

**Psychosocial Adjustment Following Stroke**

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## **ABSTRACT**

Stroke is the third most common cause of death in Australia. To date, there has been extensive research conducted on the reactive consequences following the diagnosis of stroke. In contrast, there has been limited research effort directed at understanding how some stroke survivors manage to adjust to their adversity and altered circumstances. This study took a phenomenological approach and explored the experiences and strategies stroke survivors employed in their renegotiation of living.

The study participants were 34 stroke survivors who resided in metropolitan Melbourne and in the rural and remote areas of Victoria, Australia. Data collection primarily occurred through semi-structured interviews.

Thematic analysis of the transcripts identified various psychosocial factors associated with adjustment from stroke. These psychosocial factors included: individual differences, competency, self-esteem and social support. The findings also highlighted the value of community when recovering from stroke and revealed health disparities in stroke services amongst rural and remote settings. The outcomes of the study identified distinct features of the recovery process that apply to younger stroke survivors and raised concerns specific to their age group.

Overall, the study identified a number of factors and resources consistent with the concept of resilience. Moreover, the findings indicated a strong relationship between stroke survivors and the resilient processes they engage in with their ability to adjust from their adversity. Important information has been generated providing clues for how people who do suffer negative consequences can be rehabilitated more successfully. The outcomes of the study have highlighted serious gaps in the psychosocial recovery process for stroke survivors which require urgent attention. It is essential that more appropriate programs are designed and implemented that effectively and comprehensively assist all stroke survivors in their rehabilitation and recovery.

## DECLARATION

“I, **Michelle Ann Fox**, declare the PhD thesis entitled “**Psychosocial adjustment following stroke**” is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work”.

Signature:

Date:

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## **DEDICATION**

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# CHAPTER 1

## Introduction

### 1.1 Introduction to the psychosocial aspects of stroke recovery

When encountering an adverse life event or stressful situation, individuals utilize different strategies to cope. Some cope well and manage to adapt to their altered circumstances, while others experience difficulties in coping and suffer enduring negative consequences (e.g., the onset of severe or chronic depression). To date, there has been extensive research conducted into the impact of adverse life events on the individual. However, the majority of this research has been reactive, that is it focuses on those who are experiencing problems. By contrast, limited research effort has been committed to understanding the processes of people who cope well despite their lives being adversely interrupted. There are individuals who appear to be resilient to the impact of adversity and manage to adapt well to their altered circumstances (Rutter, 2000; Rutter & Sroufe, 2000).

Studying strategies by which people demonstrate resilience can identify coping processes that are potentially open to much wider use through preventative and educational programs (Luthar & Cicchetti, 2000; Masten, Hubbard, Gest, Tellegen, Garmezy, & Ramirez, 1999). Importantly, finding out how the resilient individual copes can offer practitioners the basis for developing earlier interventions, identifying and assisting those who are experiencing maladjustment to function more effectively. Such is the aim of this research project.

Garmezy (1993) defined resilience as the capacity for successful adaptation, positive functioning or competence despite high-risk status, chronic stress or following prolonged or severe trauma. Subsequent research (e.g., Dumont & Provost, 1999; Elizur & Hirsh, 1999; Masten & Coatsworth, 1998; Spence, 1996; Tiet, Bird, Davies, Hoven, Cohen, Jensen, & Goodman, 1998) has identified several individual (e.g., internal locus of control, problem solving ability, competence, individual disposition – optimism, confidence, self-esteem) and interpersonal (e.g., positive social and emotional support, intimacy, satisfactory peer group functioning) factors that are strongly associated with

manifesting resilience to the development of psychological problems following adversity.

Research involving older adolescents and adults has indicated that resilience is also a developmental process wherein the individual's history of interactions with their environment is an important factor in determining the manner in which they cope with a current stimulus or cue (Egeland, Carlson, & Sroufe, 1993; McMillen, 1999). Importantly, as noted by Cichetti and Garnezy (1993), uncovering the processes and mechanisms that lead to competent adaptation despite the presence of adversity has not only increased our understanding of normal developmental processes, but the development of psychopathology as well.

As people age, they are at increasing risk of encountering many adverse physiological life events, one of which is stroke. Each year there are up to 60,000 Australians affected by a new or recurrent stroke (National Stroke Foundation [NSF], 2010). It is the third most common cause of death and one of the major causes of adult disability (Australian Institute of Health and Wellbeing, 2006; Kitsos, Harris, Pollack, & Hubbard, 2011; NSF, 1997). Survivors of stroke may live with permanent neurological impairment, which can vary from moderate to severe. The trauma of such life events can be very unsettling, not only for the individual but also for their extended family. Moreover, rehabilitation can be a slow, painful and difficult process.

The National Stroke Foundation in 2009 reported that strokes cost Australia an estimated \$2.14 Billion annually (National Stroke Research Institute Report, unpublished, 2005). Over 50% of stroke survivors have persisting disabilities that leave them partially or totally dependent on others to assist them with basic day to day activities. This increased dependence exacerbates and prolongs their need of individual, public and medical support, stretching limited resources and services. A high proportion of survivors, between 20-80%, also develop severe depression (Franzén-Dahlin et al., 2006; Gum, Snyder, & Duncan, 2006; Khan, 2004). As noted by Zimmermann et al., (1999), the addition of depression serves to severely disrupt the processes of adaptation. It also increases the already high levels of stress and strain for all involved.

At the same time, there are others who do not develop depression. They seem able to adjust to their environment and avoid the enduring negative consequences that can be associated with severe life disruption. For them, rehabilitation is quicker, more

successful and their quality of life is greatly enhanced. However, little is known about how or what processes are used in renegotiation their lives. Indeed, whilst there is extensive research examining the adequacy of diagnostic methods for screening depression and other reactive consequences (Gordon & Hibbard, 1997), it would seem there is little interest in researching the pro-active processes utilized by those who successfully adapt to their life following stroke.

As suggested by Strumpfer (1999), and Rowe and Kahn (2000), studying the processes of adaptation to, and successfully coping with, chronic illness may offer important clues for how people who do suffer negative consequences can be rehabilitated more successfully. An understanding of these processes would also provide educative guidelines for earlier intervention and development of future preventative measures in the period of early recovery from trauma such as stroke.

One of the challenges faced in the delivery of health services in Australia is geographical location. It has been well established in the literature that rural population health fares worse than urban population health (Joubert et al., 2008). Multiple barriers have been identified (e.g., distance to access health services, access to allied health staff, access to appropriate services) that impact on the availability and accessibility of health services within a rural setting. But what are the implications for stroke survivors faced with these barriers at a post-acute/rehabilitation and community level? Of the limited literature available serious concerns have been raised declaring that rural stroke survivors' health is severely compromised.

This present study aimed to explore the recovery experience of stroke survivors. Not only is the focus directed to the processes individuals use in their ability to adapt well despite their adversity, but also includes the mechanisms stroke survivors adopt to avoid enduring negative consequences. By exploring this psychosocial aspect of recovery in stroke the study will not only provide practical and relevant contributions in the fields of stroke research, chronic disease management, and community health, but will also provide valuable information for improving the provision of health care services for stroke survivors in Australia.

The purpose of the current study is to address the above noted limitations in the literature, by identifying the adaptive processes stroke survivors adopt in their ability to adjust following stroke.

## 1.2 Structure of thesis

The introduction presents the reader with the outline of the present thesis. The thesis is divided into eight chapters overall.

**Chapter two** provides a definition of stroke and current practices in the delivery of stroke care. Attention is given to stroke rehabilitation with the focus on optimising physical recovery for survivors. Whilst the literature is dominated by these physical domains of recovery, this section introduces the importance of acknowledging the psychological and emotional reactions following stroke. Indeed, there is a growing awareness of the psychological consequences of stroke and the need for specialised intervention (Bowen, Knapp, Hoffman, & Lowe, 2005; Clark, Rubenach, & Winsor, 2003; White & Johnstone, 2000), yet this section explores current practices in stroke care including the long neglected area of psychological support.

**Chapter three** discusses stroke within an Australian rural context. This section introduces disparities in health, in particular, the various factors that contribute to health disadvantage for stroke survivors living in a rural or remote geographical location. Various factors are presented including accessibility to health care (Read & Levy, 2006), geographical location (O'Connell et al., 2001) and the availability of mental health services (Campbell, Manoff & Caffery, 2006; Fraser et al., 2002; Rajkumar & Hoolahan, 2004). The impact of stroke whilst living in a rural or remote region is explored in order to understand the challenges faced by this group of survivors and the effects this has on their recovery.

**Chapter four** explores the various psychosocial factors that have been associated with successful adjustment from adversity, in particular stroke. Research tells us there are underlying psychosocial protective factors into which we are yet to tap into. Rather than focusing on the negative consequences or outcomes of illness, promising developments are emerging that are taking a more pro-active review of factors that are contributing to the individuals' well-being. This section examines the importance of these various factors and the contribution they have towards recovery from traumas such as stroke. This chapter also provides a brief introduction to the concept of resilience. Particular attention is given to the processes of resilience that facilitate adjustment from adversity. To better understand how people manage to adjust from a

serious illness like stroke it is important to consider the multi-level interactions they engage in from a biopsychosocial perspective.

**Chapter five** describes the methodology and design employed to carry out the research study. Interpretative phenomenological analysis (Smith, Flowers, & Osborn, 1997; Smith & Osborn, 2004) was the framework chosen used for data collection and analysis.

**Chapter six** presents an overview of the method employed to carry out the study. It provides details about the participants, materials, procedures and analysis of the data.

**Chapter seven** presents the findings from the thematic analysis of the interview data from the stroke survivors. The findings have been organised into four main themes: life adjustment, younger stroke survivors, a resilient tendencies, and stroke within a community context. The first theme described the overall physical and psychological adjustment post stroke. The second theme focused on interests as highlighted by younger stroke survivors. The third theme presented psychosocial factors that were prevalent amongst stroke survivors who were renegotiating their lives following stroke. The final theme related to the value of community as perceived by stroke survivors.

**Chapter eight** provides an interpretation of the study findings and makes the connection with the literature presented in the earlier chapters of the thesis. This section discusses the limitations of the study and also presents recommendations for future research.

## CHAPTER 2

### The Impact of Stroke

#### 2.1 What is stroke?

A stroke occurs when there is sudden loss of blood supply to the brain resulting in tissue damage. The World Health Organisation (WHO) defines stroke as “a vascular lesion of the brain resulting in a neurological deficit persisting for at least twenty-four hours or resulting in the death of the individual” (World Health Organisation Task Force on Stroke 1989, p.1407). There are different types of stroke; these include Ischemic Stroke and Haemorrhagic Stroke.

Ischemic Stroke develops when there is a lack of blood supply to the brain due to a blocked artery. This interruption of blood supply to the brain can lead to temporary or permanent injury to brain tissue (Caplan, 1993). Symptoms may include difficulties speaking, confusion, and problems with vision. These blockages are caused by a thrombosis, embolism or decreased systemic perfusion. A thrombosis occurs when there is an obstruction of blood flow within blood vessels of the brain due to clotting or atherosclerotic plaques. If the thrombus breaks off and travels through the blood stream an embolic stroke occurs (NSF, 1997). These embolic materials travel to the upper body and block the blood flow to the brain (Caplan, 1993). Decreased systemic perfusion occurs when there is a decrease in blood supply (e.g., blood loss or myocardial infarction).

Haemorrhagic Stroke occurs when bleeding is situated within the brain. Haemorrhagic Stroke is a result of either a Subarachnoid Haemorrhage, or an Intracerebral Haemorrhage (NSF, 1997). Subarachnoid Haemorrhage involves bleeding on the surface of the brain, where there is a rupture of blisters on arteries in the brain. Intracerebral Haemorrhage results from bleeding directly into the brain (NSF, 1997).

## 2.2 Incidence

It is estimated that around 60,000 Australians are affected by stroke each year (NSF, 2010). According to Dhamija and Donnan (2007), there are over 50,000 incidents of stroke in Australia each year. Stroke is the third leading cause of death in Australia (Mitchell, Brown, Erikssen, & Tieman, 2008). In 2003, stroke claimed 9,006 lives, nearly 7% of all deaths, and there was an estimated 346,700 survivors in Australia (AIHW, 2006). As reported by Warlow, Sudlow, Dennis, Wardlaw, and Sandercock (2003), 30% of patients die within a year of stroke. Stroke predominantly occurs in the older individual (Charles, Miller, & Fahridin, 2007; Dhamija & Donnan, 2007). Around 50% of strokes occur in people over the age of 75 years (Charles et al., 2007; National Stroke Strategy, 1997) and this figure is expected to increase with the aging population (Cadilhac, Lalor, Pearce, Levi, & Donnan, 2006; Moodie et al., 2006; O'Connell et al., 2001). Warlow et al. estimated that by 2020 stroke mortality will have almost doubled as a result of an increase in the older population. Paul, Strikanth, and Thrift (2007) have ascertained the increasing burden of stroke is attributed to an aging population. According to the Australian Institute of Health and Welfare (2006), stroke mainly affects older people. The AIHW reported the prevalence of stroke increased with age from 50-54 years and peaked at 75-79 years. Conversely, a small proportion of stroke occurs in people under the age of 55. Anderson et al. (1992) estimated that the annual incidence of stroke in people under the age of 55 is 24 per 100,000, a small but significant proportion of the stroke population.

People who survive a stroke event are often faced with a physical, sensory, and/or psychological disability. Pollack and Disler (2003) maintain even though one may have a high chance of surviving a stroke, there is a significant possibility that one will have a residual disability and handicap. A report by the AIHW (2006) indicated that of the 346,700 stroke survivors in 2003, “four in five had a disability, and for every two in every five survivors their disability was caused by stroke” (p. 41). It is difficult to accurately measure the incidence of stroke in Australia as there is no national data available which discriminates between a number of variables; however, stroke is a costly condition.

### **2.3 The Cost of Stroke**

The cost of stroke in Australia has been estimated at \$2.14 Billion annually (Cadilhac, Carter, Thrift, & Dewey, 2005). As indicated by Paul et al. (2007) stroke is responsible for a significant portion of formal health-care costs. The costs associated with stroke include hospitalization for acute care, rehabilitation and nursing care (AIHW, 2006). It is anticipated that these costs will escalate given the ageing population (Moodie et al., 2006).

A significant proportion of costs are also concealed in the amount of informal care provided to stroke survivors. Dewey et al. (2003) documented the amount of informal care provided to stroke survivors in Australia and estimated the economic value of this care. The authors found that caregiver time costs represent 4% and 7% of total stroke-related costs during the first year and between 14% and 23% of lifetime costs. Overall, these figures indicate how the incidence of stroke places an enormous financial strain on the health care system. Even more concerning is that estimates indicate over the next 25 years the number of strokes occurring in Australia will be more than double, even assuming that the incidence remains the same. However, stroke does not only impact on the community, it also impacts significantly on the subsequent life quality of the stroke survivor.

### **2.4 The Impact of Stroke**

As presented in Table 1, stroke can cause a number of physical disabilities or secondary complications. Secondary complications are medical complications that arise following stroke. These complications and disabilities can include: hemiparesis (paralysis/weakness of limb), dysphagia (swallowing difficulties), visual impairments, bladder dysfunction (incontinence), ataxia (incoordination of movement), dysarthria (slurred speech), vertigo (spinning sensation), and dysphasia (difficulty thinking of words and/or understanding speech, reading and writing). Having any one of these disabilities can have an impact on the stroke survivor's ability to maintain independence. For instance, the stroke survivor who develops paralysis down one side of their body may experience difficulties with showering and dressing independently. A

further complication may result in neglecting one side of the body (e.g., patients forgetting to put their left shoe on) or ignoring one side of space – this is known as spatial neglect (Ozmer, Materson, & Caplan, 1994).

Table 1: list of the different impairments identified in stroke and syndromes.

<b>Impairment</b>	<b>Syndrome</b>
Physical	Loss of movement, or weakness in the arms or legs, incoordination of movement, unsteadiness and imbalance with gait, loss of feeling to one side or both sides of the body, bladder dysfunction, difficulty swallowing, slurred speech (Counsell, Dennis, & McDowall, 2005; D’Alisa, Baudo, Mauro, & Miscio, 2005; Singh, Hunter, Philip, & Todd, 2006).
Sensory	Impaired vision, Spatial neglect Ozer et al., 1994; Proto, Pella, Hill, & Gouvier, 2009).
Cognitive	Memory disturbance, difficulty recalling information, lack of concentration, impaired judgement, difficulty communicating (Gordon et al., 2004; Mok et al., 2004)
Psychological	Post-stroke depression, anxiety (Doshi, Say, Young, & Doraisamy, 2003; Nicholl, Lincoln, Muncaster, & Thomas, 2002).
Emotional	Emotional lability (uncontrollable episodes of laughter, crying or both, Kim & Choi-Kwon, 2000), grief (Kahn, 2004).

Others may discover that they have problems with cognition and task performance. For example, complications may arise in organization, concentration, abstract reasoning, memory and attention (Leśniak, Bak, Czepiel, Seniów, & Czlonkowska, 2008; Mok et al., 2004). Problems with memory and/or reasoning might be displayed when the stroke survivor attempts to put their shoes on the wrong feet. There may be a loss or distortion of high-order functions such as language, memory and personality (Mitchell et al., 2008; Ownsworth & Shum, 2008). Sensory problems may be displayed when a stroke survivor is unable to visually recognize an object or even sounds.

Studies have also reported psychological and emotional impairments as a consequence of stroke (Lincoln, Nicholl, Flannaghan, Leonard, & Gucht, 2003; Burvill,

Johnson, Jamrozik, Anderson, Stewart-Wynne, & Chakera, 1995). For example, depression has been identified as a common complication (Whyte, Benoit, Mulsant, Rovner, & Reynolds, 2006) impeding the stroke survivor's recovery and rehabilitation. Anxiety has also been described as a sequelae of stroke leading to lack of confidence and restricting the individual's social activities (Burvill et al., 1995). In addition, there are stroke survivors who experience emotional problems including low self-worth and embarrassment (Gillespie, Joice, Lawrence, & Whittick, 2011). Hence, stroke survivors suffering from psychological and emotional impairments are faced with many obstacles in tackling their altered lifestyles and lengthy recovery process.

Stroke can leave the individual with a combination of these disabilities including physical, sensory, cognition and psychological disorders (Nicholl et al., 2002). Furthermore, disabilities like those mentioned above reduce the capacity for individuals to maintain personal independence at a functional/physical, sensory, or cognitive level. As noted by Doshi et al. (2003) there are numerous medical complications which can occur after stroke, many of which are fatal. It is vital that complications are identified early. By doing so, stroke management is delivered early thereby ensuring any issues or complications are addressed. From the current literature available, it would appear that it is the degree or severity of these physical, sensory and cognitive disabilities that determines the functional ability of the stroke survivor (Bernhardt, Dewey, Thrift, & Doonan, 2004; Kahn, 2002).

## **2.5 Managing Stroke**

When one has a stroke, they require immediate medical management as it is a highly unstable medical condition. Evidence has indicated that early arrival to hospital, the rapid delivery of medication, and effective diagnosis of stroke through CT scans are extremely important aspects of the early acute stage in the management of stroke (Davis & Donnan, 1999; Dewey & Bernhardt, 2007; Dhamija & Donnan, 2007; NSF, 1997). Acute management of stroke aims to provide intensive monitoring, assessment and evaluation of the condition and to prevent rapid deterioration and complications (Rocco et al., 2007). During the acute phase, stroke survivors undergo a variety of diagnostic procedures that include blood tests, electrocardiographs, chest x-rays, CT scans and the administration of medication.

As a result of the extensive research carried out addressing the acute management of stroke over the past decade, health procedures and policies have been created and adopted that have effectively reduced the stroke mortality rates around the world (Doonan, 1998). Thus, subsequent research continues (Cadilhac, Moodie, Lalor, Bilney, & Doonan, 2006) aimed at developing effective, efficient and best practice policies that can be implemented pragmatically to ensure that optimal stroke care is continually delivered. Hence, the continuation of research in this area provides the foundations for best practice care in stroke.

In recent years there has been a shift towards exploring the evaluation and effectiveness of rehabilitation processes and the introduction of stroke units and/or stroke teams (Ang, Chan, Hong, & Shen, 2003; Cadilhac et al., 2006; Read & Levy, 2006). There are a number of definitions of a stroke unit but the purpose is very clear; that is, to provide a specialist stroke service that involves organization, specialization and education (Crump, Talman, & Gates, 2005). As described by the AIHW (2006, p.8), a stroke unit is defined by:

- *Patients located in a geographically defined ward area*
- *A coordinated multidisciplinary team comprising a stroke physician, nursing staff, occupational therapist, speech pathologist, dietician, social worker and, where possible, a psychologist*
- *Staff specializing in the management of stroke and having access to ongoing professional education*
- *Team meeting regularly to discuss management and discharge planning*
- *Care provided according to agreed protocols*
- *Early provision of rehabilitation.*

“Stroke teams occur when patients are allocated to specialist team care and are managed on general wards in the hospital under the care of an admitting physician” (Evans et al., 2001). Researchers are now aware of the beneficial impact that organized stroke units have on functional outcomes for stroke survivors (Arias & Smith, 2007; Cadilhac et al., 2006; Evans et al., 2001; Jørgensen et al., 2000; Pound, Sabin, & Ebrahim, 1999; Young & Forster, 2007). According to the Stroke Unit Trialist’s Collaboration (1997) designated stroke units effectively reduce death from secondary

complications and reduced the need for institutionalized care. Furthermore, patients accessing these services experienced a subsequent reduction in functional disability. Cadilhac et al. (2004) provided a comprehensive picture identifying the different processes of care and outcome measures that were characteristic of a stroke service in Australia. The study demonstrated that adherence to processes of care in stroke units contributed to improved mortality rates and reduced stroke survivor functional dependency levels on discharge. Ang et al. (2003) compared hospital length of stay and outcome after stroke between patients in a stroke unit and patients treated elsewhere, and found that non-stroke unit patients had higher acute mortality rates. As argued by Dhamija and Doonan (2007) the benefits of being treated in a stroke unit should not be underestimated.

As mentioned previously, an essential component of stroke management is the services and support offered by multidisciplinary health teams (Arias & Smith, 2007). These teams generally consist of a rehabilitation physician, nursing staff, physiotherapist, occupational therapist, speech pathologist, and neuro-psychologist, all of whom are highly specialized in the area of stroke recovery. Pollack and Disler (2003) highlighted the importance of these multidisciplinary teams, especially in their ability to set common interdisciplinary goals concerning patients and their carers. The different members of the team independently utilize their skills and expertise in assisting the stroke survivor to optimize their recovery. Furthermore, Pollack and Disler highlighted the various roles of the rehabilitation team. The rehabilitation physician coordinates the program and deals with the medical management of the patient. The nursing staff works with the physician and the stroke survivor addressing medical concerns and assisting patients in their activities of daily living. The physiotherapist treats the patient's mobility, limb weakness, balance and tone (i.e., sitting, standing, and walking). The occupational therapist addresses activities of daily living such as showering and dressing. The speech pathologist concentrates on the stroke survivor's speech and swallowing mechanisms, and the neuro-psychologist deals with cognitive deficits (i.e., information processing, memory). All of the different disciplines have a specific role aimed at providing effective management and treatment for the stroke survivor in optimizing their rehabilitation and recovery outcome.

## 2.6 Rehabilitation

Whilst medical stabilization is of the highest priority during the acute stage of stroke, the aim of rehabilitation is to optimize the patient's ability to participate in personal activities of daily living, despite their physical disabilities (Ozer et al., 1994; Warlow et al., 2003). According to the AIHW (2006), rehabilitation involves the "coordinated use of medical, nursing and allied health skills, along with social, educational and vocational services to provide individual assessment, treatment, regular review, discharge planning and follow up" (p. 10). Pollack and Disler (2003) described rehabilitation as a process that is directed at improving function and independence and preparing the stroke survivor for life after stroke. The literature to date strongly supports rehabilitation as a crucial stage of recovery (e.g., Salter et al., 2006; Young & Forster, 2007). It has been well established that rehabilitation has a positive impact on the stroke survivor's functional outcomes, a reduction in stroke mortality rates, and is also associated with a decreased length of hospital stay (Khan, 2002; Langhorne, & Legg, 2003).

As with acute stroke management, there is a large proportion of research directed towards understanding and optimizing stroke recovery and rehabilitation and the benefits of this intervention process. In recent years the research interest has significantly expanded, identifying best practice rehabilitative care and also recommending further services to deliver optimal care. Authors such as Pomey and Tallis (2000), and others (e.g., Cameron & Kurrle, 2002; Lieberman & Lieberman, 2005; Teasell & Kalra, 2004) strongly support stroke rehabilitation programs and highlight the exciting advances made in the continuation of rehabilitation research. Areas of interest have included the use of treadmills (Ada, Dean, Lindley, & Lloyd, 2009; Kuys, Brauer, Ada, & Russell, 2008), and Very Early Rehabilitation (Bernhardt, Dewey, Thrift, Collier, & Donnan, 2008). Very Early Rehabilitation is the mobilisation of stroke survivors within 24 hours of stroke onset (Bernhardt et al., 2008). According to Ada et al., a promising way of increasing walking ability post-discharge from rehabilitation after stroke is to use treadmill training. By improving stroke survivors walking ability, it is likely to improve their general wellbeing due to better health and community participation. Bernhardt et al., explored Very Early Rehabilitation, whereby

stroke survivors were encouraged to mobilise within 24 hours of stroke symptom onset. This was viewed as a simple, yet important component of effective stroke unit care.

As noted by Hoffman, McKenna, Cooke, and Tooth (2003), stroke rehabilitation is viewed as a costly and resource intensive process. Nonetheless, the evidence has clearly demonstrated the positive effects that stroke rehabilitation has on improving functional outcomes for stroke survivors (Gordon et al., 2004; Langhorne & Legg, 2003). With the growing interest in stroke rehabilitation, and concerns about its escalating costs, different programs are being investigated by researchers and health providers with the intention of identifying and adopting the most cost effective and efficient services. However, controversy has erupted over whether the different types of services fully address all the needs of stroke survivors.

To date, the different types of services include inpatient rehabilitative care, where the stroke survivor remains an inpatient within a health care facility and is treated by a specialist physician, and they also participate in intensive therapy for up to 3 hours a day over 6 days a week (Khan, 2002); home-based therapy where the stroke survivor is overseen by an interdisciplinary team that coordinates early supported discharge and therapy at home (Teasell & Kalra, 2004); and day hospital services (Roderick, Day, Peasgood, Mullee, Turnbull, Villar, & Raftery, 2001) that offer rehabilitation programs located within a community facility or hospital offering a number of hours of supervised therapy during the week.

Whilst the various programs have attracted a great deal of interest, there continues to be some tentative views regarding the systemizing of these services as standardized practice. For example, researchers (e.g., Deutsch et al., 2006; Young & Forster, 2007) have expressed concern about the stroke survivor's suitability within the various settings. Pollack and Disler (2003) noted some stroke survivors may prefer to be treated in the home environment rather than as an inpatient within a rehabilitative setting. Khan (2002) suggested that home-based care would not be suitable for those who require multi-faceted therapy. Gordon et al. (2004) proposed that a complete evaluation of the stroke survivor for a home based program is required as those with depression, fatigue syndrome, poor family support or communication, may require further assessment and subsequent specialization of their rehabilitation program. Overall, Burton (2000) described recovery from stroke as an "intensely personal

experience that involves the rebuilding and restructuring of an individual's world" (p. 307). Notwithstanding the various views on the topic of rehabilitation, the research has established the importance of a different rehabilitation services that address the needs of the individual. Furthermore, the traditional practice of inpatient rehabilitation is no longer considered as complete when the stroke survivor is discharged from a health facility. Rather, rehabilitation is considered to be an ongoing process with research (Young & Forster, 2007) highlighting the importance of continuous therapy to maintain personal independence and improve disability outcome.

## **2.7 Functional Ability and Recovery**

Functional ability refers to the basic activities of daily living as performed by an individual, such as showering and dressing, walking, toileting and eating. Functional ability following stroke has been well documented (e.g., Bernhardt et al., 2004; Kuys, Brauer, Ada, & Russell, 2008; Kwon, Hartzema, Duncan, & Lai, 2004) and constitutes a large proportion of stroke research. The literature appears to follow a continuum of recovery processes from acute stroke management, to standardized assessment, and optimizing care delivery (Crump et al., 2005). Measures of functional ability are assessment tools that provide recovery outcomes for health professionals working in the area of stroke rehabilitation. For instance, assessment tools such as the Bartel Index, the Functional Independence Measure (FIM), Activities of Daily Living (ADL) and the Modified Rankin Scale (Bamford, Sandercock, Warlow, & Slattery, 1989) provide quick, short-term, reliable indices that are reflective of the stroke survivor's current functional ability. Through the utilization of these different measures researchers, policy makers, government, and health professionals are able to develop evidence based, efficient stroke recovery programs.

In order to measure and gain information about a stroke survivor's functional ability, health professionals and researchers will assess areas of performance including personal activities of daily living (ADLs). The key components of personal ADLs measured include: showering independently, dressing upper body, lower body, feeding, walking and toilet use. As noted by Paolucci et al., (2003) and others (e.g., Johnston, Pollard, Morrison, & MacWalter, 2004; Leiberman, & Leiberman, 2005) it is through these different tools of assessment that we have gained valuable knowledge about stroke survivors and their ongoing functional ability and how this impacts on their overall

functional recovery. Hence, these measures provide evidence for what constitutes best practice care in developing rehabilitation and recovery programs. This aspect of the stroke recovery process continues to dominate the research to date, especially in areas associated with managing stroke at an acute (Davis, & Doonan, 1999; Kugler et al., 2003; Mayo et al., 2000) and rehabilitative level (D'Alisa et al., 2005; Mackenzie, & Chang, 2002).

Even though there is extensive literature available evaluating and reporting on individuals' functional ability post stroke, including recommendations for return within the community, little information of a similar scope exists for the stroke survivors' psychosocial competence. One would expect that best practice stroke care would not only incorporate assessment of functional ability, but also address other aspects of recovery including psychosocial assessment and evaluation. Failure to do so would have serious clinical implications.

The consequences of ignoring the psychological aspect of stroke recovery can have a profound effect on the individual's readjustment and rehabilitation. Problems experienced by stroke survivors' may include depression (Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001), anxiety, lack of motivation (Morris, Raphael, & Robinson, 1992), an inability to engage in social activities over the long term, and poor compliance with rehabilitation (Khan, 2004; Turner-Stokes & Hassan, 2002). As a consequence of these problems- there is likely to be an increased demand in the use of health care services. There are currently enormous gaps in the delivery of stroke care services when you consider psychological health management (Bowen, Knapp, Hoffman, & Lowe, 2005). By addressing this paucity in health care services not only do we improve the delivery of best practice stroke care, but we will also provide stroke survivors with the support and resources to facilitate a meaningful adjustment to their altered circumstances and reduce post-stroke health care utilization.

## **2.8 Post-Stroke Depression**

According to Pohjasvaara et al. (2001), post-stroke depression (PSD) is the most frequent psychiatric consequence of stroke. The term post-stroke depression will be used to indicate depression related to stroke unless otherwise indicated. Over the past 20 years there has been increasing interest investigating PSD (Robinson & Spalletta, 2010).

The prevalence of post-stroke depression is estimated to be between 20– 80% (Burvill et al., 1995; Ouimet, Primeau, & Cole, 2001; Ueki et al., 1999). Pohjasvaara et al. (1998) identified the presence of PSD 3 to 4 months after stroke, affecting 40% of patients. Kauhanen et al. (1999) found that nearly half of their ischemic stroke patients had depression 12 months post stroke. Van de Port, Kwakkel, Bruin, and Lindeman (2007) found 19% of stroke survivors were depressed at three years. Whyte, Mulsant, Vanderbilt, Dodge, and Ganguli (2004) undertook a longitudinal study of the relationship between stroke and depressive symptoms and found that stroke survivors have an elevated risk for depressive symptoms two years after stroke. It is clinically significant when studies have demonstrated that PSD can be present up to seven years post stroke (Dam, 2001). Moreover, other studies have also demonstrated the long term occurrence of depression and the potential implications of this for the stroke survivor (Åström, Adolfsson, & Asplund, 1993; Berg, Palomäki, Lehtihalmes, Lönnqvist, & Kaste, 2003; Whyte, Mulsant, Rovner, & Reynolds, 2006).

As noted by a number of authors (e.g., Aben et al., 2002; Gordon, & Hibbard, 1997; Lincoln, Nicholl, Flannaghan, Leonard, & Van der Gucht, 2003; Nicholl et al., 2002; Whyte et al., 2004), diagnosing PSD is complicated because of the difficulty in trying to distinguish which symptoms are a direct result of the stroke (Ozer, et al., 1994). For instance, fatigue has been identified as a syndrome occurring post-stroke. But fatigue has also been recognised as a feature of depression (Van de Port et al., 2007), and in the DSM-IV, is listed as one of the criteria (Bogousslavsky, 2003). Other symptoms that may require further investigations for assessment include pathological crying, tearfulness and cognitive impairment. Bogousslavsky expressed caution in diagnosing PSD because of the tendency for pseudo-depressive mood disorders to be classified as simply “depression”. However, others (e.g., Turner-Stokes & Hassan, 2002) have claimed depression as a widespread condition that remains under-recognized and under-treated.

Recent advances in research have proposed possible causes for depression to include an endogenous origin, or a psychological reaction to the event (Lincoln et al., 2003). Depression with an endogenous origin is based on the neuro-atomical or biochemical impact of a brain injury (Turner-Stokes, & Hassan, 2002). Conversely, a psychological origin may be considered as an expected emotional reaction to the

severity of disability imposed by the stroke (Gottlieb, Salagnik, Kipnis, & Brill, 2002). Khan (2004) provided a list of psychosocial contributions believed to contribute to the development of PSD (p. 832). These included:

- Grief and loss
- Financial difficulties
- Social Isolation
- Poor self-esteem, and
- Relationship difficulties

Overall, there continues to be uncertainty about what mechanisms cause post-stroke depression. Consequently, the research debate about the origins of PSD continues.

## **2.9 The Impact of Post-Stroke Depression**

Numerous authors have noted the impact that PSD has on the functional recovery of stroke survivors (Almeida & Xiao, 2007; Berg et al., 2003; Hackett, Glozier, Jan, & Lindley, 2009; Kauhanen et al, 1999; Pohjasvaara et al., 2001; Robinson, & Spalletta, 2010; Tuner-Stokes & Hassan, 2002). From the literature available it can be confidently ascertained that PSD impairs recovery from stroke (Åström, Adolfsson, & Asplund, 1993; Beekman et al., 1998; Morris, Raphael, & Robinson, 1992; Whyte et al., 2006). Post Stroke Depression is associated with loss of motivation, paucity of energy, increased fatigue, failure to achieve goals and non-compliance with rehabilitation programs (Ozer et al., 1994). Sims et al (2009) reported that depression post-stroke can have a negative effect on rehabilitation and prognosis. Post Stroke Depression has also been shown to affect personal care. Pohjasvarra et al. (1998) reported that patients with depression were more likely to be dependent in their personal activities of daily living (e.g., showering, dressing). In a later study, Franzén-Dahlin et al (2006) found that major post-stroke depression is more common amongst stroke survivors with limited functional deficits. Morris et al. (1992) found stroke survivors who had PSD also had poor motivation, anxiety, excessive dependency and an

unwillingness to act on tasks aimed at reducing their dependence, all of which adversely affected their recovery process. Overall, PSD has been associated with increased mortality, reduced social activity, prolonged inpatient hospital stays, functional dependence and poor participation in rehabilitation (Khan, 2004; Turner-Stokes & Hassan, 2002).

Even though a great deal of research effort and interest is currently directed towards diagnosing and understanding post-stroke depression (Berg et al., 2003; Cassidy, O'Connor, & O'Keane, 2004; Khan, 2004; Lincoln, Walker, Dixon, & Knights, 2004; Turner-Stokes, & Hassan, 2002; Whyte et al., 2004), there remains a fundamental need to look at the psychosocial consequences of stroke. Current stroke recovery and rehabilitative services offer models of care that are based upon the biomedical framework. There does appear to be a gradual shift towards a psychosocial approach, however, this remains slow in its progress.

While researchers and health professionals have emphasized the necessity of drawing on and addressing this psychosocial approach to stroke recovery (Almeida & Xiao, 2007; Khan, 2004; Ouimet, Primeau, & Cole, 2001; Pollack, & Disler, 2003), the research output is modest in comparison to the physical and functional domains. Recent studies have raised concerns about the inadequate psychological services available for people following stroke. For instance, Bowen et al. (2005) reported on the psychological compliance with relevant National Clinical Guidelines for Stroke, and found that current psychological services for people with stroke in the United Kingdom urgently needed attention. Bowen et al.'s review found enormous gaps in the current psychological services that needed to be addressed.

Almeida and Xiao (2007) undertook a study aimed at determining the incidence of mental health disorders post stroke and 10 year mortality associated with the incident of post stroke mental health disorders. The authors found approximately 1 in 3 patients developed a mental health disorder following stroke. They concluded that the incidence of clinically significant post-stroke mental health disorders was high and suggested that future research needed to explore preventative strategies that can be introduced in clinical practice. The research to date has identified service delivery gaps regarding the psychological aspect of recovery. There continues to be a paucity of information available about the emotional consequences of stroke. More research efforts are

required, especially if a psychological component is to be included within the context of a rehabilitative framework.

## **2.10 Emotional Reactions Following Stroke**

A number of studies have confirmed that the emotional problems encountered following stroke are far from receiving the same attention as the physical and cognitive aspects of recovery (Fure, Wyller, Engedal, & Thommessen, 2006; Mangset, Dahl, Førde, & Wyller, 2008). In recent years there has been more research efforts directed at generating knowledge about the overwhelming negative reactions encountered by stroke survivors and their experiences in recovering from stroke (Bendz, 2000; Bowen et al., 2005; Burton, 2000; Fure et al., 2006; Hafsteinsdottir & Grypdonck, 1997; Pound, Gompertz, & Ebrahim, 1998; Sisson, 1998). Subsequently, the literature has identified a variety of emotions expressed by those suffering from the consequences of stroke (Bendz, 2000; Glass & Maddox, 1992; O'Connell et al., 2001; Stone, 2005). These emotional reactions include frustration, anger, overt sadness, grief, loss, shock, vulnerability and worry (Dowell et al., 2000; Hafsteinsdóttir, & Grypdonck, 1997; Khan, 2004; O'Connell et al., 2001; Sisson, 1998). Other emotional reactions that have been known to occur include a sense of hopelessness and helplessness, embarrassment, and feelings of entrapment (Pound et al., 1998). Nevertheless, previous research has proposed that stroke recovery follows a continuum based on physical milestones.

Clearly, the personal experience of stroke is far more complicated and complex phenomenon than merely physical function. A study by Burton (2000), who tracked the experiences of stroke survivors, found that stroke precipitated a range of emotional responses that did not appear to follow any linear sequence over time. Rather, their emotional recovery was reactive, multidirectional and unpredictable. Thus, Burton's study suggested that emotional recovery is an intensely personal experience. Implicitly, it is increasingly evident that there is a much greater need for understanding and sensitivity to the emotional requirements of stroke survivors (Dowswell et al., 2000). Failure to address these emotional challenges has major implications for stroke survivor's ongoing recovery.

Amidst the emerging research exploring the emotional reactions after stroke (Burton, 2000; Catalano et al., 2003; O'Connell et al., 2001; Stone, 2005) are the

potential effects that these emotional reactions have on the stroke survivor's struggle to recover. For instance, the emotional effects of stroke can cause low motivation, frustration, lack of energy and initiative, lack of interest, and irritability, thereby impacting on all aspects of their complicated and diverse lives. In particular, these reactions can lead to a lowered level of social and leisure activities (Dowswell et al, 2000; Hafsteinsdóttir, & Grypdonck, 1997; Pound et al., 1998), a disincentive to pursue vocational employment (Flick, 1999), a reluctance to attempt challenging activities (Stone, 2005) and a negative view of self (Ellis-Hill & Horn, 2000; Ellis-Hill, Payne, & Ward, 2000). Moreover, studies have recognized that to inadequately tackle the emotional problems of stroke adversely affects their functional improvement. Banks and Pearson (2004) reported that some survivors experienced slower progress during recovery due to the difficulty in coming to terms with a changed lifestyle. Similarly, Glass and Maddox (1992) argued that stroke survivors must adjust to new definitions of themselves otherwise the difficulties experienced by survivors whilst undergoing this personal transition can lead to a complicated and lengthy recovery process. Thus, the recent literature strongly supports ongoing research that builds knowledge and promotes initiatives and strategies that lead to an appreciation of the stroke survivor's emotional experiences.

There is no doubt that research addressing the emotional reactions of stroke has increased over the past decade, however, this continues to be dominated by research underscoring the physical and functional consequences of stroke (Arias & Smith, 2007; Eriksson, Appelros, Norrving, Terént, & Stegmayr, 2007; Kwakkel, Kollen, & Twisk, 2006; Legg et al., 2007; Salter et al., 2006; Slot, Berge, Dorman, Lewis, Dennis, & Sandercock, 2008; Van de Port, Kwakkel, Schepers, & Lindeman, 2006). Importantly, we can no longer interpret the recovery of stroke exclusively within a bio-medical framework. As suggested by Medin, Barajas, and Ekberg (2006), recovery must be included within a social context. The emerging research has not only acknowledged the emotional barriers affecting the individual's ability to recovery from stroke, but also provides a clue as to what may facilitate the stroke survivors recovery process (Amarshi, Artero, & Reid, 2006; Jones, 2006; Medin et al., 2006; Vickery, Sephiri, & Evans, 2008; Vickery, Sherer, Evans, Gontkovsky, & Lee, 2008). Interestingly, Amarshi et al. (2006) proposed that rehabilitation should not only focus on the physical impairments faced by the individual, but also how to address factors within the

environment that impacts on the stroke survivor's ability to participate socially. Whereas, Vickery et al. took the view that improvement in self-esteem would be accompanied by improvement in the stroke survivor's mood, thereby positively impacting on their therapeutic gains. Thus, the primary aim of this thesis is to redirect an understanding of the stroke to include these social and emotional factors. Moreover, given the indicated concerns regarding environmental factors and current health reports of the variances in health service and provision outside of the urban areas, this thesis will also include a consideration of rural/regional environment as it impacts on the stroke survivor.

## CHAPTER 3

### The Inequities of Rural Healthcare

#### 3.1 Social Disparities in Health

Concern is growing over the increasing disparities in health amongst various segments of population. Much work has been aimed at reducing and eliminating disparities in health care. However, the literature continues to demonstrate a disturbing reality of the existence of disparities in health care that lead to health disadvantages.

Various factors have been identified as contributing to health disadvantage including socioeconomic status, environmental, cultural and educational factors (Atrash & Hunter, 2006). Other factors have also been identified in the literature. McMurray (2003) proposed various conditions that create social disadvantage, including unemployment, lack of information pertinent to good health or, cultural or language difficulties that prevent an individual from accessing information or services needed for health. Importantly, these health disparities have been evidently linked with preventable diseases and premature death (Satcher & Higginbotham, 2008).

While several factors may have been identified in the literature as contributing towards health disadvantage, one common factor, or lack of it, presents itself as a critical determinant in deciphering health advantage or health disadvantage -- accessibility to health care. According to McMurray (2003), this represents health for all and equal access to opportunities despite the difference in geography, race, age, gender, language or functional capacity. One factor that has been frequently identified in the literature as leading to health disadvantage is geographical location, in particular, living in rural or remote locations.

It has been well established in the literature that rural population health fares worse than urban population health (Joubert et al., 2008; McMurray, 2003). Rural populations experience fewer health services and infrastructure (Nicoletti et al., 2000), longer distances to travel in accessing health services (Aude, Hill, & Anderson, 2006), and they comprise of older and poorer populations (Mwachofi, 2007). Yet, the breadth of rural health investigations continues to remain limited in its scope.

We know from the research done to date, powerful inferences have been drawn exposing the significant barriers in health care within rural settings. For instance, Sample, Tomter and Johns (2007) completed interviews with care providers' (e.g., medical, rehabilitation, school and community providers) examining the systems of care across two Colorado communities between 1998 and 2001. The findings revealed that rural communities had few resources available for long-term rehabilitation and community integrated services for residence with brain injuries. Other studies have also reported on the inequities of rural-urban health care. For instance Klepac et al. (2007) investigated potential urban-rural disparities in Quality of Life (QoL) in 111 Parkinson's disease (PD) patients, using a PD quality of life questionnaire (PDQ-39) in a cross-sectional study in Croatia. Klepac et al. found that rural patients had significant ( $P < 0.05$ ) worse PDQ-39 subscale scores than their urban counterparts. Hence, living in a rural environment has a negative impact on QoL. Klepac et al. proposed that additional efforts were required in the management of PD in rural areas including, encouraging family support, closer collaboration with family doctors and more emphasis on additional services like support groups or psychological assistance.

Concerns have also been raised for those who have suffered a stroke. A study exploring the prevalence of stroke by Nicoletti et al. (2000), found several factors that contribute to a low hospitalisation rate, that is, distance to nearest hospital, poor conditions of roads, and lack of social security. With the gradual expanding research knowledge it is becoming increasingly clear that health services within rural areas continues to be insufficient. There appears to be serious disparities in accessing health care (Mwachofi, 2007) within the context of urban and rural health. Clearly more efforts are required by policy planners, researchers, and clinicians, to direct more attention towards designing more accessible health services.

### **3.2 Stroke in Rural Australia**

Australia is a vast continent which is densely populated with highly diverse communities residing along the coastal perimeters (Cadilhac, Moodie, et al., 2006; Gething, 1997). According to Gething, the provision of health services in Australia has been developed to suit these coastal residents' needs. However, for those living in rural areas of Australia, the provision of health services is comparably different, and it is well acknowledged in the literature that meeting the health needs of those living in

rural/remote areas is considered challenging. For the treatment and management of stroke, living in a rural area is considered quite risky. Anderson (2008) reviewed the *Clinical Guidelines for Acute Stroke Management* produced by the National Stroke Foundation in 2007 and reported that whilst a substantial proportion of the Australian population lives in rural or remote areas, access to stroke care units was not always available to this group.

Concerns are highlighted when one considers the importance of timing and administration of critical medication and diagnostic procedures in the treatment of stroke. The literature has certainly identified the importance of treatment within hours of a suspected stroke (Joubert et al., 2008; Warlow, Sudlow, Dennis, Wardlaw, & Sandercock, 2003). However, the reality of living in a rural or remote environment can substantially hinder the positive outcomes of early stroke treatment. An article by Read and Levy (2006), who explored differences between regional and metropolitan hospitals in Queensland Australia, found rural patients, in comparison to urban hospital patients, were less likely to receive essential tests within 24 hours of admission. These diagnostic tests included a swallowing assessment, echocardiography, and carotid imaging. Thus, it is apparent that discrepancies exist between rural and urban stroke management services, the availability of medical specialists, and the availability of diagnostic equipment.

A comprehensive evaluation of stroke services was completed in New South Wales Australia by Gill, Cadilhac, Pollack, & Levi (2007). The purpose of the investigation was to identify the nature of existing services, the perceived effectiveness of services and to establish activities of value currently in place. Data was gathered from two surveys at referral hospitals (n=16) and district hospitals (n=84), and semi-formal interviews with interested stroke team members. The results of the evaluation were consistent and comparable with the few previous studies that have investigated rural stroke services.

Overall, the findings by Gill et al. (2007) were compelling. The authors identified several key themes highlighting deficits in rural stroke care. These themes included, lack of resources (human and infrastructure), limited access to funding, lack of staff dedicated to stroke services, and lack of organised co-ordinated services. The evaluation demonstrated an urgent need for funding and resource support to be

funnelled directly into rural stroke services. Overall, the report by Gill et al. revealed some disturbing information in terms of the state of rural health in NSW. What we can establish from these results is that access to rural health services continues to be inadequate. The findings did uncover some encouraging trends which demonstrated a progression or movement towards appropriate care. This included better links between rural referred hospitals, district hospitals, metropolitan hospitals and the NSW stroke networks. Although the report identified continuing developments in stroke care, the findings offer little comfort for those who live in rural NSW and who have suffered a stroke.

Other studies have also uncovered the inequities of essential services in rural Australia, in particular, at a structural level. For instance, Smarrelli, Cadilhac, & Pearce (2001) reported rural hospitals were less likely to offer coordinated stroke services than metropolitan hospitals and large rural centres. Cadilhac, Lalor, et al. (2006) undertook a cross-sectional study of hospitals in 2004, with the aim of determining the number of stroke units in Australian acute hospitals, and found that there is no universal access to Stroke Units. Thus, many stroke survivors are not receiving evidence-based care. As mentioned by Anderson (2008), there are clinical guidelines that hospitals can adhere to and comply with. Yet, given the current literature available, it is questionable as to whether the implementation of these guidelines occurs at a national level.

Even though the literature reporting on the inequities of stroke care between rural and urban health services in Australia is limited, there are numerous studies published about the inequities in rural and urban health services within the context of chronic illness. We know from these previous studies that residing in a rural environment becomes very challenging if you suffer from a chronic illness. Difficulties experienced due to the multiple barriers faced from living in a geographically challenged area become an intrinsic part of one's lifestyle. Barriers commonly identified throughout the literature include: distances and time taken travelling to access health services (FitzGerald, Pearson, & McCutcheon, 2001; Gething, 1997; O'Connell et al., 2001), difficulty accessing allied health staff (Faux, 2005), problems with recruiting and retaining health professionals (Judd & Humphries, 2001), an ageing population (Hansen, Robinson, Mudge, & Crack, 2005), and access to appropriate health services (Krum, Tonkin, & Piterman, 2004; Lee, Somerford, & Yau, 2003). Despite the

expanding knowledge highlighting insufficient health service provisions at an acute level, very few studies exist presenting data of similar concerns at a post-acute/rehabilitation and community level.

Of the limited research reported, discrepancies are emerging about urban versus rural health service availability and accessibility during the post-acute/rehabilitative and community stage (Beesley et al., 2008; Farmer, Clark, & Sherman, 2003; Spearman, Stamm, & Tivis, 2007). Hansen et al. (2005) expressed concern for people diagnosed with dementia living in an isolated community. Experiencing isolation within a rural community impacted negatively on their provision of health care. Coping with isolation meant restricted access to dementia related services and expertise, long distances to travel for specialist services, and a limited capacity of carers to visit their relative living in residential facilities.

Similarly, FitzGerald, et al. (2001) reported on the large distances that people with chronic illness have to travel to see specialists. For many, the city was too far and arduous to make the journey and considerable planning and resources were required in order to make the journey. FitzGerald, et al. ascertained difficulties in attracting and retaining general practitioners, the limited choice of specialist consultants and the lack of professional support in the community. Spearman et al. (2007) explored services available to individuals who had sustained a Traumatic Brain Injury (TBI). They found that many basic services were deficient or non-existent for those living in a rural state. Other authors suspect the insufficiency of services is largely due to an intrinsic factor – lack of communication. According to Sample et al. (2007), “there is an information gap that seems to occur as the medically based services end and the community-based services need to start” (p. 720). There appears to be an increasing proportion of individuals requiring health services, but the availability of information on how to acquire these services is very limited.

The literature reporting on chronic illness and the limited access to health services in a rural setting is compelling. Within the context of stroke the evidence concerning impact of limited services at a rural level is sparse. Very few studies exist that provide a comprehensive picture about the availability and accessibility of services utilised by stroke survivors living in a rural setting. Clearly, more efforts are required aimed at improving specialist services and resources at a local level. By not providing

these vital and essential services, the rural community will continue to receive a sub-optimal provision of care severely impacting on the stroke survivor's quality of life.

### **3.3 Rural Mental Health**

Along with the expanding knowledge in rural health is the growing body of evidence highlighting the burden of mental health problems in rural and remote areas (Boyd et al., 2008; Campell, Manoff & Caffery, 2006; Fraser et al., 2002; Rajkumar & Hoolahan, 2004). Research to date has consistently argued that factors including access to mental health care (Fraser et al., 2002), isolation (Mostafanejad, 2006), and the lack of mental health practitioners (Judd & Humphreys, 2001) are critically impacting on the psychological well-being of rural and remote constituents. Even though these non-urban communities are listed as a priority group by the Australian government for restructuring of necessary services, Judd and Humphreys reported that rural communities receive a lower level of specialist mental health care compared to their urban counterparts.

Whilst current research is yielding valuable information about the inequitable distribution of mental health services in rural Australia, there appears to be a paucity of information regarding the mental health of stroke survivors living in rural and remote areas. The literature is almost non-existent. Very few studies, have endeavoured to explore the mental health of stroke survivors residing in a rural or remote community in Australia.

A very early study by O'Connell et al. (2001) explored the physical and psychosocial needs of stroke survivors living in a rural and regional setting in the south-west region of Victoria, Australia. The exploratory study involved interviews and focus groups with a sample mixture of stroke survivors, carers and key informants from a larger study cohort. Overall, the study found stroke survivors suffered severe physical and emotional effects as a result of their stroke. Coupled with this was the participants' general lack of understanding of stroke and how it was associated with mental illness. Evidently, these concerns lead stroke survivors' and their families to remain socially isolated and treated poorly. O'Connell et al. argued that health care providers and policy planners acknowledge the issues as outlined in the findings of their study and design health care services, whereby ongoing support is offered to stroke survivors in the

community which moves beyond the physical and attends to the human and social aspect of recovery. A number of feasible recommendations were suggested by O'Connell et al. aimed at improving rural health services for stroke survivors. However, since the publication of O'Connell et al. study there are still developments in rural health services yet to occur.

Campbell et al. (2006) investigated the prevalence of diagnosable psychological disorders in both a rural and a non-rural primary care sample in far north Queensland, Australia. Although there were a number of methodological limitations identified in the study, including a small sample size, the findings reported individuals living in a rural setting were at a higher risk of being diagnosed with a mental health disorder than those who lived in the regional setting. Furthermore, those who resided in an area for less than 10 years were four times more likely to receive a diagnosis than individuals who had resided for 10 years or more. The authors proposed the length of residence was likely to be compounded by factors including the establishment of social networks and stability, although the association between length of residence, social factors and stability were not variables measured in the study.

According to Campbell et al (2006) environmental factors were associated with psychological problems. Consequently the authors called for a major evaluation of mental health services in Australia with particular attention directed at understanding the impact of quality of life, location in the community, and access to services. Based on the findings of this study and the pressing need to evaluate mental health services, it would also be prudent to further investigate and understand the association between environmental factors and social networks. With the mounting evidence raising concerns about the acute management of stroke in rural/regional areas of Australia, one can only suspect that the psychosocial concerns of stroke survivors are severely compromised. Independent reports have identified specific difficulties in relation to health outcomes within rural communities, including lack of privacy, isolation, decreased access to health care, socioeconomic disparities, and a lower life expectancy (Gething, 1997; Judd & Humphreys, 2001; Klepac et al., 2007). For the stroke survivor, these factors are in addition to the variety of problems that are symptomatic of their illness. Nevertheless, there is still insufficient data reporting on the stroke survivor's process of adjustment within a rural or remote context.

The limited research undertaken indicates that the ability of survivors to recover from stroke in a rural setting is quite different from the urban environment (Gebhardt & Norris, 2006; Joubert et al., 2008). Thus, recovery within the rural/remote context requires serious consideration to ensure that a comprehensive appreciation of stroke recovery and rehabilitation that incorporates all aspects of needs for the individual is developed. To our knowledge, there is very limited research to date that explores the psychosocial consequences of stroke as perceived by stroke survivors living in a rural/regional area of Australia. If the current literature identifies severely limited services addressing the psychosocial domains of stroke recovery at an international level, one could speculate that these services are severely limited or non-existent within a rural/regional environment.

In order to have a fundamental understanding of the psychosocial consequences of stroke, one first needs to explore the literature and the impact of psychosocial factors on the ability of individuals to recovery or adjust from illness. From this exploration we may gather clues of how adjustment occurs for stroke services, in particular, within a rural context.

## CHAPTER 4

### Psychosocial Factors and Recovery from Illness

#### 4.1 Introduction/Overview

In Chapter 2 it was argued a considerable proportion of the stroke literature is dedicated to the physical reactions in recovery from stroke when compared to the psychological effects. Both the physical and psychological features deserve equal representation when you consider their relevance and contribution to stroke research and developments in health service provision. Chapter 3 identified disparities in health, particularly within the context of stroke and living within a rural environment. Not only are stroke survivors faced with challenges concerning their geographical location, but also their ability to access universal stroke services. This chapter will introduce the notion of protective factors in adjustment from illness including how these factors improve rehabilitative outcomes. The chapter will also discuss how these protective factors relate to the concept of resilience when people are faced with adversity like stroke. And finally, the chapter will draw on the breadth of information presented as the impetus for considering a biopsychosocial construct when exploring adjustment in recovery from stroke.

There has been a surge in the literature in recent years about the ability of various psychosocial factors contributing to an individual's sense of well-being. We know from this research available that certain protective factors have been shown to mitigate the harmful effects of stressful events such as illness (Ferguson, Richie, & Gomez, 2004; Ferreira & Sherman, 2007; Freidman, et al., 2006). For example a study by Chan, Lai, and Wong (2006) reported that positive adjustment in chronic heart disease patients was due to the operation of optimism. An earlier study by Luszczynska, Mohamed, and Schwarzer (2005) measured self-efficacy on 97 patients one month after cancer surgery and conveyed self-efficacy beliefs were associated with reported benefits. Luszczynska et al. also reported these patients focused on opportunities, were more engaged in utilising assimilative, active coping and adjusted their efforts to their altered life situation. From these earlier studies we can establish the value and

importance of examining protective factors and the implications this has for people recovering from serious illness.

#### **4.1.2 Psychological Factors**

Protective factors are the supportive resources that buffer individuals from the risks of adversity. The quest to understand how protective factors operate originated in early works by Rutter (1985) and Werner (1993). Rutter first raised attention when he proposed there was an interaction between a protective factor, risk exposure and the outcome. Around the same time Werner introduced the importance of these factors (i.e., individual dispositions) amongst high-risk children from infancy through to adulthood. Her early work was considered ground breaking and the implications identified the potential of protective factors present in the first decade of life. But how do these factors influence the ability of an individual to adjust from trauma or illness? Moreover, what is the impact of these factors for those who are negotiating life readjustment following an illness like stroke?

There has certainly been an increase in the literature about the ability of various protective factors facilitating proactive behaviour in adjustment from illness. Furthermore, from the literature available, one can establish there is quite a mixture of factors to consider. Those factors investigated have included: optimism within a palliative care setting (Hulbert & Morrison, 2006) and following a cardiac event (Bedi & Brown, 2005), self-efficacy after cancer surgery (Luszczynska, Mohamed, & Schwarzer, 2005), and the benefits of self-esteem when recovering from heart disease (Chan & Wong, 2006). Despite the high volume of empirical research uncovering a vast array of protective factors known to facilitate adjustment from illness, little is known about how they apply in the area of stroke. It is important to understand why some stroke survivors adapt well to their altered circumstances -- by doing so we can cultivate and foster an appreciation of the processes and mechanisms stroke survivors employ for successful rehabilitation. Overall, the research to date provides a strong link between protective factors and the ability of individuals to adjust from illness. However, in terms of recovery from stroke the comparative literature is very limited. Yet, there are

pioneers who have introduced the notion of these protective factors in the field of stroke research.

If you consider hope, and its positive influence for favourable outcomes it can be viewed as a fundamental concept to living (Clarke, 2003). Hope is defined as “a particular feeling that allows one to sustain belief in dire circumstances” (Lopez, Snyder, & Pedrotti, as cited in Lopez & Snyder, 2003, p. 92). Barker and Brauer (2005) undertook a qualitative study investigating stroke survivors’ (mean age = 64) perspectives on upper limb recovery. The objectives of the study were to explore how stroke survivors defined recovery, identify factors they believed influenced recovery and determined strategies to improve upper limb recovery. They found that stroke survivors maintained a process of continued hope and optimism. Although the authors recognised the study had several methodological limitations, one of the striking features of the findings was the stroke survivors attempt at maximising their recovery by ‘keeping the door open’, a process that allowed them to continue hoping for and working towards improvement and future possibilities. Given the findings of Barker and Brauer’s study we need to consider the value of hope as an individual resource, especially in terms of its association with adjustment to adversity

The importance of hope was also elucidated by Gum et al. (2006) who undertook a cross-sectional, correlational design approach and examined hopeful thinking, depressive symptoms, and participation in meaningful activities and roles for survivors (n=110) three months after stroke. They found as hope increased, activities became more strongly associated with participation. Thus, those stroke survivors’ on high-hope were better able to maximize their abilities in physical functioning and other areas to achieve better participation. Essentially, the findings suggested that having a high sense of hope when suffering serious illness will lead to improved rehabilitative outcomes. Although the study included participants at a relatively early stage of stroke recovery (three months), and the measures were self-reported in nature, it augmented and extended the knowledge about protective factors like hope, and the implications these factors have towards treatment. One would suspect with increased participation in activities there is a likelihood participants are also compliant with health treatment and management. Overall, the study reinforces the value of hope as a protective mediating

factor in the individual's ability to overcome adversity, especially within a health context.

Another protective factor that has emerged in the limited stroke research is self-efficacy. Bandura (1997) described self-efficacy as not concerned with the skills you have but what you can do with what you have under different circumstances. People with a high sense of self-efficacy tend to view negative situations as a challenge that can be dealt with through their own efforts. Dixon et al. (2007) explored the influence of self-efficacy during stroke recovery. Their study involved semi-structured interviews with 24 stroke survivors about their perspectives on what contributed to sources of self-efficacy during their rehabilitation. The data drawn from the study identified the effectiveness of addressing self-efficacy, especially in terms of maximising the benefits of rehabilitation. There were a number of factors found that influenced self-efficacy, these included the supra-ordinate themes of self, others and processes.

The study by Dixon et al. (2007) also identified how self-efficacy impacted on the experience of rehabilitation and what kept one motivated. Although the study was limited in its scope to include stroke survivors within a rehabilitation unit, the implications of the findings were promising. If we consider how a strong sense of self-efficacy can influence people through positive adjustment decisions, harnessing this psychological factor during the rehabilitation process could lead to effective recovery and adjustment outcomes for the individual. The importance of addressing self-efficacy during stroke recovery, especially over the longer term, would provide valuable insight into adjustment processes for those enduring a long term chronic illness. After all, an individual's attempt to undertake a task or to meet a particular goal will depend on whether they see themselves as efficacious in completing these actions.

Self-esteem has also been viewed as a mediator of better psychosocial adjustment following a major event, such as illness (Keppel & Crowe, 2000; Major, Richards, Cooper, Cozzarelli, & Zubek, 1998; Tam & Ng, 2002). Baumeister, Campbell, Krueger, and Vohs (2003) defined self-esteem as how much value people place on themselves. Unlike self-efficacy, self-esteem is more about the attitude towards the evaluation of self and related to personal skills, abilities, social outcomes and future outcomes (Heatherton & Wyland, 2003). In terms of how this attribute contributes to

the promotion of adjustment following an adversity like stroke, there is no literature available which considers its adaptive advantages. However, a study by Vickery et al. (2008) prompted clues to the association between self-esteem and its protective effects when they explored the causal relationship between self-esteem and functional recovery in stroke patients. A group of 176 stroke survivors completed self-reported measures of self-esteem and depressive symptoms within an acute inpatient rehabilitation hospital. They found that self-esteem is negatively impacted by stroke and that diminished self-esteem is a facet of the psychological sequelae of stroke. From a different point of view, the findings also led Vickery et al. to speculate that improvement in self-esteem would be accompanied by improvement in mood because the two constructs (self-esteem and mood) are so strongly associated. The implications of this suggests stroke survivors can psychologically benefit from interventions addressing self-esteem. Therefore self-esteem could be viewed as a resource that mitigates the effects of stressful life events like stroke, but also leads to health promoting behaviour. Thus, the importance of assessing self-esteem during the stroke recovery process is invaluable. Certainly, by understanding a person's self-esteem we can gauge the emotional response they are experiencing even with the challenges they are faced with.

So far, the search for information about protective factors in the field of stroke research has identified a number of constraints. Overall, the previous literature represents a paucity of knowledge about resources or health promoting factors (i.e., hope, self-esteem) stroke survivors draw upon to influence their positive reactions of an otherwise traumatic event. We can also resolve that little attention has been paid to stroke recovery over the longer term. Instead, as noted in the early works by Barker and Brauer (2005), Gum et al. (2006), and Vickery et al. (2008), much of the research is centred on the acute phase of stroke rehabilitation. Stroke recovery and rehabilitation cannot be defined over the short term. Rather, the rehabilitative phase is considered a transitional process that is no longer considered complete once the stroke survivor has been discharged from health services. Finally, although the research to date has identified key protective factors that operate as a type of personal resource that shields individuals from disruptive or threatening experiences, much of the attention has focused on the psychological concepts or personal traits. As mentioned earlier there is quite a mixture of factors to consider and others to add to the protective equation. Much of the interest about these factors is derived from psychological dimensions. To exclude

other factors including social features or characteristics would clearly misrepresent the important contributions they have towards adaptive processes.

### **4.1.3 Social Factors**

The literature has extensively reported on the benefits of social support and its association with individual well-being (e.g., Clark, Rubenach, & Winsor, 2003; Glass & Maddox, 1992; Pedersen, Van Domburg, & Larsen, 2004; Prilleltensky & Prilleltensky, 2006; Reddin & Sonn, 2003). Social support is simply recognised as the interpersonal exchange between people whereby they help each other (Taylor, Peplau, & Sears, 1997). In theory, social support has been defined in different ways. Dalton et al. (2001), conveyed social support as a collection of social, emotional, cognitive, and behavioural processes occurring in personal relationships that provide aid and promotes adaptive coping. Whereas Ferreira and Sherman (2007) viewed social support as the beneficial receipt of provisions in a relationship, including informational, emotional, and tangible aid (p. 91). Despite this variation in the definition of social support it is still widely recognised an essential factor that contributes to an individual's ability to adjust following adversity (Beckley, 2007; Knapp & Hewison, 1998; Tomberg, Toomela, Ennok, & Tikk, 2007).

The protective properties of social support have many advantages. For example social support is viewed as a buffer against psychological disorders (Knapp & Hewison, 1998). Research has also shown having someone available to rely on improves general health status (Tomberg, Toomela, Ennok, & Tikk, 2007). Other studies have reported individuals surrounded by family and friends inspires hope and encouragement when recovering from illness (Popovich, Fox, & Bandagi, 2007), and social support has been associated with better self-care amongst people with a chronic illness (Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008). Hence, the benefits of social support are wide-ranging and there is growing evidence demonstrating the positive effects on those who experience chronic illness (Bennett et al., 2001; Corr, Phillips, & Walker, 2004; Fong, Finlayson, & Peacock, 2006; Livneh & Antonak, 2005; Pound, Gompertz, & Ebrahim, 1999).

Although the benefits of social support has been well documented, there is little information reporting on the association between social support and stroke recovery. The reason being studies have traditionally reported on the immediate physical reactions following stroke diagnosis. Typically, the acute management of stroke involves medical intervention and intensive monitoring, including the assessment of functional ability. The attention to social support at this stage of acute recovery is not considered a clinically significant priority. Arguably, this is not the case. Excluding social support as an essential component of stroke management has serious implications. Social support is a key factor that has a significant influence on the immediate recovery process.

A very early study by Glass, Matchar, Belyea, and Feussner (1993) investigated performance in both mobility and activity and found that social support not only effected the stroke survivor's recovery but it also predicted the speed of recovery. That is, higher levels of social support correlated with a more rapid rate of recovery. The study by Glass et al. yielded useful insights into the fundamental reserves individuals draw upon under stressful and/or difficult conditions. The findings of the study by Glass et al. supported the view that social support processes can have a profound positive effect on the stroke survivors' response and immediate recovery to illness. With this in mind, it can be seen by evaluating stroke survivor's access to social support during acute management we can identify the important contribution this factor has towards the moderation of stress and in facilitating adjustment outcomes immediately following diagnosis.

The importance and value of maintaining social relationships and community contacts when someone experiences chronic illness is evident in a study by Beesley, White, Alston, Sweetapple, and Pollack (2011). They explored the experiences of 11 stroke survivors who participated in an arts health group programme and the benefits this group had on Quality of Life (QOL) and wellbeing. Even though the authors did not use a validated object tool to measure QOL, the key findings included enjoyment gained from the opportunity for social interaction and exploration of a new activity, including increased confidence, self-awareness and self-esteem. Furthermore, these gains appeared to contribute to improved self-efficacy through the participant's involvement in a new task. As a result of these findings Beesley et al. proposed that participant's

improvements in self-efficacy, confidence, QOL and participation were the direct result of involvement in an arts health programme. Overall, the study illustrated how social interaction and support can aid adjustment when recovering from illness. Even though Beesley et al's. study provided promising results about the social benefits of participating in an art group over the short term, one must consider whether the benefits would still be evident if the program was to continue over a longer duration . By monitoring and providing ongoing support over the longer term we gain a more accurate reflection about stroke survivors' progress over time and their adaptation ability.

It is worth noting that well intended social support may also be perceived as unhelpful. According to this view there are circumstances where the social support offered may have a negative effect on the stroke survivor's outcomes both physically and psychologically (Clark, Rubenach & Winsor, 2003). For instance, a study by Beckley (2007) examined the impact of social support on community participation after stroke. Ninety-five stroke survivors were interviewed at home 3 to 6 months post discharge from a rehabilitation hospital. A multivariate analysis was used to determine the effects of social support on community participation and quality and quantity of social support was measured. Beckley concluded that the quantity of social support had a slightly greater effect on community participation than quality of social support. Beckley declared this was the result of more assistance being provided to stroke survivors than was actually needed. The author drew this conclusion from participant reports claiming that even prior to their stroke, a spouse or caregiver provided support in ADL whether it was needed or not. From this, it was ascertained that stroke survivors with closer personal relationships receive more assistance, whether or not it is warranted.

Overall, the study by Beckley (2007) provided some key points about the quality of social support offered with the implications of these findings bearing impact at an acute and rehabilitative level. By completing an assessment and gaining an understanding of the stroke survivor's social support as part of the acute stroke management process, not only would this provide health professionals with details about access to social support and quantity of social support, but also the quality of social support, including the dynamics of the stroke survivors current relationships.

Clearly there is a constellation of protective factors to consider in the ability of an individual to adjust from trauma or illness. So far, the literature review has considered the biological (chapter 2), psychological and social aspects of stroke recovery. From a theoretical perspective, it is fundamentally important to understand what factors and characteristics help people to thrive and adapt despite their adversity. These protective factors or resources appear to constitute what researchers view as essential components in the adjustment process. What can be established is, these protective factors compose a framework that aligns with the phenomenon – resilience. This section has discussed the association of protective factors with adjustment from illness, it is now essential to consider how these factors connect with the theoretical concept of resilience.

## **4.2 Resilience**

### **4.2.1 What is Resilience?**

Resilience is the ability of an individual to ‘bounce back’ from adversity. It is considered the strength and courage that individuals draw upon, enabling them to overcome negative circumstances so they can continue on through life. It has been defined by Holaday and McPhearson (1997) and others (Carver, Scheier, & Weintraub, 1989; Cicchetti & Garmezy, 1993) as ‘the ability to overcome or adapt to extreme stress or adversity’ (p. 348). Resilience has also been viewed as the individual’s ability to resist or recover from hardship. Masten, Best and Garmezy (1990) defined resilience as:

*“process, capacity or outcome of successful adaptation despite challenges or threatening circumstances...good outcomes despite high risk status, sustained competence under threat and recovery from trauma” (pg. 425).*

Early definitions of resilience included factors such as personal characteristics (Garmezy, 1987; Rutter, 1995; Rutter, 1985), mechanisms and processes (Egeland, et al., 1993; Jacelon, 1997; Masten, 2001; Rutter & Sroufe, 2000), or outcomes that the individual may experience (Luthar, 1991). A large proportion of these early studies

examined what protective factors enhanced an individual's resilience (Rutter, 1985). Subsequent studies explored mechanisms and processes whereby interest focused on the pathways that have led to successful adaptation (Masten, 2001; Stein, Fonagy, Ferguson, & Wisman, 2000). Other propositions that have contributed to the definitions of resilience included the behavioural outcome of adjustment (Luthar, 1991).

Overall, the construct of resilience has not been easy to capture or measure. Early efforts at clarifying and describing the concept of resilience have led to various approaches in its meaning. This inconsistency with clarifying its meaning has extended into contemporary literature. A recent article by Greeff and Holtzkamp (2007) defined resilience within a family construct. Conversely, Hegney et al. (2007) viewed resilience as a combination of individual, group and community factors that enhance psychological wellness in communities. Whereas, Hjemdal et al. (2006) considered resilience as the protective factors, processes and mechanisms, that contribute to good outcomes. With the surge of information accumulating about resilience and the research efforts directed at assessing its construct, the phenomenon of resilience remains complicated and confusing. Current attempts to define and operationalise resilience continue to remain inadequate leaving the terminology to be ambiguous and potentially leading researchers to be misinformed. Thus, resilience falls within a constantly changing context and the irregularity of this phenomenon has meant substantial variation in its conceptual clarity.

#### **4.2.2 Why Resilience?**

There is a vast amount of research that seeks to explore and understand risk factors associated with psychopathology maladjustment (Bonanno, 2005; Cicchetti & Garnezy, 1993; Cicchetti & Rogosch, 1997; Garnezy, 1971; Hoge, Austin, & Pollack, 2007; Rutter, 1985; Rutter & Sroufe, 2000; Smith, 2006; Tiet et al., 2001; Ward, Martin, Theron, & Distiller, 2007; Yehuda & Flory, 2007). Subsequently, it has been well established that the greater the risk and/or adverse experience to the individual, the greater the likelihood that the person will develop maladaptive behaviour (Cicchetti & Rogosch, 1997; Friberg et al., 2005; Masten, 2001; Nettles, Mucherah, & Jones, 2000; Rutter, 1999; Rutter, 2000; Rutter & Sroufe, 2000). As a result there has been a large amount of work invested into exploring, understanding, and diagnosing maladjusted

behaviour with the view of uncovering and applying the most appropriate treatments (Hoge, Austin, & Pollack, 2007; Mancini & Bonanno, 2006). Moreover, the literature has recognised that there is a large variation in how individuals respond to life stressors and adversities. We now acknowledge that there are individuals who succumb to maladaptive disorders, whereas others show resilience and manage to adapt to their circumstances and even come through their negative experience strengthened (Rutter, 1995). Not surprisingly, this prompted researchers to explore the appealing effects of the notion of resilience. There has long been the assumption that those who experience adversity or trauma will succumb to the effects of these circumstances and develop disorders. As noted by Glicklen (2006) we tend to think that traumas will lead to malfunctioning behaviour, but often this is not the case. There is a developing research awareness of situations where people who are suffering from a serious illness are able to draw upon selective strengths and assets to help them combat the negative effects of illness.

As mentioned most of the early resilience literature focused on understanding developmental psychopathology in terms of maladjustment and illness (Cicchetti & Rogosch, 1997; Hauser, 1999; Holaday, & McPhearson, 1997; Kirby & Fraser, 1997; Luthar, 1991; Masten, 2001; Nettles, Mucherah, & Jones, 2000; Werner, 1993; Rutter, 1995). Over time this has broadened to include studies exploring resilience and various negative life events including post-traumatic stress disorder (Hoge, Austin, & Pollack, 2007), disadvantaged young people (Harvey & Delfabbro, 2004), and poverty (Tchombe, Shumba, Gakuba, Zinkeng, & Teku, 2012). Despite the substantial body of research devoted to understanding resilience and its conceptualisation across different types of adversity, less is known about resilience and people faced with chronic illness. Even more concerning is that research exploring resilience and stroke is virtually non-existent. At the time of writing one study was identified that had investigated resilience post stroke (deGuzman, Tan, Tan, Tan, Tan, Tanciano, & Say, 2012). Clearly more research efforts are required in this area.

Empirically, the research exploring resilience and chronic illness has been limited. This is partially due to the inconsistency and scope of distinguishing which protective factors facilitate and promote resilience. There appears to be no universal agreement on what constitutes 'resilience' (Yi, Vitaliano, Smith, Yi, & Weinger, 2008).

Yi et al. (2008) investigated the buffering role of resilience on psychological adjustment and physical health in patients with diabetes. The authors proposed the distinction between personal, definitional attributes of resilience and resilient correlates or outcomes is rarely practised, yet understanding how the different protective components change and affect each other over time would lead to advancement in the understanding of resilience. For Yi et al. the composition of resilience was defined by psychosocial factors including self-esteem, self-mastery, self-efficacy, and optimism. Hence, resilience was considered the individuals capacity to maintain psychological and physical well-being in the face of adversity.

McCabe and O'Connor (2012) carried out a qualitative study evaluating the coping strategies of people living with a chronic illness (n=17) and their carers (n=13). The authors completed a review of the literature identifying primary factors related to resilience amongst people suffering from chronic illness. Factors highlighted included coping strategies, social supports, ways of approaching illness, types of activities engaged in, strategies to cope with financial pressures, and the level of assistance provided by illness associations. The findings of the study demonstrated how intimately resilience augments adjustment outcomes for the individual. Those with increased resilience valued the support from family and friends, and used these supports to cope with the demands of their illness. They were also more likely to adopt a positive attitude and took control of their illness, all of which enhanced adjustment.

The above study while employing a qualitative methodology, thus limiting its generalizability, offered insights to the various characteristics representative of those considered resilient. What can be drawn from McCabe and O'Connor's (2012) results is resilience is not only related to a person's characteristics but includes a wider variety of sources and dynamic interactions at a systemic level. The complex interactions (e.g. social support, importance of family and friends, community activities) engaged in by those participants considered resilient heavily influenced their ability to deal with their illness. The study by McCabe and O'Connor offered a different view of the resilience construct within the domain of chronic illness. It shifted the balance away from the dominance of protective psychological factors in defining resilience and broadened the scope to include interactive social mechanisms.

Understanding resilience and its buffering effects during stroke recovery has only been recently tackled. In a qualitative study conducted in the Philippines, deGuzman et al. (2012) had nine elderly post stroke participants with residual paralysis complete a cartographic sketch, semi-structured interviews and a mask-painting activity to describe self-concept, disposition, and resilience post stroke. While there were certain consistencies absent in the methodological design, the findings revealed a number of themes that emerged from the data. Self-concept was represented by relationality and corporeality. Relationality is how people connect, interact, and find meaning with the bonds they build with others. Corporeality is the quality of being physical and material in nature – an individual's perception of self through his/her attributes. Disposition was described as phylogenetic and ontogenetic, that is, phylogenetic is the mood or temperament shown by the respondents originate (pre-stroke) from the situation or events happening in their lives. Whereas, ontogenetic is the respondents' (post-stroke) behaviours and personalities as shown because they are who they really are. In addition to these findings Guzman et al. also noted resilience was categorised under two origins: conviction and condition. Conviction was viewed as the strong persuasion or fixed belief incurred during youth. Condition was perceived as the respondents' ability to bounce back and cope after the diagnosis of stroke.

This contemporary study by Guzman et al. (2012) was unique in the way it was carried out exploring resilience and the measures the participants had taken to accept and cope with their chronic illness. According to Guzman et al. resilience falls within two categories, conviction or condition. Furthermore, they claimed resilience was sourced from a mixture of strengths and assets including past experiences and fixed beliefs. In addition, resilience was viewed as being fortified from religion, spirituality and faith. However, caution must be employed in considering these findings as the trend towards religious convictions and beliefs could largely be explained by the high proportion of Roman Catholic participants. Nevertheless, further studies exploring religion and faith as sources of resilience may prove fruitful within the resilience context.

### 4.2.3 A Resilience Framework

Resilience is evidently more than the protective traits first thought of two decades ago. It has emerged as a complex system that cannot easily be defined within a measurable context. Various authors have attempted to capture the different layers of this phenomenon in the hope of establishing an evidenced laden construct (Friborg et al., 2005; Gupta, Crawford, & Mitchell, 2006; Tusaie, Puskar, & Sereika, 2007). However, despite the large number of research efforts directed at forming an explicit definition, the extensive variations and processes surrounding this phenomenon defy one's ability to do so. As disputed by Johnson and Wiechelt (2004), researchers find variables easier to define and measure, especially if they are static factors. But, Johnson and Wiechelt also allege that the concept of risk and resilience is complex with multiple mechanisms and processes. Similarly, Almedom and Glandon (2007) declare that there is no single 'resiliometer' that a researcher can employ to measure an individual's resilience. Clearly, there has been a developmental shift. It is no longer about isolating any one factor that influences successful adaptation from adversity. Rather, it is about understanding resilience from a multi-system level that is able to capture the different individual characteristics, the complex relationships between the individual and their environment, the mechanisms and processes, and the interplay of all these factors as an evolving transactional process.

To gain further valuable information and knowledge about the transactional process of resilience, one must avoid the urge to quantify and pathologize study approaches. Whilst we have gained important and worthwhile knowledge in the field of resilience from multiple cross-sectional studies, it may prove useful and just as valuable to gain meaningful insight from individuals themselves. For instance, Harvey and Delfabbro (2004) suggested that researchers should ask people directly what they believe to be their definition of life success. Furthermore, more emphasis should also be placed on conducting longitudinal studies to ensure researchers gain a comprehensive account of resilience, especially over time. Past researchers have consistently argued that resilience is not a static or concrete trait, but rather a constantly changing context (Anthony, 2008). From the research conducted to date, there is evidence to suggest that what allows an individual to experience resilience in one situation may not necessarily

be experienced in another situation (Johnson & Wiesel, 2004). The experience of resilience is therefore very individualistic. Egeland et al. (1993) ascertained that individuals who engaged in the transactional process of resilience bring with them early experiences, expectations, attitudes and new experiences that will influence the manner in which the environment is interpreted. Past experiences, how the individual interprets their stressor, or the resources utilised to manage their adversity is part of this approach. According to Johnson (as cited in Glantz & Johnson, 1999, p. 226), resilience depends very much on who you are as a person and the intrinsic and extrinsic opportunities available to you that allow you to negotiate through life.

Kumpfer (as cited in Glantz & Johnson, 1999, p.180) proposed a transactional model as a better means for understanding ways to increase resilience in children. His model included; environmental precursors, characteristics of the resilient person, and his/her resilient reintegration or positive outcome after a negative life experience. This proposal merits great value in scientific research, as a systematic approach for increasing resilience among children offers the potential to improve outcomes and prevent further problem behaviours and poor life adjustment. Park (1998) explored personal characteristics and the theoretical perspectives of coping processes to stress-related growth and thriving. Park's model covered many elements including personality, world views, social support, socioeconomic status, pre-existing physical and psychological adjustment, and previous experience within a transactional stress and coping framework. This transactional process of stress and coping provided an interactive and engaging phenomenon between the individual and their environment. Future studies should include a broad reference of the resilience phenomenon, including participants other than children and adolescents. As we now know, resilience is a process that occurs over a life-time (Bogar & Hulse-Killacky, 2006). By adopting a dynamic transactional process of resilience across the lifespan, future research has the potential to gain a comprehensive and valuable knowledge base that has implications for future intervention programs.

The overall state of research exploring adjustment from stroke remains incomplete. There continues to be confusion and inconsistencies about what constitutes a broad range of psychosocial factors associated with resilience that facilitates or enables stroke survivors to renegotiate their lives. Studies reporting on resilience and

psychosocial adjustment from stroke are scarce, yet the necessity to further investigate this aspect of stroke recovery is high. Along with this demand is the need to consider adjustment to stroke from a biopsychosocial perspective, thus allowing for a more comprehensive approach to stroke recovery.

### **4.3 A Biopsychosocial Perspective.**

As discussed in the literature review (chapter 2) a considerable proportion of stroke care is driven by conventional medical treatment, thus aligning with the biomedical model. As conveyed by Sperry, Powers and Griffith (2008) ‘conventional medical treatment is based on the biomedical model of health wherein disease is viewed as objective biomedical reality with single case and single treatment’ (p. 369). Essentially, if you consider the delivery of stroke treatment and management exclusively from a biomedical perspective, services would remain polarised, thus limiting the scope for effective and efficient delivery of comprehensive stroke care.

In an early review, Fee & Krieger (1993) argued that science alone will not provide the only explanation and treatment of disease. Some of the criticisms the authors raised about the biomedical approach included: the assumption that biomedical interventions, operating on biological mechanisms, will be sufficient to control disease; there is little place for understanding how behaviours are related to social conditions and constraints or how communities shape peoples’ lives; and its orientation is exclusively focused on the etiology of the disease as opposed to the social determinants. The criticisms highlighted by Fee & Krieger identified a number of shortfalls consistent with the biomedical model. Evidently, these shortfalls are comparable with those discussed in chapter two.

Fortunately, there has been a developmental shift in recent years with more research attention directed at the psychological and social aspects of recovery from illness (Dowswell et al. 2000; Khan, 2004; O’Connell et al., 2001). Even more appealing is the developing interest exploring the biopsychosocial approach to recovery from chronic illness. The biopsychosocial perspective has been defined by Whitbourne (2005) as one that views development as a complex interaction of biological, psychosocial, and social processes. Biological processes incorporate changes within the

body over time that alter the body's functions and structures. Psychological processes involve cognition, personality and emotion. Social processes include those that reflect the environment or context, and are indicators that reflect the individual's position within their social structure (p. 2). With this in mind the adoption of a biopsychosocial framework is compatible within the conceptualisation of stroke treatment and ongoing recovery. Furthermore, from this viewpoint, to apply the biopsychosocial perspective in the field of stroke recovery would address the arguments outlined in chapters two and three.

It is also important to understand how this biopsychosocial perspective might align and synthesis conceptually with resilience. We know from the information mentioned earlier in this chapter that the process of adaptation depends on the individual's ability to draw upon selective strengths and resources when suffering a serious illness. These interactions may fall within the parameters of a biopsychosocial framework. An article published by Sperry (2008) discussed mind-body interactions, stress and new developments in the holistic approach to encourage growth within the individual. The author viewed the biopsychosocial model as a comprehensive means for assessing and treating chronic illness. Furthermore, they considered the model as a conceptualisation that includes all the factors that impinge upon the whole person and contribute to changes in health or mental health status (p. 370). The article supports the position which recognises the ability of people to engage in resilient processes including the interactions that occur between biological, psychological, social and environmental mediators, that impact across the whole dimension of the individual's health and wellbeing in dealing with their illness.

We know from previous research there continues to be ongoing efforts aimed at further developing the resilience trajectory. Researchers have embraced various individual (Cast & Burke, 2002; Penson et al., 2007; Steinhardt & Dolbier, 2008), biological (Garmezy, 1993; Luthar, 1991; Yehuda & Flory, 2007), cognitive (Friborg et al., 2005; Warelow & Edward, 2007), and more recently, environmental (Anthony, 2008; Griffiths et al., 2007; Hegney et al., 2007) and cultural aspects (Greeff & Holtzkamp, 2007; Ungar et al., 2007) that reflect indicators of resilience. Thus, it would be considered negligible to persist in conceptualising resilience within a traditional biomedical framework. Today, we are faced with a new frontier of resilience research

that is aligned with a biopsychosocial perspective. The focus is now on the interactions that occur between the biological, psychological, social and environmental mediators across the entire dimensions of health, and influence the adjustment outcomes of individual's suffering from a chronic illness like stroke.

In sum, although the previous research on the individual characteristics, mechanisms and processes of resilience has been well documented, relatively little attention has been paid to resilience as a transactional process. Furthermore, there is a great need for investigators to focus on the experiences of individuals who have overcome adversity, especially those across the lifespan. Whilst we have an empirical history of pathologizing children and adolescents exposed to high risk, there is still a demand for research that fosters the strengths and personal resources that influence successful adaptation from a biopsychosocial perspective. By understanding the key processes, mechanisms, and the interplay of intrinsic and extrinsic factors between the individual and their environment, we may tap into resources that assist individuals to successfully adapt to an adverse event and enrich them with the strength and resources to adjust. This study sought to identify and achieve this with a group of stroke survivors.

#### **4.4 Rationale and Conceptualisation of Present Study**

Stroke is a serious illness. Recovery from stroke can be especially challenging for those who suffer from severe physical, neurological or psychological sequelae. To date, the literature continues to be dominated by the physical reactions following stroke, whereas discussions and analysis of the psychological and emotional reactions remain limited in comparison. The momentum for the present study was, in part, due to the growing demand for more information and clarity about the psychological and emotional consequences of stroke as experienced by stroke survivors. An investigation into this area of stroke recovery will not only provide valuable knowledge, but also yield information that will contribute to a more comprehensive stroke recovery program.

Relatively few studies explore the personal accounts of stroke survivors, most concentrate on the clinical aspects of stroke and functional outcomes. Instead, the fundamental element is in exploring the stroke survivors' personal perspectives regarding their quality of life. By pursuing a more personal account, we have the potential to gain an insightful and descriptive account of how individuals adapt to their altered circumstances. By doing so, we generate essential information to help improve the health services that already exist. The exploration of personal beliefs, understanding, and attitudes should not be underestimated. By undertaking this interpretive approach towards research, we gain a comprehensive understanding of the psycho-social resilience factors individuals adopt in their successful readjustment following illness.

Past research about the effects of chronic illness, such as stroke, on health and well-being has been well documented. Much of this research has been reactive, that is, it focuses on those individuals who are experiencing problems. Contrary to this, there is expanding research exploring the proactive processes of overcoming life adversity. Yet, as indicated in the literature, further research is required. By studying the proactive processes that enable individuals to manage their stroke recovery, we are potentially identifying successful ways that will enable those who do suffer from negative consequences to receive education and intervention as a preventative measure to assist in their renegotiation of living. The purpose of the current study is to address the above noted limitations in the literature, by identifying the adaptive processes stroke survivors adopt in their ability to adjust following stroke.

The present research intends to explore and conceptualise the theoretical underpinnings identified in the previous chapters. The researcher expects to contribute to academic knowledge by illuminating the experiences of stroke survivors in their renegotiation of living following their adverse event. Finally, this present study will draw on data reflective of both an urban and rural stroke populations to provide a representation and description of recovery from two vastly different geographical environments.

#### **4.4.1 Research Questions**

With the above in mind, a number of broad guideline questions were proposed as the aims of the present study.

1. What are the psychosocial factors that facilitate adjustment to adversity for stroke survivors' in their renegotiation of living?
2. Can we frame recovery and adjustment after stroke from a biopsychosocial perspective?
3. How do stroke survivors' successfully adapt to their changed life circumstances over the longer term that is, many months or years after their stroke?
4. What are the experiences of rural stroke survivors' in their ability to adjust to their altered life circumstances in the months or years following their stroke?

## CHAPTER 5

### Methodology

#### 5.1 Introduction to Phenomenology

The German philosopher Edmund Husserl first introduced Transcendental Phenomenology in the mid-1890s. According to Husserl, Transcendental Phenomenology is how the every-day world presents to us (Willig, 2008). It is the world as experienced by the individual within particular contexts, and at particular times (Willig, 2001). Husserl was further interested in the connection between reality and how it presents itself to the human consciousness. An important concept of this paradigm, as noted by Polgar and Thomas (2000), is that different people may consciously experience the world in very different ways.

Phenomenology holds an epistemological position and consists of interpretative practices that makes the world visible and explores how we interact with the world (Willig, 2008). The knowledge derived from phenomenology is unique in that it is not contained within scientific notions or constructs, rather it is how human beings construct their world and the meanings they give to their actions. Thus, the focus is on the essence of the phenomenon under discussion, as experienced by the individual, and how they interpret these experiences they are faced with.

Schutz's (1899-1959) commitment to phenomenology was heavily influenced by the work of Husserl. He applied Husserl's concept of meaning to action and redefined interpretative sociology by providing a phenomenological grounding. Schutz created the connection between phenomenology and the social world. In Schutz's view action is defined as meaning. However in order to identify the origin of meaning, Schutz's quest was to identify the source of meaning within the stream of consciousness. Beneath the meanings attached to this world he seeks the way in which meaning is constituted through what he calls the "operating intentionality of an Ego-consciousness" (Crotty, 1996, pg. 137).

Schutz believed our social experience makes up our vast world. It is constituted by an immensely complicated network of dimensions, relations, and modes of

knowledge (Schutz, 1967). We are all unique and we view the world within our own sets of constructs (ie., values, ideas and attitudes), and bear with us previous encounters and past experiences. As individuals we bring with us a 'stock of knowledge', which consists of socially derived and socially approved typifications (Crotty, 1996). Therefore, individuals react in typical ways given the circumstances. Typifications are the categories of understanding used by people based on the history of their interactions. Schutz emphasis was on examining the everyday experiences and typifications used by people in understanding the meaning and the value we give to objects and events, and how we communicate this in our real life world.

## **5.2 Interpretative Phenomenological Analysis**

Interpretative phenomenological analysis (IPA) is a method of qualitative research that was first introduced by Jonathan Smith (Willig, 2001). It is a phenomenological method that allows the researcher to gain access to the participant's life world. Interpretative phenomenology explores the participant's experiences of reality. According to Smith, Flowers, and Osborn (1997), IPA "is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself" (p. 69). IPA is not a method of research focused on gathering quantitative measures or testing hypotheses, rather it is concerned with the cognitive and emotional entities of what individuals think about the events and experiences of the individuals themselves.

The aims of IPA are to explore, understand and make sense of the subjective meanings as interpreted by the individual about the topic under investigation. Thus, the approach is phenomenological as it is concerned with an individual's personal perception of an object or event as opposed to an attempt to produce an objective statement of the object or event itself (Smith et al., 1997; Smith & Osborn, 2004).

According to Willig (2001) IPA is based on several assumptions. Firstly, IPA is concerned with the individual's subjective experience of the world. The analysis aims to obtain knowledge about the individual's thoughts and feelings, and these in turn are implicated in their experiences (Willig, 2001). With this in mind, IPA also recognises that the researcher's understanding of the phenomenon under investigation is influenced by one's own thoughts, assumptions and conceptions. However, this is not viewed as a

predisposition towards bias, but rather a “necessary precondition for making sense of another person’s experience” (Willig, 2001, p. 66).

Secondly, IPA assumes that people experience the same events or conditions in different ways. People interpret experiences through thoughts, beliefs, and expectations they bring with them. However, at the same time IPA also recognises that the meanings people have about events are strongly influenced by their social worlds (Willig, 2001). Thus, people’s interpretations are not entirely idiosyncratic because of their constant social interactions. Finally, IPA analysis accepts that any insight produced by the analysis is the product of interpretation. This is only gained through the researcher’s engagement and interpretation of the participant’s account (Willig, 2001).

The process of IPA involves 3 phases that have been described by Moustakas (1994). These three phases include: Epoche, Phenomenological Reduction, and Imaginative Variation. Epoche refers to our ability to set aside prejudgements, preconceived ideas and prejudices about the phenomenon under investigation. It disqualifies previous commitments, perceptions and categories of the past and allows a new consciousness to present itself to the individual. Thus, as noted by Moustakas, the “Epoche includes entering a pure internal place, as an open self, ready to embrace life in what it truly offers” (p. 86).

The second phase in the process of IPA is Phenomenological Reduction. During this process self-reflection occurs and the description of the nature of the phenomenon becomes the essential focus. As noted by Moustakas (1994) the quality of the experience becomes the focus of this process. The analyst seeks to describe, reflect, and explore every angle of the phenomenon. Included within this process of IPA is the dimension of horizontalization. No matter how many times we reflect, describe, and reconsider things in our world, we cannot exhaust this process. The analyst constantly allows the nature of the phenomenon to enter their conscious awareness, only to recede and then return again (Moustakas, 1994). Thus, this process continues and is never-ending.

The final step in the process of IPA is Imaginative Variation. This stage allows the researcher to establish structural themes from the descriptions that emerged through Phenomenological Reduction. The emphasis is on the structural themes including the

meaning and essence of an experience. Moustakas (1994) identifies these structures to include time, space, materiality, causality and relationship to self and to others. The analyst is free to utilise their imaginative possibilities with uncovering the true essence and meanings of the phenomenon under investigation.

IPA is a systematic methodology that interprets data capturing the participant's experience and attempts to discover meanings and the essence behind that experience. It allows individuals to tell their story and identify themes that can be organised into meaningful clusters that represent the true nature of the phenomenon under investigation (Willig 2008). Even though IPA endeavours to interpret the participant's experience through their own eyes, Willig (2001) also acknowledges that such an investigation must implicate the researchers own view of the world in doing so. As a result, the phenomenological analysis is *always* an *interpretation* of the participant's experience (Willig, 2001).

Given the aim of IPA, it is the chosen methodology for this project. It allows the researcher to capture a true reflection of the participants' experience and gives meaning and essence to the phenomenon being investigated. This research approach does not seek to reveal facts and scientific explanations that originate with a research hypothesis. Rather, IPA is a suitable method because of the lack of scientific parameters. It is a flexible, open, and logical approach that illustrates the participant's thoughts and emotions and assists the researcher to understand the how and why individuals experience phenomena.

## CHAPTER 6

### Method

Chapter 5 described the methodological framework for completing this study. This chapter presents the method used in the study. It includes an overview of the recruitment processes, the interview techniques employed and the procedure undertaken. A description of the data analysis has been provided, including the organisation of the data set.

#### 6.1 Participants

Thirty-five stroke survivors volunteered to participate in the study. A final sample of thirty-four stroke survivors completed the interviews. The participants included 22 males and 12 females, aged 23 to 90 years. Following initial coding of data, and for purposes of analysis and development of understanding the data, these participants were nominally divided into two groups (17 rural and 17 urban stroke survivors) as per Table 2.

Table 2 Characteristics of Rural and Urban Stroke Survivors.

<b>Characteristics</b>	<b>Rural Stroke Survivors (n = 17)</b>	<b>Urban Stroke Survivors (n = 17)</b>
Males	13	9
Females	4	8
Older ( $\geq 55$ years of age)	15	8
Younger ( $\leq 55$ years of age)	2	9

At the time of interview, just over half of the participants were retired or in receipt of the Disability Support Pension. Twenty three participants were married, 3 were divorced, 4 were single and one was living in a de-facto relationship. Seven

participants were employed in either part-time or full-time work. One female participant was undertaking voluntary work and another female stroke survivor was engaged in tertiary studies. Subsequent analysis also indicated the importance of further classifying the participants according to rural and urban locations with 17 participants from the urban areas of Melbourne and 17 participants from outer rural regions of Victoria.

The participants interviewed demonstrated varying degrees of physical, sensory or cognitive impairment as a result of their stroke. Impairment included loss of movement in parts of the body, weakness in arms or legs, unsteadiness and problems with gait, some difficulty with speech, lack of concentration, memory disturbance, emotional lability, and impaired vision or spatial neglect. The severity of stroke ranged from complete dependence on others for assistance with personal care, to being independent where assistance or support was required from others occasionally. Impairment was assessed as self-reported. Of those stroke survivors interviewed, six participants required the use of a wheelchair to mobilise, four required the use of a walking stick to assist with balance, and the remainder of the participants reported they were independent. Participants identified as independent reported varying degrees of left or right-sided body paralysis.

## **6.2 Instruments**

### **6.2.1 Interview Schedule**

The data was collected through semi-structured interviews. As highlighted by Willig (2001), semi-structured interviews offer the participant an opportunity to talk about “a particular aspect of their life” (p. 22) with an emphasis on ‘meaning’. The interview schedule was developed following an extensive literature review exploring identified factors and resilience enhancing processes reported to increase adaptation and recovery following experiences of adversity. This resulted in the development of an interview schedule that explored the attitudes and perspectives of stroke survivors in their renegotiation of living following stroke. The semi-structured nature of the interview allowed the freedom of the researcher to probe the participant to elaborate on their responses. Earlier in the project a questionnaire was pilot-tested with four stroke survivors who were selected in the same manner as those who participated in the study (Appendix A). Participants involved in the pilot were not part of the larger study. The

intended interview questions were reviewed by an expert in research design and method.

The final version of the interview schedule included a semi-structured set of questions (Appendix B) to elicit each stroke survivor's accounts of the psychosocial resilient factors he/she adopted in adjusting to adversity. The interview schedule comprised of four subsections that covered topics including the stroke survivor's individual disposition, competency, self-esteem and social support. For example, participants were asked 'how they saw their future', or from whom did he/she receive 'emotional support'. Emerging issues identified during the initial interviews demonstrated a need to capture the experiences of rural stroke survivors'. Consequently, rural participants were questioned about experiences of living within a rural environment.

### **6.3 Procedure**

Prior to the commencement of fieldwork, all procedures and methods were reviewed and approved by Victoria University Ethics committee. Of particular importance was the need to identify areas of sensitivity given that this area of stroke was exploring the psychosocial consequences of this adversity. During the interviews it was envisaged that participants would be discussing very personal, and at times, stressful situations that may require additional support. Due to the sensitive nature of the interviews an information sheet was provided to participants listing sources of support should they require them following the interview (Appendix C). Participants were advised the interviews could cease at any time if he/she became distressed.

The recruitment process occurred through meetings held by the Stroke Association of Victoria and through Community Medical Centres. The Researcher was invited to attend various stroke meetings held throughout Victoria for an opportunity to discuss the research study including the purpose of the study, recruitment requirements, and to address any concerns about the study. Those stroke survivor's interested in participating in the study contacted the researcher for follow-up. Recruitment of stroke survivors also occurred through an advertisement at medical health centres. A flyer was placed on the wall in health centres around Melbourne about the proposed study inviting stroke survivors to contact the researcher for further information about the purpose of the study and any additional information. Stroke survivors were included in the study if

they experienced a first time stroke, were 18 years of age or older and provided informed consent. Exclusion criteria included participants without informed consent and participants suffering from aphasia.

As mentioned earlier, data collection primarily occurred through semi-structured interviews (Patton, 1990). In order to clarify, amplify, and/or expand the participants' responses, probing was necessary (Hoinville & Jowell, 1978). Demographic information such as date of stroke, marital status and age was obtained prior to commencement of the interview questions. The interview process involved one-on-one, audio taped interviews with the participant.

The majority of participants had interviews conducted at home by choice. Two participants completed their interviews at a community health centre, and two interviews were completed in a community centre. Prior to commencement of the interview, participants were informed interviews would be conducted separately and in confidence. The participants were also informed that any information disclosed was confidential and transcriptions could only be identified by the researcher. Participants were then asked to read the plain language statement and sign a consent form to participate in the study (Appendix D). At this point, participants were also reminded that involvement in the study was voluntary and they could withdraw from the study at any time. Participants were advised interviews would be tape-recorded and transcribed and the transcripts would only be identified through a numbers sequence to ensure confidentiality. Participants were also reminded interview tapes would be fully transcribed, and confidentiality was of a high priority. The interview transcripts have been stored under lock and key, and remain with the researcher. The interviews took on average 40 – 50 minutes to complete. One interview was unable to be completed due to continuous interruptions resulting in the corruption of data and the violation of confidentiality.

#### **6.4 Analysis**

As detailed in Chapter 5, IPA was the chosen methodological framework for the study. Thematic analysis was the method used for data analysis. This technique allowed for identifying and analysing of themes and patterns in the qualitative data (Braun & Clarke, 2006). The analysis followed the 6 phase process of thematic analysis (refer to

Figure 7.1) as outlined by Braun and Clarke (2006). As noted by Attride-Stirling (2001) and others (Roberts & Taylor, 2002; Braun & Clarke, 2006) thematic analysis is considered a suitable method as it provides a robust and practical technique for managing qualitative data and allows for large sample sizes.

Once the interviews were transcribed verbatim the next step was to familiarise myself with the data (Roberts & Taylor, 2002). This involved immersing myself in the transcripts reading and rereading the data, noting down ideas. These initial thoughts and ideas were recorded along the margins of the transcripts. During this stage loose themes, essences, or patterns were noted from my encounter with the text.

Following this initial stage a coding framework was devised (Miles & Huberman, 1984). This allows the researcher to retrieve and organize segments of the data into meaningful groups. Data was coded using different colours highlighting segments of the text and by including notes on the transcripts when interesting features appeared across the entire data set (Appendix F). Selections of text were also coded and tagged using Nvivo (NVivo revision 2.0.163 - a qualitative computer software package) to assist in data management for large volumes of data. A segment of text tagged using Nvivo has been provided in Appendix G.

After generating the initial codes, analysis involved working systematically through that data set looking for repeated patterns. The codes were sorted into categories and sub-themes. Once the initial data was coded and collated a long list of codes were presented representing the data set. A broader level of themes was established by sorting the different codes into potentially more meaningful themes. It was essential at this stage to explore the relationship between codes and themes. It was also important the themes were able to be clearly named and defined. Furthermore, codes considered not relevant or which did not fit within particular theme were discarded. At this point a set of themes were devised.

In order to refine and review each theme, the data extracts represented by each theme was reread to explore coherent patterns. According to Attride-Stirling (2007) as the themes emerge, they have to be moulded and manipulated to accommodate the new text segments, including the old ones. These themes were reviewed along with the collated data to clearly determine their distinctive meaning and to refine their

representation. It was important to ensure that each theme could easily be described and illustrated.

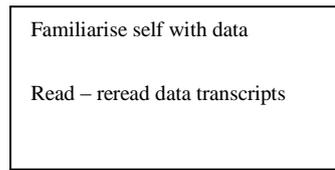
Finally, the themes were identified based on their relevance to the broader research topic and how they interact with each other. As noted by Braun and Clarke (2006) “a theme captures something important about the data in relation to the research question and represents a level of patterned meaning within the data set” (p. 82). Most importantly, the themes had to capture the true essence of what they were about. During this process it was also important to determine sub-themes, that is, themes based within themes.

## **6.5 Researcher’s Position**

In order to address transparency about the researcher’s presence in the process of analysis and interpretation a description of the ‘researcher’s position’ has been provided. As noted by Willig (2008) this is an important process due to the researchers own preconceptions, values, experiences, interests and assumptions that are likely to influence the collection and interpretation of the qualitative data.

There were many reasons for me to complete the current study. Academically, the completion of this study is to fill the requirements for my degree of Doctor of Philosophy. From a professional perspective, my career in health services has spanned over 21 years and this has predominantly involved direct contact with the public. Working as a Registered Nurse (Division 1) in a variety of large and small metropolitan hospitals has meant caring for stroke survivors’ during their acute or rehabilitative recovery process. Leading into my academic pursuit as a Registered Psychologist I was employed with the National Stroke Foundation in Melbourne, Australia, as a Project Officer. My role consisted of providing information to the general public about stroke services and resources available, assisting in the preparation of policy documents and reports, and collecting and analysing data for research purposes. Over the course of my career as a Project Officer, a Nurse and Psychologist, there were many situations that provided me with little insight as to the struggles and successes experienced by stroke survivors during their adjustment following stroke. My professional health experience in both the public and private health sector has provoked my interest in the psychosocial experiences of those living with a stroke.

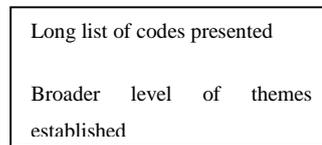
Phase 1.



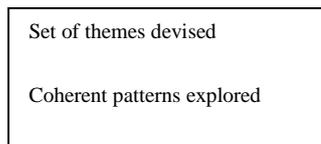
Phase 2.



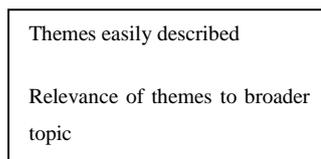
Phase 3.



Phase 4



Phase 5.



Phase 6.

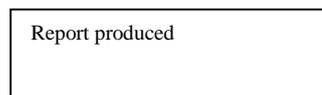


Figure 1: An Adapted version of the process of thematic analysis as described by Braum and Clarke (2006).

The results of the data analysis have been presented in Chapter 7.

## CHAPTER 7

### Results

This chapter presents the findings from the data analysis of the interviews with the stroke survivors. The responses have been organised into four main themes related to the stroke survivors' experience of adjustment following their renegotiation of living. The themes presented include; *life adjustment, younger stroke survivors, a resilient tendency, and stroke within a community context.*

The first theme describes the overall physical and psychological adjustment as experienced by stroke survivors following their diagnosis of stroke. This section presents the various challenges stroke survivors were faced with during their journey of adjustment. These challenges included physical limitations, reduced social activities, the reliance on others for assistance, communication difficulties, fatigue, initial reactions such as shock and fear, and the difficulties associated with the transition into community life.

The second theme focuses on younger stroke survivors. Areas of particular interest to this unique group included life disruption, loss of independence and freedom, vocational commitments, vocational transition, the value of employment, personal/professional development, and social support.

The third theme is related to resilience. This section presented the findings of identified factors that were prevalent in stroke survivors who appeared to be adjusting from their adversity and were engaged in their renegotiation of living. Factors identified included individual disposition, competence, self-esteem, social support, emotional support, intrapersonal factors, resilient features, and previous life experience.

The final theme related to the value of community as perceived by stroke survivors. Community was viewed as a crucial element in stroke recovery. Topics included social connectedness and environmental networks.

From the presentation and discussion of these themes it is expected that a sound understanding can be drawn from stroke survivor experiences that portray their voices and shed light on how they manage following their adjustment from adversity.

## **7.1 Life Adjustment**

Overall, the participants in the current study described their recovery after stroke as a life altering experience. They revealed their recovery not only revolved around physical impairment and improvement, but also about having to struggle with deep psychological and social impacts. Life after stroke meant considerable physical, personal, and social adjustment. The participants conveyed that their previous life goals and ambitions suddenly appeared daunting and unachievable, and fear and uncertainty tainted any thoughts about their future. Recovery from stroke was viewed as a long, arduous and often confronting journey that required a great deal of personal investment to maintain a sense of hope and to cope with adjustment. One man reflected on the significant adjustment he had to make following his stroke:

*Yeah, because things do change. I think immediately I probably was frightened and what it had done to my life. But I didn't realise how significant it was. I would say that only later on when I realised that my life was going to totally change. Now that might sound strange – a dill or something, but I don't know, I never planned it. I just thought "oh well", you know, after a period of rehabilitation, I'd just go home and when I'd gotten better I would resume my life (rural stroke survivor).*

Similar to the quotation above, all participants were able to convey their lack of readiness for the sudden impact of stroke. As stroke is an unexpected condition, these participants felt ill-prepared and perplexed about what lay ahead in terms of their plans, future, and general life adjustment. In their view, these stroke survivors were expecting a full recovery and for most this was not the case

### **7.1.2 Physical Adaptations**

All participants expressed concern about their reduced physical capacity following their stroke, and many had difficulties coming to terms with this. Participants

spoke of the initial shock whilst they were in hospital with not being able to move, go to the toilet and in some cases, speak. Physical symptoms included paralysis, numbness and constant feelings of discomfort. This change in physical capacity was profound. One woman was able to illustrate this in the following extract.

*The thing I found most difficult was how my body physically felt and what was hard. What was tiring was getting in and out of bed, with pyjamas twisting up around me and not being able to move properly. Being on the ground and having to get up and they teach you a way to get up (rural stroke survivor).*

Learning to adjust from minimal to severe physical disability affected most aspects of the participants' daily activities. Participants reported experiencing a variety of limitations from inability to walk on uneven ground to depending on someone to assist with personal care every day (e.g., showering and dressing). Having a physical impairment was considered awkward. It meant individuals weren't able to walk into shops with their partners, rather they had to sit in a car and wait. It also meant experiencing sleep disturbance, regular falls, problems with speech and complete loss of strength and endurance. The following excerpts provide a description of the limitations several stroke survivors were faced with.

*J (husband) goes in and does all the shopping by himself and I sit in the car and wait for him and just sit there and look around (urban stroke survivor).*

*But there is some things you do and some things you don't. You have to...what you learn for instance, when G (wife) is not available, I have to fall back on people like P (friend). I said, "look, G (wife) has got to go to Melbourne tomorrow, can you come and do my trousers up?" And so it is always a problem if you have to go to the toilet because I can never do that myself. "Can you come around and pick my pants up?" You learn not to be so embarrassed (rural stroke survivor).*

Having a physical disability meant missing out on pleasurable activities. Stroke was equated with limitations in daily life. This was portrayed in various activities such as the participants' inability to get on their bicycle and ride around town, or confidently

entering a shop and picking a needed grocery item, or going to a football match to watch a game.

### **7.1.3 Potential Risks**

Having physical limitations was accompanied with knowing and recognising potential risks. For instance, attending sporting events meant exposure to large crowds and the potential to be accidentally pushed or shoved, leading to loss of balance. A physical impairment was considered problematic and these participants were attempting to come to terms with this which required a lot of practice and patience. The following excerpts provide various accounts of participants discussing the difficulties they faced with their physical limitations.

*Little things, like going up and down steps then holding on to someone's shoulder going up and down steps. If there's a railing I'm fine, but if there's no railing I need someone and also if there's crowds I get a little bit nervous and sometimes in a rush you think you're going to get bowled over (urban stroke survivor).*

*I feel I'm just a bit handicapped that little bit. There's things I can't do. For instance, I love dancing and I can't dance and I can't get into it because I've lost the power in my leg. It's difficult because of the things I can't do. I do play bowls but I'm handicapped a little bit. I'd love to play in events but there's things I can't do. I play cricket. I just do it for a little while, but then I become unstable (rural stroke survivor).*

### **7.1.4 Communication**

The stroke survivors reported difficulty with their general communication abilities. According to the stroke survivors communication difficulties they encountered included difficulties with their vision, language and speech.

#### **7.1.4.1 Vision**

*Even though my eyesight's bad I did a mobility course at the Guide Dog centre and they taught me how to use my eyesight by moving my head all the time and that helped a lot (rural stroke survivor).*

Visual disturbances are considered a common result of stroke (Ozer et al., 1994; Proto, Pella, Hill, & Gouvier, 2009). Partial vision loss meant difficulties in recognising objects, space, and distances for stroke survivors. Furthermore, one of the accompanying difficulties associated with vision loss was the suspension of their car licence. Consequently, this meant social isolation and loss of independence.

*I had to rely on my daughter a lot when I first came home. To take me shopping and stuff like that because if I looked at the stuff on the shelves it all looks the same to me (urban stroke survivor).*

*I know my eyesight is definitely not as good as it used to be. I've still got this left view problem. I can turn and look to things on my right and see perfectly. I can look to my left and I have to stop and focus. I know that (rural stroke survivor).*

*I would try to knit but my eyes wouldn't cooperate really well. But I felt that you've got to persevere and not expect it to happen all at once (rural stroke survivor).*

Participants had difficulties in recognising products on shelves in supermarkets and negotiating space and distance on outings. Again, participants reported their frustration and difficulties with adjusting to these physical changes. Recovery was viewed as one challenge after another.

#### **7.1.4.2 Language and Speech**

Experiencing difficulties with language and speech was considered distressing for many of the participants, as speech is an essential means of communication. Difficulties these stroke survivors experienced led to problems with language expression, articulation and comprehension. Of those participants who underwent

speech therapy, the process was regarded as very challenging and an arduous intervention. However, once treatment was completed participants reported a sense of relief and achievement. They were pleased to have their voice back.

*My voice for example, I can't talk confidently as you would appreciate. It's my trade [this stroke survivor views his voice/ability to speak as his means of communication], it's a bit like tying a boxers hands behind his back. I lost power in my vocal chords. If you see me in a few weeks time you'll see the difference in my speech. One is I had paralysed vocal chords, two is my limited diaphragmatic function, three is paralysed lips and tongue, and so on. See also my saliva dried up which meant I couldn't talk particularly well (urban stroke survivor).*

According to the stroke survivors having a degree of difficulty with their ability to articulate themselves through language and speech affected their ability to communicate. Communication was, according to these stroke survivors, an essential means during their recovery. It provided the avenue to observe, hear and to communicate their concerns, frustrations and needs. Not having the ability to communicate was a frightening and frustrating experience for stroke survivors.

### **7.1.5 Cognition**

In addition to the physical and sensory impairments, participants also described difficulties in cognitive functioning. Cognitive impairment and its association with stroke have been extensively researched (Koh et al., 2009; Saxena et al., 2008). However, the level of cognitive impairment varied greatly between participants -- ranging from poor memory, attention deficits, impulsivity, to difficulties with concentrating and comprehension. Experiencing cognitive impairments left participants with a lack of certainty and confidence, including a lack of control. They did not trust themselves. As a result, a great deal of reliance was placed on their partners or carers, often leaving participants to feel 'useless and vulnerable'.

*I still have a problem with figures and sometimes I can't get the odd word out, it just won't come. I have trouble writing certain letters. You know 'G' [letter], I go to do a 'G' and do three different things (rural stroke survivor).*

*I know I've never been one with sales people. Like people come to the door or on the phone and do the sales pitch. And I've always said, "no I can't afford it, I'm broke, I'm a pensioner, go away." You know. And I've always been a bit like that. I got talked into a ripper of a phone deal. Well it's only about a month after I got out of hospital. The [phone company] called me on the phone and convinced me to catch a bus and get up to this shop and when I got there they talked me into signing this phone contract which I only just got out of. And I couldn't afford it. And I knew it at the time, but he just worked on me so well this man. And I was just sitting there. I still couldn't even sign my signature properly. He helped me with signing my signature. So sometimes I really get taken advantage of and I think about it later...any salesman who would come to the door at that time probably would have walked all over me (urban stroke survivor).*

Notwithstanding the above, participants spent a great deal of effort assimilating new ways of adapting to these impairments. For instance, one stroke survivor re-educated himself about the value of money and its exchange in purchases by offering to visit the local shop every day. Another stroke survivor sought the help of a neuropsychologist to develop strategies and practice tasks to manage her cognitive impairments. Managing the various impairments was no easy task and participants reported this was hard work. Two stroke survivors were able to convey the difficulties they experienced in managing their cognitive impairments.

*I was still having trouble focusing hard enough just to, you know, put a sentence together, and um, I guess it just took too much energy to worry about too much else at the time. I know that my concentration and basically everything slowed down. I had a lot of trouble focusing and concentrating on a lot of things (urban stroke survivor).*

*I can't at the moment because I just, I can't, ah, control my brain to try and make it happen that way. Sometimes I can but I can't. I might do it for a little while then all of a sudden I just go 'boom', and that's it, I can't. I can't remember it then... (urban stroke survivor).*

### 7.1.6 Fatigue

Life and adjustment after stroke is considered exhausting. There is growing evidence that suggests the effects of fatigue can have a profound impact on the patient's ability to recover (Amarshi et al., 2006; Bogousslavsky, 2003; Glader et al., 2002; Van de Port, Kwakkel, Bruin et al., 2007). With the ongoing struggle to maintain mental and physical stamina participants reported experiencing overwhelming fatigue. The increased demands of rehabilitation and efforts directed at maintaining and sustaining independence left stroke survivors with very little energy. Stroke severely affected their endurance and stamina. Participants expressed difficulty in managing previously effortless tasks and constantly remarked on how fatigued they were. For instance, fatigue affected them whilst doing even the simplest daily tasks, including mowing the lawns, walking, concentrating, and socializing.

Fatigue had a profound effect on the participants' capacity to adjust to their altered lifestyle. This persistent fatigue led to participants having to 'slow down' their activities and to take their time so as to not exhaust themselves prematurely. This proved very frustrating for many of the participants, especially when they reported a reasonable level of endurance and stamina with most activities pre-stroke. Fatigue was often compared with pre-stroke lifestyle to post-stroke lifestyle.

*I get tired still. I can't do as much as what I used to do. I go to mow the grass, I cut the front then the back. Takes longer to do physical stuff. Like I couldn't climb on the roof to check a tile (urban stroke survivor).*

All participants reported fatigue following stroke. Furthermore, participants described the presence of fatigue many years post-stroke. Fatigue had essentially become a complaint that was part of daily routine.

### 7.1.7 Psychological consequences of stroke

*The specialist told R [husband] to bring me home and do the best I can because I'm going to be no good for anything. And of course that kept going through my mind. I heard him tell R that. It kept going through my mind, 'what am I going to do for the rest of my life? You know?' (rural stroke survivor).*

### 7.1.7.1 Initial Reactions

All participants spoke at great length about their psychological reactions, in particular when they were first diagnosed with stroke. Initial reactions included shock, confusion and uncertainty, anger, fright, and frustration. The psychological and emotional consequences during this period were considered profound. These various reactions were associated with the disbelief about the diagnosis of stroke and the symptoms they subsequently experienced. Furthermore, participants reported their frustration and irritation with the process of having symptoms explained, undergoing diagnostic procedures, and the sensitivity of how their diagnosis of stroke was delivered to them.

*From then on I felt over the next couple of days, I just felt, just felt flat. And the next two or three days I was in intensive care, but I think two or three days...time just flew, and I felt pretty low. I didn't really...I wasn't able to do anything. I could swallow tablets that night, the following morning I couldn't swallow. So things changed dramatically, but, ah, when I realised I had no balance, that was when I really, that really killed me... Frustration more than anything, it was frustrating and uncertain. (rural stroke survivor).*

*...when I was taken to the hospital in emergency, I suppose in a way frustrated, I suppose that there were lots of doctors and nurses talking about "it might be this, it might be that, it might be this", and they were all asking me the same question over and over again, and it was like, I felt like, they were talking about me right in front of me but they were not telling me what was going on. And my sister and brother-in-law were allowed to come and see me after I don't know how many...how long it took. And I immediately turned to them and said, "What have they told you?" Because I felt they weren't telling me the truth (urban stroke survivor).*

### 7.1.7.2 The Psychological Consequences of Impairments

Several participants conveyed their psychological health was a direct result of their physical health. Participants spoke at great length about their psychological changes following the diagnosis of stroke. Having a physical impairment that resulted in

reduced physical activities was attributed to psychological disturbances. In four cases these psychological disturbances were clinically identified as anxiety and depression and they were subsequently treated with medication and therapy. Common themes that emerged from the interviews associated with a psychological disturbance included a sense of helplessness and hopelessness, lack of motivation, anxiety, low mood, poor self esteem and low confidence.

*Some days I do get down. I get depressed. It depends on how I feel that day, but I try to force myself to do what I want to do (rural stroke survivor).*

*To feel really good about your self I like to be able to get out and do different things. It's sitting inside that drives me nuts. I done that for a couple of years it drove me mad. I don't like sitting down. I like to be able to do things (urban stroke survivor).*

*...My husband never did anything. I did everything. Now he's doing everything, the cooking, the washing, because I can't do anything. A woman comes to shower me in the morning, every day except weekends when my husband does it...I was going to day-hospital and I didn't like it because there was other people and I cried a lot. The doctor gave me some tablets to stop me from crying. Now if I want to cry I can't. I've gone off them two years ago. But my mother died last March and I cried a little, but I was unable to cry (rural stroke survivor).*

Further to this, the various physical limitations were associated with a reduced likelihood of participants venturing out into the community and engaging in pleasurable activities they previously enjoyed. Participants frequently spoke about their reduced confidence regarding their physical appearance and how they would be perceived by the general public. Hence, participants were reluctant to engage in social interests or activities. Common emotions reported by participants included embarrassment and increased feelings of self-consciousness.

*I think I felt very poor about myself. I got quite embarrassed. I still do a bit because I'm a fairly self-conscious person. I might not seem like that, but when I walk down the shopping centres, sort of dragging my leg and sort of carrying my*

*arm, I do get awkward in social life. Like in restaurants, I still get embarrassed. Even now I walk into a restaurant and see people sort of look at me like, 'What's wrong with him?' (rural stroke survivor).*

*Thank goodness we were able to work out most of these problems, and do it sensible and I realised, it took me a while, but I realised it's a lot for her (wife) to have to look after me as well as carry on her social life. She suggested she would give up this and wouldn't go there or wouldn't do that. She'd make excuses. I said, "put me to bed at 6pm, I'll be all right". I'd have a television set in the room. She's more understanding than I am, but you've got to understand when you go through this phase of restrictions you have to give and take (rural stroke survivor).*

As a consequence of the reduced activities participants tended to venture out in the community with people who provided a substantial amount of support, such as partners, friends or family. These were people who they perceived as trusting and felt comfortable with. Several stroke survivors had the perception that their network of friends and acquaintances had reduced since their diagnosis of stroke which had repercussions for their social activities.

### **7.1.7.3 Lack of Emotional Control**

Participants likened their emotional state to a 'rollercoaster', either plummeting into feelings of sadness and loss, or escalating into feelings of happiness and contentment. Participants would experience periods of depression, followed by a period of very mild distress, which would then lead to subsequent sadness. Every day was different, but finding the emotional balance was perceived to be difficult. Emotional reactions often occurred simultaneously. Participants voiced their concerns about their inability to control their emotions and the difficulty in understanding these intense reactions. Several participants expressed their distress at their open display of grief, despair, and sadness.

*I was frustrated and I got the shits a bit and I was...I remember one time I walked out to the kitchen and I said, "I can't handle this," you know you have*

*your ups and downs, and this was the only time that I actually cried, but you know, I got on with it (rural stroke survivor).*

*Now sometimes I wonder about that. I'm one of those people. The other thing I might do is I might just be talking like this and all of a sudden I'll burst into tears. Then um, I'll probably be alright after a moment, but then depression sets in. And that's it. I can have depression for as long as two days then all of a sudden "bang" it's gone again and I'm back to getting up to going again, and then all of a sudden 'bang' crying will come ....(urban stroke survivor).*

This perceived lack of emotional control left them very confused about their ability to cope. Despite the accounts about their inabilities to cope with these emotional reactions, four participants recalled visiting a Psychologist. All four spoke of the benefits in pursuing psychological intervention and the strategies they learnt in dealing with and coming to terms with their emotional reactions. However, overall, attempting to cope with the psychological consequences of stroke appeared to have a lasting impact for many of the stroke survivors, who at the time of their interviews were still coming to grips with their recovery.

*So I'd say two and a half years after my stroke, I was still in denial and looking for some way of how I was going suddenly, you know, miraculously get better. And I think it's really only been in the last three years that I've really started to feel that I've got my life back in control again. In the last three years. (rural stroke survivor).*

*The only thing I have a problem with is sleep and I'm awake for two or three hours during the night and that's my darkest moment, mentally and physically. (rural stroke survivor).*

#### **7.1.7.4 Psychological Support**

Several participants found the psychological support as inadequate. Dissatisfaction was reported with the failure of health professionals to educate and inform individuals about the psychological reactions and the management of these conditions. Despite the intense physical rehabilitative efforts provided by health

professionals, several participants continued to experience profound psychological distress. However, of the very few (four) who did seek psychological support the benefits were remarkable.

*The most frustrating thing is the medical people don't actually sit down and tell you "this is what's going to happen" and that's the thing I can't decide whether other people should be told "you've had a stroke and this is what's going to happen". Whether you should know that or what ... (urban stroke survivor).*

*We can pick up mail if you like, or drop in anything and try and make them [other stroke survivors] feel as though somebody cares. And I think that is very important, because there seems to be a desire, not a desire, but a feeling from many people that nobody really cares and "here I am all alone". I mean without naming names, I've got a mate who in there [hospital] now who's had a stroke and he's like, "nobody loves me", he wishes he could die and all this. It's very sad, very sad for his life (rural stroke survivor).*

#### **7.1.7.5 Fear**

Associated with the emotional turmoil was the participants' trepidation about their future. This was evident in their initial reactions which included fear and uncertainty. Participants commented about their close encounter with mortality leaving them terrified of what may lie ahead. The fear of further strokes was at the forefront of their thoughts and these thoughts accompanied them in subsequent activities.

*My granddaughter, she's just started school. Last Thursday morning I went to see her off to school. My son's got three daughters too. So we've done it to the lot, we've only got one to go now (grandchild). I don't think I'll live long enough to see her go (to school), she's only two. I'll be dead before then (rural stroke survivor).*

*I've given up smoking. I've given up drinking alcohol to excess. To the excess part is very important. I actually walk across to the shops instead of driving the car or catching a cab. Before I used to...you know the Life Be In It character – Norm? He was hyperactive. I actually walk across to the shops and I eat fresh*

*fruit by choice. If I'm not careful I'm in bloody serious danger of being healthy (urban stroke survivor).*

A sense of fear concerning recurrent strokes was conveyed by most participants. Despite this fear manifesting at the forefront of their thoughts it did not hinder or restrain all participants from engaging in everyday activities and their recovery process.

#### **7.1.7.6 Emotional Liability**

Emotional liability was a disorder experienced by several participants. It is a prevalent and widespread disorder amongst stroke survivors that effects the regulation, perception, and expression of emotion (Ozer et al., 1994; Tang et al., 2009). Emotional liability is often mislabelled as depression. Stroke survivors with this condition struggle with the emotional arousal and their interpersonal interactions. Several participants were highly conscious of this disorder and the effects it had on their ability to interact with others. Participants spoke of their frustration and confusion with their uncontrolled outward expression and conveyed their embarrassment about inappropriate emotions. Even more disconcerting was the lack of information, support and expert advice offered by health professionals with managing their condition. One participant spoke of the difficulties he experienced in expressing his emotions and the embarrassment he suffered as a result of his emotional liability.

*I have a very bent sense of humour. I'm said to be emotionally labile. One would notice I might sometimes laugh inappropriately, but I might just look like a moron. The fact that I cried but that goes with the stroke, but nobody bothers with that so much. Someone might say, "my mother died last week", and I might start laughing. I just can't help that. But that's my way of expressing extreme emotion. But to you, it might be inappropriate (urban stroke survivor).*

Overall, emotional liability was considered a difficult condition to control that warranted assistance with education and strategies to manage it by health professionals.

### **7.1.8 Rehabilitation and Services**

Traditionally, rehabilitation has been viewed as a central element in the recovery of stroke survivors (Salter et al., 2006; Young & Forster, 2007). The ability to access appropriate rehabilitative services is vitally important for all participants. Education, physical exercise, and information about care, were essential components highly valued by participants whilst engaged in rehabilitation. Rehabilitation provided participants with the skills and preparation for transition back into their communities. It offered participants the opportunity to maximise their physical recovery and aim for some level of independence. Several participants were able to convey how important rehabilitation was in their recovery.

*For me, I advanced so well and I had people around me who weren't making progress at all and yet every single day I had such huge advances. One day I could move my arms, the next day my hand, next day I was moving individual fingers. Yeah, everyday it was a step where I saw that other people around me weren't doing it. So, I guess that I was just happy and grateful and they had to sort of tie me to the bed to get me exercising (urban stroke survivor).*

*They [hospital] guided me, they got me walking again. I didn't realise the speech pathologist who got me swallowing, and the physio who got me to walk had a bet with each other that one, they would beat each other, and I didn't know that at the time, and the speech pathologist won by a day. She had me eating the day before the other one had me walking (rural stroke survivor).*

#### **7.1.8.1 The Value of Professional Support**

Rehabilitation was viewed as particularly beneficial when encouragement and support was provided by health professionals. Having experienced professionals who informed participants about the nature of their rehabilitation process and encouraged participants to ask questions and seek information appeared to aid recovery and was highly regarded. One woman, who was physically incapacitated by her stroke and after a lot of convincing, eventually placed trust and belief in her physiotherapist which led to her ability to walk again.

*I mean I've come a long way and J [physiotherapist] was saying, 'just sit on the edge and we're going to start...you'll be able to walk', and I went 'bull-shit!' I just did not, I was that bad I thought 'she is insane', and I didn't have the....'fuck em!' They're not telling me I can't walk under them. I was like, they're the idiots because there's no way I'm ever going to be able to stand on my own....When she said 'now we're going to work on the pelvis' doing all this funny stuff, I'm just going 'yeah right'. But she just got into my body and she sort of ...and I said "why are we doing this?" And she explained, 'to stabilize your torso so when you stand...' she explained everything. Literally, I could not stand by myself. I literally toppled, I'd fall. They knew what they were doing, they were fantastic. I would never have believed it (rural stroke survivor).*

Conversely, there were participants who reported disappointment and dissatisfaction with the opinion of health professionals who expressed doubt or had no confidence in their ability to recover. Participants did not appreciate the negative opinions which appeared to heighten their fears and often left them feeling helpless. The following comments highlight the view of a number of participants who were initially given a poor prognosis by health professionals despite their ability to regain independence.

*Well at the time when it first happened I could see myself not being able to walk, never work again, and just...actually the doctor in Melbourne told me that I'd had a bad stroke and I'd never walk, and I'd go back home to an old people's home. This didn't help (rural stroke survivor).*

*I was assessed by the geriatric assessor at the hospital as a "basket case". I was going to be sent home and die. I wasn't very happy about that. Having said that, I was despondent, but you've got the view that I was too silly to know how sick I was (urban stroke survivor).*

*That B [hospital] had told N [wife] and myself, I would never swallow again and I would be in a wheelchair. Now that gave me a fairly deflated opinion...hey if you try, a lot of things are possible (rural stroke survivor).*

### 7.1.8.2 Transitional Care

*All I can tell you there was no outlook for me, no friends, no prospect of doing anything. Even times when (daughter) used to come and see I was all right. Her father was at work, she'd find me crying and she'd come down and do a bit of cleaning and things like that for me before I had home care come in. She'd find me down the yard crying because I didn't have my children to look after me and I've thought "what's the use of me being like this, I'm 48 years old and absolutely no good for anything". So I had nothing, absolutely nothing. Just a big black hole nobody there to help. If it hadn't been for linkages I would have gone and shot myself (rural stroke survivor).*

Although rehabilitation offered stroke survivors the opportunity for a somewhat seamless transition back into their community, participants reported this smooth transition did not always eventuate. The transition from rehabilitation to community was often reported as fractured and fragmented. Stroke survivors were faced limited to ongoing community services (i.e., physiotherapy, gyms, rehabilitation, and experienced health professionals). This transitional period was viewed as difficult and often led to set backs in the participant's recovery. Participants expressed uncertainty, isolation, sadness and overall difficulty in their ability to cope once they had been discharged home. One participant provided a description of the immense difficulties she experienced in coping with life readjustment after stroke.

*Yep, I was doing good [physiotherapy, exercises], but then it dropped off you know. When they started saying you know, 'you've got to go see... finish up that [exercises] and do it yourself'...and I just couldn't make it through. What I needed ...K [wife] would come and work my muscles and things like that...but I eventually dropped it off [exercises](urban stroke survivor).*

*Waves is a hydro-pool and I go up there once a week and I meet a lot of people up there that I didn't know before and we have a lot of fun. So I stay there for about an hour and a half. It was an exercise group when I first started but the lady who was doing it doesn't come now so we do our own exercises in the water...(urban stroke survivor).*

*He [husband] is my only, my life support. Oh yeah, my daughter and my son as well. Yes, I get lots [support] from them, yeah I do. I can get dressed myself. I can dress myself by slowly putting my pants on, then putting my pants, these [trousers] on and undress. J [husband] is the only help I get (urban stroke survivor).*

For many of the participants the support they receive once they transition back within their community is provided through their family and friends. Furthermore, from the accounts of the stroke survivors it appears that little direction is given on how to make life adjustment within their own environment.

## **7.2 The Younger Stroke Survivors**

This section presents the findings from the interviews with 11 younger stroke survivors (5 males and 6 females) with a mean age of 42.0 years. Typically, their age ranged between 23 and 55. Just under half of this group were married, with two divorced, one single, and one living in a de-facto relationship. Furthermore, six of the younger stroke survivors were employed at the time of interview and one had commenced study at a university level.

From the interviews it was clear younger stroke survivors were struggling with the various consequences of stroke. Furthermore, several themes were gleaned from the analysis of their interviews. These themes included *life disruption, the value of employment, personal/professional development, and social support*.

Stroke appeared to affect the younger participant in many ways. Given that the younger participant is positioned within a different stage of life in comparison to their older counterparts, their experiences of recovering from a stroke are quite different, and encompass issues such as career, family care, and negotiating social engagements which are not so immediately relevant to the older person who has retired, and whose family may have grown and their social life being more established and settled.

*Um...but I had no idea that it's gonna take one year, it's gonna take five years, it gonna take however long. Like, I've just returned to full-time work five months*

*ago or so, it's taken five years or so to return to full time work (stroke survivor aged 34)*

According to the younger individual, having a stroke and being left with a chronic disability placed an enormous burden on their young families, spouses, and work commitments. They spoke of personal losses including marital breakdown, loss of previous friendships, loss of their independence and major changes or disruptions to their careers. Two younger stroke survivors (one married man and a single mother) talk about the impact their stroke had on their family.

*Well what we did was, well I used to handle all the finances at home, so I handed it all over to P[wife]. Of course she took over when I was in hospital. I just left them with her even until today. She pays the bills, I let her do that, but at work, I make most of the decisions. I wasn't making all the decisions early on but the people at work knew my circumstances so they used to help me out where they didn't tell me certain things (stroke survivor aged 51).*

*Um, and I didn't realise until then just how obvious it was even to my kids that I let them walk all over me. Basically I didn't have enough confidence to even to sort of enforce. Really what we had around the house all the time, you know helping out with the housework and stuff. I had this thing where if I'm not able to do it then I don't see why I should make them do it (stroke survivor aged 35).*

### **7.2.1 Life Disruption**

Stroke was considered a traumatic experience that left them feeling bewildered, scared and extremely vulnerable. An experience of complete life disruption was echoed by all throughout the interviews and recovery included having to make sense of this unexpected life threatening experience and attempt to re-establish their lives. The participants expressed concern at their loss of /or reduced self-esteem and confidence in comparison to their pre-stroke lives. They considered themselves less able to uphold positions of power or authority, and were concerned about losing the respect of family, friends or colleagues. They indicated their frustration at being forced to reduce their responsibilities, and having to increase their dependency on others. Furthermore, losing the ability to make decisions for themselves and feeling misunderstood often left them

consumed with feelings of despair. Overall, the younger participant was left with a sense of insecurity and uncertainty about their future.

*I want more out of life and I want more money. That will come whenever. It's not an issue. I'm warm, I can feed myself, I can pay the bills. I'm not hurting. If I go out and earn an income of any sort I lose dollar for dollar on my superannuation. So there's not really any point. If I can do one session, why can't I go and get myself a full-time job sort of thing you know? (stroke survivor aged 47).*

The following is an account of the themes inherent in recovery to life following a stroke as expressed and experienced by the younger stroke survivors. They identified unique requirements and needs including: Loss of Independence/Freedom, Vocational Commitments, Personal & Professional Development, and Socialization, as important components in their recovery process.

Life disruption was also associated with loss of independence and freedom. Ingrained in this sense of loss was their inability to make longer term life decisions for themselves. Linked to this was their necessary high reliance and dependence on others to perform basic daily tasks. The participants reported frustration at having to return to living with other family members (predominately parents) or having parents move in with them in order to optimise their levels of support. A perceived disturbing shift in life post stroke was the need to transfer control of one's life over to a significant other at a time in their lives when retaining independence was considered of vital importance to their sense of identity and life purpose.

*All those sorts of things and I can't remember how I explained it to someone now but it was the fact of me losing my independence. I had people doing everything for me. That was actually harder to accept than actually having the stroke. The stroke was a side thing, it could've been anything (stroke survivor aged 34).*

*I was frustrated, very frustrated because I was still having a lot of leg cramps and limited use of my left hand. My vision was still returning to normal, and I had to be supervised by my mother all the time. And my children went to stay at*

*their fathers for a week, so I went a bit crazy until I could escape from my mother and get some independence. I'm a very independent person who has done everything by myself for the last 10 years. So six weeks of being in hospital full-time having everyone do stuff for me then having to come home and let my mum do things, I really didn't like it (stroke survivor aged 35).*

Whilst they appreciated the support received from their family, participants also reported an ongoing struggle with accepting this newly acquired dependency. Subsequently, a major goal in the recovery process that was highlighted by all of the participants was the need to work towards regaining some independence and confidence in their decision making. As noted in the following excerpt, the participants reported how important it was to progress to a stage of embarking on activities such as shopping, travelling and playing sport independently as a way of rebuilding their confidence and having some sense of independence.

*I took up badminton, competition badminton after I left rehab. Badminton became part of my rehab. One day we didn't have enough people to play and I put a racket in my hand and being a bit nervous that I'd fall over. I thought it's ok if I don't move and I found out I could hit. And I've been a regular two or three times a week (stroke survivor aged 34).*

*I suppose I'll continue doing my work and I've had to stop basket-ball and I've gone on to do Bocci and Ten-Pin Bowling (stroke survivor aged 31).*

### **7.2.2 The Value of Employment**

All of the participants expressed concern about their employment and vocational commitments. Often the stroke had left them with no option but to leave their workplace, because of their inability to fulfil their roles and responsibilities, and resulting in the development of feelings of uncertainty, insecurity, and helplessness.

*My last position was as a lecturer in accountancy. I got that on the condition that I went and got a Masters degree. Now I had the second stroke before I could do anything about getting the Master's degree. They appointed someone*

*to fill the remainder of my contract and at the end of the contract they abolished my position (stroke survivor, aged 47).*

For others, returning to work meant a series of competency tests to ensure they were able to fulfil the requirements of their positions. Several of the stroke survivors required a driving licence in order to fulfil their employment obligations. Hence, they were required to undergo retesting for their drivers licence. Retesting often meant disappointment and worry for participants about future job prospects.

*It took a long time when I was in hospital then when I came home and then I started doing a couple of days at work. They shortened my hours. Then once I got back into the routine they tested me on a forklift, then I did that. As soon as I got back they tested me in the car to drive again. Then I had to get the supervisors to watch and see how I went on the forklift (stroke survivor aged 31).*

*Yep I drive. I didn't have any problems getting it [licence] back. I got it the first time. What I'm disappointed about is before I used to drive trucks and buses and stuff like that. I'm not allowed to do it anymore (stroke survivor aged 52)*

*I wasn't very confident in my ability. I couldn't see myself walking down the street or driving a car. I drive a taxi part-time. Once again, they tried very hard to cancel my licence. They thought I couldn't do the job, but I can. That was a really important milestone. Licence is probably the most important. A licence to the average person is the most important thing. To be told you can't drive, well I could see it bothered me like anyone else in life (stroke survivor aged 53).*

Whilst a great deal of recovery time was focused on improving their functional abilities (e.g., walking, talking, dressing), a large proportion of time was also spent considering one's potential for future employment and vocational options. Concerns were not so much about the level of income and ongoing financial support, but rather what their future held, and type of work they would be suited for. The participants reported spending a great deal of time weighing up options about future directions for employment. They often asked themselves 'What do I want to do in the future?' 'What sort of job could I see myself doing?' Work was no longer considered 'just a job' as

they recalled their recovery period and attempted to find meaning in this life experience. As a result, a great deal of effort was spent in trying to clarify possible options for employment that was congruent with their disabilities. As one of the participants noted this was an intense and prolonged process;

*And I went back to another rehab. The first one was actually to return to work and the second one helped me. I thought I was already going for the course but it just confirmed me in that direction, and the last one I went to actually took me through questionnaires – one that I'm good at, what do you want out of a job? And all those sorts of questions. And when I looked at what I'm good at and what I enjoy doing and all those things you could match with. I guess I've spent so much time on the rehab side for about five years and returning to work, like training for another career, but that's all ok now, as much as I think it will ever be (stroke survivor, aged 34).*

Another stroke survivor was weighing up the options of completing a computer course:

*But interestingly enough I had experience where there was a company in St Kilda road and they specialise in running IT courses. I went to see them with the view of doing computer business...and the gist of it was I was going to have to dress in a suit. I was going to have to travel down St Kilda road everyday and work there. It became obvious to me that what was being offered was something I was going to have to pay for. That wasn't an issue. It became obvious to me that it was not what I was after (stroke survivor aged 47).*

The potential to be engaged in some form of formal employment appeared central to the participant's sense of value and self-worth. For those who were able to return to their previous employment, there was a high level of gratitude for the support offered by their employers and the opportunities they provided in returning to work. As noted by one of the participants, the support offered by her employer increased her own sense of value as a crucial member of a team:

*My work, they let me keep my mobile work phone so that I had a mobile phone. They didn't ask me to give it back. So they'd get half of my messages. I was able to use that as a mobile phone. I was able to use the phone anytime. They only*

*charged me two hundred dollars and I must have made about five hundred dollars worth of phone calls. Like people brought me in change for the phone. Um, S my boss, this is an example of the practical support in the beginning, she came in, my boss came in and said, “your job is still there’. I got emails and faxes from work and the drug and alcohol team came to visit me. I really felt part of my job. That was very, very important right from the beginning (stroke survivor, aged 42)*

Having the option of going back to work provided a sense of structure and tangible goals. Work offered an opportunity to get out during the day even if initially, they could only manage a couple of hours a day. Similarly, this provided participants a sense of independence, responsibility, a mode of income, and an opportunity to engage in decision-making. However, returning to work was considered a slow and often arduous task by the participants. Retraining, identifying personal strengths and weaknesses, including developing responsibility, was a challenge in itself.

*But to go back ...I went back to work. I finished rehab at the end of December and went back to work in January as a cook for thirty-five children in a child care centre, one handed with my right hand only. And of course my furthest thoughts were, there was no way I could do that. And then I met (staff) and it was a case of ‘I need a food processor, I need a special chopping board and spreading board’, and they were like ‘oh and what else?’ Because they got a thousand odd dollars that they can spend on each client. And I said, ‘well that’s all I need’. Because I was cooking for months before I had the stroke with a wooden spoon and a bowl and no modern sort of appliances. (Stroke survivor, aged 34)*

### **7.2.3 Personal / Professional Development**

Recovery was a period whereby the younger participants contemplated other interests and/or pursued alternative avenues for self-development or a career change. These interests included relearning to use a computer, and engaging in university/TAFE or community courses that were regarded as important or essential in broadening and enhancing their professional development. Participants reported that the courses were intellectually stimulating, challenging, provided an opportunity to meet new friends and

to network, and offered a chance to go out in their otherwise confined world. Most importantly, these courses were chosen out of personal interest.

Having a choice and pursuing an avenue of interest was profoundly important. One of the participants commented on how he came to engage in a particular course of study he had pursued because this was the area he had found that intrigued him. As he noted, prior to settling into this, he had been involved in a number of personal growth courses following his diagnosis of stroke;

*I went to the A C [the Centre for Human Growth and Development] in H, they run personal growth courses. I did quite a few personal growth courses. I have kept in contact with a couple of people or more (Stroke survivor, aged 47).*

Another participant conveyed how she had spent considerable time contemplating her future and exploring the options of where her interests lay.

*I just sort of plundered for around a while, and eventually I just decided to go back to school. I wanted to do something that has a future, something that I can work through past retirement age and there is work out there, definitely. So yeah, I decided that I'd like to do that (go to university). I started looking for enrolments and things, and found out I couldn't enrol until the following year (stroke survivor, aged 35)*

#### **7.2.4 Social Support**

Maintaining social contacts, preserving friendships, and initiating new friendships were extremely important to the younger stroke survivor. Having close friends who maintained regular contact and who offered ongoing support was considered crucial during the recovery phase. Participants spoke positively about the regular visits from their friends and the tangible assistance provided, such as cleaning their homes, doing the shopping and supplying gifts for nurturing purposes. One participant recalled the benefits she received through the close connection she had with her friends:

*Oh yeah, right from the beginning was my appearance and I didn't want to look like a hospital strokey either. So my friends bought me bright pyjamas and with*

*teddies on them and another one had top hats all over it and bright blue. A friend brought me bright blue cabin slippers he got me, and I really paid attention to how I looked (stroke survivor, aged 42).*

*That was it. I had nothing. This is part of what's wrong 24/7 seven days a week. And I'm on my own. I don't know a soul here. I don't know anyone. I've got no family here. There all in Mildura, my sister is way over the other side of Melbourne. I get to see her what, twice a year. I reckon I would come better if I was at home around my family (stroke survivor, aged 55).*

Having a wide network of friends provided the participants with someone with whom to confide in and to discuss their feelings. Friends appeared to represent a buffering system during periods when participants were feeling down. Having someone to depend on, talk to and share experiences with offered a sense of comfort and an opportunity to have a joke and laugh. Friends appeared to normalise the participant's otherwise distressing experience. However, not all participants were fortunate enough to preserve friendships. Often friendships were lost following the incident of stroke. As noted by the following excerpts, many of the participant' reported their sadness and frustration and the loss of "so called friends".

*What annoys me mostly is the so called friends I had. They've all disappeared. I don't understand anybody (stroke survivor, aged 52).*

*My brother and his family, they were very good [providing support]. Different friends have come and gone. My old friends in times gone by gave me the flick (stroke survivor aged 53).*

*I haven't got any. They're all down home. I don't mix very well. It's the last thing in the world I want (stroke survivor, aged 55).*

Younger stroke survivors who reported a reduction in friendships conveyed their dismay and loneliness with having a reduced network of friends. These stroke survivors did not have a confidant to share their experiences with, enjoy activities with, or discuss their problems or concerns with. These younger participants repeatedly voiced their loneliness.

### 7.3 A Resilient Tendency

The following section provides an account of factors most prevalent in those participants who were identified as incorporating resilient enhancing qualities. Individuals who demonstrated these resilient elements in their recovery appeared to successfully manage adjustment and re-integration back into the community, as well as improve their sense of well-being. Factors most prominently utilised by this particular group included: *Individual Disposition, Competence, Self-Esteem, and Social Support*. In addition, the interviews highlighted the presence of *intrapersonal elements* which also played a key role in the participant's ability to renegotiate their lives following stroke. Overall, the interviews identified protective composites which had a buffering effect against stress and enabled participants to manage throughout their recovery from stroke.

#### 7.3.1 Individual Disposition

Individual disposition was continuously highlighted by participants by maintaining a sense of hope, optimism and their ability to remain confident throughout their recovery. Optimistic individuals made plans, spoke about their hard work and considered them-selves lucky even in the face of adversity. Participants displaying optimistic tendencies approached challenges with confidence and viewed the source of their success as determined by self. Plans were made for the future and this was discussed with partners and family members. Hope was the element that enabled participants to strive towards an expected goal or outcome. Belief in their ability to obtain a goal meant participants acted, moved, progressed, and made changes, thereby influencing the attainment of something they desired.

*There is an increasing sense in me that it is time for me to end this experience. By end I mean recuperation. Get a focus, for the future. It's time to. This has been a wonderful experience. It's been easy, it's been frustrating, but for what it could have been, it's been so easy and gentle. If I had sat down and tried to work out how I could achieve or obtain X,Y,Z, I could not come up with something intelligent as having a stroke (urban stroke survivor).*

*At first I wasn't good. But slowly I thought I must get down the farm and walk and walk and work. When I could do that my confidence got better, and better, and better (rural stroke survivor).*

### **7.3.2 Competence**

Experiencing a sense of competence in tasks and/or activities appeared to nurture the participants' self-assurance and autonomy. Attempting to carry out, and complete activities, meant a great deal. Participants often conveyed their sheer delight and triumph at overcoming, and eventually conquering difficult tasks that were previous to their stroke, effortless. Furthermore, ingrained within the stroke survivors sense of confidence was self-efficacy and their ability to problem-solve. They believed in their own ability to control and cope with challenges as well as in dealing with stress. There were expectations of successfully performing or negotiating particular tasks and a sense of self-regulation of their abilities. Rather than avoid difficult tasks, they instead considered various options and solutions. They confidently engaged in effective planning strategies, and adjusted their abilities in regards to their circumstances.

*Three years ago the doctors were reluctant to let me fly an aeroplane. I had to really squeeze them to let me fly to B I (resort), which is (flight path). So it was an hour stretch, we'd just come back from a two-hour stretch from S to N, and I didn't even hesitate about it. My confidence is good enough for that. We probably will be going to (resort) in June. We probably be going for four weeks, we'll probably drive. Now I wouldn't have driven two years ago. I would not have considered driving to S (interstate city) let alone PD (resort). I still haven't, we still haven't made that final decision. But I'd suggest at this stage we'll be going to PD late in June for a meeting, whether we fly or whether we drive, still to be decided, but we'll go (rural stroke survivor).*

*Well, when I first came home I couldn't vacuum, I couldn't sweep. I couldn't do the dishes, I couldn't do anything like that. It took me an hour to make a bed. But I did it. But not the vacuuming, my wonderful daughter did that. But now I can ... it's still hard, it's still hard but I can do it a bit more now. ... I can't do everything. A lot of the time I'll do a bit and then I've got to sit down (rural stroke survivor).*

### 7.3.3 Self-Esteem

A high sense of self-esteem appeared to permeate into most areas of these participants' lives. They were more likely to pursue goals, achieve tasks, seek new friends, develop ongoing networks, engage in diverse social activities and have confidence in their abilities. They valued both positive and critical feedback from others. Having this positive sense of self appeared to underpin their ability to face challenges and deal with negative feedback effectively. Participants often demonstrated their sense of self-esteem in their ability to connect and socialise with others.

*...he (doctor) gave me some cortisone injections which fixed it (shoulder pain), and he mentioned there was a guy who worked at R (car parts company) that had a stroke. Sort of gave me a description of this tall bloke.....You know when I was at the rehabilitation centre one day, I saw this bloke with his arm in a sling and I walked up to him and said "you haven't had a stroke have you mate?" He says "yes as a matter of fact I have". "Do you work at R (car parts company)?" "As a matter of fact I do" (rural stroke survivor).*

*I think I felt very poor about myself. I got quite embarrassed. I still do a bit because I'm fairly self-conscious person. I might not seem like that, but when I walk around the shopping centres, sort of dragging my leg and sort of carrying my arm, I do get awkward in social life. Like in the restaurants, I still get embarrassed. Even now I walk into a restaurant and see people sort of looking at me, 'what's wrong with him?' It might seem strange, ... it's all about how you see yourself and I'm now starting to. You end up really appreciating yourself, and I think I've gotten over a lot of that now. It's much better because I do feel better about myself (rural stroke survivor).*

Categorised in the notion of self-esteem is the element of intimacy. Intimacy involves establishing a mutually satisfying close relationship with another person (Whitbourne, 2005). Participants appeared to develop a secure attachment with others; they expressed a sense of closeness and trust in relationships. They often reported feeling cared for and experienced warmth and connectedness in their different interpersonal relationships. Moreover, even though participants reported a sense of

connectedness with another person, they were also able to preserve their unique qualities.

*But at the end of the day, I always have you know, all those stupid little clips I have on most good pants. I have to have that done for me (do clips up). I can't put my belt on and I can't tie a tie. But there are some things you do, and some things you don't. You have to ... what you learn, there is that, for instance, when G (wife) is not available, I have to fall back on people like P (best friend). I said (to P) "look G's got to go to M (city) tomorrow, can you come and do my trousers up?"(rural stroke survivor).*

#### **7.3.4 Social Support.**

Social support was viewed as a crucial factor in enabling participants to successfully renegotiate their lives. The various types of support (practical and emotional) assisted in alleviating some of the multiple issues and concerns faced by individuals in their adjustment after stroke. Practical support included tangible supports such as exercise programs, home care, transport, financial assistance and vocational assistance. Emotional support was conveyed through the means of a confidante, those who listened, and the support offered by others that was not of a practical nature.

The amount of practical support provided varied amongst the participants. For several participants, a great deal of practical support was obtained through the attendance of a stroke support group. Involvement in the support group provided individuals with advice, information and tips for overcoming obstacles they faced in their recovery. Others reported small gestures of support such as the bus driver dropping the participant off at her front door or a friend picking up a participant each week so he can attend a choir group. Participants viewed this support as highly valuable and spoke consistently about the support they received during their recovery process.

Participants further noted how partners were often the 'driving force' behind their recovery process and how they pursued the necessary practical resources to encourage the participant to obtain an optimum level of recovery. One man noted the impact his wife had on his recovery and the efforts she undertook in ensuring he had access to relevant resources:

*Well probably my wife's been the main force behind it (his recovery) because she has said she wanted me to feel, you know, that I was normal. Life was going on normally, even when I first had my stroke. She'd chase up the stroke recovery person in Melbourne as to what goes on now. And this person had said that there's a stroke group and you know, stroke association in (Vic). She contacted them and they'd given us some names and remembered that probably the new group started in (suburb), so they contacted them and it's gone from there (rural stroke survivor).*

### **7.3.5 Emotional Support**

Emotional support was a pivotal element in the successful adjustment of these participants. This type of support was conveyed through the means of a confidante, those who listened, and the support offered by others that was not of a practical nature. This support increased and strengthened during the critical period post stroke, and appeared to taper off later in the recovery process. Even though the support offered tapered off following the acute period after stroke, it did not terminate completely. Moreover, this support was readily accessible when the participant's required it.

*.....if I'm feeling down or think I'm...like my kids happen to be going away for the weekend with their father or something, and I think 'I'm going to be down and miserable and yucky this weekend', I will usually plan ahead and plan to go out with friends (urban stroke survivor).*

*Well clearly the first part of this is my wife and my children. They're obviously the first network. But of course, two of the boys were living at home when I had the stroke and they were very supportive and now they've moved. One's overseas and one's in Melbourne. So I don't call them much. However, I like to get on the phone and have a chat. They say, "oh here's dad again talking about...." Not just about myself but I ask them how their lives are going and that's really good. Same with my daughter, she's terrific (rural stroke survivor).*

Having a network of friends appeared to act as a buffer against maladjustment for those participants identified as adopting psychosocial resilient factors. Long-term friends were particularly important, as the strength of their friendship and opinions were

highly valued and offered an opportunity for participants to be momentarily distracted from their diagnosis and also provided someone with whom to confide. Friends listened, empathised and provided fun and engaging conversations to participants. Participants commented that their friends provided support (emotional and practical), they offered them strength through difficult times, and thought of the small details in assisting them through recovery. Their statements highlighted the contribution their friendships made in building confidence, providing encouragement, and improving self-esteem. One woman highlighted how important her friends were to her:

*And if I didn't have him, I would have my best mate M. She'd just die for me. Like that was just what it was like, I've got friends like that. I had friends come down from Canberra all sorts of things, like people that are really very tough people (rural stroke survivor).*

*I was in hospital in St Vincent's and I rang a friend of mine. She's a good friend to come. And I was having a really good whinge. And she stopped me and said, "look, what you've got to do is to look at where you are right now, not in the future, not when you were admitted to hospital, but right now" (urban stroke survivor).*

### **7.3.6 Intrapersonal Factors**

A number of additional themes from the interviews were featured and categorised under intrapersonal factors. These were additional attributes present within the individual that appeared to also play a key role in the participant's ability to successfully renegotiate their lives following stroke. Themes included motivation, determination, perseverance, personal philosophy, and humour.

#### **7.3.6.1 Motivation**

Participants viewed their motivation as a source of ongoing energy. Several participants appeared to have powerful intrinsic impulses and drives that enabled them to perform and address unmet needs. For instance, these participants were not satisfied with a reduced network of friends, or limiting their social outings, or working within the boundaries of a set exercise program; they were motivated and driven.

*Um, yes I did and now doing exercises they (hospital staff) they couldn't stop me even in the hospital. They actually, instead of giving me physiotherapy once a day, they ended up booking me in twice every day because I was doing it anyway in my room and they thought I should be supervised. Um, and once I got home of course I did as many as I could with all the stretches and just the general moving about and um, practicing my balance and things like that (urban stroke survivor).*

### **7.3.6.2 Determination**

*Where ever you go you take yourself with you I think. So yeah, that just blew me away and people were telling me how courageous I was and they were absolutely stunned by my determination. It was like they saw this phoenix rising from the ashes in front of them and they wanted to be around this miracle (rural stroke survivor).*

As noted by Glicken (2006), determination provides individuals with the positive notion they are able to master most life situations. It is a mindset. Determination was a cognitive reflection that led to behavioural actions. Determination is what was drawn upon that allowed several participants to complete tasks and resolve issues. Not only did the participants think about and consider the notion of determination, but they also put this into action allowing it to drive their desire to recover at an optimal level.

*.....I thought well it's happened and I've got to accept it and get on with my life again. And I was determined I was going to be able to work again and speak as best as I could, and write again. I couldn't write anything. I couldn't write my name or anything and I thought well I'm going to be useless if I can't. So I was determined I was going to do it, and (rural stroke survivor).*

### **7.3.6.3 Perseverance**

Perseverance and persistence appeared to be the key in their ability to keep striving for change. These themes were accentuated when various participants continued to work on difficult tasks without giving up. Even when the challenges appeared too

daunting to overcome, participants drew on their strength to keep going and pushed themselves beyond their personal boundaries in the effort to make change. Perseverance was evident when participants pursued answers to difficult questions; or when they worked on physical impairments; or were trying to adapt to their altered lifestyle.

*And it took me months and months and months to try to wake up to get out of bed. I was just totally and utterly exhausted. Then I would work on that. And you know, it's a battle and I still think I've got the strength to keep smashing it down (urban stroke survivor).*

*I've just kept going (doing exercises) and F works...I was supposed to have a session with her Monday, Wednesday, Friday, and I finished up having sessions with her virtually nearly every day (rural stroke survivor).*

#### **7.3.6.4 Personal Philosophy**

Participants also expressed a sense of personal philosophy in dealing with adversity and life in general. These participants often reiterated statements to themselves that appeared to boost their spirits and determination throughout their recovery. Often these affirmations were focused on positive reminders or personal rewards in the efforts of assisting others. For example, 'by assisting others your life is much easier'. Participants commented that their affirmations included statements like, 'live life to the fullest, 'I've got to keep moving, or 'it was either do it, or be fucking miserable'. It was important for participants to stick with their personal philosophy, as it appeared to drive their progress in recovery. One man sums up his personal philosophy regarding his adversity;

*People say it's tragic what happened to me, but I don't feel it's tragic. I think it's one of those things. And I think you've got two solutions, you can go and say alright, I've been going bad, I feel down, or you can say it's happened but focus on the good. I think I've done that (rural stroke survivor).*

#### **7.3.6.5 Humour**

Finally, having a sense of humour appeared to have a positive impact on the stroke survivors otherwise traumatic and unpleasant experience. Several participants

engaged in and often dealt with difficult or embarrassing situations by making light of the situation and/or engaging in humorous undertones and suggestions. Sense of humour appeared to provide the participant with strength and meaning in dealing with a variety of situation.

*...my sense of humour, my ability to laugh at myself and to laugh at life. So...but I also see that you know I've still got all those capabilities that make me who I am...(rural stroke survivor).*

*...like people are so fantastic that I kind of go, 'oh look do you mind helping me with this because my hand doesn't work, oh yeah! I tell people so they don't have to guess or feel uncomfortable, or I go "ah pissed again!" you know because I wobble, or if I get up or if I tap someone on the bum in the shops, I go 'don't mind me I've got an uncontrollable arm' like...(rural stroke survivor).*

Participants who adopted psychosocial factors in combating adversity conveyed the value of intrinsic or intra-personal elements in their adjustment from stroke. These were considered additional and useful tools in overcoming the various day-to-day obstacles. Furthermore, participants viewed these supplementary intrinsic elements as powerful strategies in negotiating their way through life.

### **7.3.7 Resilient Features**

The interviews from the stroke survivors captured various characteristics that are attributed to the phenomenon of resilience. A constellation of protective factors and processes appeared highlighting resilient features that influenced life readjustment and inspired adaptation following adversity. As mentioned above various protective themes emerged including individual disposition, self-esteem, and competency leading to healthy development and positive outcomes. For instance, several participants provided accounts illustrating the interplay of personal attributes, qualities and processes shielding them from risk and maladjustment.

*In hospital I thought I might die. Whatever's going to happen? I was worried about G [wife] ultimately, and I was worried about myself. I thought, I've got to think about this on the positive side, because I can still walk, I'm fine. I am so*

*lucky. Forget about having the stroke and so lucky I can walk on both feet properly as best as I can. And the more I thought about it the more I was lucky that life was so easy. I wasn't going to let me get down on it. I was in committees, writing a book, I was secretary and treasurer of the footy club...(rural stroke survivor).*

*I thought to myself, I haven't had talks with my kids or my wife about where we're heading and what this meant. And the answer was always the same. There's no good lying there and feeling sorry for yourself and the world owes you and all this nonsense. You're better to accept what's happened and accept what you've got and thank God for your wonderful life so far (rural stroke survivor).*

*I guess I didn't cope with any adjustment very well. Just the frustration and I think it was a bit of self pity as well which didn't help. It was sort of like 'hey, you know I've had a stroke why aren't you helping me anymore?' But at the same time it was like, 'go away and leave me alone', yeah it was confusing. But after a few weeks as I said before with the kids, you really don't have a choice. You've got to adjust. You've got to, you know, get out and do things and move on. It's not a matter of not being able to or not having a choice. You have to do it (urban stroke survivor).*

Indeed these stroke survivors were illustrating various personal attributes, characteristics, and processes that appeared to enable them to overcome life adversity and to progress forward.

### **7.3.8 Previous Life Experiences**

Past traumatic experiences were viewed by participants as contributing to their present ability to adjust from adverse events. Several participants were able to recall past instances when they were faced with a stressful and traumatic event yet managed to overcome the negative experience successfully. In describing these adverse events the participants demonstrated their insightful qualities in identifying the connection between the event and how they responded. Overall, these previous traumatic events

were considered by the individuals as far more disturbing than the event stroke itself. However, despite these traumatic experiences participants perceived an opportunity to speak about these past events and how this reflects on, and determines, their ability to manage current adverse situations.

*I think what helped was I was on anti-depressants before the stroke because I've got a genetic predisposition in our family and I've had severe depression and panic disorder. I was probably born anxious with anxiety disorder. Now I look back and I had a wonderful Psychiatrist who's been the medication king. And so I've had this past of a terrible overseas trip where I completely went into panic disorder. And I travelled all over the world and it just hit me. It was terrible. It was like a war zone inside my body. And so nothing was as bad as that. So the stroke wasn't as bad as that, and I was grateful. I would just never go through that again (rural stroke survivor).*

*I was born and raised in India and I got sent to (name of school) in secondary school. I wasn't a square peg in a round hole I was a great big lump of wood in an oblong hole. I just didn't fit anyway. I was born with a congenital eye defect, so I've never had binocular vision. I've never been able to catch a ball and play ball sports well. So I didn't fit in with my peers on the sporting arena. When I got to (name of school) I spoke differently, I thought differently, I dressed differently. There was not one thing that allowed me to fit in. I hated it, absolutely hated it. I just didn't fit in. And that not fitting in remained a pattern, socially for me (urban stroke survivor).*

*I guess I've been like that for years now. And it was eleven years ago that I was diagnosed with manic depression and it was the same with that. I was quite suicidal very depressed, miserable and horrible when my marriage broke up at the end of the year. I got very independent and got a lot of self confidence, simply because I had to (urban stroke survivor).*

Past experience in dealing with adversity is perceived as instrumental in the stroke survivors' ability to successfully adjust from their current circumstances. Furthermore, how the stroke survivor interprets that past experience determines how they manage further adverse events.

## 7.4 Stroke within a Community Context.

The following section draws upon the themes that emerged from the interview transcripts within a community context. Two sub-themes are presented. Firstly, *social connectedness*, which includes identified sub-themes *structural ties* and *social capital*; and secondly, *environmental networks* which highlight environmental characteristics identified by stroke survivors including *accessibility, transportation and hospital resources*.

The section labelled *environmental networks* also provided an insight to the difficulties faced by rural and remote stroke survivors'. From the information presented concerns were raised by stroke survivors' about the difficulties they faced in accessing various stroke services and resources within their local area. The problems highlighted by rural stroke survivors' included; lack of specialist care, extended waiting periods for specialist appointments, long distances to travel, inability to access allied health staff, and lack of transport.

### 7.4.1 Social Connectedness.

Engaging within communities that fostered social connectedness appeared to represent a large proportion of resilient enhancing activities. Developing strong links with others, maintaining supportive resources, engaging in social activities, sourcing out information and seeking a sense of belonging with others had a profound effect on participant's sense of well-being. The continuation and extension of the participants' social resources appeared to act as a buffer against their adversity. Participants' recounted the different social activities they maintained following their stroke, but also echoed their involvement in new ones as well. These social activities included; bowls club, football club, choir group, going out for dinner, meeting friends, visiting restaurants, involvement in a stroke group, and travelling. Two men recount their involvement in community groups.

*Once a month, and every Wednesday I've got group physio and swimming, and every second Wednesday I've got 'Out and About'. They [group] got a grant from the government, so we have a meal, a pokies voucher, and drinks every fortnight' (rural stroke survivor).*

*I joined the stroke support group. My daughter read about it and asked if I would like to be a part of it. It's in (place). I've got stroke talk there [points to brochure]. I didn't realise there was an Australia wide group. In the mean time, I'm in touch with the (local community group). They're in the newspaper. This week it's exercise group. The first time I saw them I rang up to get an assessment. I'm motivated towards exercise. I had a great result from it (urban stroke survivor).*

Involvement in community and social groups was profoundly important to several stroke survivors. The enjoyment of sharing stories and experiences with others, the opportunities to meet people and to participate in regular outings appeared to have a momentous impact on their health and well-being. Social inclusion was perceived as a vital ingredient in the participant's ability to overcome their adversity.

#### **7.4.1.1 Structural Ties**

The structural ties between group members were important for stroke survivors within a social network. This was particularly so for those involved in a stroke group, although it did exist in other groups as well (i.e., car clubs, charitable groups).

These ties were often described as the kinship that developed between group members. It was based on trust, understanding, empathy and the provision of support. These structural ties allowed network members to discuss issues, meet regularly, and reciprocate transactions (i.e., support) when the need was required. Several participants were able to talk about the sharing of information they were provided with, or offering support when a network member was having a difficult time. Furthermore, these structural ties were cohesive and offered a sense of connection to the network members. According to Dalton et al. (2001) these 'multidimensional' relationships allow the individual to cope better with a stressor. A number of participants were able to discuss the benefits of these structural ties.

*And I was an inpatient there for quite a while. They taught me to do all sorts of things, and we found a lot of kinship I found with other people who were there, and we were able to help a lot of other people who felt down in the dumps (rural stroke survivor).*

*No I tend to try and hold back a lot of the things that I go to say because I think they must be so sick of hearing about this sort of thing, um, where in the stroke support group you don't have to feel like you have to hold back. If you feel like saying something then you just say it and it doesn't matter whether it's relative to stroke or to anything. You're just comfortable saying anything at any time. It's also good to know that there are....there's one particular member who seems very lonely a lot of the time, it just makes you feel really wonderful to sit and have a great conversation with him. He's got fantastic stories to tell, and you think because he's troubles after stroke he doesn't seem to go out a lot, um, doesn't like mixing, doesn't like leaving the house really. And yeah, I guess it's just interesting to meet someone who has got so much to talk about in so little time. Um, so you feel good in yourself that you're there supporting others but you can also talk openly as well (urban stroke survivor).*

*That wasn't so bad, but the people at the pool that I met with, we all became really close friends and we use to have afternoon tea at D's every swimming day. We had a wonderful time. It was wonderful. We use to go down in the buses and see shows in (city), things like that and my life went ahead in leaps and bounds (rural stroke survivor).*

#### **7.4.1.2 Social Capital**

The notion of acting for the good of others appeared to play a prominent role for participants living in a rural environment. Offering sympathy and empathy towards others motivated these participants to engage in pro-social behaviours that, in turn, allowed the participants to feel that they were contributing to the good of others. The motivation behind their acts of public-spirited activities included understanding the fears, frustrations and lack of support following a stroke. It appeared that their own experiences of recovering from stroke offered newly diagnosed stroke victims the opportunity to talk about their concerns, to share their feelings and exchange information that was first hand. These individuals participated in voluntary acts because they wanted to support future stroke survivors. As one participant noted from her experience in recovering from stroke:

*I would have loved someone to come and see me in (city). They used to, down in physio with people who had had strokes and that, who weren't doing too good, 'they'd say L would you come down to physio and see this person?' And I'd go down and they'd introduce me and they'd say 'this lady had no prospects of ever walking again or doing anything for herself. Have a look at her, she hasn't stopped grinning'. And you could see the confidence on their face. 'Huh, you can get better'. That's what I want to do, not that I'm qualified or anything like that. I've been there, I've done that. I know how you feel.*

Another participant talks about his stay within a rehabilitation facility and the various people he met;

*We had people who couldn't afford it [transport and accommodation close to the rehabilitation facility]. We found the younger people with family down way at Sale and Gippsland. I remember one woman who came with her kids every weekend to see her husband and she had financial problems which fortunately we decided to help with accommodation from our families and one thing and another.*

Rural participants appeared to be heavily involved in voluntary activities. Not only where they involved in the local stroke support groups and services, but they further extended their activities into other organisations or advocacy roles as well. For instance, these participants volunteered their time in other organisations including cancer support groups, recreational clubs, women's advocacy groups, or their local farming networks. One man highlights the importance of having a close-knit farming network in his local region.

*Prior to when I had a stroke, if someone like one of our farmers had any problems, I used to always organise working bees to go and do it and help them out. And people remember those things, and they've been marvellous to me.*

Involvement in these voluntary activities also provided an underlying purpose such as an opportunity for the local community to formally or informally network, addressing community concerns, sharing information, assisting others within the community, engaging in enjoyable activities and events, and to socialise at regular

intervals. Rural participants expressed their pleasure and enjoyment when they spoke of these activities and the different organisations they were involved in. Having an opportunity to converse with others and to participate in an activity lifted their spirits and provided a sense of meaning to their recovery experience.

*Three months before I had the stroke I was sitting on my tractor one day and I was thinking every little town and place have got a book of their own town. And I thought W (town) has nothing, absolutely nothing. I thought before I die, because all the people are past my age and older and dying, they couldn't tell anybody about the early days of the district. And I thought now look, we've got to do this and got stuck into it (publishing a book) and collected information and then I called a public meeting. So we worked on it and you would get money too. We ended up getting \$13, 000 from the (local government agency).... And so away we went, and we had committee meetings and a committee. All of a sudden I had a stroke, and I said to two girls on the committee, 'you'll have to take the whole thing, I can't'. But the book was launched and apparently it was all about me and it was my greatest thrill.*

*Since the stroke I've obviously joined the (club). Last night for no reason other than I was asked to be involved, I'm now treasurer of the local stroke support group, cancer centre support group, and um we're there, I've continued with rotary.*

#### **7.4.2 Environmental Networks**

A number of environmental characteristics impacted on the participants' wellbeing following their stroke. The most notable factor that featured was geographical location. Living in a rural region had a remarkable impact on the participant's adjustment. Other factors mentioned included, accessing suitable resources, interaction with health professionals and health environments. The following will provide accounts of how these various environmental factors within a rural area, influenced participants' recovery.

#### **7.4.2.1 Accessibility**

Rural participants' were deeply concerned about their ability to access health and community services. Participants' were troubled by the lack of services that included specialist care, rehabilitation, and the length of waiting periods for appointments. In order to access specialists, several participants' commented on the amount of planning, travelling and time consumed to attend appointments with specialists in larger regional or city areas. Additional burdens included difficulties in trying to secure appointments with their local doctors, and accessing other health professionals including speech therapists and psychologists to accommodate for their needs. Overall, participants' considered themselves isolated and cut-off from the health services infrastructure. The following excerpts provide accounts of the difficulties in accessing appropriate specialists and services within the rural area to accommodate for their recovery needs:

*My husband's a diabetic and he was at home when I was in E (town) in a nursing home, which was part of the hospital, a nursing home part.*

*I never had a Doctor when I had the stroke. The Doctor retired and had gone down the country. When the ambulance carted me into SW (town) in the early morning there was a Doctor on duty. He said, 'I'm your Doctor', so I was so lucky, he is marvellous. Now I've got to see him about every three months.*

*We have to go to M (metropolitan city) for specialists and things. We've got no specialists or anything here.*

*The Doctors. You've got to go to M (metropolitan city) to see them, or wait until they come here.*

#### **7.4.2.2 Transportation**

The lack of public transport and the long distances required to travel to access appropriate health services was a concern raised by most participants living in a rural area. Several participants expressed difficulties with using public transport because of their physical impairments, thus they tended to rely heavily on family members to transport them to various places. Consequently, this dependence on transport left

participants with a sense of burden on their family each time they considered a trip. As a result these trips were limited. Several participants commented on the lack of transportation and difficulties they faced with getting around;

*The disadvantages are that we are so far away as I have mentioned. Trying to get somewhere else, it's so difficult. I've got lots of friends that are within 50 to 60 kms from here that I don't see very often. So your social life is much more restricted now than what it was. From a family point of view, as I've mentioned it does make it more difficult to see anybody to enjoy my friends.*

*Well on a personal note it's probably because I have kids that are 350kms away from here. They've all had young children and I don't expect them to charter their kids up here for.... My wife and I have always been very family orientated. We've got wonderful kids, wonderful grandkids, love to see them and all that, but we don't see as much of them now as we would have if I hadn't had a stroke. Socially, my social life has stopped.*

*Things got so difficult down there. In the end J [assistant] left and I had no way of getting to SH [town] for swimming or anything like that so they put me in a taxi to come to SH and back home again after swimming. I found that devastating because I'd be right at the pool with everybody there and having a wonderful time, and then I'd get in a Taxi and go back home again to a lonely house.*

*I think the big problem was I couldn't carry on up there [country] any longer. Not being able to get around, not having my car and being able to drive.*

*Not having adequate things here, as in (the city). You've got to travel for medication and all that type of thing. That's probably a big problem.*

#### **7.4.2.3 Hospital Resources**

Rural participants also highlighted the concerns they had with accessing services in their local hospitals. Participants reported a sense of detachment and spoke of being dismissed by hospital representatives in the attempt to access hospital services, equipment, and aiding newly diagnosed stroke survivors. These participants expressed

frustration at efforts in trying to build community networks and services for the good of others, only to find they are dismissed by hospital representatives. It is well reported that one of the greatest barriers to access for rural dwellers is the geographical location (McMurray, 2003), yet several participants voiced their concerns because of their inability to access resources through their local hospital. Overall, participants conveyed that the hospital was not accommodating for their health needs. As one rural participant noted;

*For example the hospital, their facilities for stroke are absolutely shocking. They tell you 'no you can't do this, you can't do that', and I'd say 'why not?' It makes me furious. The patients most times in the H Rehab (rehabilitation facility) had people explain quietly 'we won't be able to this because....' Whereas a lot of these bumbler.... Like the treadmill I had that I used to walk on broke down. And I asked and I asked and I asked. 'yes well'. It's gone on for months. So I used to walk on a rail up on the showgrounds which was covered in bird droppings etc, and go up and around, and go up and around to try and get some exercise because you couldn't let.... In the end I said 'E [hospital staff] don't talk rubbish to me, you just say yes or no. You either intend to get that (treadmill) fixed or you don't'. 'Yeah, we intend to get that fixed'. So a month later I got one of my own because it was useless up there [hospital].*

*A [another stroke survivor] has been with me trying to get the hospital to get out and let the public know what's available [stroke services] instead of having it in closed doors and no one knows what's going on. And we suggested they get in our local newspaper and print, and tell the public what's out there.*

*What makes me mad is that the hospital will not tell us who is the stroke person there and I find out myself and then send a letter to that person to come and join our stroke group or would you like to (stroke group member) or something like that. They [newly diagnosed stroke survivor] don't know anything about that because the hospital does not tell them.*

## CHAPTER 8

### Discussion

This chapter will provide a discussion of the findings presented in Chapter 7 and will specifically refer to the data collected from the interviews with stroke survivors. The findings will be discussed in reference to the literature reviewed in the first four chapters of the present study. This chapter will also examine the implications of the findings as depicted in the data collected from the stroke survivor interviews regarding the adjustment process following stroke. In particular, this chapter will discuss the following themes, *life adjustment, younger stroke survivors, health disparities in stroke care, the value of community, and the manifestation of resilience*. The discussion will also present the limitations of the present study. Finally, the recommendations will be presented for developments in best practice stroke care.

#### 8.1 Life Adjustment.

Recovery from stroke is certainly a confronting and challenging experience. All stroke survivors in the current study expected to achieve what they classified as a reasonable amount of recovery. However, for many this was not the case. A number of critical issues were considered pertinent by stroke survivors in facilitating a more successful and seamless recovery process. The range of critical issues identified as hampering this transition included, the lack of information of what to expect when returning home, concerns about being ill-prepared for community life, the long-term nature of adjustment following stroke, and the psychological/emotional disturbances experienced.

It was argued by stroke survivors that more information provided by key individuals (e.g., health professionals) would have further promoted adjustment after stroke. Specifically, the information desired included what to expect during recovery, managing life adjustment, advice on dealing with various ongoing symptoms (i.e., fatigue), and how to access resources within the community, including psychological support and intervention. Stroke survivors' suggested this type of information would have alleviated many of their concerns and provided the pragmatic support they required.

The research literature has long established the benefits of providing this type of information to stroke survivors at the acute stage, during rehabilitation and especially when returning to the community (e.g., Carlsson et al., 2009; Cott et al., 2007; Lincoln et al., 2004; Logan et al., 2004). Equipping stroke survivors with this information is considered essential. For example, Dixon et al. (2007) identified the importance for information to be provided to stroke survivors including, what has happened and what the future holds, as it could have a dramatic effect on rehabilitation and the stroke survivors' ability to stay motivated. Other authors have also reported on the benefits of providing information post stroke. Wiles et al. (2002) examined the information exchanged between physiotherapists and stroke patients in relation to recovery, and alleged the transition between in-patients and out-patients is confusing for people and often leads to disappointment. Wiles et al. further advised that this confusion could be alleviated by communicating information about what to expect at a pragmatic level and during outpatient treatment. As outlined in the literature review of the present study concerns were raised about stroke survivors' ability to adjust following stroke with emphasis directed at the lack of information and resources provided to them. In terms of service delivery, gaps exist, and it appears much work is needed ensuring key individuals deliver this vital stroke information.

The findings of the present study and those of previous research (Dixon et al., 2007; Wiles et al., 2002) have identified the importance of vital stroke information disseminated by key health professionals and stroke services. Nevertheless, the evidence from the findings of the present study indicates that stroke survivors continue to report their dissatisfaction about the lack of information. These findings concur with O'Connell, Baker and Prosser (2003) who found that the informational needs of caregivers of stroke survivors were not being met in the hospital and community setting. Information on various topics (i.e., how to access resources, managing depression) about stroke recovery would assist and support their ability to negotiate life adjustment. Furthermore, the absence of information may have negative implications to their adjustment outcomes (e.g., emotional difficulties, uncertainty). From a clinical perspective, providing information to stroke survivors about topics including 'what to expect following stroke' would significantly reduce the confusion and uncertainty that appears to currently exist. Having this type of information available, as highlighted by stroke survivors in the present study and in previous research (e.g., Low et al., 2003;

Röding et al., 2003), would significantly improve their adjustment abilities and further aid a seamless transition between rehabilitation and their return to the community.

Concerns about the transition from hospital to home in the present study also signified the lack of continuity between rehabilitation outcomes and the stroke survivors' preparation for their reintegration back into their social environment. There was a consensus amongst respondents about the struggles and distress they experienced in returning home and coming to terms with their changed life circumstances (e.g., ceasing employment, reduced social activities, isolation, inability to drive). They reported feeling ill-prepared for this transition. Returning home did not live up to their expectations and stroke survivors conveyed their shock and disappointment at their complete life disruption. Not only were they trying to adapt to their changed physical/functional abilities, but also trying to deal with the psychological/emotional consequences and the changes in their social environment as well. There is building evidence to support these findings. The research literature has consistently demonstrated the problems in adequately preparing stroke survivors for the transition from hospital to home (e.g., Carlsson et al., 2009; Cott et al., 2007; Wiles et al., 2002). This is hardly surprising when stroke rehabilitation is delivered in a short-term, goal orientated framework. Adjustment to changed life circumstances does not occur in the short-term.

The evidence indicates adjustment following stroke occurs over the longer term (e.g., Carlsson et al., 2009; Fure et al., 2006; Jones, 2006). Young and Forster (2007) argued about the importance of long term care following stroke. In particular, Young and Forster conveyed "discharge does not necessarily signify that maximum recovery from the stroke has occurred" (p. 88). As discussed in the literature review of the present study, and in line with previous research (Banks & Pearson, 2004), there are stroke survivors who experience a slow recovery due to the difficulties in coming to terms with their changed lifestyle. Not receiving support can have serious implications. Those stroke survivors who do not receive support over the longer term are at risk of developing problems (e.g., depression, emotional distress, diminished self-esteem, isolation), and often struggle with their changed life circumstances (Almeida & Xiao, 2007; Dixon et al., 2007; Fure et al., 2006; Van de Port et al., 2007). Effective stroke services need to provide ongoing support and rehabilitation over the longer term with the option of extended services at a community level.

Most respondents in the present study spoke of the various psychological problems they encountered following their stroke (e.g., low mood, anxiety, low confidence, depression, a sense of helplessness and hopelessness). However, despite the consensus regarding these symptoms, only a small number of stroke survivors (4) received professional psychological support. Not surprisingly, these individuals reported significant improvements with their ability to manage various psychological problems. These stroke survivors were able to tackle low moods. They had good insight regarding their psychological and emotional concerns, and they possessed the strategies to cope in various situations. It appeared by equipping these individuals with the psychological strategies and support, it not only facilitated the stroke survivor's progression through the transitional period from hospital to home but also promoted the ability to adjust to a changed lifestyle. From these findings it can be ascertained that the provision of psychological services has profound benefits and implications for stroke survivors during their adjustment process.

It is well documented in the literature about the benefits for stroke survivors receiving psychological support (e.g., Carlsson et al., 2009; Cassidy et al., 2004; Vickery et al., 2008). Yet, there continues to be substantial gaps in the provision of psychological services from a stroke services perspective. This psychological aspect of stroke rehabilitation has long been neglected. The evidence indicates those stroke survivors who do not have their psychological concerns addressed will regress to a lower functioning level and experience further crisis such as depression, anxiety and distress (White & Johnstone, 2000).

Along with the psychological reactions, stroke survivors also raised concerns about the various emotional reactions they experienced. These emotional reactions included frustration, fear, uncertainty, worry, distress, and a sense of loss. This is not surprising given the trauma and suddenness of an event like stroke. As illustrated from the responses in the current study, lives had been shattered following the aftermath of stroke with the impact affecting employment, relationships, and social activities. The primary aim of their initial recovery was directed at optimising physical functioning in preparation for returning to the community. In most cases the stroke survivor's emotional concerns were neglected or ignored. All of the respondents expressed difficulties in dealing with these emotions post stroke and most were dissatisfied with

the lack of professional support available. The findings of the current study illustrate that stroke survivors are not receiving the counselling interventions so critically needed. Furthermore, the literature continues to reinforce the need for counselling interventions following an event like stroke to assist and guide individuals through the process of adjustment (e.g., Carlsson et al., 2009; White & Johnstone, 2000).

The evidence available indicates untreated mental health issues can lead to difficulties in managing various psychological adjustments post stroke (e.g., Almeida & Xiao, 2007; Fure et al., 2006; Thomas & Lincoln, 2006; Young & Forster, 2007). The provision of ongoing psychological services would reduce the impact of these psychological and emotional reactions and alleviate many concerns. Yet, the amount of psychological support available for stroke survivors remains limited. As conveyed by White and Johnstone (2000), by facilitating patient's emotional adjustment through counselling this may enhance other aspects of the rehabilitation program and patient outcomes.

To fully incorporate the provision of psychological services within a rehabilitation framework would require an entire restructure of mainstream stroke rehabilitation practices. Redesigning health services to accommodate psychosocial needs following stroke has been identified in previous research (O'Connell et al., 2001). As can be seen from the findings of the present study the psychosocial benefits for stroke survivors' should be long lasting. This restructure would allow stroke rehabilitation services to be far more efficient by firstly, ensuring a comprehensive psychological assessment is conducted including the provision of psychological services. Secondly, stroke survivors would be adequately prepared to manage the transition into their community. Thirdly, stroke survivors would be better supported within their community and over the longer term. Clearly, there is increasing evidence as documented in the present findings and in the literature (White & Johnstone, 2000) demonstrating that stroke rehabilitation based solely on the physical/functional outcome is no longer acceptable.

Essentially, it is the responsibility of health service providers, researchers, and policy makers to evaluate and review current rehabilitation and community services to design appropriate programs that effectively assist the stroke survivor in their renegotiation of living. This urgency for redesigning stroke rehabilitation programs to

include comprehensive psychological intervention has been raised by previous authors (O'Connell et al., 2001). Yet, according to the research (e.g., Anderson, 2008; Warlow et al., 2003; Bowen et al., 2005) the implementation of evidence-based practice into stroke services has been slow in progress. Recently, the *Clinical Guidelines for Stroke Management 2010* were published by the National Stroke Foundation in Australia. This document provides a series of evidence-based recommendations aimed at improving treatment for stroke and TIA (Trans-Ischaemic Attack). Moreover, the guidelines provide recommendations to assist in the management of psychological conditions such as mood disturbance. These guidelines stipulate;

*Patients and carers should be informed that mood problems after stroke are common at any stage in recovery and should be encouraged to contact a healthcare professional should any mood changes persist for two weeks or longer and interfere with daily activities (p. 107).*

The Guidelines recommend a variety of interventions that include assessment, diagnosis, and referral to an appropriate healthcare professional. These national Guidelines represent the advances achieved to date in managing the psychological and emotional symptoms following stroke. The Guidelines strive to align with current research (e.g., Carlsson et al., 2009; Fure et al., 2006; Townend et al., 2010) acknowledging the need for psychological support and intervention for stroke survivors. In retrospect, these guidelines may have been a useful and a valuable tool during the period of recovery and adjustment for stroke survivors in the present study. The expectation within a stroke rehabilitation context is these guidelines would be the fundamental premise of stroke rehabilitation, thus addressing the psychological and emotional concerns of stroke survivors in the present study and facilitating a seamless and smooth transition to community life. These guidelines would have been provided in a timely manner as well as equipping the stroke survivors' with the necessary tools to manage the ongoing struggles associated with their life adjustment.

There is compelling evidence supporting the urgency for the provision of psychological services within the stroke rehabilitation context. It is no longer appropriate to consider stroke rehabilitation within a biomedical model based on the practices of physical/functional outcomes (White & Johnstone, 2000). The research evidence (e.g., Bogousslavsky, 2003; Carlsson et al., 2009; Cassidy et al., 2004; Clark

et al., 2003; Franzén-Dahlin et al., 2006; Fure et al., 2006; Townend et al., 2010) indicates the need to factor in psychosocial interventions as an integral part of the stroke recovery process.

## **8.2 Younger Stroke Survivors.**

The outcomes of this study have distinctive features of the recovery process that apply to younger stroke survivors. Although this group identified a range of concerns similar to those of their older counterparts, they also raised unique concerns specific to their age group, including *life disruption, the value of employment, personal/professional development, and social support*. The following section will discuss these concerns as described by the younger stroke survivor.

### **8.2.1 Life Disruption**

Younger stroke survivors are at a different stage of their life in comparison to their older counterparts. Suffering a stroke at a younger age can result in significant life adjustment over the longer-term. As conveyed by younger stroke survivors in the present study, individuals were struggling with various stages of their life including, caring for young children, concerns about intimate relationships and planning for marriage, financial difficulties, career planning, and the possibility of pursuing further education. Recovery and adjustment following stroke was considered a major disruption to their current lifestyle. Whilst the provision of rehabilitation services is aimed to address their physical functioning, all younger stroke survivors yearned for assistance to help them with their psychosocial needs. These findings are comparable with previous research (O'Connell et al., 2001). This is a very complex and sensitive area of adjustment to consider due to the range of various life concerns younger individuals encounter. Although previous research (e.g., Banks & Pearson, 2004; Röding et al., 2003; Stone, 2005) has identified the complicated adjustment process as applied to younger stroke survivors, authors such as Keppel and Crowe (2000) ascertained that the management of the younger stroke survivors psychosocial recovery is of vital importance and yet, possibly the most difficult to tackle and the most likely to be overlooked.

### **8.2.2 The Value of Employment**

Decisions regarding vocational options constituted a tremendous amount of planning and energy according to younger stroke survivors in the present study. And although vocational employment was viewed as a rather important element of recovery, six individuals out of eleven were employed. Empirically, it has been demonstrated that returning to work following stroke is considered as a crucial part of the stroke rehabilitation process and is associated with improved outcomes for stroke survivors (e.g., Koch et al., 2005; Treger et al., 2007).

Participating in employment led to a number of benefits according to younger stroke survivors in the present study. It was fundamentally important for younger stroke survivors to have a sense of purpose and meaning. This was a major incentive for them to return to work. Furthermore, employment appeared to have a positive influence or impact on the younger stroke survivors' lives. For instance, employment offered a sense of value and self-worth. It also provided structure, routine and tangible goals. Those employed considered themselves as part of a team, and their jobs provided them with a sense of independence, responsibility and income. Overall, employment was considered a valuable and desired activity. Conversely, those who were unable to return to employment conveyed their disappointment and frustration with their inability to do so, and considered this as an added contribution to the negative outcomes of their adversity.

All the younger stroke survivors in the present study expressed the difficulties they experienced with their aim of returning to employment. Unfortunately, the path of working towards employment following a stroke was viewed as an arduous and fragmented journey. Factors that hampered this transition included the slow progress of recovery, inability to return to previous employment roles, lack of information and guidance, and confusion about suitable vocational options. It is well acknowledged in stroke research that returning to work following a stroke is fraught with various barriers and obstacles (Lock et al., 2005; O'Brien & Wolf, 2010).

For a number of stroke survivors in the present study, the decision about not returning to work was self-governing. A great deal of the younger stroke survivors personal time was spent deliberating about possible employment options and found the vocational rehabilitation support scarce. In most cases little or no professional

assistance was provided for vocational counselling. This lack of appropriate vocational counselling has been reported in previous research (Lock et al., 2005; Treger et al., 2007). Hackett et al. (2009) suspected that the lack of effective vocational rehabilitation strategies is because this is an area largely misunderstood. Yet, it has been argued that professional vocational counselling following stroke can lead to successful outcomes (Lock et al., 2005). Only two stroke survivors in the present study sought professional advice for vocational counselling. Consequently, one stroke survivor had commenced paid employment and the other had pursued voluntary work. Various authors have concurred on the benefits in returning to work. Treger et al. (2007) reported returning to work as an indicator of successful rehabilitation. Koch et al. (2005) advised that rehabilitation professionals, health-care providers and employers who assist stroke survivors in returning to work are regarded as instrumental supports in providing emotional support and information with identifying and implementing job accommodations.

### **8.2.3 Personal/Professional Development**

The findings of the present study also demonstrated the younger stroke survivors' interest in personal development. These individuals were seeking activities of interest that stimulated their intellectual disposition. Activities included learning to use a computer, and enrolling in community TAFE and university courses. Younger stroke survivors found these courses stimulating, challenging, and it provided them with opportunities to meet new people and to network. Importantly, involvement in these types of activities would be considered advantageous within the scope of rehabilitation and adjustment for younger stroke survivors. Very few, if any, previous studies, have explored this aspect of recovery. To my knowledge there is no available data or information that supports these findings, suggesting a more intensive exploration of this area is required.

### **8.2.4 Social Support**

Existing research (e.g., Banks & Pearson, 2004; Low et al., 2003; Stone, 2005) concurs that younger stroke survivors encounter a whole range of psychosocial issues following stroke (e.g., changed roles, body-image, and community participation). Much of this is tied up in the consciousness regarding 'self' (Keppel & Crowe, 2000; Stone,

2005). According to Keppel and Crowe, “for a young person, the most profound of all possible disturbances occurring as a consequence of stroke may be in its effect on the perception of self” (p. 17). Most of the younger stroke survivors in the present study exemplified a common perception regarding the negative changes concerning their ‘self-image’, lack of confidence, and reduced self-esteem. As a result, this often led to individuals relinquishing various social and leisure activities that would otherwise be considered vitally important as part of their adjustment process. The implications of reduced involvement in activities, in some cases, led to reports of loneliness, frustration and despair.

In terms of younger stroke survivors and their psychosocial needs, it is vitally important that stroke rehabilitation services focus on establishing appropriate programs that are unique and sensitive to their circumstances. Similar recommendations have been suggested by O’Connell et al. (2001). To deny younger stroke survivors this type of service and support would increase their risk of developing psychological and emotional disturbances, and decrease their capacity for social participation. Empirical research has indicated failure to address the psychosocial needs of younger stroke survivors leads to psychological and emotional disturbances (Keppel & Crowe, 2000; Stone, 2005). It is simply not enough for rehabilitation service providers to continue with a pragmatic approach, aimed at optimising the individual’s physical level of functioning in preparing them to return to the community and their altered lives. Current stroke rehabilitation services and practices are due for a complete restructure that also incorporates and acknowledges the psychosocial interests of the younger stroke survivor in renegotiating their lives.

As previously mentioned, there have been great advances in stroke research. Consequently, improvements regarding best practice care and policy about stroke services are emerging. With the publication of the *Clinical Guidelines for Stroke Management 2010* we are gaining valuable information and recommendations regarding the delivery of best practice stroke care. Although these guidelines provide recommendations covering *early assessment and diagnosis, rehabilitation, and community participation and long-term recovery*, further research is warranted within the context of younger stroke survivors.

As mentioned previously, by understanding and identifying the experiences of recovery and adjustment as perceived by the younger stroke survivor, we are able to fine tune the rehabilitation and adjustment experience following their stroke, thereby ensuring an appropriate, comprehensive and meaningful recovery process for all.

### **8.3 Health Disparities in Stroke Care**

The findings of the present study demonstrate a disturbing reality of the existence of disparities in health care, in particular, within the context of rural stroke recovery. It appears one's health status is severely compromised if living in a rural region of Victoria (Australia). A number of social determinants were identified in the current study that presented serious concerns in the delivery of health services to rural stroke survivors. These included difficulties with accessing specialist services and psychological support, limited or no access to essential equipment, problems with use of, or accessing amenities and stroke services, and transport issues.

The present study uncovered inequities of essential services at a local level. One of the dilemmas confronting rural stroke survivors was access to specialist services including stroke specialists (e.g., doctors, nurses) and allied health staff. Rural stroke survivors in the present study relayed their dissatisfaction with not having stroke specialists or allied health staff nearby, or not having available access to these health professionals at all. As a result, these rural stroke survivors are faced with depleted specialised health services and specialist expertise. This places rural stroke survivors at an enormous disadvantage.

It can be argued that stroke specialists and allied health professionals play key roles in the management of stroke care (Claiborne, 2006; White & Johnstone, 2000). These roles include advice about ongoing medical management following stroke, the dissemination of information related to stroke, the provision of strategies to improve lifestyle changes, and equipping stroke survivors with the necessary tools and resources to adequately prepare them for community reintegration. Numerous studies have acknowledged the importance of these specialist stroke services in the ongoing monitoring and management of stroke care and the influence this has on improved outcomes (e.g., Askim et al., 2004; Cott et al., 2007; Lincoln et al., 2004). Yet, rural stroke survivors in the present study conveyed their difficulties in accessing these key

health professionals or the absence of them altogether. Similar findings have been consistently reported in previous stroke research (e.g., Lee et al., 2003; Spearman et al., 2007). Despite this, the stroke literature concurs the ongoing difficulties faced by individuals attempting to access specialist services and allied health professionals in rural areas (e.g., Cadilhac, Moodie et al., 2006; Cadilhac, Lalor et al., 2006; FitzGerald et al., 2001; Hegney et al. 2007; Judd & Humphreys, 2001; O'Connell et al. 2001).

The inadequacy of essential services within a rural setting also filters into the provision of support and intervention for mental health. According to the accounts of rural stroke survivors in the present study, these types of services were inaccessible or simply did not exist. The various psychological and emotional problems experienced by these individuals included a sense of isolation, abandonment, fear, depression and a sense of helplessness. These associated problems were not dissimilar to those mentioned previously, but they appeared to be compounded by their geographical location. For instance, stroke survivors limited their engagement in activities and outings as a result of the distances required to travel, thus increasing their sense of isolation. In addition, psychological services were not easily accessible or necessarily available. And many of the rural stroke survivors were not able to drive, consequently limiting their transport options. Hence, one's mental health following stroke is severely compromised because of living in a rural setting. In most instances, psychological and emotional support was provided through friends, family and/or community groups.

The difficulties in accessing appropriate psychological support within rural environments have been well reported in previous studies (e.g., O'Connell, et al. 2001; Spearman et al., 2007). Nevertheless, there continues to be serious shortfalls concerning mental health and the provision of these services within rural settings. Fraser et al. (2002) argued there is a greater inequality in the distribution of specialist services amongst psychiatrists and psychologists practicing outside of metropolitan areas that are far below the proportion of Australian's population living in these areas (p. 291). Increasing the availability and accessibility of mental health clinicians would be one way of alleviating many of these concerns.

Campbell et al. (2006) argued mental health in rural locations requires urgent evaluation given the shortages of allied health services and qualified professionals. This shortfall becomes an additional disadvantage on top of the already depleted stroke

services available within rural regions. Campbell et al. further suggested that research needs to focus on three critical issues including; “developing an understanding of the level of need in a rural setting, understanding rural cultural attitudes to mental health, and an evaluation of how to provide unique mental health services for the rural setting” (p. 601). Evidently, the findings of the present study, in-line with the previous literature (O’Connell et al., 2001; Spearman et al., 2007), demonstrates a serious shortfall of essential services available for stroke survivors that impacts negatively on their well-being.

### **8.3.1 Inequities in rural health infrastructure**

The findings of the present study identified disparities in health care. Rural stroke survivors reported limited access to essential equipment, amenities, and stroke services. For example, rural stroke survivors experienced difficulties in accessing rehabilitation equipment (e.g., bikes, gym equipment). A nursing home attached to a local hospital was utilised as a rehabilitation facility. The rural stroke survivors’ accounts reflect the current state of services and amenities that currently exist within the health service infrastructure.

From a health service perspective these deficiencies in infrastructure have major implications for the rural stroke survivor and become problematic over the longer term. Stroke often leaves the individual with a physical impairment, and adaptation may require the ongoing exercise and physical maintenance to facilitate their adjustment. Any decline or diminish in their physical abilities may lead to an increase in psychological problems. These concerns have been mentioned in previous research. Claiborne (2006) raises the serious consequences of a decline in physical functioning and the psychological distress that results. There is a growing body of evidence demonstrating the inequities within the rural health infrastructure (e.g., Cadilhac, Moodie et al., 2006; Lee et al., 2003; O’Connell et al., 2001). Not surprisingly, these inequities of essential services in rural stroke care have also been reported at an acute level (Cadilhac, Moodie et al., 2006; Gebhardt & Norris, 2006; Joubert et al., 2008).

Much of the current literature addressing the inequities of health services within the rural health infrastructure, are directed at the acute stage of stroke recovery. Joubert et al. (2008) undertook a review of the provision of appropriate stroke services in rural

and regional settings and found that rural Australian stroke survivors were less likely than their urban counterparts to receive vital treatment interventions within 24 hours of admission. Furthermore, Joubert et al. reported there was no rural hospital in New South Wales that had a stroke-specific clinical nurse, in comparison to the 21 available in the metropolitan regions. Cadilhac, Lalor et al. (2006) reported within “Australia there is no universal access to Stroke Units, thus many stroke survivors are not receiving evidence-based care” (p. 704). Given that research has focused on identifying inequities of rural stroke services at the acute level, one can only speculate about the inherent nature of these inequities during the rural stroke survivors’ life adjustment phase and beyond. The findings of the present study align with those of previous research (Cadilhac, Moodie et al., 2006; Lee et al., 2003; Nicoletti et al., 2000) and do confirm that these inequities of health service infrastructure continue to be present over the rural stroke survivors’ later stages of life adjustment and beyond.

As indicated in the findings of the present study, suffering from a stroke and residing in a rural environment presented many challenges. Another one of these challenges was the rural stroke survivors’ ability to access transport. The difficulties with accessing transport were considered a significant barrier for many. According to rural stroke survivors, there was an absence of an extensive transport system with reduced, or in many situations, no access to trains, trams and regular bus services. This meant a limited and infrequent public transport service that severely compromised and restricted their ability to mobilise around their community and to travel long distances. Much of the transport was provided by carers, friends or family, and taxis. For many, along with the financial cost and inaccessibility of transport, this left a sense of dependence on others for reliance and assistance in transporting them, and/or significantly reduced their involvement in community and leisure activities.

The findings of the present study demonstrating the insufficient transport services within a rural setting is comparable with previous research (Faux, 2005; FitzGerald et al., 2001; Sample et al., 2007; Spearman et al., 2007). Gething (1997) argued people with disabilities who lived in remote and rural areas experienced double disadvantage in regard to the receipt of these types of services. Gething further conveyed that public transport within rural areas is often infrequent and the infrastructure is not as well developed as compared to urban locations.

The difficulties with accessing transport also led to serious implications with the stroke survivors' engagement in social activities. For instance, those individuals who struggled with accessing transport identified this as a contributing factor that led to their reduced involvement in local community activities. These stroke survivors conveyed a sense of community disengagement, low mood, sadness, and an increase in their sense of social isolation as a result. Despite this, every effort was made by rural stroke survivors to maintain some type of community involvement, such as the frequent use of taxis and/or relying on others for transport. The stroke literature has long-established that an absence in social participation and social contact can have a negative impact on the stroke survivors' well-being (Askim et al., 2004; Clairborne, 2006). More importantly, the findings of the present study and those of previous research indicate that reduced participation in community and social activities leads to a sense of community disengagement, isolation, and psychological/emotional problems for stroke survivors. Having access to a means of transport to facilitate community engagement for rural stroke survivors is considered vital. Overall, the evidence demonstrates insufficient services within rural locations (i.e., transportation) have a negative effect on the lives of rural individuals (FitzGerald et al., 2001; Galambos, 2005; Spearman et al., 2007).

Research to date conveys that health care disparities amongst rural populations are associated with poor health outcomes (e.g., Baker, Metzler, & Galea, 2005; Galambos, 2005; McMurray, 2003). Rural Australians are consistently referred to as disadvantaged when compared to city dwellers. Rural Australians are generally not as healthy as those who reside in urban centres (AIHW, 2010; Judd et al., 2002). At a national level, health researchers, health professionals and public health advocates continue to engage in discussions regarding the multiple rural health problems and health service issues. Meanwhile, rural stroke survivors as presented in the findings of the current study, continue to experience disadvantage and inequities concerning their health care. Thus, the problem of addressing rural health continues. According to a report by the Australian Institute of Health and Wellbeing, the continuous difficulties in addressing the concerns regarding rural health is largely attributed to the vast diversity of rural areas and their diverse populations making it difficult to categorise (AIHW, 2010). McMurray (2003) attributes the decline in health services to the economic rationalism due to the more tightly financial control of health services resulting in a

rationalisation of cost inefficiencies. Furthermore, McMurray adds this has led to the loss of existing services or the failure of rural areas to receive new services that otherwise would be available in urban areas. This is of no comfort to rural stroke survivors in the present study.

### **8.3.2 The Value of Community**

Another striking feature in the results of the present study was the value of community as presented by rural stroke survivors. Rural stroke survivors considered their connection with the local community as crucial in their ability to reintegrate back into their environment. Despite the many shortfalls regarding the disparities in health services (e.g., lack of access to health professionals, transport issues), rural stroke survivors managed to counter balance this with their powerful ability to develop strong links with others. Of particular importance was the stroke survivor's *community connectedness* and value they placed on their *membership ties* and the existence of *social capital* within the community.

#### **8.3.2.1 Community Connectedness**

Community participation and connectedness was demonstrated by rural stroke survivors in the present study through their involvement in various community activities including working bees, Rotary Club, the Returned Serviceman's League (RSL), sporting clubs, leisure activities, and advocacy and charity groups. Being affiliated with and participating in various community activities was a crucial element expressed by all rural stroke survivors. This affiliation occurred through the development of strong networks and relationships within their rural communities. Essentially, rural stroke survivors' lives were centred on community life. These findings are consistent with previous research which has identified the importance of community and participation as a central feature during the recovery phase in stroke populations (Amarshi et al., 2006; O'Connell et al., 2001). In particular, the present study found that community participation and connectedness was positively associated with the rural stroke survivors' ability to adjust from their adversity.

The research literature has long supported the notion of community connectedness and participation outlining the benefits to the individual. Prilleltensky

and Prilleltensky (2006) discussed the signs of personal well-being and attributed this to meaningful engagement in the community. Rural stroke survivors in the present study viewed their participation in community activities as a meaningful exercise that provided stimulation and a sense of normality in their otherwise challenged and disrupted lives. Instrumental to their personal wellbeing was the value and prominence of their community connections, supports, networks and relationships. Added to this equation was the opportunity for social exchange, interactions, and the preservation of their social contributions and status. Intrinsically, community connectedness represented a source of personal empowerment. As noted by McMurray (2003), “the concept of empowerment is based on the premise that if people are prepared for illness or rehabilitation from injury with both information and community support systems that help them chart their own course, they will be better able to recover from illness and/or maintain health” (p. 14).

Overall, the rural community milieu provided the environment and resources that promoted individual adjustment in the present study. Rural stroke survivors described achieving fulfilment in their lives that was enabled through their sense of community connectedness. Thus, the central focus here is the relevance of community connectedness and participation, and the substantial promotional value this has on life adjustment for rural stroke survivors. Several authors have stressed similar views about the effectiveness of community participation (e.g., Amarshi et al., 2006; Claiborne, 2006; Cott et al., 2007; Meijer et al., 2004). The findings of the present study confirm these views. Community connectedness and participation provides an important function in terms of meeting the social needs of individuals. Hence, more weight needs to be given to define and consider this construct within the delivery of stroke service provision. Typically, stroke rehabilitation practices are based on the biomedical framework limiting the scope of services to improving physical functioning over a short term. The findings of the present study would dispute these traditional practices and defend the urgent need for more suitable delivery of services that integrate environmental factors such as community over the longer term and beyond.

### **8.3.2.2 Membership Ties**

Having a sense of membership that provides opportunity for meaningful participation in community activities, including the development of social relationships

was profoundly important to rural stroke survivors in the present study. Living in a geographically defined area constituted this membership. Descriptions of membership and a sense of belonging were relayed as acceptance by other members, identifying and relating to other members, and the value of commitment as a group collective. Living in a rural community was characterised by a strong sense of identity and community spirit. Furthermore, among the rural stroke survivors there was a sense of 'kinship', affiliated with the remoteness and isolation of their community. A common characteristic highlighted by rural stroke survivors in the present study was their connection with the land. Living as/or amongst farmers rendered a deep respect for the surrounding countryside. This deep affinity with the land has also been found by Hegney et al., (2006) and FitzGerald et al., (2001). Hegney et al. describes this affiliation with the land as a factor that enhances resilience. The findings of the present study support Hegney's et al. view.

Strong network ties and social relationships promoted adjustment for rural stroke survivors in the present study. These relationships were based on interpretations of the stroke survivors' core values that included trust, security, empathy and support. Factors characterised as attributing towards their process of adjustment included the by-products of these social interactions such as the sharing of information and resources, exchanging of ideas, the development of bonds between members, a sense of belonging, and social interaction at a personal level. All rural stroke survivors conveyed their satisfaction with their ability to sustain, as well as build, these network ties and relationships within the community. Thus, the findings of the present study indicate that the maintenance or establishment of network ties and social relationships are significant protective factors in the rural stroke survivors' ability to overcome their adversity. Previous stroke literature has alluded to similar findings.

Glymour et al. (2007) explored the possible effects of social resources on stroke survivors' level and change in cognitive outcomes. The findings indicated that stroke survivors who reported social ties in multiple areas had better cognitive summary scores. A study by Claiborne (2006) who evaluated the effectiveness of a care coordination model for outpatient stroke survivors reported that a high degree of social participation assumes emotional well-being. Gorman et al., (2007) who did not look at stroke, but rather at men's mental health experiences within a rural environment, found

men expressed many reasons to feel positive despite the difficulties they were going through. Gorman et al. attributed these positive reasons to a sense of purpose and belonging found in rural communities, where families are more likely to live nearby and good social structures are in place. Evidently, the findings of the present study and those of the limited research available (Claiborne, 2006; Glymour et al., 2007; Gorman et al., 2007) indicates good network ties and social relationships promote adjustment following adversity and are an important factor for individual psychosocial health.

### **8.3.2.3 Social Capital**

Given the cohesive and supportive community capacity that is represented in the findings of the present study it would appear social capital exists. Along with the structural ties between members of the rural community, involvement of stroke survivors in advocacy groups, including the trust and interaction that was established between community members, there appears to be characteristics representing social capital. The community environment provided an opportunity whereby rural stroke survivors were brought together for mutual interests. According to Prilleltensky and Prilleltensky (2006) social capital is defined as “the collective resources consisting of civic participation, networks, norms of reciprocity, organisations that foster trust among citizens, and actions to improve the common good” (p. 265). Given this definition, it would appear social capital is operational within the rural community of stroke survivors.

The present study demonstrated the vast social networks and ties among rural stroke survivors. These networks and ties instilled a sense of trust and mutual respect among the members. Rural stroke survivors valued the bonds that were created as a collective. Further to this, rural stroke survivors were involved in activities for the greater good of the community. For instance, there were individuals who participated in charity work (e.g., raising money for the local hospital & charity groups). Others were involved with increasing the awareness of stroke services through their local media, or campaigning to their local council. Various individuals were attending the local hospital as a source of inspiration to help newly diagnosed stroke survivors. And there were individuals who were involved in local community projects such as creating a book about the history of their town. Overall, rural stroke survivors were deeply engaged in the environmental aspects of their community. Thus, the findings of the present study

demonstrate that social capital is operational and exists within the rural communities promoting a sense of social cohesion among rural group members.

Very few, if any, studies have explored the construct of social capital within the context of stroke and community participation. Nevertheless, the research available has acknowledged the value of cohesive communities and the participation of its members (Prilleltensky & Prilleltensky, 2006). Nummela et al. (2009) investigated the associations between self-rated health and social capital among aging people in urban and rural areas and recommended that the use of resources to improve social participation of citizens may be useful to enhance the health of aging people. Furthermore, Nummela et al. indicated that high participation and social support relates to better health. Consequently, it can be ascertained there are a wide range of benefits for the individual who engages in community participation and social cohesion. Evidently, the findings of the present study indicate community participation and cohesion enhances the psychosocial aspects of adjustment for rural stroke survivors.

Social capital is viewed as a powerful and essential entity that promotes the interaction between the individual and their community environment. By commissioning the notion of social capital and its application to the rural community we are focusing on the mechanisms that bring people together to promote adjustment following adversity. Thus, further research is required to explore the mechanisms, processes and resources that enhance and promote social capital within the community.

#### **8.4 The Manifestation of Resilience**

The findings of the present study identified stroke survivors who engaged in resilient behaviour. These individuals employed a range of resilient features including intrinsic and extrinsic resources they could draw upon to facilitate adjustment. Resilience was also closely associated with the presence of various psychosocial factors. These factors included *individual disposition, competence, self-esteem, social support, intrapersonal factors, and community involvement*. Overall, resilience was viewed as a transactional process that captured the individual characteristics and interpretations, the processes, including the interaction between the individual and their environment, with negotiating life adjustment. The following section will elaborate and discuss these findings further.

#### **8.4.1 Features of Resilience**

The findings of the present study indicated there are stroke survivors who managed to adapt to their altered circumstances despite adversity. These individuals demonstrated patterns of behaviour which underscored features of resilience. They were able to draw upon essential resources and strengths that promoted positive adaptation and ameliorated any stressful circumstances. Features of resilient individuals included having a positive outlook on life, setting goals for the future, having a vast amount of friends, an ability to develop friendship networks, and pursuing social engagements and activities. Similar findings have been found in previous research (e.g., Geanellos, 2005; Glicklen, 2006; Rabkin et al., 1993). Hegney et al., (2007) explored community and individual resilience in rural Australians and found some of the characteristics of resilient people to include, being positive, adaptable and flexible, having goals or a vision for the future, and willing to 'have a go'. The implications of these findings indicate that resilience has emerged as a benign and valuable concept in the promotion of adjustment and adaptive behaviour following illness.

The vast amount of literature available about the phenomenon - resilience has consistently documented the appealing effects of resilience during times of trauma or adversity (e.g., Bonanno, 2005; Hegney et al., 2007). As evident in the present study and previous research (e.g., Glicklen, 2006; Hardy et al., 2004; Steinhardt & Dolbier, 2008), resilience plays a crucial role in one's ability to interpret and respond to stressful life events. Stroke survivors in the present study were able to make a conscious decision of how they would respond to their adverse situation in a manner that would buffer them from negative life circumstances. They were able to develop ways of negotiating their personal lives and maintained a positive outlook for the future. From these findings it can be ascertained, resilience as a construct deserves more attention in its application during times of adversity such as recovering from illness.

Essentially, resilience is a useful and valuable tool helping individuals combat against negative experiences and life stressors. Earlier studies would tend to agree (e.g., Bellin & Kovacs, 2006; Richardson, 2002; Steinhardt & Dolbier, 2008). As conveyed by Hardy et al., resilience should be an important factor in the maintenance of well-being as a person ages and as a strong predictor of recovery from disease. Hence, in line with the findings of the present study and previous research, there is compelling

evidence supporting the beneficial properties of resilience in promoting adjustment from serious illness. With this in mind more concentration needs to be directed towards resilience and its association with psychosocial factors.

#### **8.4.2 Psychosocial Factors**

The findings of the present study revealed there were stroke survivors who benefited from an assortment of psychosocial factors to help them navigate through stressful life circumstances. The psychosocial factors identified included *individual differences* that comprised hope, optimism, and confidence; *competency*, including mastery, self-efficacy, and problem-solving; *self-esteem; intra-personal factors*, including determination and perseverance; *social support*, which incorporated emotional and practical support, and *environmental influences* (i.e., community and infrastructure). Consequently, a constellation of protective psychosocial elements was employed by stroke survivors.

The presence of these psychosocial elements appeared to moderate the negative effects of stroke and facilitated proactive behaviour in the stroke survivors' adaptation and adjustment. For example, they were more likely to engage in effective planning strategies, were hopeful about their future, believed in their own ability to accomplish tasks, continued to strive and push themselves in their efforts, or developed new networks of friends. Various authors have illustrated the benefits of psychosocial factors amongst different types of illness including osteoarthritis (Ferreira & Sherman, 2007), breast cancer (Friedman et al., 2006), schizophrenia (Geanellos, 2005), and HIV (Ironson et al., 2005). Hence, the evidence strongly supports the crucial role these psychosocial factors play in promoting adjustment following adversity.

It is necessary to understand and familiarise oneself with the various psychosocial factors that underpin resilience. By doing so, we develop an appreciation of the characteristics that modify or ameliorate risk. For instance, stroke survivors who tended to feel good about themselves and their social environment did not express a sense of isolation or abandonment. They viewed themselves as well respected in their community and enjoyed participating in activities. Stroke survivors who described a favourable outlook on life conveyed confidence in their abilities, and appeared to avoid any sense of hopelessness or despair. From these findings the presence of various

psychosocial factors were confirmed which provided valuable insight to the underlying nature of resilience.

Nevertheless, the findings also demonstrated that there is a great variation in how people respond to adversity or stressful circumstances. These findings are congruent with the vast amount of previous resilient research (e.g., Rutter, 1985; Rutter, 1995; Rutter, 1997; Yehuda & Flory, 2007). Psychosocial factors are not necessarily inherent in all respondents exposed to stressful life circumstances. Alternatively, the findings in the present study identified stroke survivors who experienced significant adjustment problems and were at risk of developing psychopathology. These individuals reported sadness, feeling trapped and isolated, a sense of helplessness and hopelessness, and low confidence. It is strikingly clear there is variation in how people respond to adversity (i.e., stroke). Unfortunately, not all individuals are blessed with the repertoire of psychosocial factors that promote adjustment. However, by identifying the different psychosocial factors present amongst resilient individuals we can, as outlined by Jacelon (1997), capitalise on the resilient person's strengths by providing assistance to individuals who are not inherently resilient.

Previous research (Glicklen, 2006; Hardy et al., 2004; Rutter, 1995) has long established the presence of multiple psychosocial factors that promote resilience. However, very few studies have explored the impact of several factors in relation to resilience and adjustment from illness. Clearly, from the findings of the present study, the value and contribution these psychosocial factors have in association with resilience, and one's ability to recover from illness, should not be underestimated. Hardy et al. (2004) advocated for further research to fully elaborate the relationship between resilience and various psychosocial factors. The findings of the present study have recognised the value of this relationship and the interplay that occurs between them, in particular, when adjusting from serious illness.

#### **8.4.3 Resilience as a Transactional Construct**

As discussed in the literature review (chapter 4), resilience is more than the protective factors initially thought of two decades ago. It is a multi-level system made of various mechanisms and processes. It is not exclusively defined by the interplay between psychosocial factors and the individual as originally thought. As illustrated in

the findings of the present study, it is force that captures the experiences, interpretations, attitudes and the engaging processes that occur between the stroke survivor, others, and their environment. The research literature to date, documents resilience as the subjective interpretation of how individuals respond to their adversity, how they negotiate resolutions, and essentially how they think about it (Egeland et al., 1993; Glicklen, 2006). Johnson (as cited in Glantz & Johnson, 1999, p. 226) viewed resilience as a concept that changes across time, circumstance and context. The findings of the present study align with Johnson's view.

The findings have also identified that past experiences provide valuable insight in how individuals interpret their situations and utilise the resources to manage their adversity. With this in mind, resilience is regarded as a process that occurs across time. The findings illustrated examples of stroke survivors who described various stressful and negative life events (i.e., school bullying, early psychological trauma, relationship breakdown) that required personal negotiation and adjustment. These individuals spoke of past traumatic experiences and hardship, yet despite these difficult and threatening situations, they managed to adapt to their circumstances and "bounced back" from adversity. Given these findings, it can be argued that resilience is not a static and concrete trait but rather, a constantly changing phenomenon that allows individuals to negotiate through life. Thus, resilience can be considered as a force that permeates across the lifespan.

As noted in the literature review it was proposed by understanding the key concepts surrounding resilience (e.g., mechanisms, processes, and interplay between the individual & environment) we may tap into resources that would assist individuals to adapt and adjust to an adverse event. Importantly, these resources could be factored into stroke rehabilitation programs designed to support and improve stroke survivors' renegotiation of living. Developing resilience intervention programs for individuals recovering from a serious illness would be an effective treatment option. These programs would be designed to empower individuals and build on their inner strength, including the provision of essential resources and information to navigate and manage stressful situations. During the delivery of resilience intervention, emphasis would be directed at various psychosocial factors including building self-esteem, developing social networks, and developing skills to deal with and resolve crisis. The findings of

the current study support the need for further research to determine the effectiveness this type of resilience intervention.

The benefit of implementing resilience intervention programs has been reported in previous research (e.g., Steinhardt & Dolbier, 2008). Steinhardt and Dolbier examined the effectiveness of a 4-week resilience intervention program to enhance resilience, coping strategies, and protective factors on college students during an increased period of academic stress. Steinhardt and Dolbier found the resilience program offered useful treatment in stress-management and stress-prevention for the college students. In particular, they found that the experimental group had greater resilience and more effective coping strategies (i.e., higher problem-solving). Furthermore, the group had higher post-intervention scores on the protective factors of self-esteem, self-leadership, and positive affect. The implications of a resilience program designed for individuals recovering from stroke, is far reaching. A resilience intervention program would be an effective means of treatment leading to significant positive outcomes for the individual. Thus, further research is warranted.

Overall, resilience has been identified as a valuable yet complex phenomenon that comprises of many intricate layers. Contained within these layers are various personal attributes, qualities, intrinsic and extrinsic factors, as well as the multiple mechanisms and processes that occur in its application. Resilience is not static, nor an inflexible concept, but rather, a dynamic transactional process that occurs between the individual and their environment. Resilience as a phenomenon permeates across the lifespan and brings with it past experiences and interpretations. From this information we have the potential to develop intervention programs to promote adjustment from adversity such as stroke and to reduce the risk of psychosocial problems (i.e., PSD, emotional disturbances) and stressors.

In order to support an understanding of the comprehensive characteristics that contribute to the concept of resilience, as accounted for by stroke survivors in the current study, a transactional framework is proposed. This proposal would consider six major constructs that have been identified from the findings of the current study: Individual Differences, Competency, Self-Esteem, Social Support, Intrapersonal and Environmental factors. As noted these constructs include intrinsic and extrinsic constructs that interact between the individual and with their environment. Hence, the

psychosocial resilient framework can be considered transactional in its nature. This framework provides a broad yet simple interpretation of the complexity of the phenomenon resilience as portrayed by stroke survivors. Based on the results of this study further research determining the benefits of a proposed psychosocial resilience framework and its application in the delivery of stroke rehabilitation programs is warranted.

## **8.5 Limitations of the research**

Even though the current study has provided valuable information about the experience of stroke, there are limitations to consider. In order for the participants to complete the semi-structured interview they needed to be able to communicate effectively, thereby ruling out those participants who were experiencing a communication disorder which could lead to under-representation in the sample. Furthermore, given the sampling procedures adopted within the current study, we cannot lay claim to a broad generalisability. The study included younger stroke survivors (the youngest 23 years of age), therefore caution must be considered when interpreting the results as developmentally they are not similar, and their experience of stroke maybe quite different than their older counterparts. Finally, those within the early period of recovery (a couple of months post stroke) may have many other issues of adjustment as compared to those included in this study who have had, in some cases several years to adapt and adjust to their perceived levels of disability and experiences of life adversity. Given these limitations, it can be established that longitudinal research is warranted which would involve a larger population.

## **8.6 Recommendations**

The present study highlighted a number of concerns regarding current practices in the provision of stroke services and the stroke survivors' ability to adjust from stroke. Although the stroke literature to date continues to be prolific in disseminating information about evidence-based care, there are several suggestions to be considered. Firstly, a significant amount of focus is urgently required at addressing the psychological and emotional sequela following stroke. As found in the present study and in previous research (e.g., Alaszewski et al., 2004; Bowen et al., 2005; Townend, et al., 2010; White & Johnstone, 2000), current stroke practices are not adequately

addressing the psychological needs of stroke survivors. Instead, a great deal of attention is directed at the physical/functional aspects of recovery while the psychological and emotional issues continue to be neglected.

Furthermore, psychological support is required over the longer term. Recovery and adjustment from stroke is not necessarily complete following discharge from hospital services or programs. Stroke survivors in the present study continued to experience profound psychological and emotional difficulties and adjustment many months, even years following their stroke. The continued availability of specialist psychological services offering assessment, treatment and ongoing support is recommended. It is anticipated at a national level this psychological support would also comply with the *Clinical Guidelines for Stroke Management 2010*, penetrating through all urban and rural community services. Evidently, there is a demand for programs addressing the psychological and emotional consequences following stroke that includes educational information, resources, and discussion about what to expect during adjustment in the months or years, following stroke.

Given these recommendations thus far, stroke rehabilitation and adjustment can no longer be interpreted within a biomedical framework based on functional/physical abilities. Instead, conventional stroke rehabilitation services would duly benefit from a radical restructuring whereby the psychological, social, and environmental aspects of stroke recovery are given equal weight in service provision. Stroke service need to be considered within a biopsychosocial framework. To continually interpret stroke rehabilitation within the traditional biomedical context is inappropriate and neglectful. As outlined in the present study there are many facets to consider in the delivery of stroke services and programs to ensure a comprehensive approach is implemented. Only then will services truly reflect a contemporary and all-inclusive biopsychosocial model of recovery and adjustment to stroke.

Secondly, a systematic review of current stroke programs is justified to assess the relevance and effectiveness for younger stroke survivors. Current stroke rehabilitation programs are not adequately addressing their needs. It is reasonable to expect these programs will need to be redesigned to incorporate age adaptive modalities of treatment. Particular attention should to be directed towards the younger stroke survivors' psychosocial aspects of adjustment including vocational issues, parenting

roles, body image and intimate/social relationships. In order to ensure a comprehensive program is developed and targeted at younger stroke survivors, further research is warranted given the limited literature currently available. Through acquiring this additional knowledge we may develop effective programs aimed at facilitating a smooth transition back into the community and beyond.

Thirdly, addressing the current barriers and health disparities that exists across rural areas within the context of stroke services necessitates a high priority. The research literature supports this view (e.g., Cadilhac et al., 2006; Joubert et al., 2008; National Stroke Foundation, 2002). A comprehensive and accountable evaluation of access to health services and infrastructure across the acute, post-acute and community level needs to occur at a government and policy level. This evaluation would be justified with substantial input from rural researchers, health professionals and individuals suffering from a chronic illness, like stroke. The disparities in health services that currently exist across rural territories have long been debated over the past decade, and yet we continue to neglect this area. Certainly, by improving access to services and by providing sustainable infrastructure, rural stroke survivors are able to benefit and better manage their adjustment following stroke over the long-term.

Community participation and involvement in social networks are crucial elements that promote adjustment following stroke. Thus, more attention should be given in assisting and encouraging stroke survivors to participate in activities at a local community level. Furthermore, from a health systems framework we need to extend the scope of stroke rehabilitation and the provision of stroke services to incorporate a community context. There is a great deal of value in understanding the mechanisms behind the various constructs of community and its application during the transitional phase of stroke adjustment.

The development of programs within the local community aimed at providing stroke survivors with practical and resourceful information would be highly desirable. Information would need to address topics such as accessing support groups, voluntary organisations, and recreational and leisure activities. Consideration would also be given in developing resources to facilitate and encourage community networking, accessing mental health services and practical information on what to expect when recovering and

adjusting from stroke. These programs should aim at strengthening community participation across the rural and metropolitan domains within Australia.

Finally, more attention should be directed at the construct of resilience and how it applies during the adjustment process following stroke. More specifically, the evidence calls for careful consideration in the development of interventions that support and nurture the transactional nature of resilience that would enhance an individual's ability to adapt to their circumstances rather than succumb to maladaptive disorders. Part of this process would be extracting and capitalising on the broad assortment of psychosocial factors adopted by individuals who demonstrate proactive behaviours thereby enriching those who are struggling with the tools and resources that would foster and augment their personal strength. For this to occur, consultation would need to occur between health professionals, policy advisors, researchers and providers of stroke services who could then direct their knowledge and expertise in promoting this concept of a resilience framework from a biopsychosocial position. Further research is warranted to determine the validity of a resilience framework as an intervention strategy to support and assist people in their recovery and adjustment from an adversity like stroke.

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## APPENDICES

Appendix A	Pilot Interview Questions
Appendix B	Semi-Structure Interview Questions
Appendix C	List of counselling support services
Appendix D	Consent Form
Appendix E	Segments of data transcripts
Appendix F	Segments of NVivo data coding

## APPENDIX A

### Potential questions for Stroke Survivors

1. How did you view your situation immediately following your stroke?
2. Can you recall following the time of your stroke, how you saw your future and what you thought it may have entailed?
3. Tell me how you view your situation now.
4. Did you feel that you had any control over decisions made or events that occurred after your stroke?
5. How did you feel following your stroke, what was your confidence like?
6. Did you feel that you were capable in adjusting to this life adversity?
7. Where there situations where you felt you were not capable, or found it extremely difficult in adjusting? Tell me more about it.
8. Tell me how you dealt with issues or problems that arose following your stroke. Can you give me an example?
9. Did you need much prompting from others to undertake tasks in your recovery? If not, tell me what prompted you to attempt tasks. If yes, how much prompting was necessary?
10. Did you take the initiative to have some control over the process of recovery? Ie., seeking information, building on exercise abilities, taking the next step in recovery, or resuming activities.
11. What was your confidence like initially after your stroke?
12. Tell me about your confidence now.
13. From whom did you seek emotional support following your stroke? Do you feel this was an adequate amount of support? Why?
14. Tell me about the supportive network you can access now? Ie., friends, groups etc.
15. From where do you receive your practical support? Ie., help, information.
16. Do you perceive this support as adequate?

## APPENDIX B

### Interview Questions

1. How did you view your situation immediately following your stroke?
2. Can you recall following the time of your stroke, how you saw your future and what you thought it may have entailed?
3. Tell me how you view your situation now.
4. Did you feel that you had any control over decisions made or events that occurred after your stroke?
5. How did you feel following your stroke, what was your confidence like?
6. Did you feel that you were capable in adjusting to this life adversity?
7. Where there situations where you felt you were not capable, or found it extremely difficult in adjusting? Tell me more about it.
8. Tell me how you dealt with issues or problems that arose following your stroke. Can you give me an example?
9. Did you need much prompting from others to undertake tasks in your recovery? If not, tell me what prompted you to attempt tasks. If yes, how much prompting was necessary?
10. Did you take the initiative to have some control over the process of recovery? I.e., seeking information, building on exercise abilities, taking the next step in recovery, or resuming activities.
11. What was your confidence like initially after your stroke?
12. Tell me about your confidence now.
13. From whom did you seek emotional support following your stroke? Do you feel this was an adequate amount of support? Why?
14. Tell me about the supportive network you can access now? I.e., friends, groups etc.
15. From where do you receive your practical support? I.e., help, information.
16. Do you perceive this support as adequate?

17. Do you access any groups or services in the community?
18. What community groups do you belong to?
19. If yes, how helpful are these groups? If no, would you like to be involved in some community groups?
20. What do you gain by being involved in a community group?
21. Do you belong to any religious organisations?
22. What sort of activities would you like to be involved in?
23. Do you think the groups and services available adequately cater for all stroke survivors? If no, why not?
24. Have you attempted to be involved in active sporting activities? If so, tell me about it.
25. Tell me about your network of friends and colleagues you have.
26. What sort of information following your stroke would have been beneficial to you?
27. Tell me how you dealt with your work situation?
28. What sort of work related activities are you involved in now?
29. If you are not working, would you like to be involved in some type of work activity?
30. Tell me what you would gain out of being involved in work/employment?

#### Rural Stroke Survivor's

31. Tell me what living in a rural/remote environment has meant for you as a stroke survivor?
32. What have you gained from living in a rural environment in your stroke recovery?
33. What has hindered your recovery as a consequence of living in a rural environment?
34. Tell me about the access to supports and services you have as a stroke survivor?
35. Tell me about your network of family and friends?

## APPENDIX C

### List of counselling and support services

National Stroke Foundation	(03) 9670 1000
Carers Victoria	(03) 9650 9966 1800 242 636
Stroke Association of Victoria	(03) 9434 3463
Beyond Blue	(03) 9810 6100
Life Line (03) 9662 9030	13 11 14

## APPENDIX D

### Victoria University of Technology

#### Consent Form for Participants Involved in Research

##### INFORMATION TO PARTICIPANTS

We would like to invite you to be a part of a study that examines what psychosocial factors stroke survivors adopt in their ability to cope following stroke. Past research has identified the negative psychological consequences of stroke that often leads to depression and mood disorders. Other stroke survivors seem able to adapt to their environment and avoid the enduring negative consequences that can be associated with this severe life disruption. This research study will explore the strategies that these people adopt in their methods of resilience and develop a greater understanding of the psychosocial factors that enable them to successfully recover from stroke.

##### CERTIFICATION BY PARTICIPANT

I,  
Of

Certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the experiment titled:

Coping in the Face of Adversity. A model of Resilience for Stroke Survivors.

I certify that the objectives of the experiment, together with any risks to me associated with the procedures listed hereunder to be carried out in the experiment, have been fully explained to me by:

Michelle Fox

and that I freely consent to participation involving the use on me of these procedures. I am also aware that I will be interviewed, and confidentiality will be maintained.

Procedures: Interviews that will be taped recorded and transcribed.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this experiment at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed .....

Witness other than the experimenter: }

Date: .....

..... }

Any queries about your participation in this project may be directed to the researcher Michelle Fox ph. 96884173. If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 Ph. 03 96884710.

# APPENDIX E

lack of resources & key individuals.

difficult down there, in the end J left (assistant) and I had no way of getting to S H

for swimming or anything like that so they put me in a taxi to come to S H and

back home again after swimming. I found that devastating because I'd be right at

the pool with everybody there and having a wonderful time and then I'd get in a

Taxi and go back home again to a lonely house. And I'd start crying again until

such times..... I was talking to a lady at the pool and I said I hate going home

after swimming to a quite house. She said, 'I'll tell you what love, a couple of us

get together and we have a cup of tea and then they go home and ..... why

don't you do that? We'll get the taxi to come to my place and pick you up'. So

that went on for a really, really, long time and the taxi would pick me up from D's

and I'd be as happy as Larry and looking forward to going swimming. So I

continued on with the walking group. After J left I had to have the taxi bring me

up to walking group and then they'd come and pick me up to take me back to L

B. That wasn't so bad, but the people at the pool that I met with, we all became

really close friends and we used to have afternoon tea at D's every swimming

day. Then D had to go to Ballarat to live near her son, they wanted her to go

there for a retirement village. Because he lived there and wanted her close to

him so the rest of use who have afternoon tea decided we'll have to take it on

ourselves, which we did too. We had a wonderful time. It was wonderful. We

use to go down in the bus, buses and see shows in Melbourne, things like that

and my life went ahead in leaps and bounds. They (girlfriends) let me make the

tea, they let me wait on them. No, I've got to do this myself. I never cried after

that. They accepted me as I was. They were wonderful and to let me make a

cup of tea and walk around with that in my hand, it was great. I used to say to

them, 'off you go, go home and I'll do the dishes', and I'll say 'no, I don't do the

dishes at your place, you don't do them at my place'. We were very, very close.

L and I were the only two that get around together. One of our other friends, she

had a slight stroke and she went very strange. She said to me one day at

walking group, 'L, I've heard you've been talking about me behind my back', and

I thought she was joking with me but she was fair dinken. So I wanted to find out

what I was supposed to have said. Because usually you can .....real badly,

distance

lack of supports

time constraints  
- lack of resources

effects social engaging

motivated self-esteem

support practical resources

Problem Solving together

Problem Solving

Developed relationship

important part of group

intimacy friends

lack of infrastructure

activities a

lack of traction/

socially enlightening

is an important role

bring out

poses individ

further

imitations

activities

developing

relationships

bring friends

practical

point

boundaries

this? As each block fell into place after it, that block was going to be a possibility,

would  
pre stroke hope  
optimism

M Opportunity

- intimacy. Partnership.

D Was a challenge but we got there. Hang on, the more we can get there the more we can move forward. So did that answer that?

hope, optm  
goals

= one step at a time.  
- Progress.

M Beautifully

D But it was, as you achieve something

M You can say 'yes I can face it, I can deal with it'.

D That's right. And um, yesterday I was working with a guy down there and when I was working I never ever wanted to be an auditor. I did not want to audit because I just, as one of my accountant friends said to me 'you've pulled the wool over our eyes for years, you told us what you wanted us to know, and you concocted enough stories to be able to support your arguments, we knew twelve months later they were a pack of lies when you told them to us', but, I'm just uneasy on that. I've been auditing other things since, and primarily auditing superannuation funds on a fairly regular basis now and I'm very comfortable. So its something that twenty years, long before the stroke, I have overcome that lack of desire to be involved in that.

pre stroke

work  
Adjusted  
confidence  
pre stroke

M Ok. Were there situations where you felt you were not capable or found it extremely difficult in adjusting? This is after your stroke.

D After the stroke?

M Yeah.

D I don't think I had too many areas. The further I got away from the...out of hospital, no I don't believe I had a real...because once I left St John of God I came to A.C and A.C....and St John of God had told me and N the chance of you being in a wheelchair for the rest of your life is pretty strong. Up to A.C, F met me the physio and had a casual talk to me about the weather, and football and the truck out there, and we were having a nice talk, she's a nice girl and she went away and D.M who I knew very well, the boss from the other hospital. He came in that night at five o' clock and he called Fiona in and said 'this is the plan I've drawn up, I had a discussion with D, this is the plan we've drawn up and we're going to get him walking,' and that was, I left Ballarat at midday, I got to Bendigo at one thirty, eight o'clock the next morning, I was on a balance machine to find out what's going on up here. St John of God had never done anything like that, and she said straight out 'the brain considers the center of your gravity, the center of your balance is in the middle of your left foot. No wonder you can't stand up. I'm going to teach the brain up there for you, we're going to teach the brain D that the center of gravity is in the middle of your legs again, and there's gong to be some adjustments. You are going to have to compensate.

discrepancy in hosp.

was dang ok.

Des blocks with  
lack of hop  
optimism  
from hosp  
paraplegia  
\$ support  
involves pt in  
management  
exercise  
annoyed i  
lack of  
interest.  
power/role  
encourag  
explanations

M And you were quite capable and happy to do that.

D Her attitude, and there attitude gave me the confidence, I thought 'hang on' and then I got right behind, I know that some other stroke members have given up easier. I've just kept going and Fiona works...I was supposed to have a session with her Monday, Wednesday, Friday and I finished up having sessions with her virtually nearly everyday. Now 'you're over there D and this is what I want you to do, I'm going to go and work on with M over here. I'd like you to do these exercises.

exercise  
persistence  
perseverance  
Motivated

gratitude. Explanations.

perseverance  
determination  
motivation  
Self initiate

M Even though it wasn't one on one, she's giving you a strategy to practice, and you had to do it

Relates i pt.  
Appreciative.

Insight change  
in management.  
appreciates  
explanations

awareness of  
need to be  
determined.  
assentive  
persistent.

## APPENDIX F

NVivo Nodes Segment of Data	Data Tagged
Community Infrastructure	<p>ID: 31 Paragraph 45</p> <p><i>I've still been involved in a lot of social activities and I have a lot to do with legacy and I don't know if you know what legacy is</i></p> <p>Paragraph 65</p> <p><i>See we live in a country area and with all due to respects, there's not nearly as much here as there would be in the city, in the way of apartments or hospices</i></p> <p>Paragraph 65</p> <p><i>My wife will take me up to the local hospital. But we find it terribly difficult to get assistance from medical people. When we first started to argue with them, that we would like to know anybody who had a stroke to offer them a membership and support to help them.</i></p> <p>ID: 26 Paragraph 53</p> <p><i>Housing for the aged, action group. Public Tenants association, the (community group) association, the Advisory Council (group) in the city of (council), the Welfare Officer at (place). The committee of the aged at AH. A few other things.</i></p> <p>ID: 19 Paragraph 121</p> <p><i>I can access where we are now at the centre with the S group and the (association). I've been twice to, my wife and I have been twice to weekends at (place), been twice to (group) the (group) organised a dance. You know you sort of go to country meetings or wherever and we come down to (place) here once a month for this particular meeting I'm involved in and I've been involved for three years. I've recently accepted (role) and really they're a good group.</i></p> <p>ID: 13 Paragraph 233</p> <p><i>I don't think so, because there is always work to be done at the show grounds, at the lions park, sometimes somebody wants something done. Some of the committee's have lunch there and we put that on.</i></p>
Adjustment	<p>ID: 25 Paragraph 90</p> <p><i>..felt like I was that close to being committed to (hospital). I remember saying if I don't start laughing soon I'm going to end up there. It was that close, it really felt that close. So I started laughing and didn't stop.</i></p> <p>Paragraph 9</p> <p><i>When I came home well first off I didn't live where I'm living at the moment. I lived in a unit by myself. With the lines crossed. I was extremely happy there. But it was advised that I shouldn't go home to the flat by myself. That I should go somewhere where I could receive help, where I need it.</i></p> <p>ID: 15 Paragraph 66</p> <p><i>My situation now, um, it's going well. I'm literally completely recovered from the stroke and I'm very independent again.</i></p> <p>Paragraph 122</p> <p><i>Um, but after a few weeks as I said before with the kids, you really don't have a choice. You've just got to adjust, you've got to know, get out and do things and move on.</i></p>