. 1, thinking style
	SS resilience	Attitude Past adversity builds strength	E.g. walking Support seeking Int. 5 (Omitted)
Support	Informal Support	Positive family support/family cohesion in caring Support at work Friendships/Social Spirituality Lack of understanding from others Lack of support/offers of support	Int. 1 ("ventilation") & Int. 4 (SS) "These places, these doctor's these ladies... They've never made one suggestion". Page 12, Int.7
	Formal support/Services	G.P Lack of support/offers of support	

Stroke support groups
 Nursing staff
 Live in carer

Employment and financial strain

Work schedule

Changes in hours

Satisfaction from working

Self-worth

Loss of self-efficacy/identity

Financial costs

Increased costs due to disability, e.g.,
 house adaptation, physio, speech pathology, gym, transport, homecare, medication, wheelchair and other aids
 Loss of things could afford prior to the stroke

Cognitive and Behavioural Changes

SS functioning

Aphasia (expression and comprehension)

Memory

Personality (behavioural) changes

More obessional-e.g.
 about environmental issues
 Sense of humour is more childish
 SS more angry and irritable
 Obnoxious
 Motivation
 Anosognosia

Physical environment

House structure

Adaptations

Literally moving closer to services

Int 1."The boys built a rail
 and he can get up and down the stairs"
 I think we sort of probably
 need to be a bit closer to hospital..."

Social functioning

Social Isolation

Reduction in social activities and friendships

Physical health

Caregiver's physical health

Poor sleep (emotional/medical cause?)
 Low energy (emotional/medical cause?)
 Medical conditions, e.g., Psoriasis

"Worn out"

Positive changes	Enhanced relationships	More time together	
		More affectionate	
		Enhanced appreciation of friendships and who really cares	
		Family pulls together/cohesion/unites	
		Realise own resilience	Int. 24
		Feels rewarding to help others	Int. 23
		Appreciation	
		Found spirituality	
		Personality changes or previous attributes that were not healthy are gone	
		Realise the greater public awareness of disability or kindness in humans	Int. 24 and Int. 28, respectively
Resources access Improvements in SS	Greater awareness of health and stroke and influenced others	Int. 16 and Int. 31	
	Mixing more with people	Int. 31	
	Government/Centrelink bonus scheme (Related to caregiver's perspective)	(Not a prevalent theme)	
Needs	Independence	Alone time/respite	
		Holidays	
		Separate activities-especially outside the home	
		Physical Mobility	
		Disabled Toilets	
	Education/knowledge	Respect	
		About nature of stroke and prognosis	
		Types of support services or groups	
	Support	Face to face	
		Caregiver training	
		Emotional-to talk/psychological/counselling	
		Friendships	
		Family assistance	
		Financial	
		Support Services	
Positive Messages			

Rehabilitation and Medical services
etc

Respite and home care: Practical-home
based respite and home care to go out
more/be independent etc

Face to face tailored home Ax of SS
situation and needs

Int 7. page 12. "As I say, I'm so
disappointed with people's..."

Follow ups

Equal attention to stroke as other medical
problems

Podiatrist

Low cost

Adequate nursing homes.

Int. 1

With activities for SS
and tailored to their levels

Help SS with motivation to practice skills

A cook

Rehabilitation, e.g. Physios

Psychological assessment

Volunteers to sit with SS

SS to return home/in better living
circumstances/healthy SS
Support services not required/no
needs

Adjustment/Caregiver
activities/Burden

Roles change

e.g. household

Increase in other responsibilities

E.g. Driving the SS to places

Severity of stroke/disability

Exacerbates effect of current medical
conditions

E.g. Energy levels

Caregiver characteristics

Caring personality and history of
looking after people

"Over-accommodating" for SS and
reinforce and maintain SS withdrawal and
lack of motivation

Patient

Overprotective

Hardworking

	Independent Resilient Commitment/obligation	Belief will burden others if ask for help	
Access to services/resources	Neglect and uncertainty re. post-discharge services Lack of appropriate resources and access to them	Left without support post-discharge-uncertain of what to expect Unaware of available support E.g. Respite care that will accept SS difficult-rejected by facilities. Accessibility Persistence required Parking permit, taxi permits Housing commission Financial assistance Rehabilitation	"Too far away", "short staffed"
Evaluation of services and resources	Satisfied Utilised/Received/Offered Neglect/ lack of communication/poor communication Helpful but not regular/ongoing Poor Quality	Dissatisfaction with Centrelink Hospital Hospital staff Rehabilitation, e.g. Physiotherapists and doctors Rehabilitation Respite care Inappropriate timing of access Nursing homes DVA Hospital Care Recruitment Officer Lack of education re. stroke and prognosis	Interview 17, line 17
	Education Lack of follow-up appointments/ongoing support Reassurance and regular check ups Expensive Satisfaction	Neurology Acute hospital stay Pharmacotherapy helpful Clinical trial G.P	

Respite care
Physios
Speech Pathology
Rehabilitation centres
ACAT
Psychological services
Clinical trial
Homecare
Centrelink carer's allowance
Neurologist
Stroke support groups
DVA
Parking permit
Cleaners
Acute Hospital Stay
Nursing homes
Taxis

Messages from health
professionals

Negative messages

Int. 17. "bed side manners"

Independent Coder: Final theme list

Themes	Theme components	Examples
Independence v. dependence	Caree's independence affects carer's provision of care	Interview 1: "It's very hard to care for Patrick; he's very independent". Interview 9: "Well a major event, even here, even now, I say I'm reading and she sit down there, she wants to stand up, she has to call me. I have to stand up and go there and help her to stand up you know, there's so many things she depends on me and I've lost much of my freedom."
	Carer's independence affects requests for support	Interview 1: "But then again I don't like to impose on them".
	Caree concern regarding carer's perceptions of dependence	Interview 2: "sort of thing so I think she, she sort of looks, the changes that she's thinking I'm an invalid and she's looking after an invalid a bit and she's got to look after some things or do some things..."
	Mismatch between perceptions of dependence	Interview 2: "So but when I think of her as a carer I don't think she fully understands what's wrong with me right and she has a picture of what she thinks I should do and she doesn't listen to my side or doesn't absorb what I say when I say I think we s
	Drive for independence and acceptance of environmental changes	Interview 1: "we organised the house to suit him more. We changed my bedroom to the down chairs...we had our bedroom upstairs..and when he came home he didn't like being in the downstairs one so we had to change back".
	Carer's resentment at loss of independence	Interview 3: "Hmm, that's what I resent that, I do resent not having independence". Interview 3: "His real dependence on me. I find that quite heavy, sometimes".
	Caree's difficulties in accepting caree role	Interview 4: "Whereas previously, I'd never been sick in my life. For me, that was probably the worst part, I'd never been sick in my life. I sort of broke my elbow when I was a kid, falling off my bike, and that was really it. So I wasn't used to being, having things wrong with me".

Experience of carer	Concern for caring role affect QoL	<p>Interview 2: "but I wouldn't like to think it's oh, restricting or inhibiting particularly my wife right and I don't think it is but I worry that she doesn't seem to have any ambition that's all and whether that's something to do with me or whether it's" Interview 21: "Yeah, I do. I try not to, but sometimes I get quite frantic about it and think what if I'm in a bed, what if I can't get out, what if I'm in a home, what's Robert going to do. I don't want him to be tied to somebody who's in a bed, that worries me. "</p> <p>Interview 37: "Because of the way he was. He would have been a burden"</p>
	Misunderstanding of needs	<p>Interview 2: "I go down the shopping centre and that if there's tiles along the floor I'm following the line of the tiles, that keeps me in a straight line and that so I don't think she fully recognises it, she thinks the problems are physical.</p> <p>Interview 2: ". Some of the things that might have been critical or knocked you off or something have been fixed in a temporary way so maybe those problems have been solved and you hope they don't come up in another problem that's all". Interview 21: "I don't know. Whenever I bring it up, he is a really positive person, he always has been. So he just says, "I'm not worrying about it until it happens. We'll face it when it happens." I say, "What if I can't move my arm, what if I'm in a bed?" he says, "I'll worry about it when it happens." Interview 21: "Yes. I think what really scares me is I'll have another stroke by myself and no one will be there and I'll be in the middle of people in the city or something and"</p>
	Uncertainty about the future	<p>Interview 3: "So we're sort of lucky to have him and he's sort of accepted cancer, but the stroke was just out of leftfield, and to destroy his intellect and all that he really has made him quite, probably bitter really about it." Interview 7: "Yeah, well you know, she remembers what she was and what she is now."</p>
	Adjustment	<p>Interview 4: "While I was in hospital, I was thinking, what's going to happen now, what will Jo do?".</p>
Experience of carer	Concern for carer	<p>Interview 1: "caring for daughter with schizophrenia as well." Interview 20: "to make sure that the house still functions, so I'm taking care of Helen's Dad as well as Helen. I don't have a problem with that, that doesn't worry me, but it's just an additional load that has had to happen"</p>
	Multiple carer roles	<p>Interview 1: "Ongoing things, Patrick's diabetes and his stroke, mmmm, he had bypass heart surgery as well".</p>
	Frustration at ongoing health problems	

Need for time out	Interview 1: "But I do need to have a little bit of time to myself occasionally. And ahh...sometimes I go and sit in the park for a while and think of nothing". Interview 3: "Because of where we are, we're sort of together all the time, and it's, I think". Interview 34: "Anyway what I was going to say, I make sure that I continue with my interests. I go to exercise classes twice a week, and I go to, even though I've got hardly any central vision I've got good peripheral vision, I can't drive or read or write or knit or sew, those things have all gone, but I could still cook and Es can, I cook Christmas cakes and puddings and shortbread and he can measure out what I can't see on the scales, and so we manage that way"
Concern expressing difficulties with carer role	Interview 1: "I wouldn't feel right doing that at home, people would get too concerned".
Fear of recurrence	Interview 3: "But I think the worst part for me after it happened was, after the shock sort of settled was just living with the fear that it was going to happen again, and coming home from the hospital and sleeping in the same bed and thinking are you al
Concern regarding ability to care if things worsen	Interview 3: "I mean because there's no way in the world I could look after him at home if he was worse".
Emotional effects	Interview 9: "Well you know it's emotional, with this problem, you know, this problem of course you're too busy to laugh, smile and joke you know. " Interview 9: "It's been hard on me, you know, not too easy, it's because it's coming, she could have had a heart attack, it's not because of her." Interview 9: "After what's happened to her, nothing is positive. You know before I enjoyed myself, I travelled, you know, we travelled a lot and sometimes in the night, do you want to go out, yes, so I'd jump in the car... you know." Interview 9: "Of course, you meet friends, "are you coming Saturday at the XXX?" – no thank you. "Come on"... you know, we went there as I say, with a lot of friends, so we finish up... more isolated" Interview 37: That's right. Emotions, yes, she had her ups and downs, but didn't fall into depression. She just, more emotional, more that sadness and worry and normal feelings"
Managing own health problems	Interview 9: "I was worn out from going. I could not walk, I could not talk, I could not drink and she was a bit upset, her mother looked after her, but she came in hospital" Interview 34: Well because of my blindness, it's twice as difficult for me to find things. Puts the cutlery in the wrong sections, and I'm scratching around trying to find it, or oh just probably unimportant things, but frustrating for me because of my lack of vision."

Familial and social support	Family support	Interview 2: "Now I'm lucky because me son one of them lives at home and the other one only lives a few blocks away and so any sudden thing they'll jump in and do something". Interview 4: "I suppose that's another positive because the kids have been mar
	Sharing of the caring role	Interview 1: "And my kids are great, they say mum if you want to go out or something we'll look after dad while you're gone".
	Family assume roles based on skills	Interview 1: "My daughter, my daughter Sharon is brilliant, she has taken over all of that stuff because she is..I think she worked in Tafe for a little while or something...she knows the system so she's working on it".
	Support of friends	Interview 1: "I've got a couple of good friends that I can unload on, this one particular girl is a...very good listener". Interview 4: "The girlfriends she has, she's still got. She's probably a bit more dependent on them now." Interview 20: "Yeah I suppose because as a full time student you know, you can shuffle your study time, it's not like a job, so in that sense I've been fortunate, all this year I've done a practicum at XXX Hospital in the rehabilitation ward and palliative care as experience for myself and I've just, I haven't had to back out of that on a Tuesday ever because of Harriet, I've backed out of it because of my study but I've never, so that's never cut across that, because I think it's really valuable that in a way she is centrally located in Sydney and that she can call an ambulance if she has either a panic attack or another stroke. So I'm able to shuffle things a lot, I don't have a huge group of friends, so I don't need to see my friends and I can ring people..."
Relationship	Changed sexual relationship	Interview 1: "sex has gone out the window". Interview 3: "he sort of can't feel properly anymore so sort of making loves different". Interview 3: "Yeah I don't feel the same; his touch isn't the same on me either."

		<p>Interview 1 "He's become very affectionate...which is really nice".</p> <p>Interview 20: Well yeah I think it's brought us closer because I think I've been fairly considerate of us, I actually have in the times put us through some very interesting difficulties with my ego with me wanting to do this, and me wanting to do that."</p>
	Change in intimacy	
		<p>Interview 4: "To me, the things that used to annoy Jane got worse. So her life was harder in that sense, that the things that she capable of, dealt with before became harder because they were all, to me not grossly different, but just, I don't know, things just got harder for her".</p> <p>Interview 4: "So I think that's sort of, I mean, we've always been a bit like that and that's exacerbated that, I think. We've now got to the point where it's annoying her immensely, I would think. So I think that things we may have had some issues with have sort of just got worse, a bit worse, but not, you know, we still laugh about it".</p>
	Exacerbation of existing problems	
		<p>Interview 4: "She's a bit more, cold is not the word, because she's very caring. We argue a bit more, well, we speak harsher. I swear a lot more than I ever. I suppose my temper's probably, and hers reacts to it, I think."</p>
	Increased strain	
Occupational and recreational	Effects on carer's work	<p>Interview 1: "I've had to arrange at work that I get off about two or three so that I can go and get him from the factory". Interview 9: "Well you know, I cannot do anything myself, you know. Before I was in real estate and I was going out and just talking with the people to do some business. Now I can't leave, for shopping I have to go there"</p>
		<p>Interview 1: "I'm sort of tied down to him more than I was...I would get in the car and go where I wanted to go". Interview 1: "Yes we go out less... the kids have bought me a computer and I'll play scrabble". Interview 4: She probably hasn't got as much time". Interview 7: "Going out with friends and, I enjoy myself, you know, I used to enjoy myself during the weekdays, go somewhere, so dancing you know." Interview 9: "Yeah, I must give up so many things, you know, once a month, we have a Saturday, a dancing Saturday and many times I came, now I don't dance..." Interview 34: We used to play indoor bowls together on a Wednesday night, but I stopped that because I don't want him to drive at night. "</p>
	Restriction of recreational activities	

Stroke-related behaviour	Anger/frustration/etc.	Interview 1: "And he does sometime he is just like his father was...it's scary". Interview 1: "Oh I could cry just thinking about it, because it's not my Patrick". Interview 4: "I mean, she sees that probably my personality has changed in the sense that I'm much harder on, maybe pick on her about things she does and things like that". Interview 34: Well because I've got to keep my eye on what he does, tends to put things in the wrong place and I'm always going on a search for something, and he might mislay his keys or the other Friday when it was raining he couldn't find his umbrella, so the frustrations of meals, going on a search for this, that and the other thing nearly drives me crazy"
	Caree's awareness	Interview: 4: "I mean, she sees that probably my personality has changed in the sense that I'm much harder on, maybe pick on her about things she does and things like that".
Adjustment	Questioning fairness of stroke	Interview 1: "why did it happen to him, this is what I get angry about, you know it shouldn't have happened to him... should have happened to some bastard".
	Acknowledgement of need to accept	Interview 1: "Yeah, it is. I mean I've put it behind me, that's just crazy to do that, to think that way all the time, and I don't do it all the time".
	Difficulty adjusting to caree's disability	Interview 1: "watching him walk around the table was tearful stuff and just seeing him so inadequate wasn't right".
	Change of goals	Interview 3: "And I called packing up your dreams because you can't do them any more".
Environmental changes	Acceptance	Interview 20: I'm very happy to accommodate anything that she wants because I'm okay, you know, she's the one that's got the difficulty."
	Rearrangements to home	Interview 1: "The boys built a rail and he can get up and down the stairs".
	Moving closer to services	Interview 3: "so I've sort of pushed steps that way. I think we sort of probably need to be a bit closer to hospital and RPA maybe, because if we, he has to have treatment down the track we really' Interview 2: "only that it sort of confirms that you're, you can do things together, one will look after the other"
Positive outcomes	Change of perspective	Interview 1: "You realise what is important and what is not important. I mean it's not important if Patrick leaves the butter out of the fridge and it goes off does it? Who cares...".

		<p>Interview 1 "He's become very affectionate...which is really nice".</p> <p>Interview 34: Mm, because they are, they're spending a lot more time together and he actually wants her to sit down with him. Before he used to sit down and have his own lunch, not wait for anyone else. It's like he wants her to sit down and spend more time together.</p>
	Increased intimacy	
		<p>Interview 37: As a family and the outer family has gone closer. I think that's what's made the stroke, I mean, it's a bad thing to happen and a bad way to get together, but I think that's just brought the family a lot closer". Interview 37: Like before, it was like, she had family friends and all that stuff, but they wouldn't come over on a regular basis. Once in a blue moon. But now there's always someone in the house. Like, every time I come here, there's always someone here. I"</p>
	Affirmation of relationship	
		<p>Interview 3: "Maybe the positive is just the friendships, how wonderful, you realise just how important they are and how wonderful people can be."</p>
	Affirmation of friendships	
		<p>Interview 4: "I don't think anything particularly good came out of it, except she used to always say to me that, after I sort of didn't, her perception I didn't really support her while she had chronic fatigue, that she was never going to look after me... Yeah, at the time. That never came true".</p>
	Affirmation of caring	
Support services	Financial concerns	<p>Interview 2: "So there's little things that come up all the time and instead of my wife having to take it out of her money". Interview 7: "Yeah it's been hard, you know. A bit of a toll you know, the years have gone now without..." Interview 7: "you know financially or I don't know what kind of help they can give to us." Interview 7: "Well now it's more the financial than emotion, before you know, I was working in the real estate, you know, sometimes there was good money coming in and now..."</p>
	Insufficient information	<p>Interview 2: "Now when the doctor found I had it it was a bit like putting a sticker on the wall on the chart saying I found another one. He didn't actually tell me what the outcomes might be and where you started to fix it". Interview 20: I didn't know it was going to take two years until Helen came back from the stroke support group and said oh they're saying it's still early days for me. I said oh really? Yeah it will be two years. Oh okay."</p>

Insufficient support

Interview 4: "Well, I think the aftermath of the whole thing was we didn't get, and I don't know whether it was our fault or what, we were really left on our own". Interview 34: Give them some hope at least. If there is a slight improvement, you know that there was some kind of, something did come through. The littlest things, but they just, the negativity in those doctors are unbelievable"

Support groups

Interview 20: "stroke support group has been a really good place for her to go and yet even that, for all of its help, she's probably one of the youngest people in it, there are people who are much worse off than her which she talks about," Interview 21: "So the group that I'm in, they have some terrible problems, so I know I'm one of the lucky ones but even saying that, it's a bloody hard slog every day." Interview 21: "No, I think it's important and this has got nothing to do probably with you or but if you can tell XXX or somebody, I think the best thing for people to do is join a group of people who've had a stroke, a stroke support group. That has really, really helped me and I just think that maybe something they should tell people to do."

Minimal disability = minimal impact on life

Interview 8: "Yeah, well there hasn't been many changes love. I dress myself, I get my showers and I do everything else. She's always particular about my doctor's appointments and she makes them, but she is really easy to live with. I don't interfere. She has her own friends. She had people here last, well I normally go into the bedroom and not because I have to, because I'm just interested in TV and that and they were ladies, so I thought I would leave them alone. But I've been very lucky really. Whatever I had, if I had a stroke, I didn't notice it much." Interview 8: Very little change. I look after myself really. Get my showers and do everything. Go up the road. She's made a difference because, she came when I was sick and she still thinks I'm sick but I don't feel sick. I'm a lot slower than I was and my legs gotten worse, but that is about it. She's very very good and I couldn't imagine a better carer than her."

The saturation of themes

Participants		Indep.	Emotional functioning	SS-caregiver relationship	Resilience	Support (formal and informal)	Employ. & financial	SS cognitive/behaviour changes	Physical environment	Social functioning	Physical health (caregiver)	Positive changes	Needs	Adjustment	Severity of stroke	Charact.	Access to services/resources	Evaluation of services/resources	Health professional messages
1	(C)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0
2	(SS)	1	1	1	1	1	1	0	1	1	1	1	1	1	0	0	1	1	0
3	(C)	1	1	1	1	1	0	1	1	1	1	1	1	0	0	0	1	1	0
4	(SS)	1	1	1	0	1	0	1	0	0	0	0	1	1	0	1	1	1	0
7	(C)	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	0
8	(SS)	0	1	1	0	0	0	1	0	0	0	0	1	0	0	1	0	0	0
9	(C)	1	1	0	1	1	1	0	0	1	1	0	1	0	0	1	0	1	0
11	(C)	1	1	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	0
13	(C)	1	1	1	1	1	1	0	1	1	1	1	1	0	0	1	1	1	0
14	(C)	0	0	0	0	1	1	0	0	0	0	0	1	0	0	0	1	1	0
15	(C)	1	1	1	1	1	1	0	0	0	1	1	1	0	0	0	1	1	1
16	(C)	1	1	0	1	1	0	0	0	0	1	1	1	1	0	1	1	1	0
17	(SS)	1	1	1	0	1	1	0	1	0	1	1	1	1	0	0	1	1	1
18	(C)	1	1	1	1	1	0	1	1	1	1	0	1	1	1	0	1	1	1
19	(SS)	1	1	1	0	0	1	0	0	0	0	1	1	1	0	0	1	1	1
20	(C)	1	1	1	1	1	0	0	1	0	0	1	1	1	1	0	1	1	0
21	(SS)	0	1	1	1	1	0	0	0	0	0	0	0	0	1	1	1	1	0
22	(C)	1	1	1	1	1	1	1	0	1	1	1	1	1	0	1	1	1	0
23	(C)	1	1	1	1	1	1	1	0	1	0	1	1	1	0	1	1	1	1
24	(C)	1	1	1	1	1	1	0	0	0	1	1	1	1	0	0	1	1	1
25	(SS)	1	1	1	0	1	1	0	0	0	0	0	0	1	0	0	1	1	0
27	(SS)	1	0	1	0	1	0	0	0	0	0	0	0	1	0	0	0	1	0
28	(C)	1	1	0	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1
29	(C)	0	1	1	0	0	0	0	0	0	1	0	1	1	1	0	0	1	0
30	(SS)	0	1	1	0	1	0	0	0	1	0	0	0	0	1	1	1	1	0
31	(C)	1	1	1	1	1	1	1	0	0	1	1	1	1	1	0	1	1	1
32	(C)	1	1	1	0	1	1	0	1	0	1	1	1	1	0	1	0	0	0
33	(SS)	1	1	1	0	0	1	0	1	0	1	1	1	1	0	0	1	1	0
34	(C)	0	1	1	1	1	0	1	0	0	1	0	1	0	1	0	1	1	0
37	(C)	0	1	1	1	1	0	1	0	0	0	1	1	1	0	1	1	1	1
Total		23	28	26	19	26	18	13	9	10	19	19	26	21	11	15	25	28	8

Note: Numbers in bold indicate the first time a sub-theme was mentioned. 1= Sub-theme mentioned; 0=Sub-theme not mentioned; C= Caregiver; SS= Stroke survivors; Indep.=Independence; Employ. & financial=Employment and financial strain; Adjustment=Adjustment and caregiver burden; Charact.=Caregiver characteristics.