

The "lived experience" of long-term stroke survivors in Newcastle, Australia.

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STATEMENT OF ORIGINALITY

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These manuscripts have been a collaborative effort with the researchers listed below.

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ABSTRACT

Aim: The aim of this thesis was to explore the long-term experience of community dwelling stroke survivors at 1, 3 and 5 years after stroke.

Design: A qualitative study using a modified grounded theory approach. The primary data collection method was semi-structured interviewing.

Setting: Community dwelling stroke survivors in metropolitan Newcastle, New South Wales, Australia.

Participants: Twelve community dwelling stroke survivors (4 participants from each cohort) discharged from a tertiary referral hospital. 6 men and 6 women aged between 42 and 92 years of age participated in this study.

Main Outcome Measure: Qualitative outcomes were participants' perceptions using in-depth, semi-structured interviews with participants from 3 community based cohorts of stroke survivors at 1, 3 and 5 years post stroke.

Results: Four main themes emerged from the data that were experienced by participants within each cohort and between cohorts. These were feelings of altered participation in life, low mood, modulating factors and experience with the health system. A modified grounded theory approach was used for data analysis using a process of constant comparison.

Conclusions: Altered participation and mood changes continued well beyond discharge and in some cases commenced after discharge in this sample of stroke survivors. Lifestyle changes were further influenced by experiences with the health system and knowledge about stroke, as well as the presence or absence of insight, hope for the future, faith, and support. Use of qualitative methodology extends our understanding of the extent and nature of life-style changes after stroke. There is a need for enhanced services to monitor and address the ongoing needs of community dwelling stroke survivors'.

CHAPTER ONE: INTRODUCTION

1.1 Background

Stroke is widespread, affecting people of all ages and with the potential to cause life-long impairments in physical, cognitive, behavioural and social function. However, functional recovery from stroke can continue for many years after stroke onset. Rehabilitation has been shown to be effective in facilitating recovery using an interdisciplinary approach and close liaison with the stroke survivor, family and carer (Khan, Baguley & Cameron, 2003).

Occupational therapy is a health profession with a specific focus on providing functional rehabilitation to maximize participation in meaningful activities. Occupational therapy service delivery after stroke is underpinned by consideration for the holistic needs of the stroke survivor to facilitate return to pre-stroke lifestyle (Legg, Drummond & Langhorne, 2007).

There is a growing interest in patient-centred practice within the current health system. Patient-centred care has been shown to improve patient satisfaction and outcomes when resources are tailored to individual needs (Higginbotham, Albrecht & Connor, 2001). However, current constraints on the health system have generated pressure for early discharge from rehabilitation after stroke. As a result, therapist's priorities for stroke survivors are often centred on restoring independence in mobility and activities of daily living (ADL) to ensure safe discharge. The subsequent trade-off is reduced attention for intervention directed towards patient goals regarding adaptation to life roles (Liu, Chan & Chan, 2005). A qualitative study undertaken by Cott (2004) identified that adults with chronic disabilities felt inadequately prepared for community living following discharge from rehabilitation. Similarly Burton (2000) noted that the priority of many stroke survivors was on the social context of recovery rather than functional abilities which is commonly the focus of the health system.

With an ageing population and increasing longevity there is a growing interest in long-term outcomes after stroke, such as functional independence and Quality of Life (QOL). Recent research has shifted from measuring outcomes pertaining to morbidity and mortality to measuring changes in community participation (Liu et al, 2005).

We have conducted previous research in the Hunter region on the functional outcomes and quality of life of community dwelling stroke survivors at 1, 3 and 5 years post-stroke (White et al, 2007). This research involved a larger, retrospective, cross-sectional study of 91 stroke survivors at 1, 3 and 5 years; the design and methods of this study have been previously reported (White et al, 2007).

In summary this study identified that stroke survivors' function did not change significantly between cohorts and that a high proportion of survivors required community services. This was despite reasonable cognitive and physical recovery after stroke. Health related quality of life (HRQoL), was measured by the Stroke Impact Scale 3.0 (SIS) (Duncan, Bode, Min Lai & Perera, 2003). The larger study did not aim to diagnose depression and used the SIS to assess participants' perceived function after stroke. The SIS is a widely used scale of perceived function post stroke. Results identified that the proportion of participants experiencing low mood, as measured by the Emotion domain subset of the SIS, was similar across the 3 cohorts and up to 5 years post stroke (White et al, 2007). A key finding was that the poorest domain of function, as measured by the SIS, was the emotion domain.

Clear gaps in knowledge were identified regarding the reasons for why low mood persisted despite reasonable cognitive and physical recovery. The publication of the results of this study is provided in Appendix B.

1.2 Research Aims

The main aim of this study was to explore the lived experience of people with stroke living in the community. Key areas to be addressed included influences on adjustment, occupational engagement, experiences with the health system and long term support needs. Such information was considered essential to address the ways that the health system could respond to prevent handicap and increase stroke survivor participation in normal life activity.

These aims arose from the White et al (2007) study since the research team were concerned that there was a need for greater understanding of the relationship between recovery and associated variables in order to deliver relevant services to community dwelling stroke survivors. Limitations of quantitative methodology to elicit in-depth, descriptive information regarding this phenomenon led to the development of this qualitative study. It was anticipated that results from a qualitative study would help identify patients requiring specific intervention. Participants were identified from each cohort (within the previously described quantitative study) using purposive sampling in order to achieve maximum variation by including stroke survivors with a diverse range of experiences, across various timeframes after stroke. Data obtained from the participants were considered as a whole, rather than within the individual cohorts, as persistent experiences were noted across the 3 time points.

1.3 Context of Study

1.3.1 Stroke

Stroke is a cerebrovascular disease and is caused by a disturbance of blood supply to the brain (Australian Institute of Health and Welfare [AIHW], 2004). Stroke occurs when an artery supplying blood to the brain suddenly becomes blocked (ischaemic stroke) or bleeds (haemorrhagic stroke), accounting for 85% and 15% of cases respectively (AIHW, 2004). Outcome after stroke is dependent on the lesion size and location. Other influencing factors are age and the presence of pre-existing comorbidities (Hankey, 2002).

The impact of stroke on the health system is profound, with as many as 53,000 Australians suffering a stroke each year (National Stroke Foundation website [NSF], 2006). Stroke is one of the leading causes of long-term adult disability in the Australian population and the second leading cause of death (AIHW, 2006).

1.3.2 The Impact of Stroke

Stroke can have a devastating consequence and can lead to the experience of long-term changes in lifestyle and activity levels (Khan et al, 2003). Symptoms generally occur immediately after stroke and may affect motor, sensory, and cognitive function, each unique in clinical presentation and prognosis. Although there are general principles of stroke recovery, the pattern of recovery differs for each individual (Hankey, 2002).

Previous research has demonstrated the link between poor QOL and physical and psychosocial functional limitations after stroke (Anderson, Hackett & House, 2004; Neau et al, 1998; Parikh et al, 1990; Sinyor, Kaloupek, Goldenberg & Coopersmith, 1986). However, to date, studies have primarily focused on mortality and stroke reoccurrence over time (Hankey, Jamrozik, Broadhurst & Anderson 2000). Currently, researchers are exploring functional and emotional states. In an Australian context, Sturm and colleagues (2002a), using the North East Melbourne Stroke Incidence Study (NEMESIS), identified that many stroke survivors report poor HRQoL within two years following stroke onset. When considering the role of community-based rehabilitation services it is accepted that they have a role in increasing community participation but the ideal make-up of the services is not known (Sturm et al, 2002b). Knowledge relating to the ideal service components that have a positive influence on stroke outcomes may be elicited by research that explores the stroke survivors experience and expectations (Sturm et al, 2002a).

There remains limited research exploring the long-term experience of stroke survivors and factors that impact upon adjustment in the community. A growing body of literature (including qualitative research) provides some insight into factors affecting the long-term experience of stroke survivors including the impact of loss of function and social isolation (Alaszewski, Alaszewski & Potter, 2004; O'Connell et al, 2001; Pound, Gompertz & Ebrahim, 1998; Van de Weg, Kuik & Lankhorst, 1999). The importance of improved understanding of the nature of stroke survivors' long-term experience and their therapeutic need, is influenced by recent trends within the health system focusing on evidence-based practice, patient outcomes and HRQoL.

Further research will contribute to the evidence base to help tailor services that facilitate best outcomes. Qualitative studies provide an ideal opportunity to obtain an in-depth understanding of the needs of stroke survivors in these important areas.

1.4 Study Focus

The current study was conducted in Newcastle, a typical Australian coastal city situated within the Hunter Region on the coast of New South Wales, Australia. Newcastle has a population of 541,744 (Australian Bureau of Statistics [ABS], 2006). Hospital based stroke services are provided by acute stroke units and stroke rehabilitation units in two tertiary referral centres. Routine follow-up is provided following discharge from hospital back to the community. Patients that are not discharged to institutional care, but with any persisting changes in activity levels, are referred to ongoing rehabilitation which may involve access to outpatient/day hospital or home based allied health and nursing.

1.5 Scope and Importance of this Study

As highlighted above, stroke is common in Australia and remains a major health concern. Nearly a third of all strokes are fatal while another third of stroke survivors remain disabled (AIHW, 2004, NSF, 2006), making up one in four of the chronically disabled population in Australia (AIHW, 2004). Residual neurological deficits can affect lifestyle and create barriers to participation in valued activities due to physical, sensory, cognitive and emotional difficulties (Khan et al, 2003). In addition, mood disorders including post stroke depression (PSD) are common after stroke and have been shown to impact on rehabilitation outcomes (Anderson et al, 2004; House et al, 1991).

Rehabilitation therapies can help address neurological deficits by focusing on patient goals regarding ADLs, work, leisure and social pursuits (Kielhofner, 2002).

However, with regards to mood disturbance such as PSD, there remains insufficient evidence regarding the ideal management (Hackett, Anderson & House, 2005). Similarly, many studies indicate that depressive symptoms post stroke have previously been under-recognised and inadequately treated (Hackett et al, 2005). More research is required to improve clinical practice regarding the management of PSD.

Chapter Two will present an overview of the literature around the experiences and rehabilitation needs of patients post-stroke. Gaps in the literature will also be identified. In particular, gaps are reflected in the limited number of Australian studies and qualitative studies exploring the long-term experience after stroke. There is a greater need for studies which explore the impact of stroke with long-term adjustment and stroke survivor's experience with the local health system.

This study will address research gaps by capturing the lived experience of long-term community dwelling stroke survivors. Qualitative methodology, using a modified grounded theory approach, provides the opportunity to gain in-depth information. Grounded Theory focuses on the current experience of a person's life and their interactions within their own social context (Grbich, 2007). Findings help interpret the meaning regarding interactions observed (Grbich, 2007). The use of semi-structured interviews provided the opportunity for stroke survivors to share their experience of stroke, the rehabilitation process and their adjustment to stroke over time.

1.6 Researcher's Background

The researcher's interest in the area of stroke care developed from working as an occupational therapist with people who had sustained a stroke. During this time specialist, stroke specific occupational therapy skills were developed throughout a range of settings including the acute setting, rehabilitation, community-based rehabilitation, community education and health promotion.

The experience of working in various rehabilitation settings provided opportunity to observe the variability in peoples' adaptation to stroke at differing time points and in differing contexts ranging from hospital to community.

The researcher noted that, for many people, difficulties in acceptance and adaptation post stroke impacted upon their rehabilitation experience. The rehabilitation process is centred on identifying goals with the patient. These goals predominantly focus on the resumption of previous roles or activities of pleasure. Allied health therapies, including occupational therapy, addressed stroke-related impairments that restricted performance in these activities to maximise return to pre-stroke lifestyle. In many situations it was noted that the patient's ability to identify goals or to participate fully in the rehabilitation process was significantly impacted upon by the grieving process and by a sense of loss of hope. The onset of depression also affected participation in rehabilitation as it reduced a patient's ability to initiate, and be motivated towards, activity. This further affected goal attainment post-stroke and resulted in reduced QOL. Many stroke survivors expressed an ongoing desire to return to their previous lifestyle and the activities and relationships that were a part of that life.

The extensive clinical background of the researcher in the area of stroke care delivery had the potential to bias the focus or direction of the interviews in the direction of the researcher's experiences and expectations. A grounded theory approach used a reflexivity approach to underpin the study to deal with this common issue of bias, encountered when health professionals conduct health system research. Reflexivity involves a constant process of self-reflection regarding how pre-existing knowledge, values and beliefs impact on data collection, and analysis (Grbrich, 2007). Accurate analysis of the transcripts was further enhanced using triangulation of methodology, achieved by consensus coding with a member of the research team (who was from a different professional background) and member checking (Creswell, 1994).

These processes are outlined in greater detail in the Chapter Three.

The researcher is currently employed in a research role with the Hunter Stroke Service and is undertaking numerous other research projects in the area of post-acute stroke.

1.7 Definition of Terms

Terminology used in this thesis is been defined in the following glossary and provides an orientation and overview.

1.7.1 Activity

Activity refers to the execution of a task or action by an individual. It represents the individual perspective of functioning (World Health Organisation [WHO], 2001).

1.7.2 Functioning

This term refers to body functions, body structures, activities and participation. It refers to the positive aspects of interaction between an individual and that individual's contextual factors (WHO, 2001).

1.7.3 Goals

A goal is a statement of general purpose or intent (Hankey, 2002).

1.7.4 Health Related Quality of Life

Health related quality of life is how a person's health affects their ability to carry out normal social and physical activities (Baune & Aljeesh, 2006).

1.7.5 Locus of Control

Locus of control refers to a person's beliefs about whether they can control their circumstances (Kielhofner, 2002).

1.7.6 Occupation

Occupation refers to purposeful activities that are either centred on play, rest, or productivity (Kielhofner, 2002).

1.7.7 Participation

Participation pertains to a person's involvement in a life situation. It represents the societal perspective of functioning (WHO, 2001).

1.7.8 Quality of Life (QOL)

QOL pertains to a person's satisfaction (or dissatisfaction) with broad life areas such as social, environmental, economic and health aspects (Baune & Aljeesh, 2006).

1.7.9 Post Stroke Depression (PSD)

Depression after stroke is common (Hackett et al, 2005). The term "post stroke depression" is used to indicate depression related to stroke.

1.7.10 Rehabilitation

Rehabilitation is a treatment program designed to assist a person with a physical or mental disability to regain maximal function and as much independence as possible (Freeman, 1998).

1.8 Synopsis

This chapter has introduced the concerns associated with the impact of stroke in Australia. There is a lack of literature on the long-term experience of community dwelling stroke survivors. More evidence is required in order to deliver effective community based services that support stroke survivors.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This thesis presents the findings from a study that seeks to increase knowledge of the experience of community-dwelling stroke survivors using qualitative methodology in order to improve understanding of their engagement with the health system and long term support needs. This information will be used to help deliver relevant services to community-dwelling stroke survivors. Anecdotal reports from clinical experience suggests there is variability in stroke survivors' needs over time following discharge after stroke, due to factors such as mood disturbance, social isolation and access to supportive services. Variability in the experience of stroke survivors' suggests the need for long term monitoring of stroke survivors to minimise disruption to life (Steultjens, Dekker, Bouter, Leemrijse & van den Ende, 2005). To help identify service priorities there is a need to better understand these real needs of stroke survivors. This requires processes which help to identify these needs.

In this chapter important topics relevant to the study aim will be reviewed. Firstly, an overview of stroke will be presented, including methods to classify the severity of stroke and approaches to facilitate stroke prevention. Secondly, the impact of stroke on lifestyle will be considered as will rehabilitation processes that help minimise handicap. Theories that underpin rehabilitation will also be considered. Finally, evidence of known contributors to outcome after stroke will be reviewed. The chapter will demonstrate the variations between stroke types and individuals that influence outcome, gaps in evidence and a need for evidence based recommendations about the long-term support needs of stroke survivors.

2.2 Overview of Stroke

Stroke refers to the disease of blood vessels in the brain resulting in permanent or transient injury (Mills, Cassidy, Katz, 1997). The two main types of stroke are ischaemic stroke (caused by blockage of blood vessels) and haemorrhagic stroke which occurs when a blood vessel bursts. Stroke can affect people of all ages although the risk of stroke increases with age (Hankey, 2002). Additional risk factors include: smoking, excessive alcohol intake, obesity, raised blood cholesterol, high blood pressure and arterial disease (Hankey, 2002). Rehabilitation can assist people to resume a productive life and should commence as soon as possible after stroke (Van Peppen et al, 2004). Stroke affects people differently and depending on the type and location of the stroke, rehabilitation may be required to assist recovery for many years (Fang et al, 2003).

2.3 Impact of Stroke

Stroke can affect any part of the brain and the consequences can be lasting. Impairments alter normal body functioning and may include motor and sensory impairments, visual problems, cognitive, emotional and speech difficulties. Most recovery occurs early after stroke but can continue for many years (Hodics, Cohen & Cramer, 2006). Studies indicate that 30% of stroke survivors will require ongoing assistance with ADLs, 70% experience vocational impairments and 20% require assistance to walk (Bamford, Sandercock, Dennis, Burn & Warlow, 1991). Many studies reflect the experience of reduced community participation despite functional recovery (Sturm et al, 2002b). Outcomes can be influenced and/or further compounded by personal and social factors (Glass, Matchar, Belyea & Feussner, 1993).

Most stroke survivors will return to living in the community, with only 12% requiring admission to more supported care such as residential care facilities (AIHW, 2004). The permanency of lifestyle changes is often not appreciated until a patient is discharged from inpatient rehabilitation and returns to community living. Given that the experience of stroke is different for each person, the response of the health system needs to be flexible enough to identify and address this individual variability.

As a starting point it is useful to have an understanding of the type and severity of the stroke. Stroke classification systems have been well established and can assist in this process.

2.4 Stroke Classification

Classification of stroke according to the location in the brain and the extent of injury helps determine appropriate prevention and treatments strategies (Dewey et al, 2003). The Oxfordshire Community Stroke Project (OCSP) classification is a widely used system established to assist in defining ischaemic stroke (Bamford et al, 1991; Mead, Lewis, Wardlaw, Dennis, Warlow, 2000). Once brain imaging has excluded cerebral haemorrhage, patients are classified into the following syndromes: total anterior circulation infarction (TACI), partial anterior circulation infarction (PACI), posterior circulation infarction (POCI) and lacunar infarction (LACI). This classification system is useful because it identifies patients with potentially different outcomes (prognosis) as well as assisting identification and prioritisation of appropriate therapies (Bamford et al, 1991). Haemorrhagic strokes are less prevalent than ischaemic stroke and patients experience poorer outcomes, although they can achieve good outcomes, especially if complications are avoided in the first few days (Barber, Roditi, Stott & Langhorne, 2004)

Survival remains a key measure of stroke outcome (Hankey et al, 2000). Other long-term outcomes of stroke survivors, such as level of dependency, are also important. Extensive research has been undertaken on the OCSP as a predictor of stroke complications and prognosis (Bamford et al, 1991; Dewey et al; Mead et al, 2000; Sturm et al, 2002b). Additional studies have investigated the incidence and outcomes of OCSP subtypes including identifiable patterns of case fatality, risk of recurrence and long-term dependency (de Jong, van Raak, Kessels & Lodder, 2003; Ilzecka & Stelmasiak, 2000; Pinto et al, 1998; Tei et al, 2000). The TACI subgroup is likely to result in poorer functional outcomes and have higher mortality rates at 1-year post stroke (Bamford et al, 1991). The risk of stroke recurrence is highest in the PACI subgroup while POCI and LACI strokes tend to be milder with better outcomes expected (Bamford et al, 1991).

With changing demography and the aging population, the incidence of stroke is expected to continue to rise. Improvement in risk factor management and acute treatment is likely to increase survival, resulting in increasing demands on health services and providers (ABS, 2006). Accurate classification of stroke plays an important role in guiding service planning.

2.5 Stroke Prevention and Acute Management

The risk of stroke increases with age although within Australia approximately 50% of strokes are under the age of 75 years with around 5% of strokes under the age of 45 years (NSF website, 2006). The median age for the onset of first ever stroke is 77 years (AIHW, 2004). Risk factor modification is central to stroke prevention.

Modifiable risk factors include high blood pressure, smoking, diabetes, high blood cholesterol, lack of exercise, excessive alcohol consumption, atrial fibrillation, and carotid stenosis (AIHW, 2004).

Community education to increase knowledge of stroke warning signs and appropriate response to symptoms is a growing focus within the health system. Public campaigns within Australia seek to increase community awareness with regards to risk factors of cerebrovascular disease and treating symptoms of stroke as an emergency, therefore seeking immediate medical attention (Kothari et al, 1997). Early recognition reduces time to treatment and increases the opportunity to access effective treatments and prevention (Wolf & Singer, 1988).

Similarly, recent advances in technology have given rise to the development of thrombolysis therapy to assist survival of the cerebral ischaemic penumbra, the portion of the brain which has not yet died (Davis, Lees & Donnan, 2006). Delay in hospital presentation denies patients this potentially life-saving treatment. This emphasises the importance of early symptom recognition. A key concern is that local studies within the Hunter Region have shown gaps in public knowledge in recognising stroke symptoms and thus the potential for delayed presentation to hospital (Yoon, Heller, Levi & Wiggers, 2001).

2.6 The Recovery Process

The extent of recovery and restoration of altered brain tissue function after stroke may require reorganisation of the residual neural network (Barnes, Dokins & Bogousslavsky, 2005). Neurological rehabilitation is characterised by therapies that prevent further brain tissue deterioration and associated complications, and maximise restoration of function and performance in daily living (NSF, 2006).

Many factors contribute to brain tissue reorganisation, or neuroplasticity, such as active movement, skills learning and environmental conditions (Calautti & Baron, 2003; Kriesal, Bätzner & Hennerici, 2006). While the neurophysiology of brain recovery is not completely understood, rehabilitation aims to facilitate neuronal reorganisation and ultimately to maximise independence (Calautti & Baron, 2003; Rossini, Calautti, Pauri & Baron, 2003). This is achieved by therapy focused on enhancing reorganisation of brain function which therefore facilitating relearning of fundamental skills in mobility and self-care.

There is limited evidence to support the benefit of rehabilitation therapies on stroke recovery (Carr & Shepherd, 2000, Page, Sisto, Levine & McGrath, 2004a). However an increased interest in task specific therapy and constraint induced movement therapy (Hakkennes & Keating, 2005; Page et al, 2004a) suggests repeated practice of a motor task may be effective in reorganising surviving neural tissues. While motor recovery tends to plateau more quickly than functional recovery, gains can still be made even in the chronic stage after stroke (Page, Gater, Bach & Rita, 2004b): although there are few studies examining the effect of rehabilitation interventions on brain activation patterns and most have been conducted within several months after a stroke, when most recovery has occurred (Calautti, Leroy, Guincestre, Marie & Baron, 2001; Carey et al, 2006).

Animal studies using rats as subjects have also highlighted the benefits of rehabilitation on brain activation patterns, particularly in an enriched environment, in improving functional outcome after stroke (Dinse, 2004; Nygren, Wieloch, Pesic, Brundin & Deierborg 2006). The application of enrichment in human stroke rehabilitation would entail conducting therapy in an environment with increased sensory, motor, and cognitive demands that reinforces desired behaviours (Dinse, 2004).

2.7 Rehabilitation Settings

It has been well documented that early rehabilitation, provided by established stroke units, is instrumental in saving life and reducing dependency post-stroke (Hankey, 2002; Langhorne & Duncan, 2001). A stroke unit is a dedicated area within a hospital for the management of stroke and is staffed by a multi-disciplinary team with dedicated staff (Hankey, 2002).

Rehabilitation continues across all phases of care, such as acute, post-acute and community settings. Studies have shown the benefit of rehabilitation in facilitating recovery (Stroke Unit Trialists' Collaboration, 1997). In particular, allied health research has shown the benefit of early therapy after stroke (Jorgenson, Kammergaard & Nakayama, 1999). However, clinical experience suggests that access to allied health intervention (within the public health system) is limited after discharge from hospital, due to the reduced numbers of allied health working in the community as compared to the hospital (Larson, 1996).

This has the potential to limit the opportunity for recovery years after stroke despite evidence suggesting the benefit of rehabilitation several years after stroke to assist with maintaining functional gains and facilitating adjustment (Dean, Richards & Malouin, 2000; Ouellete et al, 2004; Tarkka, Pitkänen & Sivenius, 2005; Wade, Collen, Robb & Warlow, 1992). However, research is required to identify the ideal components of therapy that enhance outcomes (Sturm et al, 2004).

2.8 Factors Influencing Transition to Community Living

2.8.1 Community Support

The process of learning to live a productive life, despite residual impairments, requires close consideration of the stroke survivor's own environment. Clinical experiments involving rats have demonstrated the benefit of an enriched environment in improving functional outcome after stroke (Nygren, Wieloch, Pesic, Brundin & Deierborg, 2005). For humans, this has been best achieved within the stroke unit (Teasell, Bitensky, Foley & Bayona 2005). Growing literature however, indicates the contribution of early supported discharge programs in reducing hospital length of stay while achieving similar outcomes to inpatient rehabilitation services (Meijer, & van Limbeek, 2005).

Ongoing functioning and the transition to home is further influenced by the availability of comprehensive support and the continuity of services. Formal community support is characterised by post-acute care such as allied health, nursing and social services while informal assistance often comes from family and, sometimes, friends (AIHW, 2006). For many people, requiring higher levels of care, the need for transition to residential care may be averted by the availability of comprehensive support and the continuity of services in the community. The Australian Institute of Health and Welfare has identified that approximately 50% of stroke survivors require assistance with healthcare, household chores, home maintenance and mobility. Others required additional assistance with cognitive and emotional tasks.

There is growing acknowledgement for the benefit of longer term, community-based services and rehabilitation for disabled (Anderson et al, 2002; Barnes et al, 2005; Mahnken, 2001).

This is of significant interest to stroke clinicians since it has been estimated that approximately 25% of people with severe disability living in the community have had a stroke (Barnes et al, 2005).

There is limited literature identifying the longer-term support needs of stroke survivors. There is likely to be a diverse range of need according to the unique experience of each stroke survivor. Recent studies have made an increased contribution to understanding concerns regarding access to services and experiences with the health system. These included concerns raised by stroke survivors including lack of individualised care, failure to address issues pertaining to QOL, inadequate access to home-help, financial advice, and issues accessing assistive devices and equipment (Nosek, 1993; McKeivitt & Wolfe, 2000; Wiles, Pain, Buckland & McLellan, 1998). Furthermore, patients have expressed concerns that rehabilitation is concentrated within the acute and post-acute phases when they are less able to maximise the expertise of their treating therapists' due to emotional distress and difficulty adapting to body changes while simultaneously processing the new information that guides recovery.

There is benefit in undertaking research at a local level to verify these results in an Australian context and to quantify needs and service delivery gaps. This data will aim to guide service planning at a local level.

2.8.2 Social Support

The support of family and friends is a further, integral component of the transition home. Correlations between social support and health and outcome after stroke have been well documented (Astrom, Asplund & Astrom, 1992; Wyller, Holmen, Laake & Laake, 1998). Supportive family networks as well as broader social networks which

have been linked to better outcomes (Angeleri, Angeleri, Foschi, Giaquinto & Nolfe, 1993; Kotila, Numminen, Waltimo & Kaste, 1998).

There is limited evidence supporting the effectiveness of peer support, such as stroke support groups, although these are commonly recommended to stroke survivors by health professionals (NSF, 2006). Stroke support groups are typically underpinned by provision of information (usually by a guest speaker), social and rehabilitation activities and a meal (NSF, 2006). Models of peer support are used widely by different disease groups which provides some evidence towards confirming the face validity of their effectiveness (NSF, 2006).

2.9 Recovery

2.9.1 Maintaining Patient Priorities throughout Rehabilitation

Successful rehabilitation after stroke can vary from patient to patient. As discussed earlier, neuro-rehabilitation focuses on neuronal organisation and restored independence is a common focus (Swain, French & Cameron, 2003). Consideration is also given to patients' preferences and values throughout the rehabilitation process. The benefits of active patient involvement in goal setting during the rehabilitation process have been well documented (Law, Baptiste & Mills, 1995). Research indicates that patients who are actively involved in decision making demonstrated increased feelings of autonomy, improved patient satisfaction and better outcomes (Ford, Schofield & Hope, 2003).

Patient involvement in the rehabilitation can be hard to measure. In recent decades several qualitative studies have attempted to understand barriers to patient involvement by exploring the perspective of the stroke survivor during the rehabilitation process. These have demonstrated differences in patient priorities as compared to health professional priorities (McKevitt, Redfern, Mold, Wolfe, 2004). Studies involving

health professionals have demonstrated a tendency to focus on physical tasks in preference to those valued by the stroke survivor in facilitating resumption of their pre-stroke life style and maintaining their former identity (Doolittle, 1991; Kauffman, 1998).

Insight into the priorities of stroke survivors beyond the hospital setting has also been identified by qualitative research. For example, Gubrium, Rittman, Williams, Young & Boylstein (2003) identified that priorities and routines can vary from day to day in contrast to discrete goals identified during inpatient rehabilitation. The stroke survivor also uses differing means to monitor or measure their progress. Some of these included how the stroke survivors define themselves using techniques such as comparison with others, comparison with previous performance or anticipated performance (Gubrium et al., 2003). In order to ensure that rehabilitation is as successful as possible, the health system and health professionals needs to ensure that therapy is tailored to the individual and their goals.

Traditionally the biomedical model has focused on physical rehabilitation outcomes (Carr & Shepherd, 2000). There remains the need for greater consideration of the personal experience of the recovery from stroke and how this influences the rehabilitation process, in contrast to a tendency to focus on maximising independence and addressing discrete physical goals. Regular and formal physical assessment does not continue to the same extent, if at all, following discharge to the community (Gubrium et al, 2003). This reinforces the need for therapy focusing on patient priorities.

Active participation in the rehabilitation process, such as goal setting, has also been shown to give the stroke survivor the opportunity to experience a sense of control during a time that can be confusing and distressing. Hammel (2006) suggests that maintaining a sense of control is facilitated through decision making and implementation of choice. Examples of how this may be achieved in the rehabilitation setting can vary from involvement in goal setting to the timing of therapy etc.

The experience of loss of control has been documented in many studies as a common experience and has been shown to have a negative influence on the rehabilitation process (Becker, 1993; Carpenter 1994). Locus of control refers to how people view their situation in relation to events. People who have an external locus of control are more likely to be passive, rely on others and are less motivated (Wallston & Wallston, 1981). Those with an internal locus of control can be expected to positively adjust to disability as they are more able to come to terms with their experiences and assume more responsibility (Hammell, 2006).

Physical independence is predominantly an ideal of the post-industrial society (Hammel, 2006). Cross-cultural research challenges this ideal by highlighting the value of the experience of interdependence (Wirz & Hartley, 2002). Interdependence is characterised by engagement in relationships with others within society and the reciprocal provision of care (Walmsley, 1993). In this way people continue to experience recognition for their contribution in society, despite any residual disabilities. A strong emphasis within post-industrial societies on achieving and maintaining physical independence has the potential to lead to greater social isolation as the stroke survivor expends energy on activities of daily living, often at the expense of leisure or social activities.

However, increased interest in patient's perspective can counter this and is consistent with the growing recognition of patient-centred care. Patient-centred care incorporates a focus on the stroke survivor's values as a priority - thus providing the opportunity for rehabilitation to focus on the broader context and interests of the patient. As a result, rehabilitation goals reflect patient preferences regarding their lifestyle. More research is required to explore the experience of stroke survivors and the factors that enhance their lifestyle and wellbeing. This requires greater exploration of patient perspectives and interpretations of their experience of independence after stroke.

It may be that there is a preference to receive help with activities, such as basic self-care, in order to maximize their energy for activities of greater personal meaning (Hammell, 2006; Yerxa, 1998).

Understanding of patient perspectives of rehabilitation should underpin the ongoing professional development of staff providing rehabilitation services.

2.9.2 Occupational Therapy Context

Occupational therapists are concerned with the occupational nature of people and their ability to maintain physical and emotional health through engagement in meaningful occupations (Wilcock, 1998; Zemke & Clark, 1996). Occupations are unique to individuals and vary according to societal influences, personal interests, beliefs and needs (Kielhofner, 2002). Understanding the post-stroke experience is of interest to occupational therapists since the effects of stroke can be devastating, producing substantial changes to functioning. Approximately 50% of stroke survivors experience residual impairments resulting from neurological damage which can affect performance in occupation and ultimately in QOL (Hankey et al, 2000; Niemi, Laaksonen, Kotila & Waltimo, 1998). Occupational therapists have a role in promoting health in the stroke survivor by facilitating engagement in occupation.

As previously noted, occupations are unique to individuals and vary according to societal influences, personal interests, beliefs and needs (Kielhofner, 2002) and have been linked to life satisfaction and health (Hemmingsson & Jonsson, 2005). Occupational therapists can therefore have a role in promoting health in the stroke survivor by facilitating engagement in occupation. Intervention aims to assist stroke survivors to continue to feel they are making a meaningful contribution despite ongoing functional restrictions (Friedland, 1998).

How this is achieved remains a challenge for therapists working with stroke survivors due to the diverse needs of patients once they return to the community. Areas of focus include treatment, education and health promotion. However, there also remains limited availability of allied health resources, including occupational therapy in the community (Australian Health Workforce Advisory Committee, 2004). There is limited scope to address lifestyle factors which influence QOL and how these may change over time.

Qualitative studies in the occupation therapy context highlight the experience of occupational loss. Contributing factors include performance standards and access to transport (Morgan & Jongbloed, 1990), difficulties with adjustment (Reid, 2004) and increased effort to organise habits and overcome difficulties (Lampinen & Tham, 2003; Wallenbert & Jonsson, 2005). There remain clear gaps in our knowledge since these studies have tended to focus on the stroke survivor's experience within the first few months following stroke and may not represent the longer-term sequelae of stroke (Bhogal, Teasell, Foley & Speechley, 2003; Grimby, Andren, Daving & Wright, 1998; Murray & Harrison, 2004; Mumma, 1986; O'Connell et al, 2001).

2.9.3 *Quality of Life*

Occupational therapy facilitates participation in valued occupations and the experience of a sense of meaning and locus of control which can enhance QOL. There is a growing emphasis within the health sector on QOL following injury or illness. Quality-of-life assessment measures changes in physical, functional, mental, and social health and assist to identify the personal and financial costs and benefits of new programs and interventions (Testa & Simonson, 1996). As a result, QOL is now viewed as an outcome of health care as well as a consequence of illness or injury (Buck, Jacoby, Massey & Ford, 2000; Testa & Simonson, 1996). Measurement of QOL helps determine the effectiveness of intervention and can guide stroke service planning to address ongoing needs due to residual impairments or patient preferences.

HRQoL assists in quantifying QOL and measures the impact of disease on the physical, emotional, and social aspects of patients' lives as compared to what they perceive to be ideal (Cella & Tulsky, 1990; Williams, Weinberger, Harris, Clark & Biller, 1999). Predictors of QOL after stroke have been shown to include: medical comorbidities, depression, perceived social support and functional status (Carod-Artal, Egido, Gonzalez, Varela de Seijas, 2000; King, 1996). Sturm et al (2002a), using the NEMESIS study, identified that many stroke survivors within Australia make gains with basic ADLs but report poor HRQoL within 2 years following stroke onset.

The majority of this QOL research has used quantitative methodology. While making contributions to clinicians' understanding of the impact of stroke, significant variations between studies have been identified due to variances in methodology and the definition of QOL used in the studies (Sanders, Egger, Donovan, Tallon & Frankel, 1998). There is no gold standard for measuring QOL after stroke and the use of QOL

instruments, particularly generic instruments, does not fully capture the experience as described by stroke survivors. This makes it difficult to accurately prioritise needs regarding the provision of stroke care and allocate resources accordingly. These factors highlight the benefit of qualitative research in understanding the impact of stroke on perceived health and well-being. Similarly more research is required on the long-term experience of QOL many years after stroke and on the factors that determine or maintain QOL.

2.9.4 *Chronic Disease*

Stroke is an acute event but it may also be classified as a chronic disease, since the ongoing impairments experienced by many survivors, especially for people who have had a moderate or severe stroke, may be endured over a lifetime.

Chronic disease is defined as any health problem that may require ongoing interventions and management over many years and even decades (New South Wales Chronic Disease Strategy, 2005). There is an increase in the prevalence of chronic conditions worldwide and this is largely due to increasing longevity, technological and therapeutic advances in medicine, and lifestyle behaviours (New South Wales Chronic Disease Strategy, 2005).

Chronic disease management principles are relevant to stroke service delivery as they seek to improve functioning by reducing symptom severity and the impact of any disease progression on lifestyle (Grumbach, 2003). Program components typically promote treatment adherence, activities that promote health, self-monitoring of health and symptom management (Bayliss, Steiner, Fernald, Crane & Main, 2003). Understanding how services can facilitate this in the long-term stroke survivors remains limited.

To date there has been a focus on the chronic disease management programs in addressing generic experiences across disease groups with common risk factors (New South Wales Chronic Disease Strategy, 2005). The benefit of self-management principles in people with comorbid conditions is also relatively unexplored (Bayliss et al, 2003). This is of interest to stroke clinicians since many stroke survivors experience comorbidities.

Management of a chronic disease, such as stroke, offers additional challenges due to the wide variation in symptoms experienced. Many stroke survivors experience other comorbidities that influence functional abilities (Hankey, 2002). These may have contributed to stroke onset, and ongoing residual stroke symptoms may further exacerbate physical and cognitive functioning.

Research that generates data on factors that facilitate and maintain adjustment to stroke, many years down the track, will help inform service planners of the ideal make-up of services to address living with chronic disease including stroke specific aspects. This is of great significance with an ageing population leading to more people likely to be living with multiple comorbidities, therefore increasing demand on the health system to provide effective services.

2.10 Personal Influences on Recovery

Previous research has demonstrated the link between mood disturbance and physical and psychosocial functional limitations after stroke. Such limitations include: physical impairments, poor QOL and reduced social activities (Anderson, 1992; Neau et al, 1998; Parikh et al, 1990; Sinyor et al, 1986; Sturm et al, 2002a).

2.10.1 Self-Efficacy

Participation in activities following stroke may be further influenced by reduced confidence and reduced self-efficacy (Mendes de Leon, Seeman, Baker, Richardson & Tinetti, 1996; Robinson-Smith, 2002). Self-efficacy refers to a person's beliefs of how well they can competently carry out actions necessary to deal with life events, irrespective of physical capabilities (Bandura, 1997). Feelings of self-efficacy may vary depending on the nature of the task undertaken.

A review of the qualitative literature in this area outlines the impact of self-efficacy after stroke due to changes in identity and self-concept (Bhogal, et al, 2003; Doolittle 1991; Mumma, 1986; O'Connell, et al, 2001). However, research has demonstrated that stroke survivors with a positive self-efficacy report higher QoL and fewer depressive symptoms (Robinson-Smith, 2002). Positive self-efficacy is modulated by the ability to exercise choice and maintain a sense of control, despite disability levels (Hammell, 2006; Rochette & Desrosiers, 2002).

This reinforces the benefit of facilitating an internal locus of control and the associated benefits in maintaining positive self-efficacy and aiding adjustment to stroke. The health system can play a role in fostering positive self-efficacy in stroke survivors to minimise the psychological impact of stroke, such as post stroke depression (PSD).

2.10.2 Post Stroke Mood Disturbance

Altered mood is common after stroke and a recent systematic review of observational studies by Hackett et al (2005a) indicated that one third of stroke survivors will experience PSD at some stage after stroke.

Furthermore, many stroke survivors are left with mood disorders and depressive symptoms which do not meet the strict criteria for major depression as outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association; 1987; Pohjasvaara et al, 1998). However, the experience of low mood and subsyndromal or minor depression in stroke survivors can continue to impact on life after stroke (Herrmann, Black, Lawrence, Szekely & Szalai, 1998; Rollman & Reynolds, 1999). Identification of appropriate interventions for subsyndromal depression is important in order to reduce the risk of major depression and disability (Lyness et al, 2006).

Accurate identification of the extent and context of post stroke mood disorders can be difficult due to features of stroke, such as altered cognition and communication skills, which may confound diagnosis. PSD is of concern as it has been shown to have an impact on rehabilitation gains and outcomes (Anderson et al, 2004; Ebrahim, Barer & Nouis 1987; Hackett et al, 2005a; House et al, 1991; Sinyor, Kaloupek, Goldenberg & Coopersmith, 1986; Huff, Steckel & Sitzer, 2003). PSD has also been correlated with increased mortality (Morris, Robinson, Andrzejewski, Samuels & Price, 1993.), and psychosocial impairments (Parikh et al, 1990).

As a result, PSD has the potential to lead to poorer health outcomes and reduced QOL (Ahlsio, Britton, Murray & Theorell, 1984; Ebrahim et al, 1997; Sturm et al, 2002a). Increased research into the experience of PSD and subsyndromal depression after stroke is needed in order to identify accurate treatments and maximise QOL.

In the past, evidence demonstrated that PSD was under-recognised by the health system, leading to delays in the initiation of appropriate treatment (Kalra, Gloria, Wilson & Roots, 1995; Rigler, 1999).

This failure to adequately identify and address PSD can be partly attributed to difficulties in diagnosis, due to the overlap of depressive symptoms with altered cognition and communication deficits and problems with self-report after stroke (Turner-Stokes & Hassan, 2002). Identification of PSD has improved (Carota et al, 2005) however there is still a need for improvements in its management. Inadequate assessment of PSD may also stem from the lack of clear evidence supporting the prescription of antidepressant after stroke (Anderson, et al, 2004). Similarly there is limited evidence supporting the benefit of other therapeutic strategies such as counseling or “talking therapies” (Hackett, et al, 2005b).

Traditionally research has indicated the greatest risk for PSD occurs within a few months after stroke onset (Burvill et al, 1995). However, Hackett, Yapa Parag & Anderson (2005a) report that the risk is similar in the early, medium and long-term recovery stages whereby long-term was considered any timeframe beyond 6 months post stroke. Furthermore PSD can persist over time and may also develop many months after stroke onset (Hackett et al, 2005a). As a result there is no best practice approach towards the management of depression.

2.10.3 Social Isolation

Impaired social networks have been frequently cited as a consequence of stroke and are associated with the experience of PSD (Hackett et al, 2005a; Schubert, Taylor, Lee, Mentari, Tamlo, 1992). Restricted social networks can lead to feelings of social isolation which are common post-stroke and are influenced by factors such as mobility difficulties, communication deficits and stigmatisation (Mukherjee, Levin & Heller, 2006). The benefit of social support has been widely demonstrated in post-stroke research as a key factor in facilitating stroke survivors to return home and remain at home despite residual deficits (Hankey et al, 2000; Langhorne et al, 1999).

Such social support includes the concern expressed by family and friends, assistance with practical tasks and social gatherings.

Social networks have long been recognised as a moderator or coping resource in the experience of stress in a person's life (Ogrodniczuk, Piper, Joyce, McCallum & Rosie, 2003). Restricted or inadequate social support lends itself to the argument that a person is at risk of not coping and experiencing heightened distress (Ogrodniczuk et al, 2003).

2.10.4 Stigmatisation

Social stigma is a common consequence of disability, such as stroke. Social stigma is a socially constructed phenomenon experienced by people with visible and non-visible disabilities. The experience involves feeling constantly reminded that they are different to people around them which subsequently leads to feelings of being devalued (Phemister & Crewe, 2004). Stigma has been identified as a cause of discomfort, anxiety, avoidance and withdrawal from social settings (Simpson, Simons & McFayden, 2000). The experience of stigma and feeling undervalued can further impact upon impaired self-efficacy (Simpson et al, 2000).

A factor that contributes to further withdrawal from social networks, is feeling socially unacceptable or undesirable (Gordon, 1998). This is a concern for the health system since stroke survivors are already at high risk of social isolation largely due to mobility restrictions.

The capacity of the health system to accurately identify the experience of stigma in patients will influence timely referral to appropriate resources. Counseling services can facilitate a more adaptive response and/or coping strategies to prevent any further downward spiral in feelings of negativity and self-doubt (Karlovičs & McColl, 1999).

Stroke can lead to visible and less visible disabilities such as communication changes, fatigue, and impaired cognition. Stone (2005) contends there is a greater risk of stigmatisation with the experience of less visible difficulties, as the disability is considered less societally legitimate. Stigmatisation can contribute to feelings of altered self-perception, confusion, reduced confidence and lead to greater social withdrawal.

2.10.5 Adaption

The experience of stroke is a major life event that often creates a barrier to a person being able to resume his/her previous lifestyle. This is most likely to be due to the experience of physiological impairments. However, another key barrier is the fear of having another stroke and facing mortality (Sjögren, 1983). Fear of future stroke is a realistic concern but can become dysfunctional when it impacts on QOL. Understanding of the extent of these experiences and how people respond to adversity can assist service providers to better facilitate recovery from stroke (Wylle et al, 1998).

Research has outlined that difficulties with adaptation after stroke can create a barrier to progress in rehabilitation leading due to poorer outcomes and reduced community participation (Kendall & Buys, 1998). In turn, this can lead to increased health care costs due to the need to access services for longer periods of time as motivation or goal achievement is restricted by the ongoing experience of distress, such as grief and loss.

There are several ways of conceptualising the adjustment process, which may merit greater inclusion in models of stroke service delivery. Linear models of adjustment view adjustment as a series of stages similar to the stages of grief (denial, anger, bargaining, depression, acceptance) identified by Kübler-Ross in 1969 (Kübler-Ross, 1969; Kendall & Buys, 1998).

The limitation of such a model is that it fails to recognise difference in the responses of individuals or factors that constrain progression through the stages (Kendall & Buys, 1998).

Theories exploring recurrent processes of psychosocial adjustment centre on the premise that adjustment processes are ongoing throughout life. The recognition for the need to make adjustments as they arise is in contrast to the process suggested by the Kübler-Ross model. The benefit of models underpinned by a recurrent process of adjustment viewpoint is well supported by research studies undertaken by Charmaz (1995) exploring adaptation when a person faces different aspects within their environment. Each period of adjustment and acceptance may be characterised by physical and cognitive adaptations to their life (Charmaz, 1995). It may also involve constant modification of self-efficacy whenever a new loss, such as the inability to perform an activity, is experienced (Charmaz, 1995).

The recurrent model reinforces the need for long-term community based stroke services that are responsive to the changing needs of stroke survivors over time. This is consistent with the focus on patient-centred care service delivery and provides flexibility to accommodate variation in the time that different individuals may take in adjusting to the impact of stroke. The recurrent model recognises that circumstances will arise in the future that may require further intervention. This is also in accordance with chronic disease management which recognizes the unpredictable nature of the chronic disease experience on function (Kleinman, 1988).

2.10.6 *Coping*

There is growing research exploring the association between coping strategies and improved QOL after stroke (Darlington et al, 2007). However more research is required to further identify the determinants of effective coping and how they impact QOL (Jonsson, Lindgren, Hallstrom, Norving & Lindgren, 2005).

It is useful to make a distinction between 'Coping' and 'Strategies' when reviewing the strategies used to make successful lifestyle adjustments after stroke.

"Coping" refers to mental processes adopted to help "maintain a sense of value and meaning despite illness" (Pound, Gompertz & Ebrahim, 1998, p 121). "Strategies" refers to actions or "things people do to minimise the impact of illness on their everyday lives" (Pound, Gompertz & Ebrahim, 1998, p 121).

Stroke research has identified that stroke survivors employ an array of coping strategies such as: preserving energy levels (Folden, 1994), maintaining hope (Bays, 2001; Folden 1994; Häggström, Axelsson, Norberg, 1994), maintaining independence (Mumma, 1986), maintaining feelings of control (Folden, 1994; Rochette & Desrosiers, 2002), and spiritual practices (Giaquinto, Spiridigliozzi & Caracciolo, 2007). Similarly Krause (2004) identified that older adults with strong social support networks are better at coping with the effects of stress than those without support networks.

2.10.7 *Resilience*

In considering how people cope with the long-term impact of stroke it is worth reviewing the literature on resilience. Resilience refers to a person's ability to "overcome odds, or make markedly successful adaptations" (Fraser, Richman & Galinsky, 1999).

It is considered a dynamic and a positive quality, usually evidenced during a time of transition when a person is required to resist or handle multiple stressors (Mangham, McGrath, Reid & Stewart, 1995; Goodley, 2005). However, to date, most literature regarding resilience has focused on children and younger adults (Fraser, et al, 1999).

Studies show that resilience is facilitated by individual, familial and societal variables (Garmezy, 1993, Rutter, 1990). Such variables may include the provision of emotional and social support, strong role models, religious affiliations experiencing hope and meaning in life in facilitating resilience (Giaquinto et al, 2007; Grotburg, 1995; Jacelon, 1997). The positive role of family support has been well documented in stroke literature (Glass et al, 1993; Tsouna-Hadjis, Vemmos, Zakopoulos & Stamateoloppulos, 2000). These results gives insights to the health system regarding practical ways of fostering resilience in stroke survivors.

2.10.8 The Experience of Ageing and Stroke

The experience of ageing can compound the experience of stroke. Many stroke survivors have pre-existing medical comorbidities that impacted upon lifestyle and QOL prior to the stroke. For many people the onset of a stroke has the potential to increase functional difficulties already being experienced due to the onset of additional physical, emotional and cognitive impairments. Alternatively, the stroke survivor may develop additional comorbidities after their stroke that impact on any goals made in rehabilitation.

Depression is common post stroke but it is also common late in life (Lyness et al, 2006; Rogers, 1993). Research has identified that restrictions in physical functioning, especially activities of daily living (ADLs) and altered social support are a strong predictors of depression in the ageing (Oxman, Berkman, Kasl, Freeman & Barrett, 1992).

These are frequently experienced after stroke and reinforce the need for services that prevents further functional changes closely monitors changes in mood after stroke.

These findings highlight variations in the experiences of stroke survivors that call for the need for long-term access to services to facilitate positive adjustment to stroke. In particular, service delivery should look at ways to prevent social isolation and maintain functioning.

2.10.9 Research Issues in Stroke

In line with the growing interest in long-term post stroke outcomes, there is a need for more qualitative enquiry into stroke and its consequences. Objective measures have traditionally focused on assessing impairment and changes in activity after stroke (Pound et al, 1998).

Qualitative research can provide the means for capturing the consequences of stroke which are not easily identified in quantitative research (Pound et al, 1998). The benefit of qualitative data is that it can convey additional information and themes pertaining to personal experience not measured by quantitative assessment (Van der Gaag et al, 2005).

2.11 Key Issues to Emerge

Adults with stroke represent a large proportion of people living with chronic disability in the Australian community. Many are at risk of reduced QOL due to persisting neurological deficits and psychosocial experiences. Chapter 2 has outlined a critique of the literature exploring outcomes and factors impacting upon recovery after stroke which influence community participation.

The following chapter will outline the methodology used to undertake this study.

CHAPTER THREE: METHODOLOGY

3.1 Chapter Overview

Long-term management of the complexity of issues arising from community dwelling stroke survivors is a challenge for clinicians. Research suggests that optimal conditions for recovery are present mostly in the first few months after stroke. Following this barriers to community reintegration may exist due to ongoing physical, psychosocial or emotional reasons (Ward, 2005). An understanding of the long-term experience of stroke is required in order to effectively promote QoL after stroke. Qualitative methodology provides a means for achieving this (Grbich, 2007).

There has been an increase in the use of qualitative research methods to investigate the phenomena of stroke. Results provide greater understanding of the complexity of the experience of stroke including response to stroke onset (Yoon & Byles, 2002), experiences with the hospital system (Pound et al, 1995), coping strategies (Pound et al, 1998), information provision (O'Mahony, Rodgers, Thomson, Dobson & James 1997; Wiles et al, 1998) and the experience of altered functioning (Alaszewski et al, 2004; O'Connell et al, 2001; Van de Weg, Kuik & Lankhorst, 1999).

This chapter presents the methodology underpinning this qualitative study that explores the experience of stroke survivors living in the community. This study aims to build on existing knowledge by obtaining data in a regional Australian population and exploring any potential variability in post-stroke experiences at varying stages post stroke.

3.2 Description and Rationale for Study Design

Qualitative research recognises that life and experiences may be complex. In the health professionals' understanding of a disease process, insight is best gained by exploring the experiences of those dealing with their illness within their own social and cultural setting (Strauss & Corbin, 1998).

Interviewing is the most common method of data collection in qualitative research (Valle, King & Halling, 1989). Other methods include observation, lectures, seminars, newspaper articles, television shows and other media (Strauss & Corbin, 1998). In-depth, semi-structured, private interviews can increase the likelihood of personal discussion relating to experiences, attitudes, behaviours or lived experience of a person which cannot be measured or experimented (Valle et al, 1989). This data is frequently illustrated with quotes from the participants themselves in order to preserve, convey and present the viewpoints of participating individuals (Hamell, 2006). This enhances comprehension of participants' experiences and interpretations (Creswell, 1994).

Grounded theory is a widely used method of qualitative research that involves the generation of a theory from data using a rigorous research method (Strauss & Corbin, 1998). This is achieved through both an inductive or deductive approach and enhances understanding of human behaviour which cannot be achieved through traditional quantitative methods (Elliot, 2005). The grounded theory approach is beneficial when little is known about a topic and there is a need for enhanced theoretical understanding (Grbich, 2007). Such an approach provides the opportunity to identify the elements of the context being studied (Grbich, 2007).

A grounded theory approach to qualitative research has been widely used in health research addressing a wide range of issues regarding the delivery of health services since research questions are open, rather than focused on hypothesis testing, as is characteristic of quantitative research methodology (Elliot, 2005). Hypotheses may be formulated as conceptual ideas emerge from the data. This is achieved by focusing on the concerns experienced by participants and how they attempt to resolve them.

Grounded theory methodology allows for the development of theory from the experiences of the study participants, that is the theory is grounded in data. A grounded theory approach incorporates data collection, coding and analysis using a process of constant comparison without the theory development component (Bogdan & Biklen, 1998). This entails an ongoing cycle of data collection and simultaneous analysis. This process provides a means for greater understanding of the topic as data is collected (Rice & Ezzy, 1989).

A modified grounded theory approach was therefore used in this study to facilitate the generation of concepts, not theory, that would increase understanding of the experience of community dwelling stroke survivors and minimise the influence of potential pre-conceptions (Creswell, 1994).

3.3 Participants

As outlined in Chapter One, participants were identified from a retrospective, cross-sectional cohort study (White et al, 2007) of community dwelling stroke survivors in metropolitan Newcastle. An overview of the study is presented as follows:

3.3.1 Retrospective Cohort Study

The study assembled 3 retrospective cohorts, each comprised of 30 participants:

- Cohort 1: People who had had a stroke 1 year ago.
- Cohort 3: People who had had a stroke 3 years ago.
- Cohort 5: People who had had a stroke 5 years ago.

Stroke survivors were identified from hospital records/separations from the John Hunter Hospital (JHH), the largest tertiary referral hospital and the main hospital servicing Hunter residents. The cases were defined by: admission to JHH, alive at discharge, history and examination consistent with stroke as determined by a stroke physician. Mortality status was determined by linkage of data with data from the Registry of Births, Deaths and Marriages. Starting from health records in January 2000, 2003 and 2005, consecutive participants were contacted via mail-out, until 30 participants were recruited in each cohort. Exclusion criteria consisted of cognitive impairment (Mini-Mental State Examination [MMSE] Score ≤ 16) (South, Greve, Bianchini & Adams, 2001), inability to give informed consent and current residence in a nursing home, i.e. only community dwelling stroke survivors (including hostels) were contacted.

3.3.2 Baseline Data from Cohort Study

Demographic, stroke subtype and comorbidity data was collected from hospital records to enable participants to be adequately described and cohorts to be compared. Brain imaging was available in all cases.

Patients with haemorrhagic stroke were included. Ischaemic stroke sub-type was classified using the OCSP classification (Bamford et al, 1991; Mead et al, 2000) into the following syndromes: total anterior circulation infarction (TACI), partial anterior circulation infarction (PACI), posterior circulation infarction (POCI) and lacunar infarction (LACI). This classification system identifies patients with potentially different outcomes (prognosis) as well as assisting with identification and prioritisation of appropriate therapies (Mead et al, 2000).

3.3.3 *Instruments used in the Cohort Study*

Well-validated quantitative measures were administered during a face-to-face interview. Stroke sub-type was classified using the OCSP classification system (Bamford et al, 1991). Disability was assessed using the Modified Rankin Scale (MRS) (Sulter, Steen & De Keyser, 1999). Mental status was assessed using the MMSE (Folstein, Folstein, McHugh, 1975). Social support was measured using the Multidimensional Scale of Perceived Social Support (MDPSS) (Canty-Mitchell & Zimet, 2000) which is a brief instrument used for assessing the hierarchical structure of perceived social support. The MDPSS has been well validated It has been well validated in a range of populations including cardiovascular disease populations and the elderly (Blumenthal et al, 1987; McReynolds & Rossen, 2004). Stroke specific function was assessed using the Stroke Impact Scale (SIS) (Duncan et al, 2003). The SIS provides a comprehensive measure of function and HRQoL based on self-report in the domains of strength, memory, emotion, communication, ADL, mobility and handicap. The SIS has undergone extensive psychometric testing (Duncan et al, 2003). Higher scores achieved on the MDPSS and the SIS reflects higher levels of perceived functioning.

3.3.4 *Current Qualitative Study*

Thirty-seven participants from the White et al study (2007) consented to participate in semi-structured interviews and twelve people were selected, four from each Cohort. This number of participants selected for interview is in line with previous qualitative research producing thematic saturation, a situation where no further themes emerge (Strauss & Corbin, 1990). Although there was the provision for further interviews to be done if required, thematic saturation was achieved during the initial twelve interviews and, thus, no subsequent interviews were scheduled. All participants elected to be interviewed in their own home. The duration of the qualitative interviews ranged from 45 minutes to 90 minutes. Each interview was audio recorded with the permission of the participant.

Sampling in qualitative research is concerned with identifying participants who can provide insight into specific and personal experiences being examined rather than obtaining a representative sample, as would be sought in a quantitative study. Purposive, maximum variation sampling was undertaken in this study to identify men and women of different ages and with different living arrangements so as to reach as heterogeneous a sample as possible (Strauss & Corbin, 1998).

Consenting participants from the retrospective study (White et al, 2007) were invited to participate in this qualitative study and were asked to answer some brief questions and provide simple additional demographic information, such as living arrangement and receipt of community services. The responses to these questions were used to assist the selection of four participants within each cohort, capturing a range of demographics and living situations.

3.3.5 *Procedures*

The interviews followed a semi-structured format. This interview guide was developed during a pilot study by the researcher as part of a post-graduate qualitative research methods course. Three participants were interviewed in order to pilot and refine an interview guide. Based on these results a final interview guide was developed to be used for the remainder of the study. See attached Interview Guide Questions, Information Sheet and Consent Form in Appendix C

Analysis was undertaken using a modified grounded theory approach. A schedule of questions was used for the interviews, but the iterative nature of the study using a semi-structured interview format, meant that discussion was not limited to pre-determined areas of inquiry. The semi-structured format allowed for clarification and discussion of particular points raised during the interview. To create a comfortable atmosphere each interview began by asking participants to describe the 'story' of the onset of stroke and their life before the stroke. Subsequent questions explored post-stroke lifestyle and problems and difficulties faced in life after the stroke. This provided the opportunity for rapport building allowing the person to talk openly about their experiences. The interview was designed to cover a range of points developed during the pilot study in order to explore the phenomenon of interest. However, use of the interview guide did not restrict the range of issues raised by the participants and new themes emerged during the course of interviews.

3.4 Field Notes

The tape recorder failed to record during one of the interviews. This was noticed immediately and extensive field notes were made following the interview by the researcher.

In addition, a second, brief audio recorded interview was conducted with the consent of the participant. The field notes were treated in the same manner as the transcripts of interviews during the analysis phase (Glaser & Strauss, 1967).

3.5 Data Analysis

As soon as possible, after each interview, the oral data was transcribed into written text, with pseudonyms used in place of participants' names and other identifying details altered. The transcription was undertaken by the researcher or a research assistant, and then checked for accuracy.

Data analysis was undertaken using a constant comparative method utilising modified grounded theory. Each interview was transcribed, conceptualised and coded. Coding was undertaken as follows:

3.5.1 Open Coding

The first step of the coding process was open coding which involved a literal line by line reading and interpretation of the transcripts. Each transcript was coded by the primary researcher (J. W.) and a code book was developed. This is the first level of understanding whereby transcripts are read and conceptualized, line by line, in order to gain a comprehensive sense of the participants' experience. Memos and codes were written in an adjacent margin. Coding involved the use of descriptive words from the data.

These codes were compared between the data from each transcript and modified until a final name for each code was allocated. This required the researcher to constantly move between transcripts as emerging concepts were explored and related to each other.

3.5.2 *Primary Coding*

Subsequently primary coding was performed using these interpretations to generate first order codes. These were then given a label or code consisting of four letters in order to facilitate retrieval between the transcripts (for example, feelings of frustration were labeled as FRUS). These codes explained participants' behaviour, beliefs, and emotions surrounding their experience which could be explored in subsequent interviews. This continued to involve a process of constant comparison whereby transcripts were read and re-read in order to clarify and code as reflected by the stroke survivor.

3.5.3 *Axial Coding*

The next level of analysis was axial coding and involved a grouping of the first order codes into coherent themes. This final level of analysis involved the examination of relationships and interactions between the various codes related to the experience of stroke, emotions and community participation. For example, all codes that appeared to influence mood were grouped and influences of these relationships were sought. The final level of analysis involved the selection of major categories which outlined the relationships and interactions between the codes related to the experience of stroke, emotions and community participation. Quotes were recorded that summarised the subjective experience.

At this stage increased meetings were held with the study supervisors. After each meeting the amended codes were reapplied to the transcripts.

To ensure accuracy consensus coding was undertaken by 2 researchers (J.W and P.M.). Following independent coding of the transcripts by each researcher, there was a process of comparative coding including discussion of the codes and how they were developed.

Differences in researcher perspective were resolved by negotiation and consensus and fed back into the analysis to cross-check codes and themes and develop an overall interpretation of the data

Rigor was further enhanced by incorporating a search for negative cases (cases which appear to disconfirm or refute any conclusions arising from data) (Miles & Huberman, 1994) use of participant's words and member checking (checking (testing the data with the members of the group from which they were collected) (Driessen, van der Vleuten, Schuwirth, van Tartwijk & Vermunt, 2005) whereby transcripts were mailed to participants for them to review and to add or remove any information from their transcript (Creswell, 1994; Glaser & Strauss, 1967). To assist participants in this process due to potential cognitive and communication difficulties, the participants were contacted by phone within a few weeks of receiving the mail-out to clarify their feedback. However no changes were made to the transcripts or their interpretation by the participants.

3.5.4 Trustworthiness

Validity of qualitative research process is enhanced through rigour of methodology and in the interpretation of results (Creswell, Hanson, Clark-Plano, Morales, 2007). This was achieved through careful study using a modified grounded theory process. External validity is ensured as the process remains constant even though there are variances in participants and their contexts (Stern, 1985)

Lincoln & Guba (1985) outline that trustworthiness in qualitative research is achieved by addressing a criteria of credibility, transferability, dependability and confirmability.

3.5.5 *Credibility*

Credibility relates to the evaluation of the truth value within the research being undertaken. For the purpose of this study this was achieved by incorporating a search for negative cases, use of participant's words and member checking (Creswell, 1994; Strauss & Corbin, 1990), whereby transcripts were mailed to participants for them to review and to add or remove any information from their transcript. Participants were contacted by phone within a few weeks of receiving the mail-out to obtain their feedback. However no changes were made to the transcripts or their interpretation by the participants.

The use of reflexive analysis meant the researcher critically appraised their relationship with the data and the study context, taking account any preconceptions (Krefting, 1991; Lincoln and Guba, 1985). In addition peer debriefing ensured the researcher remained open to the data and did not demonstrate bias during the data analysis (Lincoln & Guba, 1985).

Issues that were identified were explored in subsequent interviews with other participants to clarify and extend interpretation of the data. This enhanced the rigour of the process prior to undertaking full scale thematic analysis of data involving coding and categorising data, thus leading to the development of themes relating to the research questions.

3.5.6 *Transferability*

Transferability in qualitative research can be considered the equivalent to the external validity in quantitative research (Lincoln & Guba, 1985). This involves providing sufficient details in order for the emergent findings to be tested in other studies, while acknowledging that qualitative studies cannot be replicated (Stern, 1995)

3.5.7 Dependability

Dependability refers to the reliability of the study and the examination of design related factors that may influence the study (Lincoln & Guba, 1985). Since it is not appropriate to replicate qualitative research in its entirety, dependability is achieved through a transparent approach and documentation of methods and findings (Lincoln & Guba, 1985).

3.5.8 Confirmability

Trustworthiness is important and the researcher adhered to well established processes to ensure credibility of the study. Careful attention to processes lends itself to an appropriate and relevant conclusion (Corbin & Strauss, 1997)

The results of these qualitative data will be described in Chapter Four. A discussion of these results and implication for clinical practice are presented in Chapter Five of this thesis.

3.6 Ethics Approval

Ethics Committee approval for this project was obtained from Hunter New England Human Ethics Research Committee

CHAPTER FOUR: RESULTS

As described in Chapter three, 12 semi-structured interviews were undertaken to obtain insight into the post stroke experience and in-depth information about ongoing needs and concerns. An interview schedule with a set of open-ended, semi-structured questions was used as a guide for the interviews, but did not limit the emergence of new themes for discussion. Purposive sampling was used to recruit stroke survivors with a range of different backgrounds.

4.1 Characteristics of Participants

Equal numbers of men and women were interviewed, two males and two females from within each cohort. Table 1 outlines key demographic data and quantitative data obtained from a previous study (White et al, 2007). All participants had experienced an ischaemic stroke. Five participants were classified as dependent following their stroke and seven were classified as independent, using the MRS (Sulter et al, 1999). Age ranged from 43-92 years.

Table 1 Participant Demographics and Post Stroke Functioning

Participant Number	Sex	Age	Marital Status	Years Since Stroke	OCSP ¹	MRS ²	MMSE ³
1	Male	92	Widowed	1	PACI ⁴	4	28
2	Male	60	Divorced	1	PACI ⁴	3	23
3	Female	66	Married	1	PACI ⁴	4	29
4	Female	78	Widowed	1	POCI ⁵	3	29
5	Female	43	Married	3	PACI ⁴	2	29
6	Female	81	Widowed	3	TACI ⁶	1	28
7	Male	58	Married	3	PACI ⁴	2	30
8	Male	78	Widowed	3	LACI ⁷	1	30
9	Female	74	Separated	5	PACI ⁴	1	28
10	Male	70	Married	5	LACI ⁷	2	29
11	Female	79	Married	5	LACI ⁷	1	28
12	Male	82	Married	5	POCI ⁵	3	30

¹OCSP indicates Oxfordshire Community Stroke Project; ²MRS indicates Modified Rankin Scale; ³MMSE indicates Mini-Mental State Examination; ⁴PACI, Partial Anterior Circulation Infarction; ⁵POCI Posterior Circulation Infarction; ⁶TACI, Total Anterior Circulation Infarction; ⁷LACI, Lacunar Infarction; ⁴PACI, Partial Anterior Circulation Infarction.

The use of semi-structured interviews provided the opportunity for stroke survivors to be questioned about their personal experiences after stroke. A vivid account was obtained from participants recruited at three different time points post-stroke about their experiences of stroke and their new life.

The aim of this study was to identify factors that influenced long-term well-being and adjustment to stroke, as well as areas of ongoing concern which may need closer attention from the health system, particularly regarding the delivery of allied health community services. The interviews were conducted with participants sampled at three time points and the four main themes to emerge were common to all participants. There were no significant or consistent differences between the three cohorts in participants' experiences, responses and attitudes regarding stroke.

4.2 Identified Themes

Differing themes were identified during the coding process. These are summarised as follows:

1. Altered Participation in Life
 - i) Functional restrictions and role loss

2. Low Mood
 - i) Depressive feelings
 - ii) Feelings of frustration
 - iii) Feelings of reduced self-efficacy
 - iv) Feelings of dependency
 - v) Feelings of loss
 - vi) Effects of social Isolation

3. Modulating Factors after Stroke
 - i) Lifestyle Modification
 - ii) Hope
 - iii) Social support
 - iv) Resilience

4. Experience with the Health System

Knowledge about stroke

- ii) Communication with the health system
- iii) Issues of dignity
- iv) Transition

4.2.1 *Theme 1: Altered Participation in Life*

i) Functional restrictions and role loss

Participants in this study identified a central experience of residual physical, cognitive or communication impairments. This was evident in a number of common expressions by participants, such as: “I used to” (Interview 1, male, age 92), “It’s more difficult” (Interview 12, male, age 82) and “It’s impossible” (Interview 7, male, age 58).

All participants reported that they had ceased participation in one or more occupations that were manageable before the stroke. There was a common experience of regret at having to relinquish valued activities. Most participants made reference to the permanency of changes to their lifestyle as a result of stroke.

“The stroke changed my life altogether, you can’t get it back. “

(Interview 10, male, age 70).

“I can’t go fishing. I went fishing with my young bloke the other day but oh, I never fished, I just sat and watched him.”

(Interview 2, male, age 60).

Participants expressed an ongoing wish to return to those activities undertaken before the stroke. The extent to which this was achieved varied between participants, depending on the amount of residual disability. The broad range of activities of value identified by participants reflected their individual characteristics. For most participants self-identity was linked to performance in their pre-stroke activities. These included home maintenance, gardening, sports such as golf and bowling, craft and games, and service to others such as caring for grandchildren or volunteering in the community.

“Because she [daughter] had been working full-time, I was doing the washing and ironing and babysitting for those 12 years. They just went by so quickly and ah, since I have had the stroke I have not been able to do what I used to do”.

(Interview 11, female age 79).

“Odd jobs around the house like painting, and gardening and so forth.....I cannot do anything now.”

(Interview 12, male, age 82).

Most participants were aware of the significant changes to their lifestyle and that there was no likelihood of “getting back” (Interview 10, male, age 70) to how things were before the stroke. The subsequent experience of altered participation in valued activities was linked to changes in perceived quality of life.

“It is nowhere near as good, you could call it quality if you like.”

(Interview 9, female, age 74).

4.2.2 Theme 2: Low Mood

i) Depressive Feelings

A significant finding in this study was the extent of the experience of low mood that may not have met the criteria for major depression as defined by DSM-IV. These mood changes were unrelated to the time of stroke and level of disability. The majority of participants reported feelings of sadness and that they no longer “cared” (Interview 7, male, age 58) about the things they previously did. Suicidal ideation was present in one participant who indicated “[I’d be] better off dead” (Interview 1, male, age 92).

“You feel disappointed, down hearted, sorry.”

(Interview 10, male, age 70).

“Oh, it gets you down, you know. Yeah, it gets you down a bit”.

(Interview 2, male, age 60).

The majority of participants reported feelings of sadness, disappointment and being “fed up” (Interview 4, female, age 78). The largest contributors towards low mood were changes in functional abilities and the relinquishment of valued activities, which had to be “given away” (Interview 7, male, age 58).

Reduced participation in activities was directly linked with clearly expressed feelings of apathy and “lost interest” (Interview 7, male, age 58). This caused people to cease activities that they still were functionally capable of performing. A cycle of increased withdrawal from valued activities was described which appeared to result in further inactivity and boredom. These feelings were a precursor to frustration.

ii) Frustration

The experience of frustration and low mood were often concomitant and strongly linked to functional limitations. All participants expressed negative feelings about “not being able to do what I like” (Interview 11, female, age 79) and being “fed up” (Interview 4, female, age 78).

“Frustrating...you can’t do nothing. You can’t mow the lawn, you can’t go fishing, not allowed to have a beer, can’t smoke any more”.

(Interview 2, male age 60).

Experiences of frustration were compounded by the need to take extra time or the inability to complete a task.

“It’s more frustrating than anything else because you cannot do what you did before. You think you can do it until you try to do it and there is no way in the world.

(Interview 7, male age 58).

Experiences of frustration were compounded by the need to take extra time or the inability to complete a task.

“That is the frustrating part. You can’t make your limbs move the way that you would like to.”

(Interview 6, female, age 81).

Anger was commonly associated with frustration and participants reported feeling “impatient” (Interview 4, female, age 78) and “cranky” (Interview 11, female, age 7) or

had an increased tendency to “flare-up” (Interview 7, male age 58). Such feelings were noted when participants experienced minor as well as major difficulties with task performance.

“You get frustrated with yourself and angry... I get very angry.”

(Interview 3, female, age 66)

iii) Feelings of reduced self efficacy

A notable relationship was identified between self efficacy and low mood. This was expressed in a variety of ways such as feelings of being “useless” (Interview 1, male, age 92) and “unproductive” (Interview 3, female, age 66). The lost ability to continue to partake in their pre-stroke lifestyle continually reinforced for one participant their being “different and not the same as everyone.” (Interview 6, female, age 81). Reduced self efficacy was further manifested when participants were dissatisfied with performance outcome and the quality or “thoroughness” (Interview 6, female, age 81) previously achieved.

“Well in a way it makes you feel like you want to give up because you are not improving as you expected to. You got to accept the fact that you are not going to get better.”

(Interview 7, male age 58).

“I am just a hindrance. I accept that.”

(Interview 9, female, age 74).

Such feelings of lost competency were seen to impact on their self-confidence and led to further withdrawal from participation in activities. Some participants had made a conscious decision to withdraw due to feelings of “embarrassment” (Interview 7, male,

age 58). This phenomena was most evident in participants with speech impairments who experienced stigmatisation from the broader community.

“I think I am talking funny so I sort of get out of the road.”

(Interview 10, male, age 70).

Reduced self efficacy was also influenced by the need to depend on other people after the stroke. This was exacerbated if the inability to undertake these previously valued activities were central to a participants pre-stroke identity, such a maintaining the home, leisure and work activities.

Participants experiencing greater levels of frustration appeared to have additional mood changes related to reduced self efficacy and difficulties with adjustment to their post-stroke lifestyle. For example, one participant said

“You feel different and not the same as everyone.”

(Interview 6, female, age 81).

Another noted

“I still have it in my mind that I might get better, but I know that I cannot.”

(Interview 7, male, age 58).

iv) Feelings of dependency

Many participants were required to rely on other people for assistance which contributed to the experience of low mood. This was exacerbated by the inability to undertake valued activities that were central to a participants pre-stroke identity, such a maintaining the home, leisure and work activities.

The extent of dependency varied according to residual impairments and the most common restrictions related to activities of daily living.

“Have to get help to do up a shirt or pull a jumper down, put on a coat...small things that you are used to doing for yourself.”

(Interview 10, male, age 70)

“I can not wash or wipe up because I can not stand very well, I do not do any house work now, I do not cook, I do nothing.”

(Interview 12, male, age 82)

Participants found the need to rely on others and their loss of independence was “hard to accept” (Interview 4, female, age 78) and this was observed as being a major contributor to distress.

“You got to rely on people, unfortunately.”

(Interview 7, male, age 58)

v) *Feelings of loss*

Residual physical, cognitive or communication impairments all contributed to role loss. Most participants expressed regret at the extent of activities relinquished and lack of progress.

“I used to go round [hostel] units here and [serve] communion... I was really involved. I just can't any more...it is a bit upsetting.”

(Interview 4, female, age 78).

There was a sense that life had “changed forever” (Interview10, male, age 70) and that the quality was “no where near as good” (Interview 9, female, age 74). This varied between participants and one participant responded

“I don’t think you ever adjust, it is something that you still think about. You still get down on yourself because you cannot do what you would like to do, because you are not capable any more. Unfortunately it does take a while to realise you are not capable - takes a lot of set backs.”

(Interview 7, male, age 58).

Feelings of guilt, loss and having “paid the price” (Interview 7, male, age 58) were common in participants who felt they were to blame for their stroke. Participants identified a range of causative factors such as “drinking” (Interview 2, male, age 60) or “stress” (Interview 3, female, age 66)

“I was working 16 hour days, plus overtime and it just caught up with me.” (Interview 7, male, age 58),

“I probably created a lot of problems my self the way my lifestyle was because I used to enjoy quite a few smokes and drinks and I did not look after my health I have paid the price”.

(Interview 7, male, age 58),

“Yes I was pushing myself, I was pushing.”

(Interview 9, female, age 75),

vi) Effects of social isolation

The majority of participants reported changes in their patterns of socialisation with friends and family after the stroke. This was strongly linked to being “confined” (Interview 9) and having reduced ability to physically access the community due to mobility restrictions and transport issues. Participants found it difficult to get out of the house to visit people or attend group-based activities such as church, sport etc.

Participants reported spending significantly reduced amounts of time with both friends and family as compared to their pre-stroke lifestyle. All participants expressed feelings of loss and regret regarding reduced frequency of contact with people and even the loss of some friendships.

“The only people I see now is my family, that’s all I see now.”

(Interview 10, male, age 70)

The experience of social isolation was an additional cause of distress in participants.

“I do miss the kids (grandchildren). I miss them very much.”

(Interview 11, female, age 79)

Very few participants had developed new or alternative relationships to replace changed or lost relationships. However, for several participants this was achieved by attending new group based activities such as a stroke club (Interview 9) or hostel-based activities (Interview 4).

4.2.3 *Theme 3: Modulating Factors after Stroke*

Low mood was experienced as a continuum from lesser to greater emotional distress. Participants' positions on this continuum were modulated by various factors. These facilitated adaptation to the stroke and consequently facilitated community reintegration.

i) Lifestyle Modification

The majority of participants had consciously or unconsciously re-constructed a life characterised by new routines. For some participants this related to the use of adaptive equipment or altered approaches to carry out a desired occupation.

"[When] I am going to get things ready for tea I usually think about it half an hour before and get everything organised. I never used to do that before I used to just be a bull at a gate and get into everything but not now."

(Interview 5, female, age 43).

Participants with insight into their abilities and limitations appeared more able to effectively problem-solve barriers in order to accomplish a desired task. This led to enhanced feelings of independence and choice, which assisted in the maintenance of a positive self-efficacy.

"I have slowed down a lot now and have accepted [I need to do] that. I have to be careful."

(Interview 5, female, age 43).

Many participants demonstrated increased reflectivity towards their post-stroke lifestyle. One participant clearly stated having a renewed sense of what was important in life after having come so close to death.

This was characterised by the desire to choose activities that provided a sense of purpose and pleasure over more extraneous tasks. One respondent reflected

“I sit down now and think, “Well blow the house work, I will crochet.” I enjoy that more, whereas before I would run around doing everything. I have slowed down a lot.”

(Interview 5, female, age 43).

Similarly, participants appeared to benefit strongly from comparing their own situation with that of other stroke survivors and reported that seeing other people with more severe disabilities helped them to appreciate their progress.

“I have had a few friends or people I know who have had strokes who are worse off than I am. I am quite thankful that I am not as bad as they are.”

(Interview 7, male, 58).

ii) Hope

Another key feature that modulated the experience of stroke related to maintaining feelings of hope. For many participants hope was centered around “living for others” (Interview 10) and seeing milestones achieved in the lives of children and grandchildren. These included marriage, the birth of grandchildren, or the graduation of grandchildren from school and university.

“We’ll hopefully see 50 years of marriage. I want to see my wife turn 70, me turn 75 ... yeh that’s good. All our kids are getting closer to 50 and I want to see all that.”

(Interview 10, male, age 70).

A number of the participants reported that having a strong faith in God was a significant source of hope.

“If it was not for God I would be a lot worse with my stroke I think.”

(Interview 9, female, age 74).

Other participants placed their hope in “getting back” (Interview 7) to valued occupations, such as golf. Another participant expressed the valuing of being able to maintain participation in valued activities.

“It is important that I do all those things myself to get out of the house and I do love going shopping cause that’s my entertainment, my shopping day.”

(Interview 11, female, age 79).

iii) Social support

Acceptance of the support of family, friends and loved ones was another key coping strategy, which some viewed as “essential” (Interview 11, female, age 79). This included the provision of practical support or emotional support.

“Well they understand you, even when I am tired and I feel I cannot express myself they know what I am talking about.”

(Interview 7, male, age 58).

“I have a good family. They don’t like to let me think that they are helping me, but they are. I get family support. As far as I am concerned my family is the most important thing.”

(Interview 8, male, age 78).

The experience of a life disrupted by stroke is not typically associated with positives, however some participants reported that key relationships were central to facilitating adjustment to the stroke. In particular, some of the participants who were married gained a new appreciation for how much they were loved, especially by their spouses. This fostered a sense of purpose following the stroke, and was a source of encouragement and motivation to try to keep improving.

“I learned a lot more about my wife and kids all their love and affection.” (Interview 10, male, age 70).

“I think it has brought [my husband] and I closer together because we are together all of the time and we are helping each other so in that respect we have grown closer together.”

(Interview 11, female, age 79).

Relationships with children and grandchildren were consistently identified as being the least likely to change, although some participants were concerned at the extra responsibility they perceived their grandchildren were assuming.

“I have 21 grand kids, and two or three sort of panic over me.”

(Interview 10, male, age 70).

While not all the participants had an extended family network, most participants identified the importance of maintaining a supportive, social network that included friends and family.

“Having a family that cared, or friends that cared, that’s the main thing, getting those things when you need them. I have never been on my own.”

(Interview 12, male, Age 82).

iv) Resilience

An interesting theme in this study was that of resilience (and of having achieved mastery during previous life experiences and challenges) in facilitating greater adjustment to stroke. Most participants identified that overcoming previous adversity in life had equipped them with skills “to stand on their own two feet” (Interview 9) – skills which were transferable to their experience of stroke. Participants felt that difficult life experiences helped them “Not to take things for granted” (Interview 6) and to “Make today count.” (Interview 11)

“I have had a pretty hard life, but I have handled it well, considering.”

(Interview 1, male, age 92).

4.2.4 *Theme 4: Experience with the Health System*

Stroke survivors described a diverse range of scenarios which had an impact on their experience with the health system, both during hospital admission or while community-dwelling over a one to five year time-frame.

i) Knowledge about stroke

The theme of “knowledge” around the issue of stroke emerged as a prominent finding. “Knowledge” in this context was a multidimensional factor and was central to participants’ responses to stroke onset. Gaps in participant knowledge about stroke led to a cycle of fear of future stroke, feelings of stigmatisation and uncertainty when dealing with the health system.

Pre-stroke Knowledge

There was evidence in the interviews that most participants lacked pre-stroke knowledge of stroke risk factors and warning signs. As a result a sense of bewilderment was commonly expressed and was salient in respondents' "story-telling" around the stroke experience.

"I cannot understand what caused it to happen...I did not know what a stroke was."

(Interview 1, male, age 92).

"And I really did not notice it. I went down to get a hair cut and as I went to walk down the street I took up all the footpath I just, I could not walk. I was lucky to get back home actually. I had no idea how to ring [wife] to let her know where I was, I could not even remember the phone number."

(Interview 7, male age 58).

Poor knowledge of stroke was evidenced by the failure of the majority of participants to respond to their stroke symptoms as an emergency. Many participants continued to conduct their daily activities and postponed seeking medical attention because they perceived it as inconvenient or unnecessary and thought their symptoms would resolve.

"I got up that morningI felt just funny I thought something was wrong I filled the day out when I came home I [called] the doctor."

(Interview 11, female, age 79).

“I refused to go [to the doctor] because it was the day before my 80th birthday.”

(Interview 12, male, age 82).

Post stroke knowledge

Following discharge from hospital to the community, the participants' interview responses highlighted ongoing knowledge gaps that appeared to be as limiting as had been their lack of knowledge pre-stroke. Many participants remained fearful that they would experience a subsequent stroke and that this was “always in the back of my mind” (Participant 11, female, age 79). Though essentially a realistic concern, fear resulted in dysfunctional responses by some participants' with close monitoring or avoidance of perceived risk factors - often to the point of impairing quality of life or social interaction. Such responses appeared to correlate with their experience of, and interpretation of, their acute stroke.

“The young blokes say ‘have a proper beer’ but I am too scared to....in case something else goes wrong.”

(Interview 2, male age 60).

Several participants questioned whether the onset of their stroke may have been prevented by appropriate stroke knowledge in others. For most participants this pertained to health professionals with whom they had contact about their health prior to the stroke. In most cases concern was directed towards people who they considered experts, especially their local General Practitioner. (Family Physician). For example, one participant reported that their General Practitioner did not treat a previous, minor stroke as an emergency.

“I was falling over and I could not walk straight and I was doing this in the [general practitioner] surgery.”

(Interview 1, male, age 92).

“Maybe my GP [general practitioner] could have helped me in the beginning.”

(Interview 9, female, age 74).

Community Stroke Knowledge

Lack of knowledge regarding stroke within the broader community was also highlighted by participants’ experiences of stigma as a result of ongoing residual impairments.

“They are a little bit standoffish..... like there is something disease-ridden about you.”

(Interview 3, female, age 66).

“I am a loner that way since my stroke. I cannot talk with people. I think I am talking funny so I sort of get out of the road.”

(Interview 10, male, age 70)

The participants’ perceived lack of knowledge about stroke and stroke outcome had considerable effect upon accessing appropriate care and adapting to life post-stroke. This theme of “knowledge” was seen to have implications for another principal theme that emerged in the study pertaining to “communication”.

ii) Communication with the health system

Communication Regarding Treatment

Participants perceived that communication with the health system, and within the health system, was ineffective.

It was apparent that many participants experienced frustration due to gaps in the transfer of knowledge between treating health professions involved in their care, at both an inpatient and outpatient level (see below). Additionally, confusion was experienced when participants felt they had received insufficient explanation about their treatment.

“The only reason I went to them [outpatient services] was because I was sent to them.”
(Interview 7, male, age 58).

This lack of communication could be seen to compromise participants’ confidence in their therapeutic pathway.

“I did not find it helpful [sitting on a ball] at all. I was scared I was going to fall. The physiotherapist wanted me to turn my head [while sitting on the ball]. Well have you ever tried it? I could only do what was comfortable.”
(Interview 9, female, age 74).

“That is one thing that amazed me in hospital after the stroke nobody ever worked on my hand, never touched it.”
(Interview 3, female, age 66).

Furthermore, areas for improvement in system processes were identified based on reports of dissatisfaction with communication within the health system. For example, the lack of communication between various health professionals at triage and in subsequent assessment and management phases of the participants’ journey through their hospital admission created frustration. An example is the complaint by one participant of “being asked the same questions by everyone.” (Interview 9, female, age 74).

Additionally, some participants didn't feel adequately informed about their ongoing care once they were discharged. This made it difficult to actively participate in decision-making in relation to their health.

"He [Specialist] was finished with me...but I was determined to find out more. So, I made my own enquiries." (Interview 8, male, age 78).

Another participant was distressed about the experience of residual impairments which led them to resign from work. It was evident that communication regarding post-stroke occupational expectations had not been suitably clarified.

"I thought I was going really good and then I got involved with Commonwealth Rehabilitation Service [a government return to work service] and that sort of made me realise I was not as far progressed as I thought I was."

(Interview 7, male, age 58).

iii) Issues of Dignity

Perceived lack of respect from the health system was a further distressing experience reported by some participants'. For example, one participant's experience of incontinence left them feeling ashamed and undignified.

"It [incontinence] is disgusting, just disgusting... the nurses in the hospital would come in the morning and change the sheets and used to make you think you should be ashamed of yourself."

(Interview 1, male, age 92).

Another participant overheard a discussion between staff relating to their treatment, which they found demeaning. This participant felt that a particular staff member did not want to treat them and was trying to persuade a colleague to conduct the treatment session.

“I overheard them ...You are not dead. You might be a little bit slow, but you are not dead.”

(Interview 9,, female, age 74).

iv) Transition

Early Days

The transition from hospital to community care was problematic for many participants. The inpatient experience of poor communication and transfer of information has already been outlined (above). This theme also emerged during this transitional period. Lack of information meant that for some participants the transition home was characterised by feelings of uncertainty.

“You sort of feel a bit lost for a while. You wonder how you are going to cope.”

(Interview 4, female, age 78).

“I thought I’d just come out and be as good as gold. But as soon as I came home I realised that things were different.” (Interview 6, female, age 81).

Not all participants were routinely referred to outpatient therapy following discharge from the hospital setting. While the reasons for this are unclear, some participants felt there was a lack of information on how to access ongoing care. Participants commonly adopted a passive approach towards this and didn’t actively seek the support they desired.

“If I was younger, I would be a bit more inclined to. Yes, if I was younger you would want more help with that.”

(Interview, male, age 58).

One participant expressed concerns about the “capabilities” of community-based staff in dealing with issues specific to stroke. For example, the ability of General Practitioners (GP) to be experts in stroke. In this case they found their GP was unable to provide them with sufficiently detailed information about their stroke and sufficiently expert management.

“They [Specialist] said to go back to your GP [general practitioner]...I don’t know if that was a wise idea. He is a lovely guy, don’t get me wrong.... but I am not sure that he is at that level as far as stroke victims are concerned.” (Participant 8, male, age 78).

Despite these misgivings, overall participants were satisfied with the community services they received and their outcomes.

“Without them I would not have got back to where I was.”

(Interview 7, male, age 58).

Down the Track

The majority of participants expressed an ongoing desire to return to valued activities. These varied widely and the extent of role loss and participation has been previously described earlier in this chapter. The absence of longer term re-assessment from allied health staff was apparent as none of the participants had been reviewed following discharge from therapies within the first few months after stroke.

Those participants who had experienced functional improvements or had identified new goals had no opportunity to access additional therapeutic advice. This was linked with uncertainty about the availability or type of services, many years after stroke.

“I would like to know what services were available, you know.”

(Interview 2, male, age 60).

“Well I think I should be made more aware of what is available to me.” (Interview 6, female, age 81).

4.3 Synopsis

The results of this study revealed a range of experiences that affected lifestyle after stroke. These were important to the stroke survivors and provide a context for further exploration of how community services can be best provided to minimize distress and facilitate ongoing community reintegration. Stroke survivors tended to grieve most over the impact of residual impairments on participation in valued activities.

There was a common experience of low mood suggesting the need for improved intervention from the health system. A range of coping strategies were identified which helped reduce feelings of distress and aided participation in valued activities. The need for clearer information about stroke and management of stroke across the phases of care was identified as a key area of need. Experiences with the health system highlight the scope for change in processes surrounding communication and follow-up after stroke. All the themes support the need for ongoing professional development in staff. These findings have implications for rehabilitation practice and for further research and are presented in the final chapter of this thesis.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The concluding chapter of this thesis provides an overview and discussion of the findings within the context of existing literature. Key findings identified pertained to altered level of participation, mood disturbance, modulating factors and experience with the health system up to five years after stroke. These are of significance to health care practitioners and help inform priorities for therapeutic intervention. The contribution of these themes to the existing body of knowledge about stroke recovery is discussed. Limitations of the study are outlined and implications for service delivery, education and research are discussed.

5.2 Overview and Discussion of Findings

This study explored the experiences of community dwelling stroke survivors, the factors influencing their engagement with the health system and identified areas of ongoing need. The literature review established the clinical importance of the study, demonstrating that stroke is prevalent in the Australian population and is a concerning health problem. Furthermore the literature highlighted the wide variations influencing stroke recovery and the issues affecting community reintegration and participation. It demonstrated the ongoing gaps in knowledge concerning the long term experience of stroke and the factors which help or hinder successful reintegration into the community, despite residual deficits.

The results provide valuable Australian data that extends understanding of the long-term experience of stroke survivors. Results will be used to inform and facilitate local reorganisation of community based service delivery. Interviews were undertaken with stroke survivors at three time points, one, three and five years after stroke.

Common themes were identified in this study and these themes over-lapped between the experiences of the four participants within each cohort of this study. While interviews were conducted with participants at different time points, the data was analysed as a whole. The results from these interviews, as reported in this thesis, contribute to new knowledge for stroke clinicians, stroke survivors and health planners about the experience of local, community dwelling stroke survivors.

5.3 Key Findings

This study validated the need to explore the experiences of stroke survivors up to 5 years post stroke. The use of qualitative methodology was useful in identifying extensive lifestyle changes experienced by the participants’.

The experience of life changes including altered participation and low mood reinforces the need for community based stroke service delivery beyond the first year after stroke to address this. Such therapy may be further influenced by knowledge gained from this study regarding modulating factors used by stroke survivors and their perceived experience with the health system. The themes identified in this study target areas to be addressed immediately by health professionals working with stroke survivors’.

The accounts of stroke survivors in this study depicted the complex and challenging nature of the return to community living after stroke. The themes were linked between the three cohorts adding to clinical understanding about the complexities of the long-term experience of stroke. This is in accordance with previous qualitative literature exploring the impact of stroke (Mc Kevitt et al, 2004; O’Connell et al, 2001).

In addition, the result of this study identified common factors that played a role in the experience of low mood. These results increase understanding about mood disturbance post stroke and the factors that influenced the onset and/or perpetuation of

low mood. The accounts of the study participants' also highlighted the depth of emotions experienced after stroke since participants were left with mood disorders and depressive symptoms which do not meet the criteria for major depression (Lyness, et al, 2006). Quantitative data was available to assist comparison between participants and further validate these qualitative results. Quantitative data identified that while post stroke functioning remained stable between the 3 cohorts (White et al, 2007) there was a similar proportion of participants experiencing low mood across the three cohorts and up to five years post stroke.

A prominent finding concerned the impact of reduced community participation due to altered participation and role loss. This resulted in grief and changes in self efficacy. There were indications that stroke survivors were reluctant to receive help when their functional changes resulted in increased dependency on others. Some participants also expressed concerns, thinking their stroke may have been prevented or that they themselves had played an aggravating role in the onset of stroke. The ongoing experience of distress reflected the lack of knowledge and availability of ongoing support. A lack of understanding regarding stroke and stroke prevention was evident throughout the phases of care. As a result, areas for improvement in processes and response of the health system were identified which may help to lessen feelings of distress experienced by the stroke survivor and improve continuity of care. Discrepancies in communication between the stroke survivor and health professionals highlight possible areas for ongoing professional education. These are highlighted by accounts of the hospital experience and the transition back home into community life. Modulating factors were also identified which assisted to attenuate the impact of stroke.

These findings have implications for the provision of care by the health system and are discussed under the key theme headings.

5.3.1 *Altered Participation in Life*

This study highlights the complexity of factors that influence participation following stroke. A wide range of physical and psychosocial factors were identified affecting post stroke participation in meaningful, pre-stroke activities in participants. This included home maintenance, hobbies, sports and community based activities such as spending time with friends and family. These findings are consistent with other qualitative studies identifying the common experience of loss due to changes in physical functioning (O'Connell et al, 2001), social situations (Mumma, 1986; Pound et al, 1998) and identity (Ellis-Hill et al, 2000).

Our study participants were interviewed at longer intervals following discharge after the acute stroke, than in previous studies (Faircloth, Boylstein, Rittman & Gubrium, 2005; Maclean, Pound, Wolfe & Rudd, 2000). Results demonstrated that altered participation in activities was shown to persist up to five years after stroke even when minimal residual deficits were experienced. Role loss and increased dependency on others were associated with increased distress and contributed to low mood. Previous research has clearly demonstrated this link between mood disturbance and functional limitations (Ahlisio et al, 1984; Anderson, 1992; Mumma, 1986;). Research exploring PSD has closely linked the experience of PSD with physical impairment, poor psychosocial outcomes, poor quality of life and reduced social activities (Anderson et al, 2000; Neau et al, 1998; Parikh et al, 1990; Sinyor et al, 1986). Ongoing community based rehabilitation may assist stroke survivors to resume valued activities by addressing difficulties in the areas of emotional and physical functioning.

The extent of role loss was an interesting finding given that the majority of participants in this study had made a reasonable physical recovery from stroke. This suggests that ongoing participation in the community after stroke may be influenced by factors other than physical capacity.

Results from this study identified that reduced participation in the community was apparent in all participants and was irrespective of time post stroke. Stroke displays an extremely varied spectrum of residual impairment resulting in disability and reduced participation (Sturm et al, 2002a). Premorbid abilities and psychosocial issues may further impact on participation (Khan et al, 2003). While this study identified common factors contributing to reduced participation among participants, additional factors were unique to individual factors and may have been linked to personality and individual living contexts. For example – preference for participation in home based versus community based activities.

The experience of each participant highlighted the need for access to rehabilitation beyond the first year of stroke. Improved therapeutic outcomes may have resulted in increased community participation. Overall the individual differences of the participants confirmed the need for services to be underpinned by a patient-centred philosophy that considers the holistic and specific need of each stroke survivor.

It is difficult to separate the constructs of physical, mental and social well-being and the impact they have on overall health (Wilcock, 1998). Deprivations in these areas have been shown to have a negative impact on health and is a great concern to health workers. Contributions by the WHO address this link between people, health and their environment and the subsequent impact on ability to participate in local environments (Wilcock, 1998; Clark et al, 1999).

The development of the International Classification of Impairment, Disability and Handicap (ICIDH-2) by the WHO (WHO, 2001) has made a significant contribution to the recognition of the impact of environmental factors on health.

The ICDH-2 has been widely adopted by deliverers of rehabilitation services to assist address barriers to successful community reintegration. The most recent version, the International ICDH-2: International Classification of Functioning, Disability and Health (ICDH-2) (WHO, 2001) incorporates a stronger recognition of the wider determinants of health. The ICDH-2 is organised into two parts which are outlined as follows:

Part 1. Functioning and disability

Body functions and structure

Activities and participation

Part 2 Contextual factors

Environmental factors

Personal factors

The development of part 2, namely, the contextual, environmental and personal factors as part of the ICDH-2 broaden the scope of use of the model. This allows for enhanced recognition for factors such as communication, mobility, self-care, domestic life, interpersonal interactions, major life and community. These are of significant relevance to community reintegration after stroke and have been confirmed by the results of this study

This need for longer-term service delivery is supported by evidence that shows there is a long timeframe for improvement after stroke (Khan et al, 2003). As a result rehabilitation should be available for as long as functional improvement is achievable (Hack et al., 2003). The availability of therapy beyond the first year of stroke provides support for ongoing stimulation, for recovery and to ensure continuity of care and respite for carers (Dowswell, Dowswell, Lawler, Green & Young, 2002).

The results of this study reinforce this as the participants' identified ongoing physical and psychosocial difficulties that warranted therapeutic intervention. The availability of these services may contribute to enhanced participation and QOL.

5.3.2 *Mood Changes*

The experience of low mood was a notable finding in this study and a number of themes were identified that contributed to depressive feelings including: feelings of frustration, feelings of reduced self-efficacy, feelings of dependency, feelings of loss and social isolation. These themes reinforce current literature describing the common experience of changes in mood, social support, and functional abilities and quality of life after stroke (Carod-Artal et al, 2000; King, 1996).

Traditionally, research has indicated the greatest risk for PSD occurs within a few months after stroke onset (Carod-Artal et al, 2000). However Hackett et al (2005) has since reported that the risk is similar in the early, medium and long -term recovery stages, whereby long term was considered any time frame beyond 6 months. Qualitative results from this study contribute descriptive data which supports the experience of altered mood for many years after stroke. Participants within each cohort experienced one or more of the identified categories (feelings of frustration, feelings of reduced self-efficacy, feelings of dependency, feelings of loss and social isolation), which suggests that low mood is influenced by various factors. These results are in accordance with current literature outlining the experience of changes in mood, social support, functional abilities, and quality of life after stroke (Barg et al, 2006; Carod-Artal, et al, 2000; King, 2006;). These experiences had far reaching implications for well-being and functional capacity, persisting up to five years after stroke.

While severity of low mood was not assessed formally, the themes identified raise the question as to whether they were an expression of the depression continuum. The participants in this study, did not label their experiences as depression, however it has been well established in the literature that many mood disorders do not fit DSM-IV classification of major depression. As a result the themes identified regarding low mood in this study may be a cue for practitioners and therapists to explore the possibility of ongoing mood disturbance in community dwelling stroke-survivors.

Literature indicates that older adults tend to report depressive symptoms in terms of somatic experiences rather than psychological symptoms (Barg et al, 2006) or they use different terminology to describe low mood compared to treating health professionals (Williams, Rittman, Boylstein, Faircloth, Qin Haijing, 2005). This is of interest to health professionals since many stroke survivors are older adults. Overall such research reinforces the complexity in identifying mood disturbance and suggests the need for health professionals to pay close attention to self reports of all the stroke survivor.

Results identified the experience of distress due to increased social isolation following stroke, however, data suggests that greater support was available from family members. Previous qualitative research suggests that stroke survivors define the extent of their recovery by their social context (Burton, 2000). As a result the community health care setting can be considered an ideal place to implement strategies to prevent social isolation within the context of a stroke survivors own environment (Von Koch, Holmqvist, Wottrich, Tham, & Pedro-Cuesta, 2000).

PSD is a concerning health problem and is not unlike other psychiatric morbidity which also often goes undetected in the community (Carr, Lewin, Reid, Walton & Faehrmann, 1997). If PSD goes undetected by the hospital system then it is often left to the General Practitioner (GP) to identify and treat the disorder.

GP management of mood disorders can lead to improved outcomes (Ormel, Koeter, van den Brink & van de Willige, 1991; Zung, Magill, Moore & George 1983). Literature outlines the benefit of training GPs to improve detection (Joukamaa, Lehtinen & Karlsson, 1995; Marks, Goldberg & Hillier, 1979). There is similar merit in training health professionals in the recognition, assessment and management of mood disorders after stroke. This requires further exploration in undergraduate health related training and ongoing professional development in staff working in stroke.

Research suggests that health professionals tend to delivery therapy that is focused on physical goals (Daniels, Winding & Borell, 2002; Neistadt & Seymour, 1999; Radomski, 1995). However, results from this study reinforce the need for health professionals to explore in greater depth other factors that influence physical functioning such as mood and self efficacy. The community setting and individual context of the stroke survivor provides the opportunity for enhanced allied health intervention processes since there is flexibility to tailor intervention. Many stroke survivors also experience greater insight into the extent of residual impairments following discharge home which can assist the identification of meaningful goals. As a result there is great potential to prevent unnecessary role loss and mood disturbance.

The experience of reduced self efficacy was identified as a contributor to mood disturbance and lead to altered participation in valued activities. This result is supported by a study undertaken by Mendes de Leon et al (1996), identifying a relationship between reduced self-efficacy and impaired physical performance. Health professionals can play a key role in the maintenance of participation by enhancing feelings of self efficacy and control (Doolittle, 1992; Folden, 1994).

The experience of stigmatisation was also identified as a contributor to low mood in this study. This is in keeping with studies identifying that stroke survivors experience difficulties in settings where their altered physical and social appearance is apparent (Jacobsen, Axelsson, Osterlind & Norberg, 2000). This can be further compounded by the need to use adaptive equipment and can result in non compliance with therapeutic advice in an attempt to avoid stigma (Gitlin, Luborsky & Schemm, 1998). Issues surrounding the use of adaptive equipment were not captured in this study and the experience of stigma was primarily linked to social constructs. In particular, stigma was associated with cognitive, speech and motor deficits. Such results call for close liaison between health professionals. Therapy and compensatory therapeutic strategies can help to prevent withdrawal from participation and low mood. Education for the stroke survivor and the community plays a role in increasing understanding of the impact of stroke which can alleviate negative response due to lack of knowledge and fear.

The depth of information obtained in this study highlights the role of ongoing rehabilitation in addressing the complex relationship between physical and psychosocial impairments after stroke in order to prevent role loss and stigmatisation. Assessment and education regarding the experience of emotional changes should be maintained across the stroke care continuum for stroke survivors and health professionals alike.

5.3.3 Modulating Factors after Stroke

A number of modulating factors were identified in this study, which assisted to attenuate feelings of distress and assist adaptation to stroke. These included making lifestyle modifications, maintaining hope, the benefit of social support and resilience. These experiences have been identified in previous qualitative literature. For example, a study by Rittman et al (2004) also highlighted that stroke survivors identified strategies and routines to assist/manage the experience of increased idle time.

Clarke and Black (2005) demonstrated that stroke survivors can maintain a high QOL by reorganising priorities and accessing formal and informal support to maintain previously valued levels of activity.

The value of maintaining social networks and the opportunity to compare with other stroke survivors have been highlighted in several studies. These have been primarily conducted in the acute stroke setting focusing on adjustment and adaptation to stroke (Mumma 1986; Pound et al, 1998; Rochette & Desrosiers 2002; Reid 2004). For example, Close and Proctor (1999) identified that stroke survivors and carers learned to live with the uncertainty of life after stroke through interaction with other patients and health staff.

The experience of previous life stress has been identified as a predictor of PSD (Hackett et al, 2005a). Resilience is a quality that has been shown to help people deal with adversity in life (Rochette & Desrosiers, 2002) and drawing on resilience can increase feelings of control (Walsh, 1996). Results from this study provide some preliminary insights into the experience of resilience in adjusting to stroke. A range of factors which assist in responding to a difficult event have been identified including: belonging to a social group, experiencing hope, having meaning in life, varied problem solving skills and being able to see beyond current circumstances (Viemero, & Krause, 1998; Clarke, Marshall & Black, 2002).

Modulating factors identified in this study warrant incorporation into therapy. However research is required to explore their impact on low mood. The identification of modulating factors that influence physical and psychosocial outcomes may subsequently benefit from transfer across the rehabilitation continuum. In this way increased knowledge about resilience also provides support for the ICDH-2 regarding Personal Factors which can influence health outcomes.

5.3.4 *Health System Experiences*

This thesis has highlighted common themes that were experienced within the health system by participants. These findings have implications for the provision of care by health systems and processes of care in the community practices.

Poor community knowledge of stroke and stroke symptoms is a concern in terms of timely and appropriate access to health services. The results of this study support the need for ongoing community education regarding stroke and stroke prevention due to poor knowledge. This is of significance since previous local studies within the Hunter Region have shown gaps in public knowledge in recognising stroke symptoms and the need for early presentation to hospital (Yoon et al, 2001; Yoon & Byles, 2002). Education has been shown to be beneficial in reducing the time to treatment following symptom onset and optimising access to effective treatment (Yoon et al, 2001). Feelings of uncertainty and fear of a relapse due to poor knowledge appear to influence the rehabilitation process and confidence following discharge home. As a result, findings from this study further support the need for ongoing community education regarding stroke and stroke management. In addition, education can play a key role in increasing community awareness of disabilities resulting from stroke and in modulating reactions of individuals in the community to post-stroke disability. More education might be expected to improve early access, survival and independence as well as reduce the distress experienced by the stroke survivor as a result of stigmatising attitudes.

Another key finding was linked to perceived gaps in communication with the health system. For example participants experienced uncertainty with health system processes. These require further confirmation in future studies and clarification with health professional perceptions.

It should be noted that the impact of personality factors or cognitive deficits regarding participants' perceptions was not explored in this study. Previous research has demonstrated that patients often don't recall information conveyed to them by the health system (Forster et al, 2001). However these results support the need for continuing professional education of health professionals regarding the concerns of stroke survivors and strategies to assist knowledge transfer to stroke survivors. This has the potential to significantly reduce anxiety or feelings of disrespect experienced.

The need for long-term services such as monitoring, assessment and therapy to maintain or improve physical and psychosocial function was identified. Such services need to be flexible to accommodate changes in the needs of stroke survivors over time.

Participants identified having a lack of awareness about their potential for recovery or knowledge about the availability and role of rehabilitation services. These experiences appeared to be compounded by the limited availability of systematic re-assessment and access to therapy by the public health system following discharge from hospital. Participants within each cohort continued to experience unmet goals that may have benefited from access to continuing therapy. Research indicates that clinical improvements occur late after brain injury, even in stroke survivors who are considered to have reached a recovery plateau (Hodics et al, 2006).

The experience of uncertainty about treatment processes and, in some cases, the inability to meet identified goals, such as return to work, suggests the need for improved processes to ensure fewer discrepancies between the patients' and health the professionals' goals (Anderson et al, 2004). This is consistent with the delivery of patient-centred approaches.

Findings also reinforce the benefits of supporting GPs in stroke management. This is of particular relevance in an era of early discharge which has increased the demands on the GP concerning post-acute management. Improved community knowledge of stroke risk factors and the initiation of primary and secondary prevention strategies, predominantly by GPs, have been shown to contribute to a marked reduction in stroke incidence. For example, the United Kingdom has seen a 30% reduction in the incidence of first-ever stroke and a 50% decline in intracerebral haemorrhage over the last 20 years as a result of preventative strategies implemented by GPs (Rothwell et al, 2004). Resources should continue to be allocated accordingly to support GP management of stroke.

Families often take on much of the responsibility in the long term care of the community dwelling stroke survivor. Often it is the GP who is required to coordinate this care, playing a key role in the management of the stroke survivor and their immediate family (Khan et al, 2003). Ongoing contact with the health system may therefore be of great benefit in providing carer support. GPs and community health professionals need to be a major source of information and counselling to assist adjustment to the changes following stroke.

5.3.5 Strengths and Contributions of Study Data

This study generates unique data on the experience of Australian community dwelling stroke survivors and provides local data on the experience of stroke in Hunter region. Qualitative methodology provided the opportunity for the selection of participants with a broad range of experiences.

The use of semi structured interviews allowed participants to express their varied experiences particularly with regards to ongoing needs and the diverse influences on adjustment, which are often not captured by quantitative measures. This suggests that qualitative methodology should be employed in future research of post stroke functioning.

This study identified participants at three different time points in order to capture potential differences in adjustment to stroke over time. No significant trends were identified to indicate that the needs of stroke survivors vary over time. The extent of the experience of low mood and reduced participation in valued activities reinforces the need for long term, community based therapy tailored towards facilitating ongoing participation, beyond the first year after stroke. The four themes identified in this study help inform priorities for therapeutic intervention.

The objective sampling frame in the White et al (2007) study, from which participants were identified, suggests that the information is likely to be representative of the experience of stroke in community dwelling stroke survivors. While there are positive results from previous prospective studies (Carod-Artal et al, 2000; Williams et al, 2005) we sampled participants at three time points and established the long lasting impact of stroke and the apparent lack of attenuating effects over time. The selection of participants with a broad range of experiences for this study provides support for the validity of the finding that there was little difference between the cohorts at each time point.

The finding of this study meet the initial project aim to explore the long-term experience of community dwelling stroke survivors at one, three and five years after stroke and identify perceived areas of ongoing need.

5.4 Limitations

Several limitations are acknowledged in this study. Accessing participants from a retrospective, observational cohort design limits the ability to make interpretations regarding changes in post stroke functioning in individuals over time. Sampling bias is likely due to the process of participant selection for the original cohort. Therefore this sample source may not entirely be representative of the wider stroke population due to the potential impact of volunteer bias (relatively healthy) of participants, and survivor bias.

The qualitative methodology strategy employed in the study also impacts on the transferability and applicability of results. The sample was selected to obtain a range of views from stroke survivors of differing age, gender and disability. However the study inclusion criteria excluded people with severe cognitive and language deficits who were more likely to have had a severe stroke and may have a more distressing experience to report. Future research should include patients with more severe stroke. This study sample was adequate to achieve data saturation, which is a critical component in implementing qualitative methodology. However, the aforementioned factors could limit the application of the findings to some elements of the community.

The interviews, while sampling stroke patients at varying times post-stroke, were conducted cross-sectionally rather than longitudinally. Qualitative interviews were limited to one interview per participant and therefore may not have captured any changes over time. Further interviews of individual participants at multiple time-points would be of value in future studies. On the other hand, the results of this study are of worthy of interest to the broader rehabilitation context.

In conducting a grounded theory study it is inevitable that the researcher is an instrument in the research process, and therefore, influences the data synthesis and conceptualising.

The degree of subjectivity will necessarily impact on the credibility and transferability of the study. These problems were carefully considered throughout the study, in particular in the course of data analysis. The main strategies used to counter this involved the development of concepts using open, selective and theoretical coding processes. In addition triangulation of data was undertaken which involved member checking and consensus coding with a practitioner from a different health care background to the principal investigator.

5.5 Recommendations and Implications

A number of recommendations and implications arise from this study. First recommendations for health professional practice are presented. Second, specific recommendations for general rehabilitation practice are discussed. Third, broad perspectives for future research are proposed.

5.5.1 Implications for Health Professionals

One of the key findings highlighted how health professionals can support stroke survivors in return to their post stroke lifestyle and to resume participation in valued activities by addressing difficulties in the areas of emotional and physical functioning. Specific therapy can be targeted towards designing a supportive and safe therapeutic environment to enable clients to gain confidence and competency. The results suggest the need for long term, community-based therapy tailored towards addressing emotional changes and facilitating and maintaining participation after stroke. This may assist stroke survivors' return to meaningful occupations, many years after stroke onset.

Participants in this study experienced difficulty in adapting to change and in returning to their pre-stroke lifestyle. These results are consistent with the findings of study by Wallenbert & Johsson (2005) in stroke survivors up to seven months post stroke.

As a result the health professional in a community context plays an essential role in the provision of advice, being a role model and supervising the restoration of function. This is of key significance given that this study highlighted the extent of role loss and the lack of uptake of alternative roles over time. This may require enhanced creativity among community based health professionals in exploring opportunities and strategies for community reintegration (Pound et al, 1998). Challenges for clinicians include development of clinical intervention strategies that promote participation in the many varied life interests identified by stroke survivors. Similarly there is a need for the ongoing identification of strategies to reduce loneliness and social isolation (Pound et al, 1998). Overall the health professional should be sensitive to patient goals regarding resumption of pre-stroke activities. Wallenbert & Jonsson (2005) identified that feelings of frustration by participants can outweigh the benefits, as perceived by the health professional, of adopting new habits and roles.

Determining the extent of cognitive, behavioural and physical deficits is an important first step in setting goals in rehabilitation (Khan et al, 2003). Prioritising goals should be undertaken with the assistance of the stroke survivor and the family. This is consistent with patient centred care philosophy which currently underpins much of service delivery in the field of rehabilitation. It is well documented that this involves close collaboration with the patient and their family in goal setting and decision making. This has the potential to impact greatly on a patient's perception of their experiences after stroke as well as with the health system.

In an era of increased longevity clinicians are required to have an enhanced understanding of the life long nature of chronic disease, such as stroke or other comorbidities that the patient may experience.

Such results reinforce the ongoing challenge for services to be focussed on the individual's goals and for therapists to provide increased choice as part of service delivery. There may also be benefits in increased flexibility regarding the timing of service delivery.

The participants in this study highlighted individual experiences that resulted in reduced feelings of self efficacy. This was compounded by reported discrepancies in communication with health professionals. Such results highlight the need for occupational therapists to develop skills in counselling in order to encourage positive self identity, convey information and promote acceptance after stroke (Murray & Harrison, 2004). Counselling intervention should be underpinned by close collaboration with medical, social work and psychology colleagues. This may assist stroke survivors' return to meaningful occupations, many years after stroke onset.

However, since there is a lack of access to health professionals many years after stroke there is limited evidence surrounding models of care that may facilitate functional restoration in stroke survivors. Such restoration may include the implementation of and teaching of adaptive strategies. Typically allied health services are provided to stroke survivors in the first few months after stroke when significant functional impairment and disability is present (Larson, 1996). However this study suggests that many principles of allied health intervention such as facilitating independence and participation in meaningful activity are essential in order to promote health in the long term stroke survivor (Khan et al, 2003).

5.5.2 *Rehabilitation Service Delivery Implications*

Stroke leads to a wide range of emotional, social, cognitive and physical disabilities that may benefit from rehabilitation, to support the stroke survivor to return home and maximize QOL.

There is growing interest into the exploration of QOL after stroke, however, comparison of the results between studies is made difficult by methodological variances. Despite these methodological issues, variables consistently associated with lower QOL after stroke include: depression and functional restrictions (Astrom, Adolfson & Asplund, 1993), stroke severity (Niemi et al, 1998; Viitanen, Fugl-Meyers, Bernspang & Fugl-Meyer, 1988; Wyller & Kirkevold, 1999), altered social support and comorbidity (de Haan, Aaronson, Limburg, Langton, Hewer, van Crevel, 1993).

Results of this study add support to these findings as well as generate further understanding about the factors that restrict functioning after stroke, impacting on QOL and are cause for immediate response from the health system. Key areas include provision of education about stroke and stroke prevention, adequate assessment and monitoring of mood is provided at all stages of the rehabilitation continuum and therapy that maximise community participation. Services that target these areas may assist modulate against adverse influences on QOL since multi-disciplinary collaboration has been shown to be a component of successful stroke rehabilitation (Hankey, 2002).

Processes of rehabilitation require ongoing review and input to ensure fewer discrepancies between patient and health professional goals (Anderson et al, 2004). This involves the need to address the delivery of stroke services and the provision of ongoing health professional education. Target audiences should include nursing and allied health staff as well as medical practitioners.

Current literature documents that carers and stroke survivors do not readily retain information that is provided to them in the hospital setting. This is a key area to be addressed by health professionals with regards to strategies that assist with knowledge transfer and the delivery of evidence based practice.

Future research is required to explore the best ways to assist knowledge transfer as it is a significant issue once the stroke survivor has been discharged home. Strategies that may more effectively assist knowledge transfer may include the increased availability of case management or monitoring services.

Strategies to promote patient-centred approaches and the increased incorporation of patient goals are also required. This requires close consideration of referral criteria for the provision of long term rehabilitation services and processes regarding setting goals and the provision of therapy. Furthermore, results from this study highlight that flexibility of service delivery within the health system is a key factor in responding to changes experienced by the stroke survivor over time.

Strategies to increase stroke service team collaboration, communication, education and service planning have recently been enhanced at a local and state level with the implementation of the Greater Metropolitan Clinical Taskforce (Stewart, Dwyer & Goulston, 2006). This network has provided funding for additional stroke staff and resources to address these key areas of need with the view to improve patient outcomes.

5.5.3 *Implications for Future Research*

This study reinforces the use of qualitative research methodology in understanding the long-term experience of stroke survivors. The results provide key data that can be used to develop and review service delivery. It makes a valuable contribution towards the delivery of relevant services and is pertinent as the population experiences greater longevity.

This study provided insights into gaps in service delivery in addressing ongoing mood disturbance and functional restrictions, many years after stroke. They also provide evidence to support models of therapeutic intervention in these areas.

The study identified a number of modulating factors, which assisted in attenuating feelings of distress and assist adaptation to the consequences of stroke. These included strategies that served to enhance self-efficacy, such as maintaining a sense of control through prioritisation of activities, sustaining feelings of hope, social networks and resilience. The results suggest that low mood can still occur despite the development of relevant coping skills. Further research is required to improve our knowledge of coping skills since understanding and regarding how people cope is essential for providing good care (Persson & Ryden, 2006).

This study highlighted common perceptions and experiences with the health system that can inform the ongoing professional development of health professionals. Participants identified experiences which indicated their lack of understanding regarding health system processes and there were examples of this being associated with impingements upon participants' sense of dignity.

These require further confirmation in future studies and clarification with health professional perceptions. Research is also required to explore strategies to assist knowledge transfer to stroke survivors. This has the potential to significantly reduce any anxiety and fear experienced.

Health system research should continue to explore a model of service delivery that best facilitates and monitors ongoing community reintegration.

CHAPTER SIX: CONCLUSION

The results of this study represent the long-term experience of community dwelling stroke survivors in an Australian context. Key findings demonstrate coherent, plausible narratives of stroke survivors up to five years, using community based cohorts of stroke survivors at one, three and five years post stroke. This is important as there are few Australian studies exploring the long term experience of stroke in the community and using qualitative methodology.

These results are notable as they are consistent with international findings while simultaneously documenting the Australian experience of stroke. They also add to a growing body of knowledge concerning the consequences of living with stroke in the community and the evidence base for ideal models of stroke service delivery.

This study identified key issues pertaining to difficulties with participation in the community, low mood, modulating factors and experience with the health system. A striking finding was that these results were not linked to functional independence and persisted up to five years post-stroke. These results help inform ongoing support needs and the organization of ideal models of care for long term stroke survivors.

The availability of allied health services and the delivery of long term services remains limited due to resources constraints. This study provides evidence to advocate for increased health resources, especially within the public health system, in the community. Private practitioners may assist to address the gap in service in the interim.

Implementation of changes in practice requires resources, education and support and should be underpinned by research to review its effectiveness. This study has demonstrated the benefit in using qualitative methodology in post stroke research.

Overall the results of this study suggest that the functioning of stroke survivors following discharge to the community remains problematic. Analysis of data highlights that stroke survivors' emotional well-being remains a significant concern.

Analysis of data in this study support the need for a more extensive prospective study which explores physical and psycho-social changes over time



“I cant”: The occupational experience of stroke survivors in a community setting. A Qualitative Study.

Abstract

The objective of this study was to explore the long-term experience of community dwelling stroke survivors and identify influences on occupational engagement after stroke. In-depth, semi-structured interviews were conducted with 12 participants and a grounded theory approach was used for data analysis. Six men and 6 women aged between 42 and 92 years of age participated in this study. Time post stroke varied between 1, 3, and 5 years. The findings identified 3 key themes from the data. The core theme “I cant” described changes in occupational engagement. The core theme “I feel” identified feelings associated with managing struggles in life as a result of stroke. The core theme “But now” identified modulating factors in adjustment to the experience of stroke. A concerning finding for the health system was the extent of depressive symptomatology attributed to reduced occupational engagement. This calls for improved assessment and education regarding mood changes post and should be underpinned by interventions. The essential role of the occupational therapists in this context is to provide support and education regarding mood changes and to promote participation after stroke.

Introduction

Stroke is one of the leading causes of long-term disability in the Australian population and the second leading cause of death (Australian Institute of Health and Welfare and National Heart Foundation, 2004; National Stroke Foundation, 2006). Physical and psychosocial limitations are common post-stroke (Anderson, Hackett & House, 2004; Hankey, Jamrozik, Broadhurst & Anderson, 2000). Post stroke depression (PSD) is one feature of the post stroke experience, affecting at least 25% of stroke survivors (Huff, Steckel & Sitzer, 2003; Burvill et al., 1995). PSD is a concerning health problem because of its impact on rehabilitation gains and outcomes (Anderson et al, 2004; Ebrahim, Barer & Nouri, 1987; Hackett, Anderson & House; 2005; House, Dennis, Mogridge, Warlow, Hawton & Jones, 1991; Huff et al., 2003; Sinyor, Kaloupek, Goldenberg & Coopersmith, 1986).

To date, studies looking at long-term post stroke outcomes have primarily focused on mortality and stroke reoccurrence over time (Hankey et al., 2000) although some investigators are exploring functional and emotional states. Within Australia, using the North East Melbourne Stroke Incidence Study (NEMESIS), Sturm et al. (2003) identified that many stroke survivors report poor health related quality of life (HRQoL) within 2 years following stroke onset. HRQoL measures the impact of disease on the physical, emotional, and social aspects of patients' lives as compared to what they perceive to be ideal (Cella and Tulsky, 1990).

Occupational Therapists are concerned with the occupational nature of people and their ability to maintain physical and emotional health through engagement in meaningful

occupations (Wilcock, 1998; Zemke & Clark, 1996). Occupation refers to purposeful activities that encompass play, rest and productivity (Kielhofner, 2002). Occupations are unique to individuals and vary according to societal influences, personal interests, beliefs and needs (Kielhofner, 2002). Understanding the post-stroke experience is of interest to occupational therapists since the effects of stroke can be devastating, producing substantial changes to functioning. Approximately 50% of stroke survivors experience residual impairments resulting from neurological damage which can affect performance in occupation and ultimately HRQoL (Hankey et al., 2000; Niemi, Laaksonen, Kotila & Waltimo, 1988). Occupational therapists have a role in promoting health in the stroke survivor by facilitating engagement in occupation. This is a growing area of clinical focus since changing demography and an ageing population has seen a rise in the incidence of chronic conditions (New South Wales Chronic Disease Prevention Strategy, 2005).

Emotional changes after stroke have also been shown to contribute to poorer health outcomes and reduced HRQoL (Ebrahim et al., 1987; Sturm et al., 2003). Mood disturbances can be exacerbated by lack of independence after stroke which has been correlated to altered sense of meaning and reduced self-efficacy in the stroke survivor (Hankey et al., 2000; Robinson-Smith, 2002; Wilcock, 1998; Yerxa, 1998;). Self-efficacy refers to a person's beliefs of how well they can competently carry out those actions necessary to deal with life events, irrespective of physical capabilities (Bandura, 1982). Feelings of self-efficacy may vary depending on the nature of the occupation undertaken. Research has demonstrated that stroke survivors with a positive self-efficacy report higher QoL and fewer depressive symptoms. (Robinson-Smith, 2002). Positive

self efficacy is modulated by the ability to exercise choice and maintain a sense of control, despite disability levels (Hammell, 2004). Adaptive skills that provide a sense of control while addressing emotional and practical needs can therefore promote QOL (Clarke & Black, 2005; Viemero & Krause, 1998). Previous studies highlight a range of adaptive strategies employed by stroke survivors', such as maintaining: independence, participation in meaningful activities, social support, hope, resilience and the minimalisation of stroke symptoms (Clarke et al., 2005; King, 1996; Pound, Gompertz & Ebrahim, 1998; Rochette & Juhani, 2002; Viemero & Krause, 1998).

There has been an increase in the use of qualitative research methods to investigate the phenomena of stroke. Results provide greater understanding of the complexity of the experience of stroke including response to stroke onset (Yoon & Byles, 2002), experiences with the hospital system (Pound, Bury, Gompertz & Ebrahim, 1995), coping strategies (Pound et al, 1998), information provision (Wiles, Pain, Buckland, McLellan 1998) and the experience of altered functioning (Van de Weg, Kuik, Lankhorst 1999; Alaszewski, Alaszewski & Potter, 2004; O'Connell et al., 2001). Qualitative studies in the occupation therapy context highlight the experience of occupational loss.

Contributing factors include performance standards and access to transport (Morgan & Jongbloed, 1990), difficulties with adjustment (Reid, 2004), increased effort to organise habits and overcome difficulties (Wallenbert & Jonsson, 2005; Lampinen & Tham, 2003). There remain clear gaps in our knowledge since these studies have tended to focus on the stroke survivor's experience within the first few months following stroke and may not represent the longer-term sequelae of stroke (Bhogal, Teasell, Foley &

Speechley, 2003; Grimby, Andren, Daving & Wright, 1998; Murray & Harrison, 2004; Mumma, 1986; O'Connell, Hanna, Penney, Pearce, Owen & Warelow, 2001).

The current study was conducted in Newcastle, a coastal city situated in the Hunter region of New South Wales, Australia. The main aim of this study was to explore the long-term experience of stroke and identify influences on occupational engagement in community-dwelling stroke survivors.

Methods

Ethics

Ethics Committee approval for this project was obtained from Hunter New England Human Ethics Research Committee

Recruitment

This study was a qualitative study of 12 participants at various time points after stroke (1, 3 and 5 years). Participants were identified from hospital records/separations from the John Hunter Hospital (JHH), the largest tertiary referral hospital and the main hospital servicing Hunter residents. The participants were identified by: admission to JHH, alive at discharge to community, history and examination consistent with stroke as determined by a stroke physician. Exclusion criteria consisted of severe cognitive impairment, inability to give informed consent and current residence in a nursing home, i.e. only community dwelling stroke survivors (including hostels) were contacted. Purposive sampling was used to identify 12 participants in order to capture a wide range of life experiences and phenomenological variation as a result of stroke (Strauss & Corbin,

1990). This was achieved by a mail-out to gain consent whereby potential participants were asked to answer some brief questions relating to their demographics. The responses to these questions were used to select participants with a broad range of demographics and experiences.

Procedures

The selected participants were subsequently contacted by the researcher to arrange an interview time. All participants opted to be interviewed in their own home. Interviews were undertaken within a few weeks of consent. The duration of the interviews ranged from 45 minutes to 90 minutes. Each interview was recorded with the permission of the participant. The interviews followed a semi-structured format and each interview began by asking participants to describe the onset of the stroke and their life before the stroke. Subsequent questions explored post stroke lifestyle and influencing factors. This provided the opportunity for rapport building allowing the person to talk openly about their experiences. This number of participants selected for interview is in line with previous qualitative research producing thematic saturation (Strauss & Corbin, 1990).

Data Analysis

All interviews were transcribed verbatim, with identifying data removed. A grounded theory approach provided the strategies for data collection and analysis. (Glaser & Strauss, 1990).

A Grounded Theory approach incorporates data collection, coding and analysis using a process of constant comparison (Bogdan & Biklen, 1998). This entails an ongoing cycle

of data collection and simultaneous analysis. Open coding required each transcript to be read and re-read in order to gain a comprehensive sense of what the participant was conveying. Memos were written in a column alongside the written text describing the experiences which were coded using descriptive words from the data. Selective coding involved the development of central categories and themes explaining participants behaviour, beliefs, and emotions surrounding their experience which could be explored in subsequent interviews. This required the primary researcher to constantly move between transcripts as emerging concepts were explored and related to each other. These were then given a label or code consisting of 4 letters in order to trace them between the transcripts. Theoretical coding involved the formulation of themes and the interactions between stroke, emotions and community participation. Quotes were recorded that summarized the subjective experience.

Consensus coding was undertaken by the 1st and 3rd authors with over 50% of the transcripts in order to verify and validate the codes and main themes relating to the experience of stroke as expressed within the transcripts. Consensus was gained via extensive discussion of the codes and how they were developed. Rigour was also enhanced through the use of grounded theory approach incorporating coding, search for negative cases, use of participant's words and triangulation of methodology which involved member checking (Glaser and Strauss, 1967, Krefting, 1991). The preliminary thematic interpretation of data was mailed to participants and comments were sought in response to data interpretation. No substantive negative cases were found.

Characteristics of Participants

Thirty seven participants consented to participate in semi-structured interviews. Twelve people were selected according to gender and demographics. Key demographics are outlined in Table 1.

All participants had experienced an ischaemic stroke and equal numbers of men and women were interviewed, 6 males and 6 females. Quantitative data was obtained on participant functioning. Five participants were classified as dependent following their stroke and 7 were classified as independent, using the Modified Rankin Scale (Sulter, Steen & De Keyser, 1999). In general, all participants were experiencing residual impairments following their stroke such as hemiparesis, dysphasia and cognitive changes. Age ranged from 43-92 years.

[Insert table 1]

Results

The results are discussed under key themes that emerged from the study and related to altered occupational engagement, emotional responses and coping strategies following stroke. The core theme “I can’t” was related to changes in occupational engagement. The core theme “I feel” identified the key feelings associated with managing the struggles in life that were linked to the experience of stroke. The core theme “But now” identified coping strategies and other modulating factors in adjustment to the experience of stroke. Differing concepts were identified when the content of the main themes were organized into subcategories which outlined contributing factors to the central theme of interest. These are summarized as follows:

1. Altered occupational engagement – “I can’t”

2. Emotional responses
 - i) Impact on Self Efficacy – “I feel different”
 - ii) Frustration – “I feel frustrated”
 - iii) Depressive Feeling – “I feel down hearted”
 - iv) Effects of Social Isolation – “I miss them”

3. Modulating Factors – “But now”
 - i) Hope – “I hope”
 - ii) Social support - “Someone who is there for me”
 - iii) Resilience – “I have done worse than this”

Altered Occupational Engagement - “I can’t”

OT is centred on the belief that occupation or “doing” is important for health (Wilcock, 1998). This study identified a core theme, “I can’t”, that described the participant’s central experience of residual physical, cognitive or communication impairments. This was evident in a number of common expressions by participants, such as: “I used to” (Interview 1), “It’s more difficult” (Interview 12) and “It’s impossible” (Interview 7).

All participants reported that they had ceased participation in one or more occupations that were manageable before the stroke. There was a common experience of regret at

having to relinquish valued activities. Most participants made reference to the permanency of changes to their lifestyle as a result of stroke.

The stroke changed my life altogether, you can't get it back.

I can't go fishing. I went fishing with my young bloke the other day but oh, I never fished, I just sat and watched him.

Participants expressed an ongoing wish to return to those activities undertaken before the stroke. The extent to which this was achieved varied between participants depending on the amount of residual disability. The broad range of occupations identified by participants reflected their individualised characteristics. For most participants self identity was linked to performance in pre-stroke occupations. These included home maintenance, gardening, sports such as golf and bowling, craft and games, and service to others such as caring for grandchildren or volunteering in the community.

Because she [daughter] had been working full-time, I was doing the washing and ironing and babysitting for those 12 years. They just went by so quickly and ah, since I have had the stroke I have not been able to do what I used to do.

Altered occupational engagement was depicted by changes in perceived quality of life.

It is nowhere near as good, you could call it quality if you like.

Emotional responses -“I feel”

Impact on Self Efficacy – “I feel different”

Reduced participation in meaningful occupations was strongly linked with feelings of self-efficacy. Changes in self-efficacy were a notable finding in this study as a result of role loss.

I feel useless, I suppose... just useless.

There was an explicit link between self-efficacy and negative emotions observed throughout the study and many participants expressed having a negative view of themselves since the stroke. Negative feelings were exacerbated by the inability to undertake valued activities that were central to a participant’s pre-stroke identity. This further diminished feelings of self efficacy.

I just don’t feel that I am as necessary to [my daughter] as I was before.

At the end of the day you think, “What have I done that has been productive?

NOTHING!”

Maintenance of self-efficacy was linked to the ability of participants to exercise choice and sustain participation in meaningful occupations. For participants who saw no potential for change in their circumstances, the result was feelings of disempowerment.

I think it is a waste...you are not achieving and unproductive. I can't see myself ever being productive again – and that is where it is disappointing.

For these participants there appeared to be an emerging pattern whereby participants felt unable to undertake tasks and had lost confidence. This was linked to further withdrawal from participation in activities.

For some participants withdrawal from occupations of interest was a conscious decision due to diminished self efficacy as a result of stigma. This phenomenon was most common in participants with speech impairments who experienced stigma from the broader community.

You got to the stage where you were too frightened to talk and become embarrassed.

Many participants were required to rely on other people to assist in maintaining involvement in occupations that constituted their pre-stroke lifestyle. Maintaining independence was highly valued by the majority of participants and the need to rely on other people was “hard to accept” (Interview 4) and a major contributor to distress.

The extent of role loss and dependency varied between participants depending on stroke severity. The most common restrictions experienced related to performing activities of daily living (ADLs).

Have to get help to do up a shirt or pull a jumper down, put on a coat...small things that you are used to doing for yourself.

The expression of negative feelings related to the need to rely on others was widespread. Such feelings were a precursor to the experience of frustration.

Frustration: "I feel frustrated"

The experience of frustration and depressive feelings were often concomitant. Many participants' were "very frustrated" (Interview 12) about the physical and psychosocial limitations that impacted upon their desired lifestyle and "not being able to do what I like." (Interview 11)

Frustration was further evidenced when extra time was required to complete a task or when the quality of the task was altered.

Instead of taking my 5 minutes to get dressed, it takes me 5 minutes to do up a shirt.

Depressive Feelings: "I feel down-hearted"

The experience of depressive feelings was a significant trend in this study. It was directly related to dependency and occupational loss. Many participants expressed sadness or disappointment; "it gets you down" (Interview 2), that was unrelated to the time since the onset of their stroke or the extent of their impairments.

The depressive symptomatology of apathy and “loss of inclination” (Interview 7), were identified in many participants. This further led to withdrawal from valued occupations as a result of altered mood rather than functional restrictions. The outcome was a cycle of inactivity and boredom which exacerbated feelings of frustration.

Extremely boring. Thank goodness [for the day therapy] centre I go to, or the brain would go stagnant.

Effects of Social Isolation: “I miss them”

The majority of participants reported changes in their patterns of socialization with friends and family after the stroke. This was strongly linked to being “confined” and having the reduced ability to physically access the community due to mobility restrictions and transport issues. Participants found it difficult to get out of the house to visit people or attend group-based activities such as church, sport etc.

Participants reported spending significantly reduced amounts of time with both friends and family as compared to their pre-stroke lifestyle. All participants expressed feelings of loss and regret regarding reduced frequency of contact with people and even the loss of some friendships.

The only people I see now is my family, that’s all I see now.

The experience of social isolation was an additional cause of distress in participants.

I do miss the kids (grandchildren). I miss them very much.

Very few participants had developed new or alternative relationships to replace changed or lost relationships. However, for several participants this was achieved by attending new group based activities such as a stroke club or hostel-based activities.

Modulating factors - “But now”

The “I feel” emotional responses, outlined above, were experienced as a continuum from lesser to greater emotional distress. Participants’ positions on this continuum were seen to be modulated by various factors. These facilitated adaptation to the stroke and consequently facilitated community reintegration.

The majority of participants had consciously or unconsciously re-constructed a life characterized by new routines. For some participants this related to the use of adaptive equipment or altered approaches to carry out a desired occupation.

[When] I am going to get things ready for tea I usually think about it ½ hour before and get everything organized. I never used to do that before I used to just be a bull at a gate and get into everything but not now.

Participants with insight into their abilities and limitations appeared more able to effectively problem-solve barriers in order to accomplish a desired task. This led to enhanced feelings of independence and choice, which assisted in the maintenance of a positive self-efficacy.

Many participants demonstrated increased reflectivity towards their post-stroke lifestyle. One participant clearly stated having a renewed sense of what was important in life after having come so close to death. This was characterised by the desire to choose activities that provided a sense of purpose and pleasure over more extraneous tasks. One respondent reflected

I sit down now and think, “Well blow the house work, I will crochet.” I enjoy that more, whereas before I would run around doing everything. I have slowed down a lot.

Similarly, participants appeared to benefit strongly from comparing their own situation with that of other stroke survivors and reported that seeing other people with more severe disabilities helped them to appreciate their progress.

I have had a few friends or people I know who have had strokes who are worse off than I am. I am quite thankful that I am not as bad as they are.

Hope: “I hope”

Another feature which modulated the experience of stroke related to maintaining feelings of hope. For many participants hope was centred around “living for others” (Interview 10) and seeing milestones achieved in the lives of children and grandchildren. These included marriage, the birth of grandchildren, or the graduation of grandchildren from school and university.

A number of the participants reported that having a strong faith in God was a significant source of hope.

If it was not for God I would be a lot worse with my stroke I think.

Other participants placed their hope in “getting back” to valued occupations, such as golf.

Social Support : “Someone who is there for me”

Acceptance of the support of family, friends and loved ones was another key modulating factor. This included the provision of practical support or emotional support.

Having a family that cared, or friends that cared, that’s the main thing, getting those things when you need them. I have never been on my own.

Resilience: “I have done worse than this.”

An interesting theme in this study was that of resilience (and of having achieved mastery during previous life experiences and challenges) in facilitating greater adjustment to stroke. Most participants identified that overcoming previous adversity in life had equipped them with skills “to stand on their own two feet” – skills which were transferable to their experience of stroke. Participants felt that difficult life experiences helped them “Not to take things for granted” and to “Make today count.”

Discussion

This study highlights the complexity of factors that influence occupational engagement following stroke. A wide range of physical and psychosocial factors were identified affecting participation in meaningful occupations in participants.

Our study participants were interviewed at longer intervals following discharge after the acute stroke, than in previous studies (Maclean et al., 2000; Faircloth, Boylestein, Rittman, & Gubrium, 2005). Results demonstrated that altered occupation or occupational loss was shown to persist up to 5 years after stroke, regardless of disability levels. Role loss and dependency were associated with increased distress. This is consistent with previous research demonstrating the link between mood disturbance and functional limitations. For example, research into PSD has closely linked the experience of PSD with physical impairment, poor psychosocial outcomes, poor QOL and reduced social activities (Anderson et al., 2004; Neau et al., 1998; Parikh et al., 1990; Sinyor et al., 1986).

The most bothersome complaint identified by participants related to feelings of frustration. The source of frustration was linked to reduced engagement in occupations as result of residual impairments. This builds on evidence highlighting the benefits of maintaining participation in occupations on health and well-being. The participants themselves did not label their experiences of frustration and low mood, as a result of occupational changes, as depression. The health system currently acknowledges that PSD is under-recognised and under-treated (Anderson et al., 2004). The results of our study suggest that clinicians may be alerted to the possibility of PSD by stroke-survivor reports of frustration.

The parallel experience of reduced self-efficacy and reduced autonomy were additional factors identified impacting mood disturbance and leading to altered occupational engagement. This result is supported by a study undertaken by Mendes, Seeman, Baker, Richardson & Tinetti. (1996), identifying a relationship between reduced self-efficacy and reduced physical performance. The extent of role loss was an interesting finding given that the participants in this study had generally made a good physical recovery from stroke. This intricate relationship between occupation and emotion is consistent with research outlining the complexity of relationships between psychological responses and QOL (Ahlsio, Britton, Murray & Theorell, 1984).

A number of modulating factors were identified in this study, which assisted to attenuate feelings of distress and assist adaptation to stroke. These included strategies which served to enhance self-efficacy, such as maintaining a sense of control through prioritisation of occupations and making choices. Other modulating factors included comparison with others; sustaining feelings of hope, social networks and resilience. These findings are in accordance with research conducted in the acute stroke setting focusing on adjustment and adaptation to stroke (Pound et al., 1998; Rochette & Juhani, 2002; Mumma 1996; Morgan et al., 1990; Reid, 2004) and provide support regarding the transfer of these strategies to subsequent setting along the rehabilitation continuum.

This study reinforces the use of qualitative research methodology in understanding the long-term experience of stroke survivors. The exclusion of people with severe cognitive and language deficits limits the ability to generalize findings. The interviews, while

sampling stroke patients at longer time points after stroke, were conducted cross-sectionally rather than longitudinally and do not capture changes over time within individuals. This would be of benefit in future studies.

However the depth of information highlights the role of occupational therapy in addressing the complex relationship between physical and psychosocial impairments after stroke in order to prevent occupational loss, maintain social networks and facilitate coping. Typically occupational therapy is provided to stroke survivors in the first few months after stroke when significant functional impairment and disability is present (Larson, 1996). However this study suggests that many principles of occupational therapy intervention such as facilitating independence and participation in meaningful activity is essential in order to promote health in the long term stroke survivor (Willard and Spackman, 1993). Intervention should be underpinned by appropriate assessment and management of mood disorders and close collaboration with medical, social work and psychology colleagues. This may assist stroke survivors' return to meaningful occupations, many years after stroke onset.

Overall the results of this study suggests that:

- Despite good functional recovery, the participants in this study experienced ongoing barriers to occupational engagement.
- Identification of a correlation between altered mood and occupational engagement lends further support towards the relationship between health and occupation.
- Monitoring of PSD in stroke survivors is a key concern for the health system

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“Exploring Post Stroke Mood Changes”

1 Running Head: Exploring Post Stroke Mood Change

2

3 Title: Exploring Post Stroke Mood Changes in community
4 dwelling stroke survivors: a Qualitative Study.

5

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49 **Abstract:** Exploring Post Stroke Mood Changes in community dwelling
50 stroke survivors: a Qualitative Study.

51 **Objective:** To explore the long-term experience of mood changes in community
52 dwelling stroke survivors at 1, 3 and 5 years after stroke.

53 **Design:** A qualitative study using a modified grounded theory approach. The
54 primary data collection method was semi-structured interviewing.

55 **Setting:** Community dwelling stroke survivors in metropolitan Newcastle, New
56 South Wales, Australia.

57 **Participants:** Twelve community dwelling stroke survivors (4 participants from
58 each cohort) discharged from a tertiary referral hospital. 6 men and 6 women
59 aged between 42 and 92 years of age participated in this study.

60 **Main Outcome Measures:** Qualitative outcomes were participants' perceptions
61 using in-depth, semi-structured interviews with participants from 3 community
62 based cohorts of stroke survivors at 1, 3 and 5 years post stroke.

63 **Results:** Four main categories of mood change were described by participants
64 including feelings of frustration, reduced self-efficacy, dependency, and loss.
65 Factors which modulated these mood changes included the presence or absence
66 of insight, hope for the future, faith, and support. A modified grounded theory
67 approach was used for data analysis using a process of constant comparison.

68 **Conclusions:** Mood changes continued well beyond discharge and in some
69 cases commenced after discharge in this sample of stroke survivors. Use of
70 qualitative methodology extends our understanding of the extent and nature of
71 low mood after stroke. There is a need for enhanced services to monitor and
72 address low mood.

“Exploring Post Stroke Mood Changes”

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74 **Key Words:** Outcomes Assessment; Depression; Cerebrovascular Accident,

75 Rehabilitation; Qualitative Research

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97 **Introduction**

98 Altered mood is common after stroke and a recent systematic review of
99 observational studies by Hackett and colleagues indicated that one third of stroke
100 survivors will experience post stroke depression (PSD) at some stage after
101 stroke¹. Furthermore, many stroke survivors are left with mood disorders and
102 depressive symptoms which do not meet strict Diagnostic and Statistical Manual
103 of Mental Disorders (DSM-IV)² criteria for major depression³. However, the
104 experience of low mood and subsyndromal or minor depression in stroke
105 survivors can continue to impact life after stroke⁴. Identification of appropriate
106 interventions for subsyndromal depression is important in order to reduce the risk
107 of major depression and disability⁵.

108

109 Accurate identification of the extent and context of post stroke mood disorders
110 can be difficult due to features of stroke, such as altered cognition and
111 communication skills, which may confound diagnosis. However there is
112 increasing interest in functional and emotional outcomes since PSD has been
113 shown to be associated with poorer rehabilitation outcomes^{3,4, 6-12}. There is a
114 need for more research into the experience of subsyndromal depression after
115 stroke in order to facilitate treatment and maximise quality of life (QOL).

116

117 Previous research has demonstrated the link between mood disturbance,
118 including PSD, and physical and psychosocial functional limitations⁹⁻¹⁹. Reduced
119 confidence and reduced self efficacy has been shown to result in altered
120 participation in activities in diseases such as stroke^{20,21}. Self efficacy refers to a

121 person’s beliefs of how well they can competently carry out actions necessary to
122 deal with life events, irrespective of physical capabilities²². Stroke survivors with
123 a positive self-efficacy report higher quality of life (QOL) and fewer depressive
124 symptoms²⁰. In contrast, a lack of self efficacy has been shown to lead to
125 learned helplessness in patients with chronic disability²³.

126

127 Qualitative research methods can be applied to assist in the understanding of the
128 complexity of the experience of stroke survivors including interactions with the
129 hospital system²⁴, coping strategies²⁵ and altered functioning²⁶⁻²⁸. There has,
130 however been limited exploration of the experience of stroke survivors beyond
131 the first few months leading to gaps in our knowledge. In a previous paper²⁹, we
132 reported on functional outcomes and quality of life using quantitative measures in
133 a group of community dwelling stroke survivors at 1, 3 and 5 years post-stroke.
134 In the current paper, we qualitatively explore the experiences of mood
135 disturbance in the same cohort.

136

137 **Methods**

138 This qualitative study involved twelve semi-structured interviews with stroke
139 survivors at 1, 3 and 5 years after stroke.

140

141 *Recruitment*

142 Participants were identified from a larger, retrospective, cross-sectional study of
143 91 stroke survivors at 1, 3 and 5 years; the design and methods of this study have
144 been previously reported²⁹. In brief, participants were identified from hospital

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145 records/separations from the John Hunter Hospital (JHH), the largest tertiary
146 referral hospital servicing Hunter residents within New South Wales, Australia.
147 Inclusion criteria included: admission to JHH, alive at discharge to the
148 community, and history and examination consistent with stroke as determined by
149 a stroke physician. We aimed to avoid excluding participants with cognitive or
150 communication deficits. Thus, participants were excluded if they had severe
151 cognitive impairment (Mini-Mental State Examination Score ≤ 16)³⁰ or were
152 unable to communicate sufficiently to participate in an interview. Further
153 exclusion criteria included inability to give informed consent and current
154 residence in a nursing home: that is, only community-dwelling stroke survivors
155 (including those in hostels) were contacted. Exclusion was determined at the
156 time of the face-to-face interview.

157

158 *Sampling*

159 In order to obtain more details on the experience of stroke survivors, all
160 participants from this larger cohort were invited to participate in this qualitative
161 study using a mail-out which included some brief questions about demographics
162 and living situations.

163

164 In total, thirty seven participants consented to participate in semi-structured
165 interviews and, based on information gained from the mail-out, twelve stroke
166 survivors were selected, four participants from each of the 3 cohorts (1, 3 and 5
167 years). Purposive, maximum variation sampling was used to identify men and
168 women of different ages and with different living situations so as to reach as

169 heterogenous a sample as possible³¹. This allowed for the selection of
170 participants who could best provide insight into specific and personal experiences
171 regarding the issues being examined, rather than obtaining a representative
172 sample, as would be sought in quantitative research. All participants chose to be
173 interviewed in their own home.

174

175 **Data Collection Methods**

176 *Qualitative Interviews*

177 The duration of the qualitative interviews ranged from 45 minutes to 90 minutes.
178 Each interview was recorded with the permission of the participant. A single
179 interview was conducted by the primary author (J.W.) with each of the twelve
180 participants. A modified grounded theory approach was used to facilitate
181 generation of concepts that would increase understanding regarding mood
182 disturbance after stroke and minimise the influence of potential pre-
183 conceptions^{31,32}. A schedule of approximately 12 questions (see Figure 1) was
184 used for the interviews, but the iterative nature of a semi-structured interview
185 format meant that discussion was not limited to pre- determined areas of inquiry.
186 To create a comfortable atmosphere each interview began by asking participants
187 to describe the ‘story’ of the onset of stroke and their life before the stroke.
188 Subsequent questions explored post stroke lifestyle and problems and difficulties
189 faced in life after the stroke (for example “Can you tell me about the changes in
190 your relationships”).

191

192 **Insert [Figure 1]**

193

194 *Supporting Quantitative Data*

195 Demographic, stroke subtype and co-morbidity data were available from hospital
196 records as described previously²⁹. Well validated quantitative measures were
197 administered during a face-to-face interview prior to the semi-structured
198 interviews. Stroke sub-type was classified using the Oxfordshire Community
199 Stroke Project (OCSP) classification system³³. Disability was assessed using the
200 Modified Rankin Scale (MRS) a 6-point scale to explore limitations in activity³⁴.
201 Mental status was assessed using the Mini-mental State Examination (MMSE), a
202 well validated tool that measures orientation, registration, attention and
203 calculation, recall and language³⁰. Stroke specific function was assessed using
204 the Stroke Impact Scale (SIS)³⁵. The SIS provides a comprehensive measure of
205 function and health related quality of life (HRQoL) based on self-report in the
206 domains of strength, memory, emotion, communication, Activities of Daily Living
207 (ADL), mobility and handicap. Higher scores achieved on all of the afore-
208 mentioned study measures, except the MRS, reflect higher levels of functioning
209 (and perceived functioning).

210

211 **Data Analysis**

212 All interviews were transcribed verbatim, with identifying data removed. Data
213 analysis was undertaken using a modified grounded theory. Grounded theory
214 methodology allows for the development of theory from the experiences of the
215 study participants, that is the theory is grounded in data. A modified grounded
216 theory approach incorporates data collection, coding and analysis using a

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217 process of constant comparison without the theory development component³⁶.

218 This entailed an ongoing cycle of data collection and simultaneous analysis,

219 whereby each transcript was read and reread by 2 members of the research

220 team (J.W. and P.M.) prior to consensus coding.

221

222 Each interview was transcribed, conceptualised and coded. The first step of the

223 coding process was open coding which involved a literal line-by-line reading and

224 interpretation of the transcripts to identify a wide range of categories from the

225 data. These categories were given a label or code consisting of four letters in

226 order to facilitate retrieval between the transcripts (for example, feelings of

227 frustration were labeled as FRUS). Constant comparison involved comparing the

228 emerging codes between each transcript. The next level of analysis was axial

229 coding which involved identifying relationships between codes and the grouping

230 of codes into coherent categories. For example, all codes that appeared to

231 influence mood were grouped and influences of these relationships were sought.

232 The final level of analysis involved the selection of majorb categories which

233 outlined the relationships and interactions between the codes related to the

234 experience of stroke, emotions and community participation.

235

236 To ensure accuracy, consensus coding was undertaken by two researchers (J.W

237 and P.M.). Following independent coding of the transcripts by each researcher,

238 there was a process of comparative coding including discussion of the codes and

239 how they were developed. Differences in researcher perspective were resolved

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240 by negotiation and consensus and fed back into the analysis to cross-check
241 codes and themes and develop an overall interpretation of the data
242
243 Rigor was further enhanced by incorporating a search for negative cases (cases
244 which appear to disconfirm or refute any conclusions arising from data³⁷), use of
245 participant’s words and member checking (testing the data with the members of
246 the group from which they were collected³⁸) whereby transcripts were mailed to
247 participants them to review and to add or remove any information from their
248 transcript. To assist participants in this process (in case of potential cognitive
249 and communication difficulties), the participants were contacted by phone within
250 a few weeks of receiving the mail-out to clarify their feedback. However no
251 changes were made to the transcripts or their interpretation by the participants.
252 There was the provision for further interviews to be done with additional
253 participants if required, however thematic saturation (a situation in which no
254 further themes were emerging) was achieved during the initial twelve interviews
255 and, thus, no subsequent interviews were scheduled.

256

257 *Ethics*

258 Approval for this project was obtained from the Hunter New England Human
259 Ethics Research Committee.

260

261 **Results:**

262 Four types of emotional and psychological factors related to mood change were
263 reported by participants (feelings of frustration, reduced self-efficacy,

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264 dependency and loss). These feelings were modulated by four internal factors:
265 insight, optimism, faith, and resilience.

266

267 The demographics and post stroke functioning of the twelve participants are
268 outlined in Table 1. Overall the participants had experienced an ischaemic
269 stroke, and equal numbers of men and women were interviewed. Ages ranged
270 from 43-92 years. The majority of participants did not live alone, had a partial
271 anterior circulation (PACI) stroke, and intact cognition. Five participants were
272 classified as dependent (MRS ≥ 3 and ≤ 5) following their stroke and 7 were
273 independent (MRS ≤ 2), using the MRS. There was no consistent trend with
274 regards to perceived functioning, as measured by the SIS.

275

276 [Insert Table 1]

277

278 A notable finding in this study was the consistency with which low mood was
279 reported across the 3 time groups, type of stroke, and level of disability. The
280 majority of participants reported feelings of sadness and that they no longer
281 “cared” (Participant 7, male, age 58) about the things they previously did.
282 Suicidal ideation was present in one participant who indicated “[I’d be] better off
283 dead” (Participant 1, male, age 92).

284

285 “You feel disappointed, down-hearted, sorry.”

286 (Participant 10, male, age 70).

287

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288 “Oh, it gets you down, you know. Yeah, it gets you down a bit.”

289 (Participant 2, male, age 60).

290

291 The most prominent precipitators of low mood were changes in functional abilities

292 and the relinquishment of valued activities, which had to be “given away”

293 (Participant 7, male, age 58). Reduced participation in activities was directly

294 linked with clearly expressed feelings of apathy and “lost interest” (Participant 7,

295 male, age 58). This may have lead to a cycle of increased withdrawal from

296 valued activities resulting in further inactivity and reported boredom.

297

298 These feelings were a precursor to frustration.

299

300 **Feelings of Frustration**

301 The experience of frustration and low mood were often concomitant and strongly

302 linked to functional limitations. All participants expressed negative feelings about

303 “not being able to do what I like” (Participant 11, female, age 79) and being “fed

304 up” (Participant 4, female, age 78).

305

306 “Actually it is more frustrating than anything else because you cannot do

307 what you did before. You think you can do it until you try to do it and there

308 is no way in the world you can.” (Participant 7, male, age 58)

309

310 Experiences of frustration were compounded by the need to take extra time or

311 the inability to complete a task.

312

313 “That is the frustrating part. You can’t make your limbs move the way that
314 you would like to.” (Participant 6, female, age 81)

315

316 Anger was commonly associated with frustration and participants reported feeling
317 “impatient” (Participant 4, female, age 78) and “cranky” (Participant 11, female,
318 age 7) or had an increased tendency to “flare-up” (Participant 7, male age 58)

319

320 “You get frustrated with yourself and angry... I get very angry.”

321 (Participant 3, female, age 66)

322

323 **Feelings of Reduced Self-Efficacy**

324 The second factor related to mood change, feelings of reduced self efficacy, was
325 expressed in a variety of ways such as feelings of being “useless” (Participant 1,
326 male, age 92) and “unproductive” (Participant 3, female, age 66). The lost ability
327 to partake in their pre-stroke lifestyle continually reinforced for one participant
328 their being “different and not the same as everyone” (Participant 6, female, age
329 81). Reduced self-efficacy was further manifested when participants were
330 dissatisfied with performance outcome and the quality or “thoroughness”
331 (Participant 6, female, age 81) previously achieved.

332

333 “Well in a way it makes you feel like you want to give up because you are
334 not improving as you expected to. You got to accept the fact that you are
335 not going to get better.” (Participant 7, male, age 58)

336

337 “I am just a hindrance. I accept that.” (Participant 9, female, age 74)

338

339 Such feelings of lost competency were seen to impact on their self-confidence
340 and led to further withdrawal from participation in activities. Some participants
341 had made a conscious decision to withdraw due to feelings of “embarrassment”
342 (Participant 7, male, age 58). This phenomenon was most evident in participants
343 with speech impairments who experienced stigmatisation from the broader
344 community.

345

346 “I think I am talking funny so I sort of get out of the road.” (Participant 10,
347 male, age 70)

348

349 **Feelings of Dependency**

350 The third factor related to mood change, feelings of dependency, was identified
351 when participants were required to rely on other people for assistance which
352 contributed to their experience of low mood. This was exacerbated by the
353 inability to undertake valued activities that were central to a participant’s pre-
354 stroke identity, such a maintaining the home, leisure, and work activities. The
355 extent of dependency varied according to residual impairments and the most
356 common restrictions related to activities of daily living.

357

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358 “Have to get help to do up a shirt or pull a jumper down, put on a
359 coat...small things that you are used to doing for yourself.” (Participant
360 10, male, age 70)

361

362 Participants found the need to rely on others was “hard to accept” (Participant 4,
363 female, age 78) and this was observed as being a major contributor to distress.

364

365 “You got to rely on people unfortunately.” (Participant 7, make, age 58)

366

367 **Feelings of Loss**

368 The final factor related to mood change, feelings of loss, was characterised by
369 the experience of residual physical, cognitive, or communication impairments
370 which all contributed to role loss.

371

372 “I used to go round [hostel] units here and [serve] communion... I was
373 really involved. I just can’t any more...it is a bit upsetting.” (Participant 4,
374 female, age 78).

375

376 There was sense that life had “changed forever” (Participant 10, male, age 70)
377 and that the quality was “nowhere near as good” (Participant 9, female, age 74)

378

379 Feelings of guilt, loss and having “paid the price” (Participant 7, male, age 58)
380 were common in participants who felt they were to blame for their stroke.

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381 Participants identified a range of causative factors such as “drinking” (Participant
382 2, male, age 60) or “stress” (Participant 3, female, age 66)

383

384 “I was working 16 hour days, plus overtime and it just caught up with me.”
385 (Participant 7, male, age 58)

386

387 Changes in social patterns were commonly reported, characterised by reduced
388 frequency of contact with friends and family, particularly friends. The experience
389 of social isolation was an additional cause of distress in participants, due to
390 feelings of loss.

391

392 “I do miss the kids [grandchildren], I miss them very much.” (Participant
393 11, female, age 79)

394

395 **Modulating Factors**

396 These feelings of frustration, reduced self-efficacy, dependency, and loss were
397 modulated by four internal factors. These four factors were insight, optimism,
398 faith, and resilience, which existed on a continuum of high to low. When these
399 modulating factors were present, participants experienced more positive mood.

400 When these modulating factors were absent, participants’ were more likely to
401 experience/report feelings of frustration, reduced self efficacy, dependency and
402 loss.

403

“Exploring Post Stroke Mood Changes”

404 Insight referred to a participant’s ability to comprehend their abilities and
405 limitations and to effectively problem-solve barriers in order to accomplish a
406 desired task. This led to enhanced feelings of independence and choice, which
407 assisted in the maintenance of a positive self-efficacy.

408

409 “I sit down now and think, “Well blow the house work, I will crochet.” I
410 enjoy that more, whereas before I would run around doing everything. I
411 have slowed down a lot.” (Participant 5, female, age 43)

412

413 Optimism was another key factor that modulated the experience of stroke. For
414 many participants optimism was centered around “living for others” (Interview 10)
415 and seeing milestones achieved in the lives of children and grandchildren. These
416 included marriage, the birth of grandchildren, or the graduation of grandchildren
417 from school and university.

418

419 The modulating factor of faith was characterized as a significant sense of hope
420 through a relationship with God.

421

422 “If it was not for God I would be a lot worse with my stroke I think.”
423 (Participant 9, female, age 74)

424

425 The modulating factor of resilience (and of having achieved mastery during
426 previous life experiences and challenges) was an interesting finding in this study,
427 facilitating greater adjustment to stroke. Participants felt that overcoming

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428 previous adversity in life helped them “Not to take things for granted” (Interview 6,
429 female, age 81) and to “Make today count” (Participant 9, female, age 74).

430

431 Resilience was strongly linked with experiencing ongoing support of family,
432 friends and loved ones. This included the provision of practical support or
433 emotional support.

434

435 “Having a family that cared, or friends that cared, that’s the main thing,
436 getting those things when you need them. I have never been on my
437 own.” (Participant 10, male, age 70)

438

439 **Discussion**

440 The main aim of this study was to explore the experience of mood changes in
441 community dwelling stroke survivors. Results demonstrated that altered mood
442 was present in participants at 1, 3 and 5 years post stroke. The use of qualitative
443 methodology highlighted common themes influencing the onset and/or
444 perpetuation of low mood including feelings of frustration, reduced self-efficacy,
445 dependency, and loss.

446

447 Traditionally research has indicated the greatest risk for PSD occurs within a few
448 months after stroke onset³⁹. However Hackett et al has since reported that the
449 risk is similar in the early, medium and long -term recovery stages, whereby long
450 term was considered any time-frame beyond 6 months¹. Our qualitative results
451 contribute descriptive data which support the experience of altered mood for

“Exploring Post Stroke Mood Changes”

452 many years after stroke. Participants within each cohort experienced one or
453 more of the identified categories (feelings of frustration, reduced self-efficacy,
454 dependency and feelings of loss), which suggests that low mood is influenced by
455 various factors. These results are in accordance with current literature outlining
456 the experience of changes in mood, social support, functional abilities, and
457 quality of life after stroke^{40,41}.

458

459 The current study was a sub-study of a larger retrospective, cross-sectional
460 cohort study exploring the outcomes of community dwelling stroke survivors at 1,
461 3 and 5 years post stroke²⁹. In summary this study identified that stroke
462 survivors' function did not change significantly between cohorts and that a high
463 proportion of survivors required community services. The larger study did not
464 aim to diagnose depression and used the SIS to assess participants' perceived
465 function after stroke. The SIS is a widely used scale of perceived function post
466 stroke. Results identified that the proportion of participants experiencing low
467 mood, as measured by the Emotion domain subset of the SIS, was similar across
468 the 3 cohorts and up to 5 years post stroke²⁹. A key finding was that the poorest
469 domain of function, as measured by the SIS, was the emotion domain.

470 Qualitative results add an in-depth understanding of this experience and further
471 validate and outline the extent of low mood. The twelve participants in this study
472 were not remarkably different to participants in the larger study²⁹, see Table 2.

473

474

Insert Table 2

475

“Exploring Post Stroke Mood Changes”

476 While the severity of low mood was not assessed formally in the current study,
477 the results do raise the question of where the participants were in the spectrum of
478 depression. While the participants this study did not label their experiences as
479 “depression”, it has been well established in the literature that many mood
480 disorders do not fit the DSM-IV classification of major depression. As a result,
481 the categories identified regarding low mood in this study may be a cue for
482 practitioners and therapists to explore the possibility of mood disturbance in
483 community dwelling stroke-survivors. Terminology surrounding feelings of
484 frustration, reduced self efficacy, dependence and loss are not used extensively
485 in depression measures which assess mood changes after stroke. Future
486 research should explore whether these concepts assist in identifying mood
487 changes in stroke survivors.

488

489 Correlations between social support and health and outcome after stroke have
490 been well documented^{42,43}. Supportive family networks as well as broader social
491 networks have been linked to better outcomes^{44,45} However, reduced social
492 networks have been frequently cited as a consequence of stroke and can be
493 associated with the experience of PSD^{4,12}. Results from this study identified the
494 experience of distress due to reduced social networks following stroke. Future
495 research should explore methods to increase support networks or maximize the
496 benefit of existing networks.

497

498 These results also provide evidence to support more research into models of
499 therapeutic intervention addressing mood changes many years after stroke

500 onset. Current literature highlights that there is a lack of evidence regarding
501 models of service delivery that adequately address mood⁷. Turner-Stokes and
502 Hassan (2002)¹⁷ suggest that care pathways may be one approach to improving
503 the management of mood change after stroke. Our results highlight immediate
504 areas for attention in order to prevent distress due to altered functioning, reduced
505 social networks and to facilitate coping. Typically, community based
506 rehabilitation is provided in the first few months after stroke however this study
507 suggests that longer term interventions may be necessary to prevent mood
508 changes and promote health and QOL.

509

510 Functional independence after stroke is a key measure of post stroke outcome,
511 however, our results suggest that low mood can still occur despite reasonable
512 post stroke recovery. Our findings identified a number of modulating factors,
513 which attenuated feelings of distress and facilitated adaptation to the
514 consequences of stroke. These included strategies that served to enhance self-
515 efficacy, such as maintaining a sense of control through prioritisation of activities,
516 sustaining feelings of hope, social networks, and resilience. We plan to explore
517 this in future research since an understanding of how people adjust after stroke is
518 important in order to provide good care²³.

519

520 *Study Strengths*

521 This study generates unique data on mood disturbance in Australian stroke
522 survivors and provides baseline data for ongoing measurement of outcomes
523 following stroke in this region. The strength of this study lies in the use of

“Exploring Post Stroke Mood Changes”

524 qualitative methodology to obtain a description of mood disturbance after stroke
525 using semi-structured interviews. There was also the opportunity to draw links
526 between this study and quantitative data from a larger study. The use of an
527 objective sampling frame in this study and the consecutive identification of study
528 participants has been previously reported. Such results suggest that the
529 information is likely to be representative of the experience of PSD in community
530 dwelling stroke survivors.

531

532 *Study Limitations*

533 The study used multiple cross-sectional samples at 1, 3 and 5 years post-stroke;
534 this limits the ability to make interpretations regarding changes in post stroke
535 functioning in individuals over time. The next step would be to confirm these
536 findings in a prospective, longitudinal cohort. The accurate identification of mood
537 is also influenced by the use of the Emotion domain of the SIS in contrast to a
538 formal, standardized assessment of mood. The study was intentionally aimed at
539 community-dwelling stroke survivors in order to inform community service
540 provision; the study excluded people with more severe strokes, such as people in
541 nursing homes, and is subject to survivor bias limiting the generalisability of the
542 study. Qualitative interviews were limited to one interview per participant and
543 therefore may not capture any changes over time.

544

545 *Conclusion*

546 Overall the results of this study suggest that in spite of reasonable recovery and
547 maintained function, low mood is still experienced by community dwelling stroke

548 survivors. The use of qualitative methodology was sensitive in identifying the
549 themes that play a role in the onset and experience of low mood. Monitoring of
550 mood in stroke survivors remains a high priority for the health system. These
551 data support the need for a more extensive study into the medium and long term
552 needs of stroke survivors.

553

554 **Acknowledgements**

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557

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688 **Table 1 Summary of Participant Demographics and Functioning**

Participant Number	Sex	Age	Marital Status	Year Since Stroke	Stroke Sub-type OCSF	Disability level (MRS)	Cognition (MMSE)	HRQoL (lowest scoring SIS domain)
1	Male	92	Widowed	1	PACI	4	28	Communication
2	Male	60	Divorced	1	PACI	3	23	Emotion
3	Female	66	Married	1	PACI	4	29	Memory
4	Female	78	Widowed	1	POCI	3	29	Emotion
5	Female	43	Married	3	PACI	2	29	Memory
6	Female	81	Widowed	3	TACI	1	28	Communication
7	Male	58	Married	3	PACI	2	30	Memory
8	Male	78	Widowed	3	LACI	0	30	Emotion
9	Female	74	Separated	5	PACI	1	28	Participation
10	Male	70	Married	5	LACI	2	29	Memory and Participation
11	Female	79	Married	5	LACI	1	28	Participation
12	Male	82	Married	5	POCI	3	30	Participation

“Exploring Post Stroke Mood Changes”

689 OCSP indicates Oxfordshire Community Stroke Project; TACI, Total Anterior
690 Circulation Infarction; LACI, lacunar infarction; PACI, Partial Anterior Circulation
691 Infarction; POCI Posterior Circulation Infarction; MRS indicates Modified Rankin
692 Scale (0=low, 5=high, with a lower score representing higher disability), MMSE
693 indicates Mini-Mental State Examination, range 0-30 (lower scores representing
694 lower cognitive function); HRQoL indicates Health related quality of life, SIS
695 indicates Stroke Impact Scale 3.0.

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713 **Table 2: Key Demographic Characteristics of Participants (n=91)**

Characteristics	Cohort 1 (n=30)	Cohort 3 (n=31)	Cohort 5 (n=30)	<i>P</i>
Sex				.128
Female	19 (63)	11 (37)	14 (47)	
Male	11 (37)	20 (63)	16 (53)	
Mean age (y)	70.7	72.5	69.3	
Living style				.914
Live alone	8 (27)	7 (23)	8 (27)	
Not alone	22 (73)	24 (77)	22 (73)	
Marital status				.095
Married	15 (50)	18 (58)	16 (53)	
Other	15 (50)	13 (42)	14 (47)	
First ever stroke				.295
Yes	26 (87)	24 (77)	21 (70)	
No	4 (13)	7 (23)	9 (30)	
Employment history				.036
Employed	4 (13)	5 (16)	3 (10)	
Retired	26 (87)	26 (84)	27 (90)	
Carer				.543
Yes	8 (27)	12 (39)	11 (37)	
No	22 (73)	19 (61)	19 (63)	
Ethnicity				.479
Australian	27 (90)	24 (77)	27 (90)	
Other	3 (10)	7 (23)	3 (10)	
Dysphasia				.960
Yes	6 (20)	7 (23)	6 (20)	
No	24(80)	24 (77)	24 (80)	
OCSP classification				.183
TACI	2 (7)	3 (10)	0 (0)	
LACI	12 (40)	9 (29)	6 (20)	
PACI	10 (33)	12 (39)	13 (43)	
POCI	5 (17)	2 (6)	8 (27)	
SAH	1 (3)	2 (6)	0 (0)	
ICH	0 (0)	3 (10)	3 (10)	
MMSE score between 24–30	83	90	93	.085

714 NOTE. Values are n (%) or n.

715 OCSP indicates Oxfordshire Community Stroke Project; TACI, Total Anterior

716 Circulation Infarction; LACI, lacunar infarction; PACI, Partial Anterior Circulation

“Exploring Post Stroke Mood Changes”

717 Infarction; POCI Posterior Circulation Infarction; SAH. Subarachnoid

718 haemorrhage; ICH, Intercerebral haemorrhage;

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741 **Figure 1** **Interview Guide**

742 I would firstly like to ask you some questions about yourself?

743 Can you tell me about a typical fortnight before you had the stroke eg what you
744 spent your time doing, the people you saw etc?

745 How has your life changed since your stroke?

746 How do you feel about these changes?

747 Can you tell me about your experiences during your hospital admission for
748 stroke?

749 Can you tell me about your experience when you came home from hospital after
750 your stroke?

751 In the ideal world what support would you like to see provided?

752 Have you ever sought out advice or information about living with stroke, or talked
753 to anyone about it?

754 Have you experienced any changes in your relationships?

755 Would you say you have adjusted to having had stroke?

756 How do you see your life now?

757 What does your future look like?

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Jennifer H. White, Megan K. Alston, Jodie L. Marquez, Anne L. Sweetapple, Michael R. Pollack, John Attia, Christopher R. Levi, Jonathan Sturm, Scott Whyte
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APPENDIX C

Interview Guide Questions

Thankyou for agreeing to talk with me today.

This project is part of my university studies where I am looking at the needs of people following a stroke.

What I would like to talk to you about today is what has most helped you learn to live with having a stroke.

I would like to tape record our conversation, if you agree. Using the tape recorder saves me from having to write down all the important points. I will be writing down the information from the tape and, once this is done, the tape will be destroyed. Do you mind if I record our conversation.

Some research has been done into some of the main problems people experience after as stroke. I want to talk to people in the Hunter to find out more about their experiences. This information will help us develop services that best meet people's needs.

Main Question	Prompts
Life prior to stroke	
I would firstly like to ask you some questions about yourself	Age Main Occupation Other main health problems Family Friends Things you enjoy doing
Can you tell me about a typical weekday before you had the stroke eg what you spent your time doing, the people you saw etc?	???What are your passions or things you really like to spend time doing?
Activities	How did you feel? What did you enjoy about it? Why was it important? Why didn't you? What has replaced that activity?
Initial experience of stroke	
Can you remember how you felt when you were admitted to hospital with stroke?	Fear
What was your biggest hope at that time?	
Can you tell me about your first day home from hospital?	
Can you tell me about your experience when you came home from hospital after your stroke?	How or what helped the return to living at home? People Services

Main Question

Prompts

Services etc

What services were available to you when you came home?

How did they help?

What did you access for emotional and practical help?

What do you think people need to help them a few years after a stroke?

Services

Support

Therapy

Magic wand Question

What would you like now if you had the option?

Why?

In the ideal world what support would you like to see provided for stroke sufferers?

Have you ever sought out advice or information about living with stroke, or talked to anyone about it?

Who/what source?

Did you get the answer/support you needed?

Relationship changes

Have you experienced any changes in your relationships with:

Did you still want the same things from people? Did you want more?

Family?

Have you maintained the same friends?

Friends?

Strangers?

What was your experience with regards to resuming any sexual relationships?

Male/single

Do you find you have had to reach out more to others?

Adjustment

Would you say you have adjusted to having had a stroke?

How would you describe your quality of life?

How do you feel on average eg

Main Question

Comparing how you are now to that of a year or a few years ago after the stroke, is your life much different?

Motivation

How do you feel about your

Other health

Acceptance

How do you see your life now?

What has helped you accept the current life you experience due to the stroke?

Prompts

happy, sad, adjusted to the stroke, accepted the stroke?

What is hardest?

Can you identify anything that would help?

What keeps you going?

What gives you a reason to keep going?

Independence..why?

What are you proud of?

Your current level of social activity?

Your current ability to look after your self?

You current ability to do the things you enjoy?

Have you made any lifestyle changes?

Are you fearful of having another stroke?

Relative to what?

What is the main difference?

What has helped you changed your attitude?

What has help you adapt to your physical limitations?

Main Question

Have you had a easy or hard time throughout your life?

Have you experienced any other major life events that you had to deal with?

What does the future look like for you?

Prompts

What would you do differently...services...friendships?

Are there things you would like to do?

What things, people, activities are important to you?

Information Sheet

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Information statement for the Research Project

Assessing the long-term needs of stroke survivors: the perceptions of
Stroke Survivors in the Greater Newcastle Sector

(Version 2, April 2005)

Dear

You are being invited to take part in the research project identified above which is being conducted by Jenni White, a research masters student at the University of Newcastle. Jenni is conducting the research as part of her Master of Medical Science degree under the supervision of Dr Lynette Mackenzie, Occupational Therapy at the University of Newcastle.

Why is the research being done?

The purpose of this research project is to gain an understanding of stroke survivors' perceptions of post-stroke experience. Our experience suggests that post stroke survivors may be different depending on people's marital status, gender etc.

Who can participate?

As you were interviewed in the recent study "The ongoing consequences of stroke: A pilot study of 90 stroke survivors in the context of a community based, cross-sectional cohort in the Greater Newcastle Sector," you are being invited to participate in this additional study. We would like to take this opportunity to thank you for your participation in that study. As part of the new study, we need to get a good mix of people. Depending on the number of people who are interested in being involved, you may or not be required for an interview. We will choose which people to interview with the help of the consent form that includes a few questions to help us get a range of people with different backgrounds.

What would you be asked to do?

The format of the research will be an individual interview of approximately one hour, which will be conducted at a place that is convenient to you. The interview will be tape recorded and you will have the right to review the tape and or transcript (the typed interview) and ask for all or any of your information to be erased. There will be no cost to you associated with the investigation.

If you would like to participate in the research, please complete the enclosed consent form and return it in the envelope provided by Friday, May 27th 2005. Jenni will then select the mix of participants and contact them by telephone to organize a suitable date and time for the interview. Either way, Jenni will contact you to let you know. Once all interviews have been conducted and the information has been analysed, Jenni will then contact participants again to discuss the themes that emerged from the interview and ask if they want to add any further comments.

How will your privacy be protected, and risks and benefits of participating?

All the information gathered will be completely confidential and your participation is completely voluntary. Your previous participation in "The ongoing consequences of stroke: A pilot study of 90 stroke survivors in the context of a community based, cross-sectional cohort in the Greater Newcastle Sector," does not place you under any obligation to accept this invitation. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

There are no direct benefits to yourself if you decide to participate in the research. No identifying data will be placed in any verbal or written reports associated with the research. You may request a copy of the results to be sent to you on completion of the project.

Further information

If you have any concerns or would like to know more details of the research project, please contact Jenni White or Dr Lynette Mackenzie on ph: 4921 5925

Thank you for your time and interest.

Jennifer White
Student researcher

Dr Lynette Mackenzie
Principal supervisor

This research has been approved by the Hunter Area Research Ethics Committee (approval number 04/08/11/3.13) and the University's Human Research Ethics Committee, approval number: H-003-0305

If you have any concerns about your rights as a participant in this study or about how the study is being run and wish to speak to an independent person, please contact:

Dr Nicole Gerrand

Professional Officer

Hunter Area Research Ethics Committee

Hunter Area Health Service, Lookout Rd, New Lambton Heights

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**Hunter New England
Area Health Service**

Consent Form

Consent form for the research project:

Assessing the long-terms needs of stroke survivors: the perceptions of stroke
Survivors in the Greater Newcastle Sector.

(Version 1, February 2005)

Student researcher: Jennifer White
Principal supervisor: Lynette Mackenzie

I _____ (print name), agree to participate in the above research project and give my consent freely.

I understand the project will be conducted as stated in the information letter, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give a reason for withdrawing.

I agree to the researcher telephoning me at home at an appropriate time to make any arrangements.

I consent to an individual interview, which I understand will be tape recorded, and follow up phone call. I understand that I have the right to review the tapes and/or transcripts of the tapes and to request that all or part of them be erased.

I understand personal information will remain confidential to the researchers.

I have been given the opportunity to raise any questions or concerns I have and am satisfied with the responses I was given.

CONTACT DETAILS:

Print name: _____

Signature: _____

Date: _____

Phone no: _____

Address: _____

1. Do you live alone? Yes
No

2. Do you have children? Yes If yes, go to Question 3
No If no, go to Question 4

3. Do you see your children regularly? Yes
No

4. Do you have other medical conditions that cause you difficulties? Yes
No

5. Do you feel you are coping with life after your stroke? Yes
No

6. Do you use community support services?
Eg. Meals on wheels, home help Yes
No

7. Do you have supportive friends? Yes
No

8. Do you have a spiritual belief?
Eg do you go to church Yes
No

9. Do you feel you have accepted having had your stroke and how its affects your life? Yes
No

10. How would you define your health? Good
Average
Poor

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