Exploring the Long-Term Experience of Psychological Morbidity in Community-Dwelling Stroke Survivors

Jennifer H. White, MMSc (Occupational Therapy)

Thesis submitted for the award of Doctor of Philosophy

August 2013

Principal Supervisor:
Conjoint Professor Parker Magin, PhD

Associate Supervisors:
Professor John Attia, PhD
Associate Professor Jonathan Sturm, PhD

Special Acknowledgement:
Conjoint Professor Greg Carter, PhD

‘There can be no knowledge without emotion. We may be aware of a truth, yet until we have felt its force, it is not ours. To the cognition of the brain must be added the experience of the soul.’ Arnold Bennett (1867–1931)
Contents

List of Tables .................................................................................................................................. v
List of Figures .................................................................................................................................. v
List of Abbreviations ...................................................................................................................... vi
Statement of Original Authorship ................................................................................................ viii
Abstract ....................................................................................................................................... ix

Background .................................................................................................................................. ix
Aim ............................................................................................................................................... ix
Methods ....................................................................................................................................... xi
Results ......................................................................................................................................... xi
Conclusion .................................................................................................................................... xiii
List of Relevant Publications and Presentations ......................................................................... xiv
Presentations at National and International Conferences ..................................................... xiv
Publications in Peer-Reviewed Journals .................................................................................... xiv
Acknowledgements .................................................................................................................... xvii

1 Thesis Overview ............................................................................................................. 1

1.1 Outline of Candidature ................................................................................................. 1

1.2 Background to the Current Study .............................................................................. 1

1.2.1 Stroke: Context and Management ..................................................................... 2

1.3 Relevance of Research Questions ............................................................................. 3

1.4 Previous Research Undertaken by the Doctoral Candidate ...................................... 4

1.5 Significance of this Research ..................................................................................... 5

1.6 Conclusion ...................................................................................................................... 6

2 Study Overview ............................................................................................................... 7

2.1 Introduction ..................................................................................................................... 7

2.2 Research Aims ............................................................................................................... 7

2.3 Research Orientation and Methodology ..................................................................... 8

2.3.1 Overarching Research Paradigm: Pragmatism ................................................. 8

2.4 Summary of Methodology: Mixed Methods .............................................................. 8

2.4.1 Overview of the Longitudinal Mixed-Methods Approach ................................... 10

2.5 Conclusion .................................................................................................................... 11
### Part I: Stroke and Recovery

#### 3.1 Introduction

#### 3.2 Stroke and Stroke Recovery

- **3.2.1 Effect of Stroke: Stroke Onset and Classification**
- **3.2.2 Effect of Stroke on the Stroke Survivor and Their Family**

#### 3.3 Rehabilitation and the Recovery Process

- **3.3.1 Rehabilitation**
- **3.3.2 Transition to Community Living**

#### 3.4 Chronicity of Stroke

#### 3.5 Conclusion

### Part II: Depression

#### 4.1 Overview of Depression in the General Population

#### 4.2 Post Stroke Depression

- **4.2.1 Under-detection of PSD**
- **4.2.2 Aetiology of PSD**
- **4.2.3 Diagnosing PSD**
  - **4.2.3.1 Psychiatric Interview**
  - **4.2.3.2 Screening for PSD**
  - **4.2.3.3 Screening for PSD in Non-acute Settings**

#### 4.3 Frequency of PSD

- **4.3.1 Adverse Outcomes of PSD**
- **4.3.2 Risk Factors of PSD**

#### 4.4 Understanding the Persisting Nature of PSD

#### 4.5 Interventions for PSD

- **4.5.1 Community Education About PSD**

#### 4.6 Conclusion

### Part III: Anxiety

#### 5.1 Anxiety and the General Population

#### 5.2 Interventions for Anxiety

#### 5.3 Anxiety After Stroke

- **5.3.1 Diagnosis of Anxiety After Stroke**
8.7.2 Qualitative Recruitment (A Sub-Sample of 23 Participants) ........................................ 43
8.8 Baseline Screening ........................................................................................................ 44
8.9 Quantitative Data Collection ..................................................................................... 44
  8.9.1 Assessment Instruments and Other Data Collected ............................................... 44
    8.9.1.1 Disability: mRS ............................................................................................. 44
    8.9.1.2 Depression and Anxiety: K10 and HADS ....................................................... 45
    8.9.1.3 Social Support: MSPSS ................................................................................. 46
    8.9.1.4 Health related Quality of Life: AQoL .............................................................. 46
    8.9.1.5 Community Participation: AAP ..................................................................... 46
8.10 Qualitative Data Generation ..................................................................................... 47
  8.10.1 Overview of Qualitative Methodology .................................................................. 47
  8.10.2 Qualitative Interviews ......................................................................................... 47
8.11 Data Analysis ........................................................................................................... 48
  8.11.1 Quantitative ......................................................................................................... 48
  8.11.2 Qualitative .......................................................................................................... 49
    8.11.2.1 Open Coding ............................................................................................... 49
    8.11.2.2 Axial Coding ............................................................................................... 50
    8.11.2.3 SELECTIVE Coding .................................................................................. 50
    8.11.2.4 Rigor and Trustworthiness ......................................................................... 50
8.12 Conclusion ................................................................................................................ 52
9 Quantitative Publications .............................................................................................. 53
  9.1 Manuscript ............................................................................................................... 53
  9.2 Manuscript ............................................................................................................... 55
10 Qualitative Publications .............................................................................................. 57
  10.1 Manuscript .............................................................................................................. 57
  10.2 Manuscript .............................................................................................................. 59
  10.3 Manuscript .............................................................................................................. 61
  10.4 Manuscript .............................................................................................................. 63
  10.5 Manuscript .............................................................................................................. 65
11 Integrated Findings, Conclusions and Implications ..................................................... 67
  11.1 Introduction ............................................................................................................. 67
11.2 Summary of Major Findings and Relationship with Previous Literature ....................... 67
  11.2.1 Research Aim One ......................................................................................... 67
  11.2.2 Research Aim Two ....................................................................................... 69
11.3 Synthesis of Quantitative and Qualitative Findings ...................................................... 71
  11.3.1 Summary of Major Findings ....................................................................... 71
  11.3.2 Benefits of Mixed Methods Research ......................................................... 74
  11.3.3 Integrated findings ....................................................................................... 75
11.4 Strengths and Limitations ....................................................................................... 77
  11.4.1 Quantitative Strengths ................................................................................ 77
  11.4.2 Quantitative Limitations ............................................................................ 78
  11.4.3 Qualitative Strengths .................................................................................. 78
  11.4.4 Qualitative Limitations .............................................................................. 78
11.5 Implication for Clinical Practice and Policy ............................................................... 79
11.6 Service Re-Organisation and Policy Implications ..................................................... 82
  11.6.1 Screening and Education for Psychological Morbidity ................................ 82
11.7 Implications for Practice ...................................................................................... 84
11.8 Implications for Future Research ........................................................................... 87
11.9 Final Words ......................................................................................................... 87
12 References .............................................................................................................. 89

LIST OF TABLES
Table 4.1 - Review of Previous Quantitative Research Addressing Longer-Term PSD25

LIST OF FIGURES
  Figure 8.1 – Flowchart of Study ............................................................................. 40
  Figure 8.2 – Flowchart of Emergent Themes .......................................................... 41
  Figure 11.1 – Managing Psychological Morbidity Across All Phases of Care ......... 80
### LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAP</td>
<td>Adelaide activities profile</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AQoL</td>
<td>Assessment of Quality of Life</td>
</tr>
<tr>
<td>BDI</td>
<td>Beck Depression Inventory</td>
</tr>
<tr>
<td>BDI-II</td>
<td>Beck Depression Inventory, 1996 revision</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive behavioural therapy</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*</td>
</tr>
<tr>
<td>EPC</td>
<td>Enhanced Primary Care</td>
</tr>
<tr>
<td>GAD</td>
<td>Generalised anxiety disorder</td>
</tr>
<tr>
<td>GDS</td>
<td>Geriatric Depression Scale</td>
</tr>
<tr>
<td>GHQ</td>
<td>General Health Questionnaire</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>HADS-A</td>
<td>Hospital Anxiety and Depression Scale, anxiety subscale</td>
</tr>
<tr>
<td>HADS-D</td>
<td>Hospital Anxiety and Depression Scale, depression subscale</td>
</tr>
<tr>
<td>HADS-Total</td>
<td>Hospital Anxiety and Depression Scale, total score</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health-related quality of life</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Disease, Tenth Revision</td>
</tr>
<tr>
<td>IDA</td>
<td>Irritability, Depression and Anxiety Scale</td>
</tr>
<tr>
<td>K10</td>
<td>Kessler-10</td>
</tr>
<tr>
<td>LACI</td>
<td>Lacunar infarction</td>
</tr>
<tr>
<td>LoC</td>
<td>Locus of control</td>
</tr>
<tr>
<td>mRS</td>
<td>Modified Rankin Scale</td>
</tr>
<tr>
<td>MSPSS</td>
<td>Multidimensional Scale of Perceived Social Support</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>OCSP</td>
<td>Oxfordshire Community Stroke Project</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational therapist</td>
</tr>
</tbody>
</table>
**List of Abbreviations (con’d)**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PACI</td>
<td>Partial anterior circulation infarction</td>
</tr>
<tr>
<td>PHQ</td>
<td>Patient Health Questionnaire</td>
</tr>
<tr>
<td>POCI</td>
<td>Posterior circulation infarction</td>
</tr>
<tr>
<td>PSD</td>
<td>Post-stroke depression</td>
</tr>
<tr>
<td>PSUI</td>
<td>Post-stroke urinary incontinence</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>SIS</td>
<td>Stroke Impact Scale Version 3.0</td>
</tr>
<tr>
<td>SP</td>
<td>Speech pathologist</td>
</tr>
<tr>
<td>TACI</td>
<td>Total anterior circulation infarction</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>

* The DSM-IV has since been superseded by DSM-V. However at the time that this study was conducted and the thesis written all references were made to the DSM-IV.
STATEMENT OF ORIGINAL AUTHORSHIP

I hereby certify that this thesis is in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author, endorsed by the Faculty Assistant Dean (Research Training), attesting to my contribution to the joint publications.

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

I give consent to the final version being made available worldwide when deposited in the University Digital Repository, subject to the provisions of the Copyright Act 1968.

Signed:

Jennifer White
ABSTRACT

Background
Psychological morbidities such as post-stroke depression (PSD) and anxiety are common following stroke, and may influence the stroke survivors’ ability to engage in rehabilitation processes. This in turn results in reduced rehabilitation gains and long-term outcomes. Longitudinal studies are essential for documenting the course and prognosis of PSD, and other psychological morbidities, and for establishing causality in the relationships between stroke, functional recovery, depression, anxiety and quality of life (QoL). Qualitative studies are invaluable in exploring the lived experience of people with chronic illness such as stroke. To date, there have been only limited longitudinal studies of PSD and no longitudinal qualitative studies of PSD or psychological morbidity post stroke. Therefore, research undertaken for this thesis involved a longitudinal study into psychological morbidity in community-dwelling stroke survivors, using both qualitative and quantitative methods.

Aim
The primary aim of the quantitative study was to establish baseline clinical, functional and psychosocial factors associated with anxiety and depression during the 12 months following stroke. The qualitative aim of this study was to explore the longitudinal patterns of post-stroke psychological morbidity, and particularly to establish disease trajectories.

Methods
This study used a prospective, mixed-methods design, including concurrent quantitative data collection and in-depth, semi-structured qualitative interviews. Quantitative surveys were administered at baseline (as close to stroke onset as possible), 3, 6, 9, and 12 months. Qualitative semi-structured interviews explored participants’ experience of psychological morbidity. Inductive thematic analysis of participant interviews resulted in key themes concerning participants’ perceptions of the experience of psychological morbidity at baseline, three, six, nine and 12 months. Interviews at baseline were conducted until thematic saturation (a situation of no new themes emerging) was achieved according to the core objective. However additional themes emerged in subsequent interviews and our methodology provided the scope to undertake further purposive sampling to explore the additional post-stroke experiences including distress concerning return to driving and participation, fatigue and urinary incontinence. Quantitative and qualitative data were separately analysed and then considered together during a mixed methods analysis phase.

Setting:
Metropolitan Newcastle, New South Wales, Australia.
**Subjects:**
Participants in the quantitative study were patients admitted to one of two Newcastle hospitals and having a diagnosis of stroke. Participants in the qualitative study were a purposively sampled sub-set of the participants in the quantitative study.

**Recruitment and sampling**

**Quantitative**
Potential participants were identified from consecutive admissions to two out of three of the tertiary referral centres in Newcastle, NSW (Calvary Mater Hospital and Belmont District Hospital). The cases were defined by the following factors: admission to hospital and history and examination consistent with stroke as determined by a stroke physician. Brain imaging was available to aid diagnosis in 91% of cases. Patients with haemorrhagic stroke were included. Participants were excluded if they had significant language or cognitive impairment. Participants were recruited to the study between December 2007 and December 2011.

**Qualitative**
Purposive maximum-variation sampling of qualitative participants for baseline interviews considered variation in age, gender, living situation, type of stroke, level of disability (ranging from mild to moderate) and depression scores (case and non-case).

**Main Outcome Measures and Analysis:**

**Quantitative**
Valid and reliable measures documented physical and psychosocial function at baseline, three, six, nine and 12 months. The primary quantitative outcome measures were depression and anxiety, measured using the Hospital Anxiety and Depression Scale: (HADS). Secondary outcomes were disability, measured using the modified Rankin Scale (mRS); health related quality of life (HRQoL), measured using the Assessment of Quality of Life (AQoL); social support, measured using the Multidimensional Scale of Perceived Social Support (MSPSS); and community participation, measured using the Adelaide activities profile (AAP). The researchers analysed univariate associations between anxiety and depression and demographic variables using t-tests for depression and anxiety as continuous variables, and chi-squared tests when depression and anxiety were treated as categorical variables. Baseline predictors of depression, anxiety and HRQoL over time, were analysed using linear mixed models with exchangeable correlation structures, using continuous HADS Total, HADS-D, HADS-A or HRQoL scores as the outcome variable. For baseline predictors of dichotomised depression status or anxiety status, as the outcome variable, logistic regression with repeated measures was accounted for using generalised estimating equations (exchangeable correlation structures were used).
Patients needed to have at least two follow-up time points to be included in this analysis.

**Qualitative**
The qualitative study explored participant perceptions of experiences of psychological morbidity. Data analysis involved an inductive thematic approach with constant comparison.

**Results**
There were 134 participants at baseline (mean age of 75 (SD ± 12); 52% females), with 110 participants in the quantitative cohort retained at the 12 month interview. The qualitative sample included 23 participants (13 men and 10 women with an age range of 37–94). Participants in the qualitative study completed 106 interviews over 12 months.

Findings from the results are presented as seven separate analyses (2 quantitative, 5 qualitative), these being the content of the seven journal papers on which this thesis is based.

**Quantitative papers**
Analysis 1 (quantitative analysis) established predictors of anxiety and depression over time. Anxiety (but not depression) scores, improved over time. Anxiety scores post-stroke were positively associated with PSD (p < .0001), anxiety at baseline (p < .0001) and less disability (p = .0423). PSD was associated with anxiety (p < .0001), depression at baseline (p = .0057), low social support (p = .0161) and low community participation (p < .0001). The only baseline factor predicting the resolution of PSD (if the participant was depressed at baseline) was increased social support (p = .0421). Baseline factors that predicted the onset of depression (if the participant was not depressed at baseline) were low community participation (p = .0015) and higher disability (p = .0057). These findings suggest a need for the organisation of services to address social isolation and community participation in patients post-stroke.

Analysis 2 (quantitative analysis) established the experience of HRQoL over time. Higher HRQoL scores during follow-up were associated with participants having good HRQoL at baseline (p = 0.0321), younger age (p = 0.0059), lower disability (p = 0.0032), greater community participation (p < .0001) and not having a previous history of depression (p = 0.0316). Contrary to previous literature, none of the participants rated their HRQoL close to or lower than zero, indicating that no one rated their disability as worse than death.

**Qualitative Papers**
Analysis 3 (qualitative analysis) identified four different longitudinal trajectories post stroke including: resilience (n = 5), ongoing crisis (n = 5), emergent mood disturbance (n = 3) and recovery from mood disturbance (n = 10). Illness trajectories after stroke are a useful way to conceptualize and understand the pattern of psychological morbidity in stroke over time. Our results suggest that although screening for depression and other psychological morbidity may be valuable after a stroke, other clinical cues, such as reports of life-stress and impaired self-esteem, may increase sensitivity of detection.

Supplementary interviews based on emergent themes formed the basis of additional analyses:

Analysis 4 (qualitative analysis) explored return to driving and community access. Driving issues after stroke had a significant impact on ongoing adjustment to stroke. Participants received inconsistent advice regarding return to driving. Confidence and availability determined public transport use. The provision of information concerning processes for return to driving or alternates to driving should be incorporated into health systems approaches to in-hospital management, discharge planning and post-discharge follow-up care. Further interventions are required that help stroke survivors deal with changes after stroke such as maintaining mobility, confidence, and fitness to drive (or to access public transport).

Analysis 5 (qualitative analysis) explored the experience of post stroke fatigue. The results of this study suggest that in spite of reasonable objective physical recovery post-stroke, fatigue in community dwelling stroke survivors continues to be a problem post discharge and resulted in role loss. The time taken to adjust to fatigue was associated with poor knowledge about symptoms of post-stroke fatigue. Monitoring of fatigue in stroke survivors should be a higher priority for stroke clinicians who play an important role in providing education and interventions to support stroke survivors in the management of fatigue post-stroke.

Analysis 6 (qualitative analysis) highlighted the persisting impact of UI/PSUI on stroke survivors’ experience. The experience of UI/PSUI resulted in role loss and reduced HRQoL. Allied health professionals play an essential role in promoting confidence in continence management among stroke survivors’ and promote ongoing participation in valued life roles. There is a need for the management of UI/PSUI to be prioritised across acute, rehabilitation and community setting post stroke. Improved management of UI/PSUI that focusses on continence promotion may assist to minimise the impact of PSUI and improve rehabilitation outcomes.

Analysis 7 (qualitative analysis) involved follow –up of participant beyond 12 months following stroke onset. Participants reported altered function, fatigue, distress, reduced community participation and social isolation suggesting the experience of altered HRQoL. Results highlight the importance of social support and community access in
managing the emotional wellbeing of stroke survivors. Pursuing increased service access, community participation and ensuring good social support, for stroke survivors offers a practical strategy for clinicians.

**Conclusion**

This use of mixed methodology contributes to a greater understanding of psychological morbidity in the first year after stroke. Quantitative processes identified a high frequency of anxiety and depression, highlighting the need for early detection and the initiation of effective treatment at any stage post-stroke. Qualitative processes identified distinct trajectories of psychological morbidity which may facilitate the development of interventions that promote better mental health. Further emergent qualitative themes identified that ongoing HRQOL was significantly impacted by impaired driving ability, the experience of fatigue, UI and access to ongoing service. The course of PSD and anxiety is not easily predicted, but clinical implications of this study are: a need for long-term psychological monitoring of mood post-stroke, ongoing rehabilitation that addresses stroke survivors’ disability, community participation, and improved social support. Stroke survivors’ HRQoL can potentially be maintained, or improved, using interventions aimed at reducing disability and increasing social support and community participation. Overall monitoring of stroke survivors’, including the provision so psychological interventions require implementation over a longer duration than current outpatient services, which, in Australia, are typically provided in the first few months after stroke.
LIST OF RELEVANT PUBLICATIONS AND PRESENTATIONS

Presentations at National and International Conferences


Publications in Peer-Reviewed Journals


These manuscripts have been a collaborative effort with the researchers listed below. The undersigned co-authors attest that Jennifer White contributed substantially to the aforementioned publications that form part of this thesis:

Parker Magin 07/04/2014

John Attia 07/04/2014

Jonathan Sturm 07/04/2014

Gregory Carter 07/04/2014
ACKNOWLEDGEMENTS

My writing this dissertation has been supported by the encouragement and assistance of people from many areas of my life, some of whom I specifically mention here.

Firstly, I express my sincere thanks to the participants, in particular the participants in the qualitative study who openly shared their deeply personal experiences with me.

I acknowledge the support, assistance and advice of my primary supervisor, Conjoint Professor Parker Magin. I thank him for fostering this PhD journey following the completion of my Masters, which he also supervised. His immense support over these last years has made all the difference towards a positive PhD experience. In particular, the knowledge he imparted to me regarding qualitative research and analysis has been invaluable.

I also extend my sincere thanks to my co-supervisors, Professor John Attia and Associate Professor Jonathan Sturm, and acknowledge the significant input of Conjoint Professor Gregory Carter: I have greatly appreciated the patience, insights, grace and wisdom you have extended to me. My thanks also go to Associate Professor Patrick McElduff and Michael Fitzgerald for their statistical knowledge and support.

Thanks go to my manager, Associate Professor Michael Pollack, for the incredible support he has given my career, and the trust and encouragement he gave during my PhD undertaking.

I wish to express my gratitude to colleagues and friends who have supported my PhD journey and life experiences along the way. In particular, I acknowledge Louise Jordan, Lorna Davin and Stacey George.

You have all seemed one step ahead of me in this journey of life and I have gained significantly from your life experiences, love and care. I am blessed by many friends who have supported so many of my life endeavours; my special thanks go to those who have cheered me towards this PhD finish line, including Kerryn Cameron, Melanie Phillips, Shahesha Lock, Chris Graves and Mark Fisher.

Finally, I acknowledge my family for their constant love, support, encouragement and belief in me through all my academic efforts. My dearest dad became ill in the last months of my PhD, with a diagnosis of aggressive terminal cancer. I am grateful to God for the turn-around in his diagnosis and that he may yet see me graduate.
1 THESIS OVERVIEW

1.1 Outline of Candidature

This thesis was undertaken to fulfil the requirements of the Doctor of Philosophy at The University of Newcastle, Newcastle, New South Wales (NSW), Australia.

This thesis considers the interface of two major issues: psychological morbidity and stroke. In this chapter, the doctoral research is contextualised and a rationale given for examining the experience of post-stroke psychological morbidity. Firstly, the background to the current study is outlined, which includes an overview of stroke and how it is managed in Australia. This is followed by a synopsis of the relevance of the research questions, previous research carried out by the doctoral candidate that has led to the development of this current, longitudinal study and the significance of the research problem.

Chapter 2 provides an overview of the study, including an overview of its research paradigm. Chapters 3–7 provide a critique of the relevant literature and evidence that informs, inspires and guides the current study, followed by a literature review exploring depression, anxiety, health-related quality of life (HRQoL) and other influences on recovery after stroke. Chapter 8 provides a summary of the mixed-methods methodology. Chapters 9 and 10 consist of seven manuscript publications (either published, in press or under review) arising from this doctoral research and outlining its central qualitative and quantitative findings. Chapter 11 presents a summary of the results and a conclusion regarding the major findings, strengths and limitations of this research, implications for clinical practice, policy and recommendations, and the doctoral candidate and primary researcher’s final words.

1.2 Background to the Current Study

The provision of post-stroke care, including the anticipation of post-stroke psychological morbidity, is a continually developing area of stroke service delivery. While depression is a significant issue for all Australians, there is growing evidence about the extent of psychological morbidity in the stroke population, and indications that this morbidity is a difficult (and arguably not particularly well-managed) problem. This might be related to the inherent complexity of psychological morbidity and how difficult it is to identify and manage. In stroke survivors, this is compounded by the presence of stroke impairments that might confound diagnosis. Also, the experience of stroke impairments might exacerbate psychological morbidity due to difficulty sufferers have in resuming activities central to their pre-stroke lifestyle, and the effect of stroke on their personal relationships.

Psychological morbidity, most commonly post-stroke depression (PSD), is a common feature after stroke, and a recent systematic review of observational studies indicates that one third of stroke survivors will experience PSD at some stage.\(^1\) The extent of PSD is a clinical concern, and research shows that PSD leads to poorer functional and social outcomes for stroke survivors.\(^2\) Further, PSD decreases survivors' participation
in rehabilitation, which can delay recovery, and in community re-integration, which in turn restricts stroke survivors from participating in their preferred lifestyles. In order to prevent and treat PSD-related disability, stroke management guidelines emphasise the importance of early detection and management of mood disorders in stroke patients.

Early targeted therapy to treat and prevent PSD is facilitated by knowledge of the prevalence of PSD, its natural course over time and baseline predictors of later depression. A systematic review of the literature regarding quantitative predictors of PSD consistently associates PSD with disability, stroke severity and cognitive impairment. However, two methodological gaps of quantitative studies exploring post-stroke psychological morbidity are the use of cross-sectional studies that do not assess the same person over time, and/or the use of longitudinal studies that do not explore the long term personal experience of PSD. While some key longitudinal data is available, there is limited data from Australian populations.

There is a dearth of literature about the long-term qualitative experience of PSD. As a result, more research is needed to fill knowledge gaps surrounding survivors’ experience of post-stroke psychological morbidity over time and the factors that exacerbate or attenuate its symptoms. By conducting this prospective, mixed method cohort study, the doctoral candidate envisages that the results will address this knowledge gap, adding unique and important data that might inform and inspire the development of evidence-based stroke care delivery.

1.2.1 Stroke: Context and Management

Stroke can affect any part of the brain, causing a wide array of impairments. These impairments alter normal body functioning and might include all or a combination of motor and sensory impairments, visual problems, cognitive, emotional or speech difficulties. The effect of stroke impairments might be ongoing, and studies indicate that because of the extent of some or all of these impairments, 30% of stroke survivors will require ongoing assistance with activities of daily living (ADLs), such as toileting and showering. 70% of survivors will experience vocational impairments and might be unable to return to work, and 20% will require assistance to walk. Further, the experience of ongoing impairments can lead to reduced access to, and participation in, previously valued activities, even when survivors’ functional recovery is good.

The management of stroke survivors has improved in recent decades, and advancements in life-saving technology and the treatment of acute stroke have led to increased survival rates. Designated hospital-based stroke units and rehabilitation services have also proven integral to improved stroke survival. It has been well documented that early rehabilitation provided by established stroke units is instrumental in saving lives and reducing survivors’ dependency post-stroke.

A stroke unit is a dedicated area within a hospital for managing stroke and is staffed by a dedicated multi-disciplinary team, underpinned by established treatment protocols and co-ordinated goals. Overall, stroke care in Australia is enhanced by the fact that stroke units have become a feature of inpatient care in many Australian hospitals.
Once medically stable, many patients progress from the stroke unit to inpatient or outpatient rehabilitation settings. Stroke rehabilitation is integral to recovery after stroke and is characterised by therapies that prevent further brain tissue deterioration and associated complications, and maximise restoration of function and performance in pre-stroke ADLs. Many factors contribute to brain tissue recovery and re-organisation, or neuroplasticity, such as active movement, skills learning and environmental conditions. While the neurophysiology of brain recovery is not completely understood, rehabilitation has been shown to facilitate neuronal re-organisation, which promotes the return of function and ultimately maximises stroke survivors’ independence and ability to resume previously valued roles. However, despite improvements in stroke management and outcome, the experience of post-stroke psychological morbidity is a significant health concern, since it affects stroke survivors’ progress in rehabilitation and recovery. The experience of post-stroke psychological morbidity symptoms have been associated with adverse participation in rehabilitation, which potentially limits or delays survivors’ resumption of previously valued pre-stroke activities, such as personal care, community participation, sport and social outings.

1.3 Relevance of Research Questions

To date, most empirical inquiries regarding post-stroke psychological morbidity have concerned PSD. Authors have described the characteristics and severity of PSD and the extent these pose a challenge to stroke survivors’ recovery, and to treating clinicians’ provision of effective stroke services.

Greater concern stems from research suggesting that if PSD is untreated it has an independent and negative effect on survivors’ long-term physical and cognitive recovery. Further, PSD has been shown to influence the likelihood of post-stroke cardiac events and mortality.

Understanding the patterns of onset and resolution of PSD has the potential to help guide service delivery. Such patterns include survivors’ experience of depression immediately after stroke and their subsequent recovery, survivors’ experience of having no depression after stroke but subsequently becoming depressed and survivors’ depression immediately after stroke with no recovery.

The complexity and variation of the severity and experience of PSD has been well documented. For example, a study exploring two stroke registers of survivors in the first 12 months following stroke reviewed 297 first-stroke survivors at three and 12 months, and found that 45% were depressed at the three-month mark. This prevalence did not decrease over time.

Other research has explored the experience of PSD beyond survivors’ first year after stroke. A community study of 100 subjects in Sweden, who were followed at two weeks, two months, six months, 12 months and 18 months, identified that 26% experienced major depression at each point over the study’s 18-month duration. Another study of 131 stroke survivors undertaken in the Netherlands identified PSD at six months, one year and three years (23.7%, 25.2% and 16.0%, respectively).
is potential for PSD to be a chronic condition.\textsuperscript{23,24} The persisting nature of PSD requires the health system to manage depressive symptoms in the short and long term.

Compared with PSD, post-stroke anxiety has attracted a smaller number of empirical investigations; however, there is growing evidence that it might have a similar frequency to PSD. A population-based prospective study\textsuperscript{25} following 80 acute stroke patients over three years identified post-stroke generalised anxiety disorder (GAD) in 28\% of acute stage (immediately following acute stroke) patients, with no significant decrease at the three-year follow-up.

Further, there is substantial interrelation, co-morbidity and diagnostic symptom overlap between PSD and anxiety.\textsuperscript{25-28} This overlap is a challenge for stroke clinicians and policy makers alike, since they must develop adequate understanding of post-stroke psychological morbidity to differentiate between multiple psychological disorders and promote effective and appropriate management of varying conditions.

1.4 Previous Research Undertaken by the Doctoral Candidate

The doctoral candidate has conducted prior research that informs the work presented in this doctoral dissertation. Previously, a cross-sectional study\textsuperscript{27} of 91 stroke survivors at one, three and five years post-stroke was conducted by the doctoral candidate in Australia’s Hunter Region in NSW. The central aim of that study was to explore function outcomes and HRQoL, as measured by the Stroke Impact Scale Version 3.0\textsuperscript{28} (SIS), which is a widely used scale of perceived post-stroke function. The study found that stroke survivors’ function did not differ significantly between participants in the one, three and five-year sub-groups. A high proportion of survivors required community services (such as home-care), despite reasonable cognitive and physical recovery after stroke.

While PSD was not specifically addressed, it became apparent that the emotion domain sub-set of the SIS was that in which participants’ performance was lowest across the three sub-groups. An additional and concerning finding was that poor functioning in the emotion domain was present in the five-year sub-group. Such results highlighted a clear knowledge gap regarding the reasons for psychological morbidity; this gap was consistent across the study groups despite their reasonable cognitive and physical recovery.

This study also involved a qualitative sub-study\textsuperscript{29} involving twelve stroke survivors: four participants from each of the three sub-groups (one, three and five years).

The use of qualitative methodology was sensitive in identifying common themes that played a role in the onset and experience of psychological morbidity in these participants. While the participants did not label their experiences as ‘depression’, results suggested that terminology used to describe feelings of frustration, reduced self-efficacy, dependence and loss could be a clue for practitioners and therapists to explore the possibility of psychological morbidity in community-dwelling stroke survivors. This was a pertinent finding, since it is well established in the literature that mood disorders could be associated with significant psychological morbidity, despite not fitting the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition’s\textsuperscript{30}
(DSM-IV) classification of major depression. Moreover, stroke survivors with minor or subsyndromal depression are at equal risk of experiencing reduced QoL as those who meet cut-off scores for depression using established depression screening tools. Overall, the results highlighted the need for a more extensive study into needs of stroke survivors beyond the first six months post-stroke; one that further characterises psychological morbidity in stroke survivors and how they adjust after stroke.

To explore the reasons for persisting long-term post-stroke psychological morbidity, this doctoral dissertation presents results from a longitudinal prospective study using qualitative and quantitative methodology, with a focus on PSD and post-stroke anxiety. Qualitative methodology was used to explore the in-depth and personal experience of psychological morbidity within the first 12 months post-stroke, and specifically to characterise trajectories of post-stroke psychological morbidity. Disease trajectories outline symptoms and other components of the disease experience over time. Mapping these trajectories provides a conceptual understanding of patient experiences, which can assist with the planning and delivery of relevant services.

Quantitative methodology was used to identify baseline predictors (clinical, functional and psychosocial factors) associated with PSD and anxiety and at a greater number of assessment time points (five) over a 12 month period, than in my previous research. Overall, the use of mixed methodology contributed towards addressing the knowledge gap concerning the personal experience of stroke and the identification of risk factors for PSD and post-stroke anxiety. The doctoral candidate anticipates that results will potentially further inform the development of interventions that improve outcomes for stroke survivors and promote recovery and restoration of psychological morbidity.

1.5 Significance of this Research

The unique feature of this doctoral research is the use of mixed methods, underpinned by a pragmatic research paradigm. Quantitative and qualitative processes incorporating a longitudinal study design explored the experience of post-stroke psychological morbidity over a 12-month follow-up period; and the multiple influences that impact it. The significance of this doctoral research is outlined as follows:

1. The use of quantitative measures of PSD and post-stroke anxiety concurrently over multiple time points (baseline, three, six, nine and 12 months). The methods aimed to establish baseline predictors of PSD and anxiety; capture patterns of emergence and resolution of PSD and anxiety in patients based on repeated assessments over a 12-month period using face-to-face interviews.

2. The use of quantitative measures of HRQoL over multiple time points (baseline, three, six, nine and 12 months). The methods aimed to establish predictors of HRQoL, and capture patterns of emergence and resolution of poor HRQoL based on repeated assessments over a 12-month period using face-to-face interviews.

3. The use of longitudinal qualitative research that followed the personal experience of psychological morbidity in stroke survivors over multiple time
points (baseline, three, six, nine and 12 months) in order to develop trajectories of post-stroke psychological morbidity.

1.6 Conclusion

Post-stroke psychological morbidity, including PSD and anxiety, is a significant concern for stroke survivors and the health system. Research shows that PSD has a negative effect on rehabilitation, functional outcomes, QoL and mortality. Moreover, post-stroke psychological morbidity has the potential to be a chronic problem for survivors, resulting in low rates of spontaneous remission.\textsuperscript{35} This doctoral research uses mixed methods focusing on depth and breadth across the use of two methodologies (qualitative and quantitative). Mixed methodology provides unique and important evidence about the personal experience of post-stroke psychological morbidity and data on the frequency of PSD and anxiety, and identifies baseline factors that contribute to developing and/or resolving these symptoms. Although some previous researchers have explored aspects of the aforementioned factors in the stroke population, longitudinal studies incorporating both quantitative and qualitative approaches are lacking, and longitudinal studies that concurrently assess PSD, anxiety and HRQoL are infrequent. The findings presented in this doctoral research have important implications for how researchers and clinicians identify, conceptualise, investigate and manage post-stroke psychological morbidity with respect to its effect on stroke survivors and their recovery process.
2 STUDY OVERVIEW

2.1 Introduction

This program of research aimed to explore and document the experience of post-stroke psychological morbidity over a 12-month follow-up period. The theoretical framework underlying this research is a pragmatic paradigm, incorporating mixed methods (qualitative and quantitative) study processes undertaken in two concurrent parts. This study planned to provide evidence that will fill a knowledge gap and guide clinical practice decisions regarding the management of post-stroke psychological morbidity.

Firstly, a longitudinal qualitative study was used to explore the personal experience of psychological morbidity in a sub-set of participants (n = 23) of the overall study (n = 134). Post-stroke psychological morbidity is a broader construct than PSD and anxiety and includes subsyndromal mood disturbances (such as mood disorders that do not fit the DSM-IV classification of major depression) and other psychological morbidities that are relevant in the post-stroke period. There are few qualitative studies exploring longitudinal post-stroke recovery, and limited data on survivors’ experience of psychological morbidity. The doctoral candidate found no qualitative studies documenting post-stroke psychological symptom trajectories, suggesting a significant evidence gap in the current literature.

Secondly, a longitudinal cohort study of 134 consecutive stroke survivors quantified the frequency of the development (and resolution) of depressive and anxious symptoms (measured as continuous scores) and of depression and anxiety (as binary outcomes) in stroke survivors over a 12-month follow-up period. The study examined which baseline clinical, functional, psychosocial and QoL factors were associated with depression, anxiety and QoL during the 12-month post-stroke follow-up period. Results from this doctoral research expand on existing literature—and particularly provide a stronger Australian context—regarding survivors’ medium to long-term experience of PSD.

2.2 Research Aims

A longitudinal quantitative study was conducted:

(1) The primary aims of the quantitative component were to establish prevalence of depression and anxiety post-stroke and to identify baseline predictors of depression (HADS score and caseness), baseline predictors of anxiety (HADS score and caseness) and baseline predictors of HRQOL in the twelve months post-stroke. Secondary aims are to establish baseline predictors of resolution of depression and anxiety, baseline predictors of incident depression and anxiety, and baseline predictors of HRQoL over the first 12 month post-stroke.
A longitudinal qualitative study was conducted. Additional studies were conducted as emergent themes arose, in order to expand and confirm these emergent themes (outlined in Chapter 10).

(2) The aim of the qualitative component of this research was to explore longitudinally the patterns of post-stroke psychological morbidity, and to establish disease trajectories that outline the patterns of disease experience over time. While most post-stroke research examines PSD, the researchers conducting this study chose to explore the wider construct of psychological morbidity (of which mood disturbance was a prominent component).

2.3 Research Orientation and Methodology

2.3.1 Overarching Research Paradigm: Pragmatism

Effective research depends on selecting research methods that are most appropriate for answering the research issues at hand. Implementing effective research should be underpinned by a research paradigm, or theoretical framework, suitable for the issue of interest that guides the researcher and methodological approach.\textsuperscript{38–40} In order to achieve the aims of this doctoral study, the overarching research paradigm chosen to guide the process was pragmatism. The pragmatic paradigm is not committed to any one system of philosophy or reality.\textsuperscript{38} Pragmatism posits that the identification of data collection and analysis processes is driven by a research issue and the need to identify solutions concerning the specific problem. Pragmatism has no philosophical loyalty to any specific paradigm.\textsuperscript{38} Pragmatism recognises that every research method has its strengths and limitations and that the use of both positivist and interpretivist approaches can be complementary and enhance understanding of the complexity an issue.\textsuperscript{38} This doctoral research uses mixed methods, incorporating quantitative and qualitative processes, to respond to the identified gaps in empirical knowledge concerning the longitudinal experience of psychological morbidity.\textsuperscript{41–43}

For the scientific/positivist methodology undertaken in this doctoral research the researcher was concerned with gaining knowledge through quantitative processes using objective scientific methods of enquiry. The question/problem posed by this doctoral research also benefits from a interpretivist lens which allows for exploring personal experiences using qualitative methods. An inductive thematic approach underpinned by grounded theory principles was selected because of its ability to explore social processes and interaction and for theorising about social constructs.\textsuperscript{44} The combination of methodology used in this research increases the range and scope of inquiry; complexities which cannot be adequately captured by a single research methodology.

2.4 Summary of Methodology: Mixed Methods

There is growing interest in the use of mixed-methods studies that incorporate qualitative and quantitative processes to explore the complexity of the stroke
A systematic review of published literature undertaken by McKibbon et al. \(^{43}\) highlighted the capacity of mixed-methods research to explore adequately the complexity of survivors’ post-stroke experiences. Both qualitative and quantitative processes have strengths that might complement each other when there is a common research aim, which enhances the rigour of the research undertaken. \(^{38,43}\)

In the past there has been debate in the literature regarding how to integrate the expertise of qualitative and quantitative researchers and corresponding research methods with effective implementation strategies. \(^{39}\) Controversy stemmed from the fact that qualitative and quantitative research processes have historically been underpinned by completely different assumptions and paradigms. \(^{39,44–47}\) Previously quantitative and qualitative processes have traditionally fallen into two opposing camps, with writers proposing various terms to distinguish between the two. The terms used are varied - for example, Guba and Lincoln \(^{44}\) use the words ‘scientific’ and ‘naturalistic’, whereas Tashakkori and Teddlie \(^{45}\) use ‘positivist’ and ‘constructivist’, to describe quantitative and qualitative processes, respectively. However, there is growing support towards the benefits of mixed methodology research and the integration and synthesis of qualitative and quantitative study methods. \(^{39,45–46}\) Mixed methodology uses multiple perspectives and differing date generation in order to provide high quality assessment that allows for confirmation of corroboration of evidence. \(^{45–46}\) However, the majority of published stroke research uses a scientific or positivist paradigm and is characterised by large samples and quantitative designs. \(^{48}\) This paradigm centres on the belief that social and physical reality is real, rather than random, and governed by stable and observable laws allowing for findings that apply to the wider population. \(^{44}\) Empirical data therefore promotes accurate and precise measurement, independent of the researchers’ own ideas, thoughts and biases. While quantitative methods produce statistically rigorous, focused studies, they have been criticised for failing to uncover the depth of knowledge required to understand a complex phenomenon or a personal experience. \(^{49}\)

In contrast, qualitative research methodology is aligned with an interpretive or ‘naturalistic’ and ‘constructivist’ paradigm, which is based on the belief that the world is in a dynamic state of flux, with multiple subjective realities. \(^{50}\) Qualitative techniques are used to explore research questions inductively in uncontrolled natural contexts and provide an opportunity for study participants to give detailed accounts of their experiences and present their own perspectives and interpretation of these experiences. \(^{51}\) However qualitative methods used in isolation are unable to generalise beyond particular situations. \(^{40}\)

The use of mixed methods research recognises the importance of traditional qualitative and quantitative research paradigms but allows for research that provides stronger inferences than a single method. Complimentary data from studies provides the capacity for researchers to address confirmatory and exploratory research questions simultaneously. As a result triangulation of findings can enrich understanding of a given phenomenon and reflect more closely the nature of real-world patients. \(^{46}\) In-turn high quality evidence supports the implementation of clinical and health policy choices.
2.4.1 Overview of the Longitudinal Mixed-Methods Approach

Using a pragmatic paradigm, the goal of mixed methods in this doctoral research was not to employ either of the quantitative or qualitative approaches, but rather to draw on the strengths of each approach and minimise their weaknesses. Using a pragmatic approach, the doctoral candidate considered that the combination of quantitative or qualitative approaches provided the best means of understanding the experience of post-stroke psychological morbidity. As a result, integrating qualitative and quantitative processes was integral to this doctoral dissertation to highlight how multiple research approaches can be merged effectively and help build bridges between conflicting philosophies.52

A longitudinal study design was used to capture changes in stroke survivors’ experiences of psychological morbidity over time. Such a design contrasts with previously published cross-sectional study designs that take a ‘snapshot’ in time.

Cross-sectional studies can document the frequency of PSD and post-stroke anxiety, but are limited in developing an understanding of how this frequency changes over time according to demographic, social and other factors, since data are only collected at one point in time. The exploration of the same individuals’ experiences over time is best captured using longitudinal studies, which use large samples from a representative population - in this case, hospital-treated stroke survivors - and as a result are able to observe the same participants at intervals over a designated period.

There are some longitudinal quantitative research studies23,53 that have explored the frequency of PSD and post-stroke anxiety, and the risk factors and other factors affecting survivors’ outcomes at varying post-stroke follow-up times. The results of these studies are outlined in detail in this study’s literature review. There is much less qualitative longitudinal research on stroke, especially the focused enquiry about psychological morbidity. Further, serial qualitative interviews remain underused in medicine, despite their benefit in exploring the complex and dynamic effects of disease such as stroke, which might in turn inform the healthcare system.54,55,56,57 As a result, triangulation of quantitative and qualitative research processes can provide in-depth and accurate data on this complex phenomenon.49

Inductive thematic analysis of qualitative data in this doctoral research was underpinned by grounded theory.56 Further discussion of this approach is outlined in Chapter 8. Rigour in qualitative data collection depends on strategies such as immersion in data, reflexive analysis, peer debriefing and consensus coding between team members of different professional backgrounds (in this study, a general practitioner (GP) and an occupational therapist (OT) and discussion with a broader team (in this study, a neurologist, an epidemiologist and a psychiatrist).56 The use of these strategies for this study reduced the likelihood that the researchers demonstrated bias due to innate preconceptions.

Likewise rigour in quantitative data collection was upheld by consecutively recruiting participants and using a longitudinal cohort design with multiple follow-up assessments and a high retention rate. Well-validated and reliable measures were used to measure participants’ physical and psychosocial functioning.
In summary, the strength of this doctoral research design lay in: the triangulation of qualitative and quantitative methodology, through simultaneous data generation and analysis as a means to gain understanding of the experience of post-stroke psychological morbidity. This included rigorous qualitative coding processes and the use of sophisticated data analysis techniques for baseline predictors of primary outcomes and a priori outcomes measures (continuous and binary).

2.5 Conclusion

The pragmatic paradigm was well suited to addressing the research issues investigated in this doctoral research - issues that benefitted from examination using qualitative and quantitative methodologies. Equal emphasis was placed on the quantitative and qualitative aspects of the study, and the studies were conducted concurrently. However, the quantitative data, as it was obtained, helped inform the conduct of the interviews in the qualitative section of this study. Rigor was ensured through the use of an inductive thematic approach (using grounded theory processes) to analyse qualitative data and the use of sophisticated statistical processes to analyse quantitative data.
3 PART I: STROKE AND RECOVERY

3.1 Introduction
This chapter reviews important topics relevant to this study's aims. In addition, each individual manuscript includes a separate introduction outlining the relevant literature. It should be noted that comprehensive systematic and Cochrane reviews can be found elsewhere, on the assessment, treatment and management of PSD,1,35,58 and this doctoral research does not seek to reproduce these findings.

This literature review is divided into the following chapters:

1. Chapter 3: Part I: Stroke and Recovery
2. Chapter 4: Part II: Depression
3. Chapter 5: Part III: Anxiety
4. Chapter 6: Part IV: Quality of Life

3.2 Stroke and Stroke Recovery
Stroke is a major health care issue in Australia, with over 60,000 new cases of stroke each year.6 Stroke has been established as the leading cause of chronic adult disability in Australia, affecting survivors’ physical and psychosocial functioning.58 The effect of an ageing population and the increasing incidence of stroke with age have implications for recovery and rehabilitation, which includes the management of psychological morbidity. Stroke can affect people of all ages, although the risk of stroke increases dramatically with age.10 If the number of stroke survivors doubles by 2017, as is currently predicted,59 then the number of survivors that also experience post-stroke psychological morbidity will also increase.

This section provides a synopsis of stroke survivors’ transition to community living. Finally, it discusses the chronicity of stroke. With better knowledge about the experience of post-stroke psychological morbidity, there is potential to improve the provision of effective rehabilitation to stroke survivors.

3.2.1 Effect of Stroke: Stroke Onset and Classification
A stroke is a clinical syndrome characterised by an acute loss of focal brain functioning lasting more than 24 hours or leading to death.60 Stroke severity in this study is conceptually defined by the degree of neurological deficits observed after the occurrence of an acute stroke.60 Stroke can be classified into two broad categories: ischemic and haemorrhagic.60

An ischemic stroke is the most common form of stroke, accounting for approximately 80% of strokes.6,61 There are two ways an stroke can occur. *Cerebral thrombosis* refers to a thrombus (blood clot) that develops at the occluded part of a blood vessel. *Cerebral embolism* generally refers to a blood clot that forms at another location in the
circulatory system, usually the heart and large arteries of the upper chest and neck. However, in both forms, injury results from tissue anoxia caused by an interruption to the cerebral blood flow. It is important to recognise that every stroke is different, and as a result, individuals are affected in varying ways.

Classifying stroke according to its location in the brain and the extent of injury caused helps determine appropriate prevention and treatment strategies. The Oxfordshire Community Stroke Project (OCSP) classification is widely used to sub-classify ischemic stroke. Brain imaging is used to exclude or confirm cerebral haemorrhage. Ischemic stroke is classified by location: 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 with identifying and prioritising appropriate management.

The OCSP is used as a predictor of stroke complications and prognosis. The classification system is as follows:

- **Total anterior circulation syndrome (TACS):** these patients present with a combination of new higher-order cerebral dysfunction (e.g. dysphasia, visuospatial neglect); homonymous visual field deficit and contralateral motor and/or sensory deficit of at least two areas of the face, arm and leg.

- **Partial anterior circulation syndrome (PACS):** these patients present with two of the three components of TACS, higher cerebral function deficits alone or a motor and/or sensory deficit more restricted than Lacunar syndrome (LACS).

- **Posterior circulation syndrome (POCS):** these patients present with ipsilateral cranial nerve palsy with contralateral motor and/or sensory deficit; bilateral motor or sensory deficit; disorder of conjugate eye movements; cerebellar dysfunction without corticospinal long tract signs or homonymous hemianopia alone.

- **LACS:** the five common lacunar syndromes are pure motor stroke, pure sensory stroke, sensorimotor stroke, ataxic hemiparesis and clumsy hand dysarthria.

### 3.2.2 Effect of Stroke on the Stroke Survivor and Their Family

According to the National Stroke Foundation, approximately one in five individuals who have suffered stroke for the first time will die within one month, and one in three individuals will die within the first 12 months. Those who survive stroke often suffer mild to profound disability. The symptoms that an individual experiences after stroke depend on numerous factors, including which part of the brain was affected, the type of stroke that occurred and the size of the lesion. Individuals might experience a number of impairments: motor, sensory and visual impairments, speech or language disturbances and behavioural or cognitive symptoms. Many of these impairments can be long-lasting, and as a result stroke is a significant cause of disability, with at least 90% of stroke survivors living at home requiring assistance with household chores, mobility and transport.
Most informal care given to first-ever stroke survivors is provided by relatives or friends. The majority (66%) of caregivers are the spouse or daughter of the survivor, of whom more than half live with the stroke survivor.

Since stroke is often sudden, stroke survivors and their families experience rapid life changes with little or no time to adjust. Caring for family members by providing physical and emotional support has been shown to increase the caregiver’s burden. This is increased when the caregiver co-resides with the stroke survivor. In addition, lifestyle changes such as stroke survivors’ reduced social and leisure activities and reduced ability to engage in work might further affect the emotional health of caregivers and contribute to poorer QoL for both the caregiver and stroke survivor.

The challenges of caring for a stroke survivor have been well documented and include psychosocial difficulties due to survivors’ physical and functional impairments, assistance with ADLs, long hours of care, communication problems due to cognitive issues and feelings of being trapped inside the home and thus losing social and work opportunities. A report by the Australian Institute of Health and Welfare (AIHW) indicates that 23% of caregivers felt their income had decreased and 21% had additional expenses.

3.3 Rehabilitation and the Recovery Process

3.3.1 Rehabilitation

Rehabilitation treatment specific to stroke (stroke rehabilitation) has been shown to reduce the likelihood of stroke survivors’ death and long-term dependency. The intensity of therapy and augmented exercise therapy has been associated with better functional outcomes after stroke.

Rehabilitation continues across all phases of care, including acute, post-acute and inpatient rehabilitation settings.

Following discharge from hospital, community-based outpatient rehabilitation plays a role in promoting stroke survivors’ ongoing health by minimising the effect of their impairments and facilitating their engagement in valued life roles. Areas of service delivery typically include stroke rehabilitation, education and health promotion.

Stroke survivors’ preferences and values should be considered throughout their rehabilitation process. Pollock et al. recently published a research agenda concerning priorities for stroke service research, including cognition, aphasia, mobility, vision impairment, fatigue and lack of fitness. However, input from stroke survivor stakeholders indicated that interventions were likely to fail if patients lack confidence in their ability to resume their valued roles. Traditionally the biomedical model has given priority to physical tasks. As a result, there is a need for closer and ongoing consideration of stroke survivors’ priorities and factors affecting their confidence, and on the tendency of health professionals to focus on therapy that maximises independence and addresses discrete physical goals.
3.3.2 Transition to Community Living

While most recovery occurs within the initial months after stroke, recovery can continue for many years.\textsuperscript{79} However, by the end of their first year after stroke, about half of all stroke survivors will remain dependent on others for ADLs\textsuperscript{64,80} and experience ongoing handicap.\textsuperscript{81} For many, the need for transition to residential care can be averted by the availability of comprehensive support and the continuity of services in the community. Most stroke survivors will return to living in the community, with only 12\% requiring admission to more supported care, such as residential care facilities.\textsuperscript{63}

The personal experience of residual stroke symptoms can affect the extent to which a stroke survivor can resume their pre-stroke lifestyle and ability to undertake valued roles such as ADLs or returning to work. Indeed, the extent and permanency of lifestyle changes after stroke are often not appreciated until a patient is discharged from inpatient rehabilitation and returns to community living. Stroke survivors’ adjustment can be further compounded by the experience of post-stroke psychological morbidity, which has been associated with decreased community participation.\textsuperscript{3}

Central to stroke survivors’ return to community-dwelling are the best strategies to prevent and manage post-stroke complications and adverse effects such as fever, hyperglycaemia, dysphagia, falls, pain and urinary incontinence.\textsuperscript{2} Such complications can delay rehabilitation and lead to a cycle of de-conditioning that exacerbates complications; this can lead to increased morbidity, mortality, prolonged hospital stay and higher hospital costs.\textsuperscript{92} Further, the presence of medical complications post stroke is shown to be an independent predictor of poor prognosis.\textsuperscript{83} Urinary incontinence (UI) is a common consequence following stroke, and a recent longitudinal study\textsuperscript{84} on the natural history of UI after first stroke identified UI as present in 43.5\% of patients at three months and 37.7\% at 12 months post-stroke. UI is a serious health concern post-stroke and is associated with increased falls,\textsuperscript{85} PSD,\textsuperscript{2} social isolation and reduced QoL.\textsuperscript{86,87} When UI remains untreated, complications can occur such as skin breakdown, infections and falls.\textsuperscript{88,89}

Falls are also common after stroke, with between 14\% and 65\% of stroke survivors having a fall while in hospital\textsuperscript{90–92} and up to 73\% falling with the first six months following their discharge home.\textsuperscript{93,94} Falls can exacerbate a cycle of inactivity and physical outcomes that can increase the strain on caregivers.\textsuperscript{95,96}

3.4 Chronicity of Stroke

While stroke is an acute event, it may also be classified as a chronic disease, since the ongoing impairments experienced by many survivors (especially after moderate or severe stroke) can be endured over a lifetime. Chronic disease is defined as any health problem that might require ongoing interventions and management over many years and even decades.\textsuperscript{97} There is an increase in the prevalence of chronic conditions worldwide, and this is largely due to increased longevity and technological and therapeutic advances in medicine.\textsuperscript{97}

Chronic disease management principles are relevant to stroke service delivery. These principles include promoting improved functioning by reducing symptom severity and
the effect of disease progression on function. Chronic disease management principles aim to promote treatment adherence and activities that promote health, self-monitoring of health and symptom management. Understanding how services can facilitate these principles in stroke survivors long term remains limited. Post-stroke psychological morbidity might affect stroke survivors' ability to self-monitor and self-manage their symptoms. In the absence of this ability, there is an ongoing demand for stroke services to respond to these needs, which increases potential costs to the health system. The experience of PSD, and difficulties such as altered function and social isolation, can further add to stroke survivors' distress concerning the effects of managing a chronic disease.

3.5 Conclusion

Research continues to focus on ways to improve stroke rehabilitation, an essential and effective component of stroke service delivery. Evidence concerning factors that promote recovery and prevent future stroke are integral to ongoing service delivery. The effect of PSD on impaired participation in rehabilitation and outcomes is well established. Policy and service planners need to continually explore how to provide evidence-based practice regarding how to manage stroke survivors in rehabilitation settings more effectively; this might include modifying PSD and other psychological morbidities.
PART II: DEPRESSION

4.1 Overview of Depression in the General Population

According to the Australian Bureau of Statistics, depression is the most frequent and common mental disorder, as reported in an Australian household health survey.\textsuperscript{99} The term depression is used in different ways in order to describe transient experiences of low mood through to severe psychiatric disorders. Depression is considered to be a condition that (a) might come and go, (b) might be related to certain life stages and (c) might be related to either genetic and biological factors or major life events.\textsuperscript{100}

In an Australian context, a recent a recent national survey of Mental Health and Wellbeing\textsuperscript{100} indicated that approximately 18\% of Australian residents suffered a psychiatric disorder in the 12 months prior to the survey, of whom 38\% presented to a healthcare service; of these, 76\% presented to a GP. It is of key concern to the health system that most people with depression experienced significant disruption to their normal lifestyle as well as co-morbid anxiety or substance-misuse disorders.\textsuperscript{101}

The most commonly used classification system for depressive disorders is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition\textsuperscript{30} (DSM-IV), and the International Classification of Disease\textsuperscript{102} (ICD-10). The DSM-IV allows for the categorisation of severity of major depression subtypes into mild, moderate or severe depression, and into subtypes without psychotic symptoms, severe depression with psychotic symptoms and melancholia.\textsuperscript{30} In contrast, the ICD-10 system divides depression into mild, moderate and severe, with or without psychotic features.\textsuperscript{102}

The aetiology of depression is complex and is influenced by the interaction of numerous factors such as biomechanical changes, psychosocial and genetic factors.\textsuperscript{103} For example, there is potential difference in the experiences of men and women.\textsuperscript{104}

It has been well established that women are more likely to consult a GP if they suspect they are suffering from depression and are therefore more likely to be identified as depressed; however, this does not necessarily mean that more women are depressed than men.\textsuperscript{105} Other debates in the literature concern the experience of depression in different age groups. Traditionally, research has highlighted that older adults (over 65 years of age) are more vulnerable to developing depression due to the consequences of ageing and other factors such as reduced independence, reduced mobility, loss of social and employment opportunities, the experience of co-morbid illnesses and social isolation.\textsuperscript{106–108} However, there is increasing literature to suggest that younger people are at growing risk of depression.\textsuperscript{109,110} Further, the experience of life stress,\textsuperscript{111,112} other health co-morbidities and chronic disease have also been associated with depression. This can lead to the accumulated burden of adversity due to illness, poorer outcome and coping behaviours.\textsuperscript{113} Finally, differing individual temperaments\textsuperscript{114} and effective problem-solving among individuals have been shown to influence the experience of psychological morbidity.\textsuperscript{115}

There are guidelines outlining processes for assessing and managing depression in the community, including clinical depression. In Australia, the beyondblue\textsuperscript{®}: national depression initiative\textsuperscript{116} and the Black Dog Institute™ 117 provide guidelines and training.
for the targeted management of depression in the general population. Depression in the general population is frequently managed in the primary care setting. In order to further assist increase the recognition of depression in primary healthcare, the Australian government provides Enhanced Primary Care (EPC) financial incentives for GPs to undertake comprehensive mood assessments of patients using objective measures for depression such as the Kessler-10 (K10).

In fact, there are high levels of unmet mental health treatment needs worldwide. A survey of 84,850 community adult respondents by the World Health Organization found that of those with serious mental health problems (including depressive disorders), around half received no services. Fewer still receive adequate treatment and follow-up care. Even if an at-risk patient attends a medical centre, psychological morbidity is often not detected or is misidentified, with correct identification rates even lower in older adults compared with younger adults. These issues highlight the need for developing and evaluating effective depression identification and management programmes in stroke survivors, particularly in those with co-morbid physical illness.

4.2 Post Stroke Depression

Post stroke depression is considered the most common neuropsychiatric consequence of stroke. One quarter of stroke survivors will experience some form of PSD in their first year after stroke. PSD has been shown to have an adverse effect on stroke survivors' rehabilitation gains and functional and social outcomes, and is currently under-recognised by the health system; this leads to delays in initiating appropriate treatment. Further, PSD has been found to have similarities with major depression, which is a growing and concerning issue in the general population. Such evidence highlights the need to manage PSD effectively.

4.2.1 Under-detection of PSD

Under-detection of PSD leads to delay of and failure to initiate appropriate treatments. From an Australian perspective, the 2009 Australian audit of acute stroke services reported that under a quarter of all stroke patients had undergone an assessment for psychological morbidity, despite depression occurring in around one third of all patients.

This situation is not unique to Australia. For example, a Canadian medical record audit of 13 medical centres found only 4.8% of 7,000 stroke patients were diagnosed with depression, despite much higher depression rates being reported in other prevalence studies.

4.2.2 Aetiology of PSD

There is debate in the literature concerning the aetiology of PSD. One argument identified in neuroimaging studies highlights a relationship between lesion characteristics and PSD. The association of lesion location and size on depression continues to be debated and has not been confirmed by international stroke experts. At present, there is no current evidence addressing the association between lesion
volume and PSD. Some studies highlight a link between PSD and left-hemisphere lesions, while other studies have associated depression with right-hemisphere lesions and frontal lobe lesions. PSD has also been associated with white matter ischaemia and atrophy.

Conversely, it has been argued that PSD is a psychological reaction to the experience of loss or associated grief because of ongoing impairment and significant life changes after stroke, including physical, psychological and social stressors. This idea has mainly been supported by findings that stroke survivors display more ‘reactive symptoms’ and fewer ‘endogenous symptoms’ than non-stroke patients with depression.

Regardless of the aetiology, the focus should be on identifying patients who have PSD, and on evaluating treatments that can ameliorate PSD and its effect on post-stroke function.

### 4.2.3 Diagnosing PSD

Accurately diagnosing and assessing PSD is essential to ensure that appropriate treatment is initiated. However, despite the high prevalence of depression in stroke patients, its recognised association with poorer outcome and clearly defined treatment guidelines, service audits of stroke services suggest that identifying and managing mood disorders in stroke patients is sub-optimal. Under-detecting and under-treating PSD can be partly attributed to diagnostic difficulties. These difficulties could be due to the overlap of depressive symptoms with altered cognition and communication deficit, and also problems with self-report in patients post-stroke. Furthermore PSD may be difficult to distinguish from a normal adjustment to a stressful event. Another difficulty in the diagnosis of PSD is that other manifestations of depression (sleep disturbance and fatigue), may be due to the physical effects of stroke or medication side effects. These factors all contribute to difficulty in detecting depression, or, alternatively, to over-identifying depression when the symptoms are linked to a patient’s physical illness.

Fatigue is commonly seen as a symptom of depression rather than as an independent symptom; indeed, fatigue is listed as one of the DSM-IV criteria for major depression. However, there is increasing research indicating that post-stroke fatigue occurs independently from PSD. Van de Werf et al. estimated that the prevalence of fatigue without depression was 30%. Colle et al. found that only 38% of fatigued participants also experienced depression. Post-stroke fatigue is also influenced by many factors such as survivors’ general health, their experience of co-morbidities and the co-existence of physical impairments.

A variety of methods can be used to diagnose PSD or assess symptom severity. These include psychiatric interview or mood scales, either completed by patients or administered by clinicians.
4.2.3.1 Psychiatric Interview

Using the medical model, disorders of mental health are classified using either a mental status examination and either DSM-IV\textsuperscript{30} or ICD-10\textsuperscript{102} criteria for depression. The intention of a psychiatric interview is to make a disease diagnosis and to instigate treatment strategies, which aim to cure or reduce disability. However, it has been suggested that this model fails to acknowledge the social and cultural context of the person being diagnosed,\textsuperscript{172} as it gives little attention to any personal or social meanings influencing their mental health.\textsuperscript{173}

Further, many stroke survivors are left with mood disorders and depressive symptoms that do not meet the strict criteria for major depression as outlined in the DSM-IV\textsuperscript{30} or ICD-10.\textsuperscript{102} As a result, stroke survivors might experience ongoing psychological morbidity such as subsyndromal or minor depression, which still require monitoring and treatment due to the significant effect they have on the stroke survivor.\textsuperscript{53,174}

4.2.3.2 Screening for PSD

Screening is one recommended step in the process of identifying stroke survivors’ psychological conditions.\textsuperscript{175} The screening process is not diagnostic (e.g. it cannot establish whether a disorder actually exists); rather, it identifies the presence of symptoms that might indicate the presence of a psychological disorder. Thus, screening helps to identify individuals with symptoms that might require further investigation and treatment.

Moreover, screening to identify the needs of the stroke survivor is fundamental to treatment planning, whether these needs are psychological, physical, social or financial. It is important that the specific needs of stroke survivor are recognised, as they will undoubtedly affect treatment. As a result, early diagnosis and treatment of conditions can improve patient treatment outcomes.\textsuperscript{176,177}

In an Australian context, screening is supported by the 2010 National Stroke Foundation Clinical Guidelines,\textsuperscript{4} which state the following: (1) All patients should be screened for depression using a validated tool, (2) patients with suspected altered mood (e.g. depression, anxiety or emotional lability) should be assessed by trained personnel using a standardised and validated scale, (3) diagnosis should only be made following a clinical interview, (4) antidepressants can be used for stroke patients who are depressed (following due consideration of the benefit and risk profile for the individual) and for those with emotional lability, and (5) psychological (cognitive-behavioural) intervention can be used for stroke patients who are depressed.

In summary, stroke survivors might experience depressive symptoms and other symptoms of psychological morbidity that go unnoticed and untreated. Inaccurate detection and under-treatment of psychological morbidity could be due to the complex interaction and overlap of stroke and depressive symptoms, staff knowledge and time constraints, which often result in secondary stroke prevention taking precedence over screening for psychological morbidity during consultations.\textsuperscript{101} Routine mood screening is one strategy that might increase the detection rate; however, health professionals’ compliance with routine screening remains low due to various barriers, including
individual factors such as awareness of guidelines, knowledge and belief in effectiveness, and organisational factors, including time restraints and colleague support.\textsuperscript{178}

4.2.3.3 Screening for PSD in Non-acute Settings

It is important to acknowledge that 5\% to 20\% of stroke survivors are not hospitalised and are managed solely on an outpatient basis.\textsuperscript{179,180} Therefore, depending on the site of management, screening for psychological morbidity is the responsibility of acute and community clinicians alike. Typically, whether stroke patients are admitted to hospital or not, the management of psychological morbidity in the community is frequently the responsibility of GPs or primary care physicians who are the key providers of medical information, preventive interventions and other ongoing care after stroke.\textsuperscript{181,182} Despite this, many people with depression who present to a GP go unrecognised, or are inadequately diagnosed and treated by their GP.\textsuperscript{183–185} A meta-analysis found that depression screening had no effect on patient outcomes in a primary care setting; a limitation of the screening was not embedded in collaborative care. The authors, therefore, advocated for the use of screening in conjunction with supportive care, such as case management, to provide close monitoring and follow-up.\textsuperscript{186}

4.3 Frequency of PSD

Variations in the frequency of PSD have been reported to range from 20\% to 65\%,\textsuperscript{23,33,137,187,188} A systematic review\textsuperscript{189} of observational studies of the frequency of PSD identified that methodological heterogeneity within studies make comparison between studies difficult due to ascertainment bias, variation in rating of depression and the heterogeneity of cerebrovascular disease. Indeed, the heterogeneity of findings is particularly influenced by lack of a uniform measure of depression. Selection of assessment tools can lead to different findings as instruments have different constructs. For example, there is a risk of over-diagnosing PSD due to the overlap of somatic symptoms between stroke and depression, such as appetite and sleep disturbance. Heterogeneity of findings is influenced by variability in study populations, which limits generalisability of results. Further there is a risk of under-diagnosing depression in patients with cognitive and communication difficulties. In fact, the identification of whether patients are depressed before stroke is essential to determining the temporal pattern of the experience of psychological morbidity, which increases the chances of identifying causality.

Traditionally, the greatest frequency for PSD was thought to occur within a few months after stroke onset,\textsuperscript{33,38,137} peaking between six and 24 months.\textsuperscript{24} However, a recent systematic review\textsuperscript{25} of the frequency of PSD reports that the risk is similar in the early, medium and long-term recovery stages, and that one third of stroke survivors will experience PSD at some stage after stroke.

4.3.1 Adverse Outcomes of PSD

People with a stroke-related disability are often severely or profoundly limited in activities of daily living, including mobility, incontinence and language. The experience
of language, physical and cognitive disability after stroke can have a significant psychosocial impact on the survivor and are significantly associated with PSD \(^{33,103,160,191-193}\). Indeed, a meta-analysis of 51 descriptive studies found that one in three stroke patients experience significant depression after stroke\(^ {208}\) a stark contrast to the lower rate of depression reported in a sample of elderly Australians\(^ {100,350}\).

Existing literature highlights the adverse effects of PSD including poorer gains from rehabilitation\(^ {33,160,191}\), increased mortality\(^ {33,162,180}\), reduced treatment adherence, reduced social interaction\(^ {23,351,352}\), failure to return to work\(^ {23}\) and greater health care needs including impaired carer health.\(^ {33,160,191}\) Overall depressed stroke survivors are more likely to be dissatisfied with their QoL\(^ {33,141,160,191}\). From a health system point of view, PSD has also been reported to results in prolonged length of inpatient stay\(^ {102}\) and impaired participation in rehabilitation.\(^ {160}\)

Further, the National Stroke Foundation’s (NSF) hallmark study exploring 765 Australian community-dwelling stroke survivors found that 81% experienced adverse effects that are not being met by current healthcare services\(^ {100,353}\). In particular, the persisting unmet needs were attributed to the adverse experience of a lack emotional support in 73%. These data highlight a significant gap between the supply and demand of support services for stroke survivors which may exacerbate the negative impact of stroke, particularly in the case of those with poorer psychosocial outcomes.

### 4.3.2 Risk Factors of PSD

Depression is common after stroke however there remains uncertainty over its aetiology and risk factors. This uncertainty has implications for stroke management. Knowledge of the predictors of depression associated with stroke may allow for the better targeting of therapy, in both prevention and treatment. The most commonly reported risk factors for the development of PSD will now be discussed.

Important non-modifiable risk factors for PSD include female gender\(^ {20,194-196}\), family history of depression\(^ {20}\), family history of depression\(^ {20}\), and a past history of depression\(^ {198,199}\). Furthermore, the risk of PSD increases with the experiences of comorbid diseases such as heart disease or diabetes mellitus\(^ {57}\). Other risk factors pertain to social and economic components such as living alone\(^ {20,103}\), and low socio-economic status\(^ {103,196}\). Finally, following the onset of stroke the risk of PSD is associated with stroke severity\(^ {21,194,197}\), stroke location and size (debated in the literature, as previously outlined)\(^ {140}\) and cognitive impairment\(^ {131,133,196}\) (which may also be present prior to stroke onset).

As a number of these factors are modifiable, it is important to gain an understanding of how each of these factors works, individually and in concert with other factors, in order to develop optimal models of stroke care. Reviews of the literature to date suggest that the majority of research has focused on individual socio-demographic characteristics, disease, and functional outcomes of stroke as predictors of depression\(^ 1\). For example, physical disability, stroke severity and cognitive impairment are consistently associated with depression\(^ {353}\). The unmet need of stroke survivors is a new area of focus. The potential relationship between unmet need, depression and quality of life are yet to be
explored in stroke populations. Similarly, there has been limited examination of potentially modifiable and social factors, including social isolation and number and quality of supportive relationships, and health system factors\textsuperscript{353,354}. As a result there is a need to develop robust evidence regarding the prevalence and predictors of depression and quality of life for stroke survivors in order to provide timely and appropriate care.

4.4 Understanding the Persisting Nature of PSD

Post stroke depression can be persisting in nature, and a community study\textsuperscript{21} of 100 participants who were followed at two weeks, two months, six months, 12 and 18 months identified that major depression was experienced in 26% of participants at each point over the duration of the study. Hayee et al.\textsuperscript{22} interviewed 297 patients at three and 12 months and found that 45% of the sample was depressed at three months, and the prevalence of depression did not decrease over time. Similarly, Pohjasvaara et al.\textsuperscript{200} identified the prevalence of depression in interviewed patients to be 45% at 15 months.

Recent studies indicate that if PSD is not resolved in stroke survivors within 6–12 months post-stroke, chronic depression is likely to manifest.\textsuperscript{24} A study by Schepers et al.\textsuperscript{22} identified that in a sample of 131 stroke survivors, post-stroke depression was present at six months, one year and three years (23.7%, 25.2% and 16.0%, respectively), with PSD at three years being predicted by depressive symptoms at six months. The persisting nature of PSD requires the health system to manage depressive symptoms in the short and long term. A summary of key studies and the differences between them are outlined below in Table 4.1.
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Kotila$^{193}$</th>
<th>Aben$^{201}$</th>
<th>Pohjasvara$^{103}$</th>
<th>Astrom$^{23}$</th>
<th>Parikh$^{131}$</th>
<th>Berg$^{21}$</th>
<th>Robinson$^{24}$</th>
<th>Burvill$^{127}$</th>
<th>Paul$^{202}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>594</td>
<td>190</td>
<td>486</td>
<td>80</td>
<td>63</td>
<td>100</td>
<td>103</td>
<td>No specified</td>
<td>294</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>F 72.3</td>
<td>M 66.5</td>
<td></td>
<td>73</td>
<td>60</td>
<td>55.2</td>
<td>63</td>
<td>Not specified</td>
<td>74-89 range</td>
</tr>
<tr>
<td></td>
<td>Not specified</td>
<td>Not specified</td>
<td>Not specified</td>
<td>Not specified</td>
<td>M 49</td>
<td>M 68</td>
<td>M 63</td>
<td>M 57</td>
<td>M 51</td>
</tr>
<tr>
<td>Sex (%)</td>
<td>Not specified</td>
<td>Yes</td>
<td>Not specified</td>
<td>80%</td>
<td>Not specified</td>
<td>Yes</td>
<td>No</td>
<td>Not specified</td>
<td>Yes</td>
</tr>
<tr>
<td>First stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time of assessments (months)</td>
<td>3</td>
<td>3, 6, 9, 12</td>
<td>4</td>
<td>3, 12, 24, 36</td>
<td>3, 6, 12, 24</td>
<td>2, 6, 12, 18</td>
<td>12, 24</td>
<td>4, 12</td>
<td></td>
</tr>
<tr>
<td>Proportion of PSD (months)</td>
<td>41–54% at 3 months, 42–55% at 12 months</td>
<td>Cumulative 37.8</td>
<td>26% had major depression and 14% had minor depression at 4 months.</td>
<td>31% at 3 months, 16% at 12 months, 19% at 24 months and 29% at 36 months.</td>
<td>24% had major depression and 6% had minor depression at 24 months.</td>
<td>Overall: 46% of those depressed at 2 months where still depressed at 12; 12% were depressed for the first time at 12 or 18 months</td>
<td>19% had major depression and 14% had minor depression at 12 months, 21% had major depression and 21% had minor depression at 23% had major depression and 8% had minor depression at 4 months.</td>
<td>17% had depression 52 months.</td>
<td></td>
</tr>
<tr>
<td>Study type</td>
<td>Population</td>
<td>Hospital</td>
<td>Population</td>
<td>Setting</td>
<td>Hospital</td>
<td>Population</td>
<td>Setting</td>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>------------</td>
<td>----------</td>
<td>------------</td>
<td>---------</td>
<td>----------</td>
<td>------------</td>
<td>---------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Finland</td>
<td>Netherlands</td>
<td>Finland</td>
<td>Switzerland</td>
<td>Sweden</td>
<td>Maryland, United States</td>
<td>Finland</td>
<td>Seattle, United States</td>
<td></td>
</tr>
<tr>
<td>Method of Assessment</td>
<td>BDI</td>
<td>Diagnostic interview</td>
<td>Diagnostic interview</td>
<td>Diagnostic interview</td>
<td>HDS</td>
<td>Hamilton Rating Scale</td>
<td>HDS</td>
<td>PSE</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female, stroke severity</td>
<td>Not specified</td>
<td>ADL impairment, history of depression</td>
<td>Dependence, history of depression</td>
<td>ADL impairment</td>
<td>Stroke severity, functional impairment</td>
<td>ADL impairment</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

**Table 4.1 - Review of Previous Quantitative Research Addressing Longer-Term PSD**

F: female, M: male, BDI: Beck Depression Inventory, HDS: Hamilton Depression Scale, IDA: Irritability, Depression and Anxiety Scale
In summary, previous research on PSD has explored factors associated with the experience of depression. There are few studies exploring predictors of resolving depression and the extent of factors that contribute to recovery. Morrison et al.\textsuperscript{107} assessed 101 patients up to three years post-stroke and found that the reduction in depression caseness was correlated with exercise and treatment satisfaction. Moreover, better social support has been associated with recovery and reduced likelihood of PSD.\textsuperscript{104,105} Participation in active treatments also reduces the likelihood of PSD compared to patients who are not involved.\textsuperscript{108}

There is much less evidence from a qualitative perspective of the short, medium and long-term experiences and outcomes of stroke survivors. A review\textsuperscript{203} of all qualitative studies of stroke prior to 2002 identified 95 articles, with results suggesting the lived experience of stroke is affected by the extent of disruption to life and role loss, differences in priorities between patients and professionals and barriers to best-quality care. In this systematic review, 12 articles specifically evaluated interventions; however, most were small scale, one-off interviews that did not capture change in experience over time. Indeed, no qualitative studies specifically explored the experience of post-stroke psychological morbidity. To date, stroke-specific qualitative studies have explored the complexity of the experience of stroke survivors, including their interactions with the hospital system,\textsuperscript{111} their coping strategies\textsuperscript{204} and altered functioning\textsuperscript{112,205} and differences in priorities between patients and professionals that create barriers to best-quality care.\textsuperscript{203}

4.5 Interventions for PSD

There are a variety of approaches used to treat PSD, including pharmacological management, education and lifestyle programmes, and psychotherapy. Systematic reviews have shown some evidence that pharmacotherapy is beneficial in treating PSD and reducing depressive symptoms.\textsuperscript{136} Psychotherapy has a small but significant effect on improving mood scores and preventing PSD.\textsuperscript{206} For example, motivational interviewing is a talk based therapy that has been used in differing health problems where behaviour is desired or in order to support adjustment\textsuperscript{355}. A study by Watkins et al\textsuperscript{356} explored the 12 months effects of motivational interviews delivered in the period early after acute stroke and the benefit to patient's mood. The study showed that after the 12 month follow-up, 37.7\% of patients in the control group and 48\% of patients in the intervention had normal mood. In summary, a significant benefit of motivational interviewing was found over usual care for mood (p=0.020). However motivational interviewing requires access to multiple therapists which may be a limitation.

Additionally, a recent systematic review\textsuperscript{207} identified that psychotherapy can prevent PSD. As a result, pharmacotherapy and psychotherapy should be considered on an individual basis and can be used in isolation or combination.
4.5.1 Community Education About PSD

In response to the growing recognition of post-stroke psychological morbidity’s effect, there are increasing public education initiatives concerning identification of and responses to mood symptoms. In particular, the National Stroke Foundation research has released the ‘Walk in our Shoes’ report, which identifies that life post-stroke is a difficult journey. In addition, a recent initiative between the NSF and beyondblue® has developed a DVD, Tackling Depression After Stroke, that features interviews with stroke survivors, their families and their caregivers, as well as a psychiatrist, to give insights into the experience and management of PSD. These resources provide some means for providing information, resources and support for Australian stroke survivors.

4.6 Conclusion

PSD is a prevalent and disabling disorder. While screening is recommended, it is not consistently implemented, which might contribute to the under-detection of psychological morbidity. Evidence highlights that symptoms persist over time, and evidence concerning the best treatment for PSD remains inconclusive, though research shows that pharmacotherapy treatment and psychotherapy have a modest effect. Overall, more information is need about the complexity of the experience of PSD in order to improve its management.
5 PART III: ANXIETY

5.1 Anxiety and the General Population

Clinical anxiety syndromes, including GAD, are characterised by chronic, excessive and uncontrollable worry.209 Associated symptoms include irritability, restlessness and concentration problems. Somatic symptoms of GAD include muscle tension, sweating, dry mouth, nausea and diarrhoea.30 The 12-month prevalence of GAD in Australia and the United States is 2.7% and 3.1% respectively210, with a higher prevalence in women than in men. GAD has been associated with impaired QoL, social isolation, reduced work productivity and low ratings of life satisfaction.210

The experience of GAD is disabling, and international research indicates that these levels of disability are comparable to levels of depression.211,212 In addition, GAD can be a chronic and recurrent disorder with a low rate of remission.213,214 Other types of anxiety disorders include panic disorder, social phobia, obsessive compulsive disorder and post-traumatic stress disorder.30 These disorders share common features such as excessive fear, difficulty and distress managing everyday tasks.215 In addition, levels of co-morbidity with depression are high.216

5.2 Interventions for Anxiety

It can be difficult to differentiate between normal worries and clinical anxiety. Diagnosing anxiety is also made difficult by the fact that patients tend to report somatic rather than psychological symptoms.217 GAD is also commonly experienced with co-morbid medical or psychiatric conditions, which could confound diagnosis.218

A population study in the United States219 identified GAD as commonly associated with other mental health disorders, including concomitant symptoms of depression, dysthymia, somatisation, bipolar disorder or substance abuse, all of which can compromise effective treatment of GAD.

Regarding the treatment of GAD, a systematic review220 has shown the efficacy of antidepressants in the treatment of GAD. Studies show that GAD has also been treated effectively with cognitive behavioural therapy (CBT)221,222 and a meta-analysis of 35 studies223 identified that CBT was more effective in the long-term treatment of GAD than the use of pharmacologic therapies. CBT is a psychotherapy that seeks to reverse negative thought patterns and encourage recognition of the relationship between thoughts, moods and behaviours.224,225 While the review provided some evidence for the efficacy of psychotherapy using CBT, no trial was found that explored the effectiveness of other psychological therapy models. Further, in the majority of studies, the therapists employed were highly qualified and experienced practitioners, and thus might not have been representative of practitioners employed in real clinical settings. Other barriers to implementing CBT include factors such as the direct and indirect costs of treatment, access to trained mental health professionals, the experience of mental health stigma and the difficulty of patients attending therapy during work hours.226
5.3 Anxiety After Stroke

After PSD, anxiety is the most prevalent post-stroke psychological disorder. The frequency of anxiety post stroke has been confirmed by numerous trials, synthesised by Burton et al in a systematic review.\textsuperscript{30} Forty-four published studies were reviewed and the combined rate of anxiety by time after stroke was: 20\% within one-month; 23\% one to five-months after stroke; and 24\% six-months or more after stroke.\textsuperscript{30} The experience of post-stroke anxiety is not unlike that of GAD in the general population; symptoms include excessive, pervasive and uncontrollable worry.\textsuperscript{25,30}

Other psychiatric problems associated with anxiety reported in the stroke population can include agoraphobia, social withdrawal, apathy, neglect, irritability, emotionalism,\textsuperscript{33} fear of falling, fear of recurrent stroke and fear of leaving the house or being alone.\textsuperscript{227}

One European study\textsuperscript{228} assessed 532 patients consecutively admitted to four rehabilitation centres at two, four and six months after stroke using the Hospital Anxiety and Depression Scale (HADS). This study identified a frequency of anxiety of between 22\% and 25\% at two and four months respectively, and 40\% of those patients with initial anxiety remained anxious at six months after stroke. A New Zealand study\textsuperscript{165} explored anxiety at three months after stroke and identified a frequency of moderate to severe anxiety in 21.1\% of participants.

Looking beyond the initial post-stroke months, an Australian study\textsuperscript{227} assessed 294 stroke survivors at four and 12 months and found that 26\% of the men and 39\% of the women had an associated anxiety disorder, mainly agoraphobia. A population study of stroke patients\textsuperscript{28} examined 80 cases over a three-year period and identified the frequency of GAD after stroke as 28\% in the acute stage; there was no significant decrease in the three-year follow-up period.

Moreover, post-stroke anxiety is frequently experienced concomitantly with PSD, which can further affect the complexity of management and of survivors’ post-stroke physical and psychosocial function and QoL.\textsuperscript{28} An Australian community study\textsuperscript{127} exploring 294 stroke survivors identified that one third of male participants and half the female participants experienced co-morbid anxiety and PSD. A New Zealand study\textsuperscript{165} identified that the prevalence of moderate to severe depression and anxiety (22.8\% and 21.1\% respectively) was high, with co-morbidity in 12.3\% of cases. Indeed, the co-morbid experience of anxiety and PSD has been shown to worsen the prognosis of PSD and is associated with greater severity of depressive symptoms.\textsuperscript{23,190,230}

Overall, anxiety can be potentially serious and disabling, affecting stroke survivors’ daily functioning, interpersonal relationships and QoL.

5.3.1 Diagnosis of Anxiety After Stroke

Anxiety can be difficult to assess due a number of factors. Firstly, symptom overlap exists between anxiety and PSD, such as reduced energy levels, fatigue, sleep disturbance, worry, loss of appetite and loss of libido.\textsuperscript{32} Secondly, anxiety can be difficult to diagnose due to the overlap of symptoms with physical illness symptoms such as increased heart rate, pain and tremor.\textsuperscript{30}
Assessments for anxiety are in keeping with screening for any disorder of mental health and are outlined in Chapter 4 regarding the diagnosis of PSD (major depression) according to the DSM-IV, ICD-10 and screening strategies.

5.3.2 Adverse Effects of Anxiety After Stroke

Negative psychological outcomes occur frequently after stroke. Reviews of the literature confirm that to date there has been a greater examination of PSD than anxiety following stroke. Post-stroke anxiety is also common as stroke survivors experience fears or worries about their health or other aspects of life. Clinically, anxiety is a serious and disabling condition with many adverse consequences on a patient’s daily functioning, interpersonal relationships, and QoL. A review of literature highlights adverse consequences of post stroke anxiety as being increased ADL dependency after stroke, the experience of reduced social networks and worsening disability over time.

In addition, community studies have shown a high comorbidity of anxiety disorders with major depression post stroke. Indeed, anxiety may precede PSD, cause it, and/or be a consequence of it. Literature suggest that post stroke anxiety problems are common and both more stable and persistent than post stroke depression. Understanding of the adverse experience of anxiety is important as it is frequently comorbid with PSD and has been shown to negatively affect the prognosis of the depression, increase non-response to treatment, and impact on poorer outcomes, and suicide.

5.3.3 Risk Factors for Anxiety After Stroke

Non modifiable risk factors for post-stroke anxiety have been identified in the literature as being under 65 in age, female gender, having family history of anxiety and the experience of physical co-morbidities. In addition there is a greater risk for people who have previously been exposed to abuse, or violence and demonstrated substance abuse. Following stroke onset increased anxiety is associated with PSD, dysphasia, and poor outcomes resulting in impaired functional recovery. Social and economic contributors to anxiety include social isolation, and inability to work and poverty.

In cardiovascular illnesses such as coronary artery disease and stroke, anxiety has been associated with poorer outcomes and death. However, much less is known about co-morbid experience of anxiety and stroke. Despite some understanding of the predictors for anxiety post stroke, most studies have focused on PSD. As a result there is a need for more research exploring anxiety. More observational research with larger number of participants may inform interventions aimed at the prevention and treatment of anxiety.

5.4 Interventions for Anxiety After Stroke

There remains insufficient evidence to guide the treatment of anxiety after stroke. The first, recent systematic review of interventions to treat anxiety after stroke identified
studies that did not specifically address clinical anxiety. Results indicated that pharmaceutical therapy (paroxetine and buspirone) might be effective in reducing anxiety symptoms in stroke patients with co-morbid anxiety and depression. Overall, there is insufficient evidence to guide treatment of anxiety after stroke.

5.5 Conclusion

Research highlights the frequent and negative effects of post-stroke anxiety. Further, anxiety frequently occurs with PSD, and while symptoms could manifest in similar ways, they should be managed differently. As a result, more knowledge is needed about the duration, causes and management of post-stroke anxiety.
6 PART IV: QUALITY OF LIFE

6.1 Overview

Quality of life for stroke survivors has been shown to be inferior to that of the general population. As a result, there is growing interest in interventions after stroke to improve QoL outcomes. This section will explore issues affecting the relevance of QoL post-stroke.

6.2 Definition of HRQoL

Quality of life refers to all aspects of a person’s life, including physical health, psychological wellbeing, social wellbeing, financial wellbeing, family relationships, friendships, work and leisure. The term HRQoL has proved useful in healthcare, as it specifically addresses an individual’s evaluation of how changes in their health affect their lives. HRQoL is not just about physical changes and limitations caused by a condition, but the subjective evaluation of how that condition has affected an individual from an emotional and social point of view in relation to social expectations. QoL and HRQoL have become important outcomes of healthcare as well because of illness or injury.

6.3 Measuring HRQoL Post-Stroke

Advances in stroke risk factor management and acute treatment have increased survival after stroke; however, it is not clear whether survivors’ HRQoL has also improved. Accurately identifying HRQoL after stroke is essential to understanding the extent of stroke effects. The perceptions of stroke survivors concerning resuming their lives post-stroke is important, since what constitutes good recovery and good HRQoL after stroke have been shown to differ between healthcare providers and researchers, with stroke survivors focusing on meaningful life activities rather than function.

There are many reports concerning altered HRQoL after stroke. A population study undertaken in Australia showed that QoL in stroke survivors was worse than QoL in the general population in the first years after stroke, especially in relation to physical factors. While stroke survivors in this study made gains with basic ADLs, they continued to report poor HRQoL within two years following stroke. Similarly, a study exploring stroke survivors four years after stroke identified that HRQoL in 83% of the patients had not been restored to the pre-stroke level.

Generic HRQoL scales are applicable to many different populations and can be used to compare HRQoL across various disease states. Disease-specific scales focus on domains that are particularly relevant to a given condition, and, therefore, are considered to have more content and discriminant validity and to be more responsive to change. Of particular interest in stroke research is the ability to capture the experience of residual impairments, disabilities and handicaps described by stroke survivors as affecting their HRQoL, but not measured by generic instruments.
important to note that generic measures of HRQoL are often not sensitive to important differences in social functioning attributed to a given condition, and thus might fail to capture this important dimension of survivors' lives.\textsuperscript{244–246}

However, while subjective reports of HRQoL provide in-depth personal information, they are influenced by a number of factors. Firstly, they show that people feel constrained because of courtesy or express views they feel will be acceptable to healthcare providers.\textsuperscript{247} Secondly, many individuals become used to their 'sub-standard' circumstances and thus rate their HRQoL as better than it might otherwise be perceived.\textsuperscript{247,248} For example, social functioning in stroke survivors has been shown to be more important than physical functioning in determining HRQoL, which might be contrary to healthcare professionals' beliefs.\textsuperscript{249,250} Despite the issues concerning the measurement of HRQoL, that measurement is still an important component of clinical care.

### 6.4 Predictors of HRQoL After Stroke

Survival and functional status are established outcome measures after stroke. With improvements in health care, more people survive stroke but many have to cope with the physical, psychological, social and functional sequelae. As a result there is a growing interest in HRQoL after stroke covering both physical and mental factors as important outcomes.\textsuperscript{1–8,196}

The impact of stroke on HRQoL outcomes is influenced by a number of factors, including the characteristics of individual patients; their social environment, the experience of disability and the specific type of clinical and supportive care provided. Reviews of the literature confirm that to date the majority of research has focused on individual socio-demographic characteristics, disease, and functional outcomes of stroke as predictors of HRQoL. For example, common predictors of poor HRQoL include being higher in age,\textsuperscript{238,251} female gender,\textsuperscript{251} low functional status,\textsuperscript{251–254} and disability,\textsuperscript{8} the experience of medical co-morbidities,\textsuperscript{87,252,253} cognitive impairment,\textsuperscript{87,236,255} and the experience of depression.\textsuperscript{87,252,253}

However, there has been limited examination of potentially modifiable social factors (social isolation, number and quality of supportive relationships) and health system factors. There is also variability in findings of HRQoL among stroke survivors' which reinforces the importance of individual assessment and personal centred care that is tailored to each stroke survivor. A limitation in the stroke HRQoL literature is that no two studies have used the same measure. Identification of an instrument that is widely accepted by stroke researchers is needed to advance the study of HRQoL.\textsuperscript{253} As a result there is a need for longitudinal studies that examine HRQoL over time including fluctuations in HRQoL and its predictors. Greater understanding of factors impacting HRQoL and how these work in concert is needed to develop optimal models of stroke care that maximise HRQoL in stroke survivors.
6.5 Interventions for Reduced HRQoL

Health related quality of life is a broad construct that captures the varied experience of disability and impairment after stroke due to physical and psychosocial functioning.\textsuperscript{242,256} There are various opportunities for stroke clinicians to intervene with education and interventions addressing disability, increased community participation and support services.

A systematic review\textsuperscript{257} explored barriers to community re-integration, including factors such as social support, caregiver burden and depression, family interactions, family education intervention, social and leisure activities post-stroke and leisure therapy. Four studies were selected for detailed reviews of the effectiveness of social support: 10 studies for family education intervention and three studies for leisure therapy post-stroke. There was evidence that improved social support as an intervention improves outcomes and that an active educational-counselling approach has a positive effect on family functioning post-stroke. However, the studies did not achieve a consensus regarding the effectiveness of leisure therapy.

6.6 Conclusion

Measuring HRQoL after stroke is important in order to understand better the effects of stroke on survivors' recovery and post-stroke lifestyle; understanding these factors can inform stroke service delivery. Further, understanding the long-term experience of HRQoL after stroke, its determinants and its duration will also help inform stroke service delivery.
7 PART IV: PSYCHOLOGICAL SEQUELAE

7.1 Overview

Stroke rehabilitation aims to promote survivors' physical recovery and assist, improve or maintain their ADLs. A major challenge in providing stroke rehabilitation is how to address survivors' overall post-stroke psychological sequelae, including emotional and behavioural problems. Such problems can further influence survivors' participation in rehabilitation and recovery. While the experience of stroke is unique for each stroke survivor, this section will discuss common factors concerning post-stroke psychological sequelae.

Post-stroke psychological sequelae refers to the cognitive, emotional and behavioural effects caused by stroke, such as changes in identity and personality processes and the potential for social isolation and altered community integration. Therefore, psychological sequelae extends far beyond the commonly reported clinical constructs of PSD and anxiety.

7.2 Occupation and Community Re-integration

Stroke clinicians are concerned with functional outcomes after stroke and the ability of stroke survivors to maintain their physical and emotional health through community participation and the ability to engage in meaningful occupations; these include purposeful activities that encompass play, rest and productivity. Occupations are unique to individuals and vary according to societal influences, personal interests, beliefs and needs. Understanding the post-stroke experience is of interest to stroke clinicians, since the effects of stroke can be devastating and cause substantial changes to survivors' function.

Approximately 50% of stroke survivors experience residual impairments resulting from neurological damage that can affect their performance in occupations, and, ultimately, their HRQoL. Stroke clinicians help promote stroke survivors' health by facilitating their engagement in occupations.

Community re-integration refers to a survivors' ability to return to an acceptable lifestyle, such as participating in social and domestic activities, and is important for perceived QoL. Leisure and social participation are closely related to community re-integration. Community re-integration is influenced by various factors, which are discussed below.

7.3 Self-Efficacy and Locus of Control (LoC)

Post-stroke psychological morbidity contributes to poorer health outcomes and reduced HRQoL for stroke survivors. Psychological morbidity can be exacerbated by survivors' lack of independence after stroke, which has been associated with an altered sense of meaning concerning life post-stroke and reduced self-efficacy. Self-efficacy refers to a person's beliefs, and how well they can competently carry out the actions necessary for dealing with life events, irrespective of their physical
Feelings of self-efficacy can vary depending on the nature of the occupation in question. Reduced self-efficacy has been shown to cause altered participation in activities in patients with chronic disability\(^2^{61}\) such as stroke.\(^2^{54}\)\(^2^{62}\) Stroke survivors with a greater self-efficacy report higher QoL and fewer depressive symptoms.\(^2^{84}\) Self-efficacy is modulated by survivors' ability to exercise choice and maintain a sense of control despite their disability levels.\(^2^{65}\) Adaptive skills that provide survivors with a sense of control while also addressing their emotional and practical needs can, therefore, promote QoL.\(^2^{63}\)\(^2^{64}\)

Previous studies highlight a range of adaptive strategies employed by stroke survivors, such as maintaining their independence, participating in meaningful activities, seeking social support, maintaining hope and resilience and minimising their stroke symptoms.\(^2^{54}\)\(^2^{63}\)\(^2^{65}\)\(^2^{63}\)\(^2^{65}\) Closely linked to self-efficacy is the concept of locus of control (LoC). LoC refers to the extent to which people believe they have power over circumstance and events in their lives. A person with an internal locus of control believes that he or she can influence events and their outcomes, while someone with an external locus of control attributes outside factors for everything.\(^2^{66}\) People who have an external LoC are more likely to be passive, rely on others and feel less motivated.\(^2^{66}\) Those with an internal LoC can be expected to positively adjust to disability, as they are more able to come to terms with their experiences and assume more responsibility for their recovery.\(^2^{67}\) It has been suggested that fostering high levels of social support and low external LoC can improve stroke survivors' rehabilitation outcomes.\(^2^{68}\)

### 7.4 Resilience

In considering stroke survivors' long-term coping ability, the concept of resilience is important. Resilience refers to a person's ability to overcome odds, or make successful adaptations.\(^2^{69}\) Psychological resilience is defined as the ability to deal with stress without developing psychological dysfunction.\(^2^{69}\) Resilience 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.\(^2^{70}\)\(^2^{71}\) Seligman\(^2^{72}\) found that resilience itself can be influenced by various personality traits such as optimism, courage, self-understanding, hard-work, humour and the ability to endure and express emotions. Other components of resilience that have been identified include self-esteem and a sense of self-efficacy.\(^2^{73}\)

There is limited research exploring resilience in stroke survivors. Most literature regarding resilience has focused on children and younger adults and show that resilience is facilitated by individual, familial and societal variables.\(^2^{69}\)\(^2^{74}\)\(^2^{75}\) specifically the provision of emotional and social support, strong role models, religious affiliations and which promote feelings hope and meaning in life.\(^2^{76}\)\(^2^{77}\)
7.5 Social Support

Social support includes the concern expressed by family and friends, assistance with practical tasks and social gatherings. Social support can be defined as the ‘existence or availability of people on whom we can rely, people who let us know that they care about, value and love us’. Social support has been identified as having numerous health benefits, which are outlined in detail below. House et al. have identified four types of social support: emotional, appraisal, informational and supportive.

The positive role of family support has been well documented in stroke literature. A positive relationship between a stroke survivor and their family members may attenuate stress and depression and maintain survivors’ health. Impaired social networks have been frequently cited as a consequence of stroke and are associated with the experience of PSD. Restricted social networks can lead to survivors’ feelings of social isolation, which are common post-stroke and are influenced by factors such as mobility difficulties, communication deficits and stigmatisation. Overall, social support is multi-faceted, and as a result, there remain many gaps in existing knowledge about how social support contributes to health.

However, good social support has been shown to have the following health effects:

- positively contributes to immune, endocrine, and cardiovascular functioning; recovery from illness and injury and health maintenance.
- buffers stress and supports the adjustment process.
- reduces the risk of other illnesses, including depression and mortality.
- reduces the risk of mortality.
- encourages optimism and self-esteem.

7.6 Community Access and Driving

Walking and mobility independence can enhance survivors’ community participation. Residual impairments after stroke and low exercise tolerance can affect survivors’ ability to walk, or to walk effectively, which can lead to restricted community participation and a loss of valued activities. Further, experiencing these impairments often leads to greater dependence on friends and family in order to access the community.

A key barrier to community participation in Western countries is the ability to drive. In Australia, driving is central to enabling community access and allowing people to perform necessary ADLs and maintain community and social connections. Car use is integral to the Australian lifestyle, and the rate of car use in Australia is second only to that of the United States. Older Australians rate driving as the second most important instrumental activity of daily living.
Stroke can affect a person’s capacity to drive. There are wide variations in rates of survivors’ return to driving after stroke, ranging from 19–58%. Losing a driving license after stroke has profound implications for stroke survivors, and has been linked to reduced ability to perform ADLs, restricted community participation, social isolation, impaired access to community and social activities, depression and reduced QoL. Many stroke survivors rely on informal support, such as family and friends, for transport, and tend not to increase their walking or use public transport after losing their license. There is a need for rehabilitation programmes that incorporate survivors’ plans to retire from driving and support their transition between driving and non-driving. Key components should include how to problem-solve alternative transportation options and assist stroke survivors in working through their feelings of loss.

7.7 Conclusion

Central to all the concepts presented in this chapter is survivors’ ability to recover from stroke impairments and adversity. While the relationship between the variables discussed in this chapter is not yet well understood, growing evidence suggests that these variables might promote recovery after stroke. There remain clear gaps in knowledge, since relevant studies focus on survivors’ first few months following stroke and might not represent the longer-term sequelae of stroke, particularly regarding survivors’ post-stroke psychological mood.
8 METHODS

8.1 Overview
This study used mixed methods to prospectively investigate the effect of post-stroke psychological morbidity and track survivors’ mood, functional status and QoL, including an exploration of their personal experiences over a 12-month period.

This chapter presents a synopsis of the study design, research aims, primary outcomes, study setting, recruitment, data collection and data analysis strategies. Methods are also clearly reported in the publications listed in Sections 9.1 to 9.4 and 10.1 to 10.3.

8.2 Study Design
The design of this study was a mixed method prospective study involving qualitative and quantitative processes. All consenting participants (n = 134) participated in quantitative surveys exploring their physical and psychosocial function at baseline, three, six, nine and 12 months. Participants were recruited to the study between December 2007 and December 2011. A longitudinal qualitative study explored the personal experience of psychological morbidity in a sub-set of participants (n = 23) of the overall study (n = 134). A flowchart of all the studies undertaken in this doctoral research is outlined in Figure 8.1.
Figure 8.1 – Flowchart of Study
Figure 8.2 – Flowchart of Emergent Themes
8.3 Research Aims

8.3.1 Quantitative Aims

The primary aims of the quantitative component of the project were to identify baseline predictors of depression (HADS score and caseness), baseline predictors of anxiety (HADS score and caseness) and baseline predictors HRQOL in the twelve months post-stroke.

Secondary aims were establishing baseline predictors of resolution of depression and anxiety, baseline predictors of incident depression and anxiety.

8.3.2 Qualitative Aims

The aim of the qualitative component of this research was to explore longitudinally the patterns of post-stroke psychological morbidity, and to establish disease trajectories that outline the patterns of disease experience over time.

8.4 Primary Outcomes (Quantitative)

8.4.1 Quantitative Measures

(1) The primary outcomes were depression and anxiety. Depression and anxiety were both assessed using the HADS. The HADS is a widely accepted and well-validated instrument used to screen for depression (HADS-D) and anxiety (HADS-A) post-stroke. The HADS can be scored as a continuous or binary variable.

(2) The outcomes of HRQoL was measured using the Assessment of Quality of Life (AQoL).

8.5 Sample Size Calculation (Quantitative)

The estimated sample size required for this study was 130 participants. Sample size was calculated based on 95% confidence intervals around the estimate of prevalence of depression in the local study sample to within \( \pm 10\% \) of the true value. The level of significance for all analyses was set at 0.05. The calculation was based on the assumption that the prevalence would be approximately 40\%. This sample size allowed for an estimated 30\% of loss to follow-up within this ageing and frail population.

8.6 Research Setting

The current study was conducted in Newcastle, an Australian coastal city situated within the Hunter Region on the coast of NSW, Australia. Newcastle has a population of 541,744. Acute stroke units and stroke rehabilitation units in three tertiary referral centres (John Hunter Hospital, Calvary Mater Hospital and Belmont District Hospital).
provide hospital-based stroke services. Routine follow-up is provided for patients following their discharge from hospital. Patients who are not discharged to institutional care, but who experience persisting changes in activity levels, are referred to ongoing rehabilitation, which might involve access to outpatient or day hospitals or home-based allied health and nursing.

Approval for this project was obtained from the Hunter New England Local Health District Research and Governance Unit (07/04/18/5.02).

8.7 Recruitment

8.7.1 Quantitative Recruitment (All Study Participants)

Potential participants were identified from consecutive admissions to two out of three of the tertiary referral centres in Newcastle, NSW (Calvary Mater Hospital and Belmont District Hospital).

The cases were defined by the following factors: admission to hospital and history and examination consistent with stroke as determined by a stroke physician. Brain imaging was available in 91% of cases. Patients with haemorrhagic stroke were included. Participants were excluded if they had significant language or cognitive impairment (determined by a Mini-mental State Examination Score of less than or equal to 24). Dysphasia was assessed by a speech pathologist (SP), and where possible, participants with dysphasia were assisted by the SP to complete the surveys. The primary researcher (and doctoral candidate) conducted face-to-face interviews. Baseline interviews were conducted in a hospital setting. Subsequent interviews were conducted face-to-face at a time and location convenient to the participant, usually their own home.

8.7.2 Qualitative Recruitment (A Sub-Sample of 23 Participants)

Qualitative methodology provides a means for gaining an understanding of stroke survivor experiences. In order to obtain an in-depth understanding of the experiences of stroke survivors, 23 of the 134 participants in the quantitative longitudinal study were invited to participate in semi-structured interviews.

Sampling was first purposive and then theoretical. Maximum variation purposive sampling identified potential participants on the basis of sex, age, living situation and stroke type. For example we attempted to recruit both men and women, with variations in age range and living situations (i.e. single widowed, community dwelling, aged care facility dwelling). Finally, where possible, we attempted to recruit participants experiencing TACI, LACI POCI and PACI strokes, level of disability (ranging from mild to moderate) and depression scores (case and non-case) so as to reach as heterogeneous a sample as possible to explore the personal experience of stroke. Theoretical sampling refers to methods of participant selection based on their theoretical relevance rather than being pre-determined, in this case the onset and ongoing experience of stroke. All invitees agreed to participate and all chose to be
interviewed in their own home, following the baseline interview (which was conducted in hospital). Data saturation (a situation where no new themes are emerging) was achieved with 23 participants during the baseline interviews which addressed the core objectives of exploration of psychological morbidity and of psychological disease trajectories post-stroke. However additional themes emerged in subsequent interviews with regards to distress concerning return to driving, and the experience of post stroke fatigue and urinary incontinence. Our methodology provided for further sampling to undertake further interviews in order to explore new themes to the point of saturation. Participants were interviewed at baseline, 3, 6, 9 and 12 months (between January 2008 and July 2011).

### 8.8 Baseline Screening

Initial baseline data was collected from hospital records. This included date of stroke, co-morbidities and admission and discharge medications. Ischemic stroke sub-type was classified into the following syndromes using the OCSP: TACI, PACI, POCI and LACI.

The researcher introduced herself to each participant to outline the project and provide them with a plain language statement. This comprised providing potential participants with all the necessary information about the research project to enable them to give informed consent. The plain language statement explained participants’ rights, which included their right to withdraw from the study at any time, and also their right to confidentiality.

### 8.9 Quantitative Data Collection

Once written, informed consent was obtained from participants, a baseline assessment was conducted as soon as practical following participants’ admission to hospital for acute stroke. Participants were reassessed at three, six, nine and 12-month periods, dated from their admission for stroke. Participants were interviewed at their respective discharge destinations, usually their own home (following the baseline interview that was conducted in hospital). If the assessment was unable to be undertaken at the exact three, six, nine and 12 month time mark then, it was rescheduled as soon as was practicable.

#### 8.9.1 Assessment Instruments and Other Data Collected

Well-validated quantitative measures were administered during a face-to-face interview to measure changes in participants’ physical and psychosocial functioning over time. These factors are outlined below.

#### 8.9.1.1 Disability: mRS

The mRS (modified Rankin Scale) is an internationally used clinician-reported measure outcome measuring the degree of disability and dependence in survivors’ daily activities after stroke. The mRS is well accepted in stroke literature and there is extensive evidence of the validity, reliability and sensitivity of the mRS.320,321
The mRS is a simple six-point assessment that includes references to survivors’ limitations in activity and changes in lifestyle. With regards to clinical sensitivity, a change of one point on the mRS grade is considered to be clinically significant. However, a key limitation of the mRS is the negative effect of existing co-morbidities that are common in stroke survivors, such as diabetes and arthritis.

8.9.1.2 Depression and Anxiety: K10 and HADS

The HADS and K10 are depression or distress measures commonly used in primary and/or specialist care settings. The HADS, which includes depression (HADS-D) and anxiety (HADS-A) subscales, in addition to a total score (HADS-Total), has been validated for use with stroke patients without communication problems. Evidence for the diagnostic accuracy of the K10 is lacking in the stroke population. The K10, a distress screening scale used in several population-based surveys, is being used frequently by Australian GPs as an outcome measure within a national government-rebated mental healthcare plan.

While some consider the ideal assessment of post-stroke mental health to be a diagnostic interview using DSM-IV criteria, this is a lengthy and resource-intensive process requiring psychiatric interviews, which can be impractical for large-scale research or usual clinical practice. Alternatives to diagnostic interviews include screening tools, which are easier to administer and inexpensive. A number of measures, in contrast to Structured Clinical Interview for DSM-IV, have been validated for depression screening in stroke patients without aphasia, including the HADS, the Geriatric Depression Scale (GDS), and the General Health Questionnaire (GHQ).

The HADS was selected as the primary outcome measure for psychological morbidity in this study, and has been used extensively for screening for depression and anxiety in the stroke population. It was designed to not include items reflecting somatic symptoms, which makes it ideal for use with stroke patients, who often experience somatic symptoms because of stroke. The HADS has anxiety and depression subscales. Participants choose one of four answers to capture best how they have been feeling over the last week. Higher scores indicate a more negative response. The total score on the HADS is also a valid measure of distress and provides an overall measure of participants’ psychiatric morbidity. In this study, HADS-D and HADS-A scores were analysed as continuous and binary outcomes. Sensitivity analyses were conducted using cut scores to define dichotomous case and non-case anxiety and depression status, as binary outcomes. The rationale for performing both sets of analyses was that both depression and anxiety symptoms reflect a continuum of severity, and subsyndromal or sub-threshold anxiety and depression might be associated with significant psychosocial dysfunction and poorer health outcomes for survivors. Case definition, however, is still important clinically, especially in considerations of treatment. The authors of the HADS recommend that, for the anxiety and depression scales, raw scores of 8–10 identify mild cases, scores of 11–15 identify moderate cases and scores 16 or above identify severe cases. In this study we identified HADS-D and HADS-A if scores were ≥8. In modeling resolution of HADS-D and HADS-A ‘caseness’, patients with baseline anxiety and depression HADS-D and
HADS-A scores ≥8) were classified as having resolution of depression or anxiety if they had at least two time points after baseline with HADS-D and HADS-A scores <8.

8.9.1.3 Social Support: MSPSS

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), which is a brief instrument used for assessing the hierarchical structure of perceived social support. The MSPSS is an easy-to-administer self-report instrument covering 12 items, rated on a seven-point Likert scale ranging from (1) very strongly disagree to (7) very strongly agree. The total social support is the sum of the scores of from the 12 items; however, it can also be divided into three subscales: family, friends and significant others. It has been well validated in a range of populations, including cardiovascular disease populations and the elderly, and has been widely used in clinical and non-clinical samples. Other studies have revealed the MSPSS demonstrates strong internal consistency and test-retest reliability. The MSPSS Total score was used in the study.

8.9.1.4 Health related Quality of Life: AQoL

In this study, the AQoL was used to assess generic post-stroke HRQoL. This utility instrument examines five dimensions of HRQoL: independent living, social relationships, physical senses, psychological wellbeing and illness. The AQoL is scored on a life-death scale, where the lowest possible value, –0.04, represents states that are valued worse than death, 0.00 represents death-equivalent states and the highest value, 1.00, represents the best possible life state. The AQoL has been validated in the general population and in the stroke population. The AQoL generates a descriptive profile and provides a single value that quantifies HRQoL. The psychometric properties of the HRQoL have been well described and it has been validated in the non-stroke and stroke populations. The AQoL Total score was used in the study.

8.9.1.5 Community Participation: AAP

The Adelaide activities profile (AAP) is a valid measure of lifestyle activities in the elderly in Australia and in the community at large. The benefit of this scale is that it also has ADL indices that evaluate patients' abilities beyond self-care activities and include domestic chores, household maintenance, service to others and social activities. Each activity is rated with four possible responses from zero to three, with higher scores reflecting greater participation. The AAP includes a behavioural dimension not covered by any other measure. The AAP-Total score was used in the study.

Higher scores achieved on all of the aforementioned study measures, except the mRS reflect higher levels of support or functioning (and perceived functioning). In contrast higher mRS scores reflect worsening functioning and even death.
8.10 Qualitative Data Generation

8.10.1 Overview of Qualitative Methodology

This study used an inductive thematic qualitative approach underpinned by grounded theory processes to guide sampling, data collection and analysis. Grounded theory is useful for generating information especially where little is known about a given phenomenon, in this case the long term experience of psychological morbidity post stroke. The key features of grounded theory are its iterative study design, involving cycles of simultaneous data collection and analysis (where analysis informs the next cycle of data collection), and emphasis on a set system of analysis. Furthermore, thematic analysis, as in grounded theory, requires involvement and interpretation by the researcher, using set procedures, in order to identify both explicit and implicit ideas within the data that allows for theorising about constructs and the generation of themes.

Overall, grounded theory aims to generate a theory about a given phenomenon using a set of inductive and iterative techniques to interpret, construct, and develop meanings “grounded,” in the data. Indeed, the goal of grounded theory is to develop constructs/theory that are “grounded” in, or supported by the personal accounts of any given experience. It is therefore important that the grounded theory researcher does not formulate any hypothesis in advance and should approach the research with as few preconceptions as possible, in order to avoid misinterpretation. Components of the rest of this chapter will describe and justify the use of an inductive thematic approach. Furthermore the use of an inductive thematic approach is clearly outlined in the publications listed in Sections 9.1 to 9.4 and 10.3.

8.10.2 Qualitative Interviews

The researcher conducted a semi-structured interview with each of the participants at each of the five time points (baseline, three, six, nine and 12 months), and each interview was recorded with the permission of the participant.

An interview guide was utilised to guide the semi-structured interviews (18, 20) based on the research questions and a knowledge of the literature. Questions were developed around existing evidence on PSD and anxiety and following review of individual participant’s mood scores obtained from quantitative data. However there was still participant freedom to express views with his/her own words and as a result the interviews diverged from the initial interview guide and explored experiences of and feelings towards participant’s experiences. The iterative nature of data collection and analysis allowed modification of the interview schedule, included in subsequent interviews. Indeed, interviews were, as far as possible, informant-led and any emergent themes were, via the iterative data collection and analysis which allowed modification of the interview schedule, included in subsequent interviews. In interviews at baseline, individual participant’s quantitative data was used to inform and give greater context to the qualitative questions.
To create a comfortable atmosphere, each baseline interview began with the interviewer asking the participant to describe the ‘story’ of the onset of their stroke and their life before the stroke. Further questions explored their mood disturbance and other post-stroke psychological distress (e.g. ‘do you experience any ups and downs?’). Subsequent interviews further explored participants’ progress and any changes in their mood or other psychological distress. The iterative process of cumulative and concurrent data generation and analysis within this study, which incorporated a process of constant comparison, allowed emergent themes to inform continuing data generation \(^{40, 319}\). As a result the interview schedule was refined in an iterative manner from interview to interview. On the basis of emergent themes, supplementary cross-sectional interviews were conducted. Examples of interview topic guides are outlined in the manuscripts presented in Chapter 10.

These were not clinical interviews or consultations; therefore, the researchers did not make diagnoses of participants’ mood disorders and other psychiatric conditions. Instead, symptoms suggestive of psychological morbidity or emotional distress were elicited, and these included depressed moods, frustration, irritability, sleep disturbance, anxiety and excessive worry.

Some participants reported having been diagnosed with depression by their treating clinician, and this information was considered in the researchers’ interpretation of data.

8.11  Data Analysis

8.11.1 Quantitative

Quantitative analyses addressed the study aims previously outlined.

The researchers analysed univariate associations between anxiety and depression and demographic variables using t-tests for depression and anxiety as continuous variables, and chi-squared tests when depression and anxiety were treated as categorical variables.

Baseline predictors of depression, anxiety and HRQoL over time, were analysed using linear mixed models with exchangeable correlation structures, using continuous HADS Total, HADS-D, HADS-A or HRQoL scores as the outcome variable.

For baseline predictors of dichotomised depression status or anxiety status, as the outcome variable, logistic regression with repeated measures was accounted for using generalised estimating equations (exchangeable correlation structures were used). Patients needed to have at least two follow-up time points to be included in this analysis.

In modelling development of depression, anxiety ‘caseness’, patients without baseline depression and anxiety (HADS-D or HADS-A scores of < 8\(^{327}\)), were classed as developing depression or anxiety if they had at least two time points after baseline with HADS-D or HADS-A scores of ≥ 8. In modelling the resolution of depression or anxiety ‘caseness’, patients with baseline depression or anxiety (HADS-D or HADS-A scores of ≥ 8\(^{327}\) were classified as having resolved depression or anxiety if they had at least two
time points after baseline with HADS-D or HADS-A scores of < 8. Likewise a
generalized liner model was use to map changes in QOL over time. Participants
needed to have data from at least two follow-up time points to be included in the
analysis.

8.11.2 Qualitative
Semi-structured interviews, ranging from 30-60 minutes, were recorded with the
participant’s permission and, as soon as possible after each interview. Both during and
after each interview the researchers’ recorded reflective notes about the content and
process. Each interview was transcribed verbatim with identifying data removed,
conceptualised and coded. The primary researcher or a research assistant transcribed
the data and then checked it for accuracy.

Data analysis was subsequently conducted by the primary researcher (an OT) and her
principal supervisor (a GP). The researcher was located within a research setting, and
her principal supervisor was located within a university setting. The inductive analysis
process, using grounded theory principles, included the three types of a constant
comparative method. This involved: 1) Open Coding which identified units of
meaning using a process of reading the transcripts line-by-line; 2) Axial Coding
involved grouping units into interconnecting categories; and 3) Selective Coding
whereby relationships between codes where examined in the context of the research
question in order to form major categories and themes. While quantitative data was
used to inform qualitative interviews it was not taken into account during analysis and
qualitative data analysis was solely based on qualitative reports.

A detailed outline of the coding process is described in the following section.

8.11.2.1 Open Coding
The first step of the coding process was open coding, which involved a literal line-by-
line reading and interpretation of salient categories of information supported by the
transcripts. The primary researcher coded each transcript and a code book was
developed. This was the first level of understanding, whereby transcripts are read and
conceptualised, line by line, in order to gain a comprehensive sense of the participants’
experience. For this study, memos and descriptive properties were dimensionalised and
presented on a continuum that was written in an adjacent margin of the transcripts.
These were compared between each transcript and modified until a final name, or
‘property’, encompassing a concept embodied in a descriptive tag or tags, was
allocated. This required the primary researcher to move constantly between transcripts
as emerging concepts were explored and related to each other. This continued to
involve a process of constant comparison, whereby transcripts were read and re-read
in order to clarify, code and re-code.

Open coding continued until an initial set of first order codes, or open codes, were
generated. These were given a label consisting of four letters in order to facilitate
retrieval between the transcripts (for example, depressive symptoms were labelled as
DYSM). These codes encompassed participants’ behaviour, beliefs and emotions
surrounding their experience, irrespective of the research question. As a result the process of analysis and code generation informed subsequent interviews.

8.11.2.2 Axial Coding

The next level of analysis was axial coding, which involved the exploration of and grouping of the first order, or open codes into coherent categories and sub-categories. This level of analysis involved examining relationships and interactions between various codes in the context of the research question in order to form themes concerning the experience of stroke, emotions and community participation. For example, all codes that appeared to influence psychological morbidity were grouped together, and the primary researcher then sought to discover the influences behind these relationships.

8.11.2.3 Selective Coding

The final level of analysis involved an integrative process of selecting and validating major categories that outlined the relationships and interactions between the codes related to the experience of stroke and psychological morbidity experienced by stroke survivors. This process involved proposing, then checking relationships between the core and other categories. This process is described in detail in the following section.

8.11.2.4 Rigor and Trustworthiness

The validity of the qualitative research process is enhanced through rigorous methodology and interpretation of results. In this research, this validity was achieved through careful study using an inductive thematic approach. External validity is ensured because the process remains constant, even though there are variances between participants and their contexts.

Rigorous coding process involved consensus coding with the primary researcher and the principal supervisor. Consistency of findings was upheld through discussion of interpretations between to confirm codes and categories. As the codes emerged the amended codes were re-applied to the transcripts by the primary researcher and the principal supervisor. Any differences in researcher perspective were resolved by negotiation and, if necessary regrouped and recoded until consensus was reached. New codes were then fed back into the analysis to cross-check codes and themes and develop an overall interpretation of the data. Rigor was established by methods of peer review and peer debriefing with a co-researcher. Both during and after each interview the researchers’ recorded reflective notes about the content and process of the interview, in order to ensure investigator reflexivity.

Consensus coding increases reliability and rigour and enriches conceptual analysis, particularly in the case of analysis by researchers from differing professional backgrounds: in this study, the primary researcher, an OT, and her principal supervisor, a GP.
Lincoln and Guba’s work (1989) guided the analysis process to ensure trustworthiness of the data, which is achieved by addressing a criteria of credibility, transferability, dependability and confirmability.

Credibility
Credibility relates to the evaluation of the truth value within the research being undertaken. For the purpose of this study, credibility was achieved by incorporating a search for negative cases and use of participants’ words in the presentation of results. The use of reflexive analysis meant the primary researcher critically appraised their relationship with the data and the study context, taking account of any preconceptions. In addition, peer debriefing ensured the primary researcher remained open to the data and did not demonstrate bias during the data analysis.

Furthermore, any issues identified by participants were explored in subsequent interviews with other participants to clarify and extend the primary researcher’s interpretation of the data. This enhanced the rigour of the process prior to undertaking full-scale thematic analysis of data involving coding and categorising, which led to the development of themes relating to the research questions.

Transferability
Transferability refers to the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings. 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.

Moreover, the qualitative researcher enhances transferability by doing a thorough job of describing the research context and the assumptions that were central to the research.

Dependability
Dependability refers to the reliability of the study and the examination of design related factors that might influence the study. Since it is not appropriate to replicate qualitative research in its entirety, dependability is achieved through a transparent approach to the research and documentation of methods and findings. As a result, and where appropriate, the researcher should describe the changes that occur in the setting and how these changes affected the way the researcher approached the study

Confirmability
Confirmability is important, and the primary researcher adhered to well-established processes to ensure credibility of the study. Qualitative research assumes that each researcher brings a unique perspective to the study. Confirmability refers to the degree to which the results can be confirmed or corroborated by others. There are a number of strategies for enhancing confirmability. For example, the researcher can document the procedures for checking and rechecking the data throughout the study and analysing procedures for any potential bias. Careful attention to processes lends itself to an appropriate and relevant study conclusion.
Synthesis of Quantitative and Qualitative Analysis

In addition to analysis of the quantitative and qualitative data separately, the researcher analysed the data collectively to identify convergence of findings. In other words, the researcher compared qualitative and quantitative findings of participants’ experience of psychological distress. More specifically, results from the HADS, K10, AQoL and semi-structured interviews were compared as both data sources examined emergent psychological distress and HRQoL. The results of each quantitative and qualitative study are clearly presented in published manuscripts (Chapters 9 and 10) and an integration of findings is presented in Chapter 11.

8.12 Conclusion

This chapter outlined the research methods and procedures employed to explore the experience of post-stroke psychological morbidity. In order to address the gaps in previous research, this study used a mixed methods approach incorporating the collection of data through longitudinal qualitative and quantitative methodology and the collection of data at multiple time points. As a method it focussed on collecting, analysing and integrating qualitative and quantitative data findings is a single study. In combination, qualitative and quantitative processes provided a better understanding of a research problem, in this case post-stroke psychological morbidity, than either approach alone.
9 QUANTITATIVE PUBLICATIONS

9.1 Manuscript

Predictors of Depression and Anxiety in Community Dwelling Stroke Survivors: A Cohort Study

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

80% conception and design of the research
80% writing the paper and critical appraisal of content

Jennifer White 07/04/2014

John Attia 07/04/2014

Jonathan Sturm 07/04/2014
9.2 Manuscript

**Predictors of Health Related Quality of Life in Community Dwelling Stroke Survivors: A Cohort Study**

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

- 80% conception and design of the research
- 80% writing the paper and critical appraisal of content

Jennifer White 07/04/2014

Parker Magin 07/04/2014

John Attia 07/04/2014
Jennifer White

Exploring the Long-Term Experience of Psychological Morbidity in Community-Dwelling Stroke Survivors

Jonathan Sturm 07/04/2014

Gregory Carter 07/04/2014
10 QUALITATIVE PUBLICATIONS

10.1 Manuscript

Trajectories of Psychological Distress After Stroke

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

- **80%** conception and design of the research
- **80%** writing the paper and critical appraisal of content

Jennifer White 07/04/2014

Parker Magin 07/04/2014

John Attia 07/04/2014
10.2 Manuscript

Access and Participation in the Community: A Prospective Qualitative Study of Driving Post-Stroke

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

- **80%** conception and design of the research
- **80%** writing the paper and critical appraisal of content

Jennifer White 07/04/2014

p.p Belinda Miller 07/04/2014

Parker Magin 07/04/2014
10.3 Manuscript

Exploring the Experience of Post-Stroke Fatigue in Community Dwelling Stroke Survivors: A Prospective Qualitative Study

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

80% conception and design of the research
80% writing the paper and critical appraisal of content

Jennifer White 07/04/2014

p.p Kimberley Gray 07/04/2014

Parker Magin 07/04/2014
10.4 Manuscript

The Experience of Urinary Incontinence in Stroke Survivors: A Follow-Up Qualitative Study

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

- **80%** conception and design of the research
- **80%** writing the paper and critical appraisal of content

Jennifer White 07/04/2014

p.p Kate Patterson 07/04/2014

Louise-anne Jordan 07/04/2014
Exploring the Experience of Psychological Morbidity and Service Access in Community Dwelling Stroke Survivors: A Follow-Up Study

As co-authors of the paper:


We confirm that Jennifer White has made the following contributions:

- **80%** conception and design of the research
- **80%** writing the paper and critical appraisal of content

Jennifer White 07/04/2014

p.p Alexandra Dickson 07/04/2014

Parker Magin 07/04/2014
11 INTEGRATED FINDINGS, CONCLUSIONS AND IMPLICATIONS

11.1 Introduction

This chapter interprets the overall findings of the research programme outlined in Chapter 2. As recorded in Chapter 8, this study methodology adopted a longitudinal, concurrent mixed methods design, wherein the research issues were investigated using qualitative and quantitative methods. Longitudinal trajectories of post-stroke psychological morbidity were explored using qualitative analysis. Baseline clinical, functional and psychosocial factors associated with anxiety and depression during the 12-month post-stroke follow-up were analysed using qualitative methods. Clinical, functional and psychosocial factors associated with QoL during the 12-month post-stroke follow-up were also analysed using quantitative methods.

Quantitative findings concerning PSD and anxiety were presented in Chapter 9.1, while quantitative findings on HRQoL were presented in Chapter 9.2. Chapter 10.1 presented the results of the qualitative analysis concerning longitudinal trajectories of post-stroke psychological morbidity. In this study, recruitment continued until thematic saturation (a situation of no new themes emerging around the principal study aim of exploring psychological morbidity) had been achieved. This occurred after 23 baseline interviews had been completed and no further participants were recruited to the longitudinal study. Due to the iterative nature of the longitudinal study, however, there was a possibility of further themes emerging in interviews subsequent to achieving thematic saturation for the primary aim of exploring psychological morbidity. Therefore, there was provision for further sampling to be done, if required, to explore (in targeted interviews) any subsidiary themes. Several new themes emerged during the study: specifically, the stroke survivors’ distress due to their inability to drive, their experience of post-stroke fatigue and their experience of post-stroke UI. As a result, additional and supplementary interviews were conducted to explore further these concepts. The results were presented in Chapters 10.2, 10.3 and 10.4.

This chapter (Chapter 11) summarises and discusses the major findings of this project, results of synthesis of quantitative and qualitative, findings, study strengths and limitations and its implications for clinical practice, policy and future research.

11.2 Summary of Major Findings and Relationship with Previous Literature

11.2.1 Research Aim One

To establish the prevalence of depression and anxiety post-stroke and to identify baseline predictors of depression and. Secondary aims were establishing baseline predictors of resolution of depression and anxiety, and baseline predictors of incident depression and anxiety. (Chapter 9.1)
This chapter reported the frequency, severity and baseline predictors of anxiety and PSD. Post-stroke, depression scores were not significantly associated with time and anxiety scores improved significantly with time. The researchers also explored the baseline predictors of resolving anxiety and PSD present at baseline, and of developing cases of anxiety and PSD not present at baseline.

This project expanded on the scope of previous longitudinal studies of PSD in several ways. Firstly, it included an exploration of anxiety in addition to PSD, since many studies do not examine the presence of psychiatric disorders or psychological morbidity other than PSD\(^{103, 188}\). Secondly, it assessed participants at more frequent time points than in many previous studies. Thirdly, anxiety and PSD were analysed as both dichotomous and continuous variables. The rationale was that many stroke survivors are left with mood disorders and depressive symptoms that do not reach thresholds for mood scale cut-off scores or meet the criteria standard for diagnosis of major depression or other psychological morbidity\(^{30}\). Instead, the spectrum experience of psychological morbidity ranging through subsyndromal, dysthymia, minor and major depression and anxiety disorders in stroke survivors can continue to affect their lives after stroke\(^ {53}\). However, of greater concern is the association of depression and anxiety with increased mortality\(^ {17}\). Fourthly, we explored baseline predictors of resolving anxiety and PSD, and predictors of developing cases of anxiety and PSD after baseline.

For participants in this study, 31% experienced anxiety at two or more time points (baseline and four follow-up time points), while 43% experienced depression at two or more time points. These results are higher than those seen in previous longitudinal studies\(^ {210, 334}\) highlighting the high frequency of anxiety and depression post stroke. The relevance of these findings to the health system is the importance for early detection of PSD and anxiety in stroke survivors and the initiation of effective treatments.

The persisting nature of PSD in this study is consistent with that found previously\(^ {35}\), indicating that the risk of PSD is similar in stroke survivors’ early, medium and long-term recovery stages and that one third of survivors will experience PSD at some stage post-stroke.\(^ {35}\)

Studies of psychological morbidity report the frequency of GAD. The frequency of GAD has been fairly consistent across studies, reported variously as 27%\(^ {216}\), 24%\(^ {146}\) and 28%\(^ {25}\). In this study, anxiety was more frequent at baseline (47%) and caseness lessened over a 12-month period. The higher initial prevalence in this study could be due to the increased likelihood of capturing other anxiety syndromes in addition to GAD. The decline noted in this study is similar to that seen in a community study conducted in Australia\(^ {227}\) whereby anxiety symptoms also lessened over time.

This study’s identification of potential modifiable risk factors for post-stroke psychological morbidity, including lower social support and lower community participation, is consistent with previous research.\(^ {1, 103}\)

This study identified potential modifiable risk factors for post-stroke psychological morbidity; increasing social support and community participation. These factors are of clinical importance to rehabilitating stroke survivors. Multi-disciplinary teams that
establish goals with patients promoting social and community engagement could assist in managing psychological morbidity. Therapies might include rehabilitating residual symptoms that restrict mobility, education concerning physical and cognitive skills, facilitating alternate transport systems in order to improve patients’ community access and referring patients to community groups.

A Cohort Study of Predictors of HRQoL in Community-dwelling Stroke Survivors (Chapter 9.2)

This chapter reported findings on HRQoL. Research exploring HRQoL is important, as what is meant by recovery from stroke and what constitutes good QoL have been shown to differ among healthcare providers, researchers and stroke survivors.218, 220, 243 Overall, the use of mixed methods in this study allowed for the voice of stroke survivors to be heard, using qualitative interviews to discover survivors’ needs, issues and priorities concerning long-term rehabilitation and the ability to influence HRQoL, which our quantitative study found to be decreased post-stroke.56 This is the first published Australian research concerning these issues, and common findings across these targeted interviews indicated a lack of knowledge regarding post-stroke symptom management, altered participation, social isolation and psychological morbidity.

Since the experience of stroke is different for each individual, identifying factors affecting HRQoL is important. However, many stroke survivors do not appreciate the effect of stroke on HRQoL until they are discharged from inpatient rehabilitation and attempt to resume pre-stroke activities.

Higher HRQoL during the first 12 months post-stroke was predicted by higher baseline HRQoL, younger age, less disability, greater community participation and no previous history of depression. It is difficult to accurately compare quantitative results due to the use of different measures in different study populations; however, participants in this study cohort appeared to have a mean HRQoL than those in previous studies involving more severely disabled cohorts.241,336 However, the HRQoL life scores in this study were still lower than those of people without stroke and of 70 years and older living in the community.336

This study identified potentially modifiable predictors for low HRQoL: disability and poor community participation. Our findings highlight the need for improved education and therapies to address disability and increase community participation. Introducing therapies that focus on minimizing altered HRQoL have implications for changes in clinical practice and further research evaluation.

11.2.2 Research Aim Two

To develop trajectories of psychological distress after stroke (Chapter 10.1)

This chapter presents in the first published qualitative paper concerning post-stroke psychological trajectories. Trajectories that explore chronic diseases such as stroke are
There are several benefits to establishing qualitative trajectories of post-stroke psychological morbidity. Firstly, trajectories are a useful way of conceptualising and understanding the experiences and patterns of post-stroke psychological morbidity over time. Secondly, patients and stroke clinicians benefit from knowledge of prognosis and the insights gained from each trajectory regarding how to manage and control symptoms.\textsuperscript{84,327} In general, knowledge of stroke-specific trajectories of psychological morbidity can alleviate patient uncertainty. Finally, identifying factors that predict stroke survivors' recovery from post-stroke psychological morbidity is of particular significance in order to facilitate optimal stroke recovery. Distinct trajectories of progressive functional decline leading to death have been well described using quantitative methodology in disease groups such as kidney failure and palliative care.\textsuperscript{24} Knowledge gained from these trajectories has been used to develop effective interventions that address symptom management, remission and/or preparation for death in each of these disease group contexts.

The researchers of this study identified four different trajectories of post-stroke psychological morbidity: resilience, ongoing crisis, emergent mood disturbance and recovery from mood disturbance. Regarding trajectories of depressive symptoms, some work has been done using quantitative methods to document trajectories of depressive symptoms in the broader community.\textsuperscript{309} Other quantitative work has documented trajectories of depression in disease groups with cardiac\textsuperscript{310,332} and pulmonary disease.\textsuperscript{333} These trajectories frequently include categories such as the onset of depression following diagnosis, recovery from depression and persisting depression. Results of the project presented in this doctoral dissertation are in keeping with these trajectories of depression. Researchers of this study identified four distinct qualitative trajectories of the experience of post-stroke psychological morbidity: ‘resilience’, ‘ongoing mood disturbance’, ‘emergent mood disturbance’ and ‘recovered’. In addition, the researchers established that mood disturbance within these trajectories was influenced by non-stroke as well as stroke factors. This finding should be taken into account during stroke rehabilitation.

Quantitative data collection might not be sensitive enough to capture subtle changes in individual stroke survivors’ function, particularly regarding their personal and individual experience of disability, impaired social support and community participation. As a result, the qualitative findings regarding trajectories of post-stroke psychological morbidity address gaps in the understanding of this complex experience. The effect of stroke and other non-stroke factors on survivors’ experiences within each trajectory highlight the need for holistic rehabilitation, including acknowledgement and management of survivors’ life stressors and health problems.
11.3 Synthesis of Quantitative and Qualitative Findings

This section integrates the overall findings from this mixed methods study which used concurrent quantitative and qualitative processes. Firstly a presentation of the main quantitative and qualitative findings, including unique findings will be presented. This is followed by review of the merits of mixed methods research. Finally the integrated findings are presented including implications for clinical practice and policy and recommendations.

11.3.1 Summary of Major Findings

The research objectives and key findings from the individual studies highlight the significant and original contribution to the body of knowledge concerning the experience of psychological morbidity post stroke and are briefly summarised here. Further, key results from this research study are found in published form in Chapters 9 and 10.

Quantitative: The primary aims of the quantitative component were to establish prevalence of, and baseline predictors of, depression and anxiety in community dwelling stroke survivors. Secondary aims were establishing baseline predictors of resolution of depression and anxiety, and baseline predictors of incident depression and anxiety. (Chapter 9.1)

The published study, represented in Chapter 9.1 highlighted key quantitative results concerning the prevalence of anxiety and PSD. Using well established cut-scores both HADS-A and HADS-D scores results demonstrated that anxiety was more common at baseline (47%) than depression (which was identified in 22% of participants). The longitudinal approach of the study also provided data on the differing time course of anxiety and PSD. Results demonstrated that anxiety improved over time while PSD did not. Moreover HRQoL varied over time being influenced by interrelated stroke and non-stroke factors.

Further analysis explored predictors of the development of and resolution of anxiety and depression by baseline status. For anxiety, there were 46 anxiety ‘case’ participants at baseline, of whom 20 had resolution of anxiety. Of 60 anxiety ‘non-case’ participants at baseline, 5 developed anxiety. However, no variables were identified that predicted the development or resolution of anxiety.

In contrast there were 21 depressed ‘case’ participants at baseline, of whom 4 had resolution of depression. Of 85 non-depressed participants at baseline, 11 developed depression. Resolution of depression, in those participants who were depressed at baseline, was associated with increased social support. Moreover, development of depression was associated with greater disability and less community participation.

Additional analysis explored factors associated with anxiety and depression during the 12 months following stroke, results which echo with previous empirical evidence concerning predictors of PSD, anxiety and post stroke1. Specifically this study identified that anxiety caseness was statistically associated with having PSD, anxiety at baseline,
low social support and low community participation (p < .0001). Similarly, depression caseness was associated with anxiety, low social support and low community participation.

Finally this study explored HRQoL over time. Study participants had a mean HRQoL score of 0.54 which was higher than previous studies reporting HRQoL in more severely disabled stroke and community based cohorts\textsuperscript{241,336} but remained lower than that of people without stroke \textsuperscript{336}.

These results provide useful data concerning risk factors for post-stroke psychological morbidity that can be incorporated into clinical practice. Both risk identification and the implementation of early intervention strategies may be informed by these findings.

**Qualitative: The aim of the qualitative component of this research was to explore longitudinally the patterns of post-stroke psychological morbidity, and to establish disease trajectories over time post-stroke. (Chapter 10.1)**

*Psychological Trajectories post stroke*

Qualitative data analysis identified emergent trajectories of psychological distress which were shown to impact on psychological morbidity over a 12 month period. In summary, stroke survivors in multiple interviews we were able to identify common feelings of psychological morbidity. While participants did not often label their experiences as “depression,” their descriptions are consistent with a spectrum of mood disorders. Firstly, we identified a trajectory characterised by resilience in stroke survivors who did not experience mood disturbance after stroke and readily compensated for the experience of residual stroke symptoms. Resilience was closely linked with previous life experience in overcoming adversity, the use of established coping strategies and optimism. Secondly, a trajectory of ongoing mood disturbance was identified in participants who experienced ongoing distress following stroke onset and which persisted over time. Ongoing mood disturbance was linked to current life stressors, a previous history of depression and a lack of interest in goal setting. Thirdly, emergent mood symptoms were evident in some, where the experience of stroke appeared to make participants more vulnerable to the impact of other life stressors. These included family-related stress and deterioration in health (unrelated to stroke). Finally, the trajectory of emergent depression is, by definition, not identifiable at stroke onset. In emergent cases the General Practitioner (GP) may be the clinician best positioned to identify depression and initiate appropriate treatment. Case-finding in this situation will be informed by targeted assessment in patients post-stroke who experience social stressors or inter-current health problems.

Overall, many participants showed improvements in psychological morbidity over time. This study identified factors associated with recovery from low mood including overcoming fear, maximising self-efficacy, having an internal locus of control, and facilitating independence, which are consistent with previous findings\textsuperscript{84,327}. Recovered participants in this study were more likely than those with ongoing or emergent mood
disturbance to attend follow-up services, providing encouragement and continued goal setting. These findings highlight the significance of follow-up therapy beyond the first few months.

**Emergent themes**

The iterative nature of this longitudinal study allowed for the possibility of further themes to emerge in interviews subsequent to achieving thematic saturation of the principal study aim. The theme of distress concerning return to driving, post-stroke fatigue (fatigue unassociated with PSD) and UI emerged post-cessation of recruitment to the longitudinal study. The methodology provided the scope to undertake further purposive sampling to explore these experiences.

Subsequent results from emergent qualitative themes added further information to understanding of psychological morbidity post stroke since. Indeed, results confirmed and expanded upon the quantitative predictors of psychological morbidity identified in this study including disability, impaired social networks and community participation. The distressing impact of the experience of these emergent themes had a detrimental impact on participants’ HRQoL. Specifically results noted that the inability to return to driving and lack of alternate transport options; lifestyle limitations due to experience of ongoing fatigue which impacted ongoing goal attainment, and the humiliating and isolating effect of urinary incontinence led to progressive withdrawal from society and the experience of psychological distress. These emergent themes highlight additional risk factors (personal and social stressors or inter-current health problems) that were not captured by quantitative processes since surveys often lack the sensitivity to capture in-depth and personal insights.

Overall, stroke patients can present with a complex and dynamic interplay of mental illness, disease process and psychosocial issues. Findings pertaining to emergent themes highlighted that participants mostly endured these co-morbidities with little assistance and support from health professionals. Such results are concerning given the modifiable nature of impaired access to transport, fatigue and UI with an increase in targeted interventions that provide education and therapies towards promoting increased participation and management of ongoing symptoms.

**Gaps in service delivery**

Qualitative findings suggested that health practitioners were less likely to detect symptoms since they do not meet clinical criteria for depression and identification was most likely dependent on participant reports. By definition minor depression is defined as one or more periods (greater than two weeks but less than two years) of depressed mood or loss of interest in usual activities. Dysthymia is characterised by at least two years of depressed mood for more days than not, and is accompanied by additional symptoms of major depression.
Finally qualitative reports were suggestive of persisting distress. While participants did not use the words “depression” or “anxiety” to identify their feelings, expressions of distress concerning the experience of ongoing residual impairments which led to role loss and impaired community participation were suggestive of the experience of minor and sub-syndromal psychological morbidity. Since this study included a follow-up of participant beyond one year post stroke results concur that some participants were likely to be suffering from dysthymia.

Further, few participants in this study had been prescribed anti-depressants or received other support for ongoing distress such as counselling etc. This is of significant concern given the growing evidence towards effective treatment options for treating PSD and anxiety (as outline in Chapter 4.5).

11.3.2 Benefits of Mixed Methods Research
This study involved mixed methods in order to explore the longitudinal experiences of stroke survivors with psychological morbidity and better understand the phenomenon. Qualitative and quantitative approaches provide separate contributions to understanding of the stroke experience. The processes of documenting, describing, and interpreting quantitative and qualitative data provided means for a fully grounded interpretative research approach such that qualitative evidence assisted in answering questions not easily evaluated by quantitative studies.358

While there is some controversy in the literature concerning triangulation or synthesis of quantitative and qualitative research, there is benefit in combining research traditions in order to provide additional perspectives and insights that are beyond the scope of any single technique.39,40 Quantitative research is typically associated with a positivist paradigm, while qualitative research is associated with an interpretivist paradigm.43 Quantitative results tend to emphasize aggregate relationships that are derived from the average associations between variables in a study population. As a result, deviations from these associations are not emphasized, even though the relationship between variables may not be perfectly correlated. In contrast, qualitative studies are by necessity based on small and/or select samples, and as a result, the generalizability of the findings to the wider stroke population is limited. Further, qualitative studies do not establish probability estimates or effect sizes, but they can provide important support for quantitative outcomes and identify specific patient priorities and concerns not identified in quantitative process.359 Overall a synthesis of findings using mixed methods provides pragmatic advantages when exploring complex research questions whereby qualitative data provides a deep understanding of patient experiences, and statistical analysis provides detailed assessment of patterns of responses.

In this study the use of mixed methods research quantitative and qualitative data were collected concurrently and triangulated which increased the robustness of the research process. Indeed, the use of mixed methods in this research and the triangulation of data explored the experience of and the development and resolution of psychological morbidity. Further the implementation of a longitudinal study design increased the
relevance of findings and the understanding of psychological morbidity post stroke, since the temporal process of adaptation and adjustment are likely to influence survivors’ sense of HRQoL dynamically over the post stroke period.

Overall, integrated findings can better inform policy and health care decision-making and inform future development of interventions for psychological morbidity.

11.3.3 Integrated findings
This research process included a concurrent mixed method design. The flowcharts of all the studies undertaken in this doctoral research are presented in Figures 8.1 and 8.2 and demonstrate how each of the studies undertaken in the doctoral research contributed to the thesis as a whole. When seeking to understand the meaning of psychological morbidity post stroke, a mixed method approach provided the capacity to generate a comprehensive picture. This section presents findings on the synthesis of quantitative and qualitative data.

Firstly, this study established a high prevalence of anxiety and PSD at baseline and, while anxiety improved over time, PSD did not. Results from the qualitative study were consistent with quantitative results, with participant reports suggesting that psychological distress was not uncommon, though participants didn’t always label their feelings as ‘depression’ or ‘anxiety’. The qualitative data also suggested that what appeared to be sub-syndromal psychological morbidity could be quite distressing in the context of stroke. This reinforced the validity of the primary quantitative analysis of HADS-A and HADS-D as continuous variables rather than as dichotomous case versus non-case analysis.

Further, the quantitative analysis showed that depression and anxiety post-stroke were not of a consistent nature. For example, it might be thought that the initial onset of psychological morbidity might be explained by the experience of a catastrophic life-event, such a stroke, and that there would be resolution of symptoms over time. Instead, quantitative results from this study, reflect a variable temporal picture with some people developing depression/anxiety and some having resolution of their psychological morbidity. PSD was less likely than anxiety to resolve over time. These quantitative findings are supported by qualitative data which established four psychological ‘disease trajectories’ post-stroke: resilience, ongoing crisis, emergent mood disturbance and recovery from mood disturbance.

Secondly, quantitative analyses established baseline predictors of anxiety, depression and HRQoL and predictors of resolution and development of these. No variables were identified which led to development or resolution of anxiety. However, development of depression was associated with greater disability and less community participation and resolution of depression, in those participants who were depressed at baseline, resolution of depression was associated with increased social support. These statistically significant quantitative findings highlight that the interactions between psychological morbidity and community reintegration are complex and that the
experience of ongoing disability, low community participation and low social support as being threats to long-term mental health in stroke survivors. Indeed, the statistically significant findings (disability, low community participation and low social support) were very like the factors that participants spoke about in the qualitative interviews as impacting upon their psychological state and HRQoL post-stroke. Participants personal experience of disability, low social support and community participation, were manifested as expressions concerning difficulty returning to the valued role of driving, difficulty with accessing alternate transport options and the impact of fatigue and urinary incontinence on community participation. These experiences led to impaired community reintegration post stroke. Further, nearly all participants developed their own strategies for coping with the complexity of the aforementioned experience of life post stroke and often relied on family members for practical and emotional support. Thus, qualitative data offered a more nuanced understanding beyond the measured, significant quantitative associations.

Of key interest is the interplay and interaction between stroke and non-stroke factors in the experience and recovery from psychological morbidity. This was captured in the qualitative study and, while consistent with the quantitative findings, provided a richer understanding of the experience of post-stroke psychological morbidity. Participants experienced ongoing difficulty as they attempted to resume their pre stroke lifestyle. Distress was compounded by additional life stress arising from family, financial, and comorbid health scenarios. Qualitative reports of overcoming fear, maximising self-efficacy, having an internal locus-of-control and increased independence were linked with improved mood. Recovered participants in this study were also more likely to attend follow-up services which were identified as providing encouragement and continued goal setting and highlight the importance of follow-up therapy beyond the first few months post-stroke in addressing psychological morbidity and impaired HRQoL. These qualitative findings provide a context for the quantitative findings of association of better psychological outcomes with less disability and greater social support and community participation.

Conclusion
In summary, the objective of synthesising analysis of quantitative and qualitative data in this study was to explore the experiences of stroke survivors with psychological morbidity over a 12 month periods. Together, the findings of quantitative and qualitative processes inform stroke care needs and service delivery. A mixed methods approach increased the ability to interpret findings by adding to the body of knowledge on rates of depression, and the principal influences on PSD and anxiety in this population, including personal perspectives. By adopting mixed methods, using both qualitative and quantitative approaches, it has been possible to gain, a deeper understanding of the longitudinal nature and meaning of the determinants of psychological distress and personal experiences of psychological distress experienced by stroke survivors. Indeed, the present study has advanced previous research exploring PSD among stroke survivors.
This thesis identified predictors of psychological distress and highlighted that psychological morbidity post stroke is complex and might arise from several interacting situations and conditions including: biologic changes post stroke, the experience of residual symptoms and non-stroke factors which together result in impaired HRQoL. While independent quantitative predictors were identified for anxiety, PSD and HRQoL, when combined with findings from the qualitative processes findings lend themselves to increased understanding of the longitudinal experience of psychological distress post stroke. Indeed qualitative reports give greater understanding towards the personal meaning of low social support and community participation, being manifested as difficult driving and accessing transport, as well as the disabling impact of fatigue and urinary incontinence on community reintegration. Overall there is need for a holistic approach to stroke management with greater efforts toward screening for psychological distress and direct intervention efforts consistent with the broader context of an individual’s everyday life and the experience of role loss, poor community participation and lack of social support. Allied health may play a crucial role in the delivery of timely services to ensure that stroke survivors and their families are supported in their endeavours to live successfully with post stroke.

11.4 Strengths and Limitations

The combination of methodology used in this research increased the range and scope of inquiry; complexities which cannot be adequately captured by a single research methodology. A breakdown of the strengths and weakness of each method is discussed as follows:

11.4.1 Quantitative Strengths

This study addressed all relevant acknowledged predictive factors for PSD. Retention of participants in the cohort, given the frailty and considerable mortality in this group, was good, and sample size for the principal analyses was adequate.

The conduct of all questionnaire-based interviews by the same primary researcher at all-time points contributed to the reliability of the data.

Recruiting consecutive inpatients from two stroke units, a longitudinal design with multiple follow-up assessments, a high consent rate, and high retention rate were major strengths of this study. Well-validated and reliable measures were used to measure post-stroke levels of anxiety and depression, and of physical and psychosocial functioning.

This study assessed participants at more time points than those used in much of the previous research in this area; this proved a valuable way to obtain in-depth data that contributed to illustrating the study’s qualitative findings regarding trajectories of post-stroke psychological morbidity within a particular timeframe.

Overall, the results of this study also confirm gaps identified in a systematic review concerning future studies exploring predictors of depression after stroke. These gaps
include reduced selection bias, appropriate assessment of mood, dependent variable selection, adequate sample size, choice of independent variables, appropriate reporting of analysis and proper consideration of confounders.

11.4.2 Quantitative Limitations

This study assessed mood disturbance and anxiety using the HADS. This instrument has acceptable reliability and validity in this population, but a more comprehensive (and, for participants, fatiguing) approach such as the Structured Clinical Interview for DSM-IV was not practical in this study.

Our power for sub-group analyses (resolution/development of depression/anxiety), unlike our principal analyses, was limited. A further limitation of this study was the exclusions of participants with severe aphasia and cognitive difficulties which may to some extent limit generalisability of the findings. Since it may not be feasible to include all dysphasic patients in robust studies it remains difficult to assess the frequency of psychological morbidity in in dysphasic patients, the prevalence of which might have been even higher.

11.4.3 Qualitative Strengths

The qualitative aspect of this study generates unique longitudinal data on psychological morbidity in community-dwelling Australian stroke survivors. The strength of this study lies in the use of a sophisticated, longitudinal, qualitative methodology (serial semi-structured interviews) design to obtain a description of post-stroke psychological disturbance and changes over time. Subsequent interviews provided rich data identifying a complex range of experiences post stroke. Serial interview studies remain underused in medicine, despite their benefit in exploring the complex and dynamic effects of disease, which might, in turn, inform healthcare. Retention of participants in the cohort, given the frailty and considerable mortality in this group, was high and enabled exploration of emergent themes, as they arose. This study presented the opportunity for researchers to triangulate their findings with quantitative data.

11.4.4 Qualitative Limitations

One limitation was the exclusion of patients with severe communication and cognitive difficulties. Although the study sample was sufficient to achieve data saturation, which is a critical component in implementing qualitative methodology, excluding patients with severe aphasia and cognitive impairment could limit the applicability of this study’s findings to some elements of the community. Additionally, while this study’s results give insight into patient needs in the short and medium term, a longer and more comprehensive follow-up than that implemented in this study might provide further data of clinical importance.
An integrated peer-reviewed publication of triangulated qualitative and quantitative data would have been ideal. However, journal word limits make it very difficult to present combined, integrated qualitative and quantitative results for complex projects such as this mixed methods longitudinal project. However, a synthesis of findings from the qualitative and quantitative studies was presented earlier in this chapter.

11.5 Implication for Clinical Practice and Policy

Based on the quantitative and qualitative analysis findings, Figure 11.1 presents an integrated model that highlights a proposed process for assessing and managing psychological morbidity across all phases of care.
Figure 11.1 – Managing Psychological Morbidity Across All Phases of Care
Most importantly, we propose that psychological morbidity, including PSD and anxiety, should be screened for, assessed and diagnosed in the acute setting with interventions initiated as appropriate, such as pharmacotherapy and psychotherapy. Evidence to date suggests that the use of pharmacological interventions post stroke has a small, significant effect towards improved mood but may be associated with adverse events, such as seizures, falls and delirium.\textsuperscript{133} Despite the modest benefits for depression endpoints, management of psychological distress is important, especially because of the demonstrated association (in a recent pooled analysis) with mortality, even at a lower levels of distress.\textsuperscript{17}

Moreover, there might be consideration for other interventions that have proved to be of benefit in non-stroke depressed populations. These include exercise,\textsuperscript{337,338} psycho-education,\textsuperscript{336} fish oil\textsuperscript{339} and online internet resources.\textsuperscript{340} Other interventions that have proved to be of benefit in non-stroke anxious patients include exercise,\textsuperscript{338,341} psycho-education,\textsuperscript{336} relaxation and yoga.\textsuperscript{342} These interventions should be examined in stroke populations.

Patients who do not initially meet threshold scores for depression or anxiety at baseline may still have troubling symptoms or meet criteria for disorder later. Consideration should be given to monitoring for any change in patients' psychological status using repeated screening and assessment for depression and anxiety following their discharge from hospital. The frequency with which stroke survivors should continue to be screened for post-stroke psychological morbidity is open to debate, but results from this study concur with National Health Service (NHS) guidelines.\textsuperscript{177} These guidelines suggest that screening should be undertaken at least one month after stroke or just before discharge, or at a six-week follow-up. This should be followed by three and six-monthly screens and then annual reviews to identify those with emerging new problems and those with long-term problems. GPs might be best placed to provide monitoring and follow-ups, including screening for psychological morbidity, once stroke patients are discharged from hospital. If patients meet threshold scores at any time, then GPs should consider initiating appropriate treatment, including pharmacotherapy, referral to psychotherapy and referral to community stroke rehabilitation. As a result, there is a need for adequate education and support for GPs to perform screening, assess psychological morbidity and educate patients on the availability of community resources.

Community stroke rehabilitation services that complement the GP role include community-based therapies that address modifiable risk factors for post-stroke psychological morbidity, such as disability and community participation. Multi-disciplinary allied healthcare staff are well positioned to implement simple interventions to promote stroke survivors' mobility, confidence and education, and to maintain or increase their social activities and community participation.

Further, this doctoral research highlights the clear need for increased services to enable stroke survivors to re-enter the health system well beyond their hospital discharge in order to address their changing needs and promote their improved or maintained function in community participation. Such long-term follow-up of stroke
survivors requires the health system to be flexible in accommodating the changing needs of stroke survivors over time. Stroke service delivery should accommodate the varying times that different individuals might take to adjust to the effects of stroke. This also accords with principles of chronic disease management, which recognise the unpredictable nature of the chronic disease experience on patients’ function.343

11.6 Service Re-Organisation and Policy Implications

11.6.1 Screening and Education for Psychological Morbidity
While there is potential to minimise unnecessary suffering in stroke survivors, this study highlights the complexity of assessing and treating psychological disorders in the stroke population and the need for well-informed health professionals. However, clinicians who are presented with a patient who has a complex interplay of depression, medical and social co-morbidity typically do not respond in the same manner as a stroke survivor with well-defined depression, indicating the need for a more comprehensive understanding of how such circumstances affect stroke survivors. While findings reinforce the importance of the early detection of psychological morbidity and contributing factors, qualitative findings identified that the recognition and initiation of appropriate interventions was not well performed by health professionals. This is a concerning finding since both quantitative and qualitative data demonstrated the persisting experience of psychological morbidity in the 12 months following stroke, which has the potential to be prevented and alleviated with the implementation of appropriate interventions (see Chapter 4.5).

Managing psychological morbidity is a responsibility of acute, rehabilitation and community settings alike. This requires re-organising services to ensure that screening for psychological morbidity is undertaken at routine intervals across all phases of care. Change in service practices regarding psychological morbidity requires staff to be adequately trained and resourced to effectively manage patient symptoms that are detected by screening. Health services should increase the resources and capacity of acute, rehabilitation and community teams to identify and manage post-stroke psychological morbidity, including PSD and anxiety, particularly in stroke survivors exhibiting clinical psychological symptoms soon after stroke.

Indeed PSD and anxiety are different conditions with different management strategies despite the fact there may be frequent comorbidity with some overlap of pharmacological and non-pharmacological approaches. Our findings have implications regarding the need for increased provision of social support and community participation post-stroke as compared to current practice. The lack of attenuation of depression with time after stroke, together with the understanding of post-stroke psychological trajectories provided by our previously published qualitative findings from this cohort, provide support for a policy of ongoing screening that is in keeping with some current guidelines but not with common current practice.
Screening

Screening can use relatively low cost techniques for identifying suspected post-stroke psychological morbidity. Staff can be readily trained to use screening instruments and make referrals to more qualified staff if stroke patients meet threshold scores. Where language impairments exist, assessments could be carried out in conjunction with a SP.

This doctoral dissertation employed the HADS as measures of post-stroke psychological morbidity. Both the HADS was a suitable screening tools allowing for the detection of depressive and anxious symptoms and distress in this study.

The HADS is one of the most-used and well-validated measures of anxiety and depression in patients with stroke. For instance, in a comparative study the depression sub-scale of the HADS performed equally well as other major depression instruments in diagnosis of depression (with Structured Clinical Interview for DSM-IV (SCID as the gold standard)) - ‘the areas under the curve of the SCL-90 depression subscale, Hospital Anxiety and Depression Scale depression subscale, and Hamilton depression scale were almost equal, ranging from 0.81 to 0.83. The area under the curve of the Beck Depression Inventory was only slightly lower (0.78).’

Regarding the monitoring of psychological morbidity using screening, some research suggests that screening alone, in the community, has not been associated with improved patient outcomes, and that a collaborative care approach to treat detected depression is necessary to improve outcomes. These collaborative care models generally utilise a case management approach, often involving a depression care manager (for patient education, follow-up and monitoring) and a psychiatrist or other mental health professional (for supervising care managers and providing clinical advice to the treating clinician).

Collaborative care models have been associated with improved depression outcomes in primary care as well as in chronic physical disease populations, including cardiology and diabetes. A barrier to implementing the collaborative care models is the greater resource cost. It would seem that the evaluation of screening and collaborative care models in the treatment of PSD and post stroke anxiety are needed.

Stroke Clinician Education

Australian and international guidelines recommend assessment for depression with validated screening tools. However, evidence suggests that health professional's compliance with routine screening remains inconsistent due to barriers including individual factors such as knowledge, awareness of guidelines, belief in effectiveness, and organizational factors including time restraints and colleague support. Further, barriers to adequate exploration of PSD are compounded by clinician focus on stroke prevention during outpatient care visits. Findings from this research suggest the
need for ongoing, comprehensive continuing education on depression care among stroke clinicians. Because the prevalence of PSD is high, continuing education in techniques for depression screening, psychopharmacology and alternative care for depressive disorders should be undertaken by all providers who care for cardiac patients. Ongoing support and training for GPs would be integral to this model, since most stroke survivors are managed in the community following their hospital discharge; GPs are thus ideally placed for ongoing monitoring of stroke survivors. Some changes have been made in Australia to the primary care system over the last decade to improve the management of mental health conditions, especially depression and anxiety (e.g. better access to mental health care initiatives) and to promote regular screening and monitoring of psychological disorders.347

Another option towards the improved education of health professional is an expansion of the core curriculum in stroke in medical, allied health and other similar programs of study is recommended. The success of screening for distress is evident in research undertaken in other chronic disease, most notably cancer whereby screening for distress has proved to be beneficial in opening discussion between cancer patient and health professional about present concerns and unmet needs and may lead to psychosocial referrals.360.

Overall, there is a need for policy development to underpin the identification of psychological morbidity by advocating screening at all stages of the stroke care continuum so that symptoms are managed effectively, and their effect on disability and reduced HRQoL. Co-ordinated services that target these areas could mitigate against adverse influences on HRQoL, and multi-disciplinary collaboration has been shown to be a component of successful stroke rehabilitation.10 Policy makers must address the need for greater clinical education, improved access to long-term stroke interventions and monitoring to improve identification of emergent psychological morbidity or exacerbation of psychological symptoms, and to mitigate factors that result in stroke survivors' role loss and altered community participation.

11.7 Implications for Practice
Overall the integration of quantitative and qualitative findings have implications for assessment and treatment of psychological morbidity in the acute, medium and long term phases of recovery. Findings identified areas to be addressed in stroke service delivery, including the need for increased health service resources to facilitate improved management of psychological morbidity.

Patient Centred Care
The integration of quantitative and qualitative findings in this study support the importance of patient-centred care in stroke rehabilitation and the involvement of the patient (and carer/family) throughout goal setting and rehabilitation processes. Patient
centred care has been shown to encourage patient motivation and engagement in therapy and is associated with better rehabilitation outcomes and reintegration into the community.\textsuperscript{11}

Further there is a need for stroke survivors’ preferences, such as social and emotional needs, to be considered throughout the rehabilitation process. A recent stroke research agenda \textsuperscript{361} indicated that interventions were likely to fail if patients lacked confidence in their ability to resume pre-stroke roles. While the biomedical model gives priority to physical tasks there is a need for closer consideration of stroke survivors’ priorities, in contrast to the tendency for health professionals to focus on discrete physical goals.\textsuperscript{77} Qualitative findings indicated the impact of the difficult managing unseen issues such as UI and fatigue which may be overlooked by clinicians if not mentioned by the patient, therefore suggesting the need for targeted questioning toward all lifestyle issues.

\textit{Long term management of stroke survivors}

Current management of long-term stroke issues, such as psychological morbidity, is limited by the fact that the current stroke rehabilitation system in Australia does not provide long-term monitoring and follow-up for stroke survivors.\textsuperscript{348} Their limited access to outpatient therapy beyond the initial few months following their hospital discharge is in part due to government policies and the division of responsibilities between state and Commonwealth funding bodies within the disability, health and education departments.

In order to achieve a comprehensive community-based service for managing post-stroke psychological morbidity, there is a need to increase funding for allied health staff to provide longer-term interventions. In Australia, current service delivery does not include long-term monitoring and follow-up of stroke survivors; indeed, 33\% of inpatient stroke patients do not receive a rehabilitation referral.\textsuperscript{348} Service re-organisation and the provision of seamless care, might also require referral to inpatient and community rehabilitation services for survivors in the first few months post-stroke. Stroke services should provide longer-term support for monitoring and assessing survivors’ mood, and provide interventions to address survivors’ increased disability or reduced community participation; identified in the current thesis as important potential modifiable risk factors. Ideally, longer-term services would have the capacity to respond quickly to survivors’ emergent or exacerbated psychological morbidity.

Anecdotal evidence indicates that referral to outpatient stroke rehabilitation following survivors’ hospital discharge usually requires the survivor to have need for a minimum of two allied health specialties, which further restricts their access to individualised care in response to the effect of different stroke impairments. This scenario is less than ideal and unlikely to meet the needs of an ageing population; the increasing prevalence of stroke therefore requires policy makers to respond accordingly.

The longitudinal nature of this study confirm the need for increased assessment and monitoring towards the experience of and development of psychological morbidity in the medium and longer term. Emergent mood disturbance is, by definition, not
Identifiable at stroke onset. In emergent cases the primary care physician may be the clinician best positioned to identify depression and initiate appropriate treatment. Case finding in this situation may be informed by targeted assessment in post stroke patients who experience social stressors or intercurrent health problem. In fact, to facilitate recognition and appropriate management of depression in primary health care the Australian government financial incentives for General Practitioners to undertake comprehensive mood assessments, using objective measures for depression, often using the K10).

**Services to promote improved HRQoL**

Findings also reveal the need for a more regular follow-up, in order to prevent suffering and maintain or increase HRQoL after a stroke. Improved communication with and paying attention to personal suffering, disability, isolation, poor community access, UI and fatigue is essential, as shown in this thesis. As a result, adequate assessment and the development of long-term management plans should be established prior to person complains about difficulties with reintegration in life. This requires improved knowledge among all professionals about the long term needs and strategies for chronic disease management of stroke.

Specifically there is a need for interventions that promote greater confidence in mobility, education and incorporate advice regarding return to driving and alternative transport processes during all stages of the rehabilitation process. Informed allied health staff can also assist with education towards equipping stroke survivors to understand and manage fatigue (such as pacing and problem solving). Unnecessary distress can be alleviated with findings generated from this study indicating that fatigue does not worsen over time. Finally, allied health professional can play a key role in training focused on increasing toilet independence, referral to specialised allied health and incontinence nurse to assess and treat UI and provide education on management strategies. Underpinning qualitative reports and coping with residual post stroke deficits and role loss was the importance of practical and emotional support provided by carers. As a result more emphasis should also be given on the support that carers of stroke survivors provide.

**Services to promote improved social support**

Central to the synthesis of quantitative and qualitative findings is the detailed findings from qualitative data which inform in greater detail the specific nature of perceived barriers to social support, participation in valued roles and community participation. Research shows that social network and social support can mediate reduced vulnerability to depression. However poor social networks among stroke survivors, who lack support from friends, relatives, and community, might deepen their difficulties. As a result there is a need for increased interventions to promote social interaction post stroke such as regular social group activity and meeting with peers or access to senior citizen centres and other community groups for creating social relationship and social activity among older adults.
Services that promote social support in stroke services should also include the needs of carers and significant others. The impact of stroke has been shown to have profound impact on the family members who provide care to stroke survivors, with at least fifty per cent of carers experiencing depression\textsuperscript{362,363} The risk of depression for those caring for stroke survivors increases when caring for stroke survivors in both the acute and chronic stroke phases, and for those carers who experience high burden\textsuperscript{363} is sudden, and the transition to being a carer brings rapid lifestyle changes, change in personal relationship with the stroke survivor and minimal time to adjust to new roles\textsuperscript{362}. Higher levels of depression among carers are associated with communication and personality changes in the stroke survivor, along with increased physical demands, long hours of care, reduced ability for participation in social and leisure activities and limited ability to engage in work\textsuperscript{363}. The impact on the quality of life (QoL) for those caring for stroke survivors has been well documented\textsuperscript{364}.

11.8 Implications for Future Research

This doctoral research highlights areas of potential development for service delivery regarding how to address ongoing mood disturbance and functional restrictions in stroke survivors, especially within the 12 months after stroke. The following key possibility for further research arises from this study:

- Development of a complex clinical intervention that incorporates the following key components: screening for depression and anxiety for 12 months after stroke; involving routine psychological morbidity screening and co-ordinated care of long-term outcomes post-stroke
- A cluster-randomised control trial testing the effect of a complex intervention. Implicit in this study is examination of the benefit of pharmacotherapy and psychotherapy interventions
- Exploration of clinical interventions that best address survivors’ community participation and increased social support.
- Such interventions should incorporate main endpoints of interest including psychological symptoms, HRQoL and altered disability.
- Future research should address exclusions such as language and stroke severity and to follow-up a cohort for a longer time frame.

11.9 Final Words

This doctoral research expands the current knowledge base about the development of the resolution of symptoms in stroke survivors in the 12 months post-stroke, and provides key insights into the lived experience of post-stroke psychological morbidity and its effect on community re-integration and recovery in a community-dwelling cohort.

There is an opportunity for health professionals to develop empowering partnerships with stroke survivors surrounding routine screening for psychological morbidity. A shift towards promoting longer-term monitoring and management of stroke survivors must
be undertaken, and should consider the factors that support and hinder psychological morbidity. Directing sustained attention to factors that impede stroke survivors’ community participation and lead to their social isolation may be first simple step towards improving health outcomes in longer-term stroke survivors.

The availability of allied health services and the delivery of long-term services remains limited due to resources constraints. The study provides evidence of the need for increased health resources, especially within the public health system and the community.

Implementing changes in practice requires resources, education and support, and should be underpinned by research to explore its effectiveness. This study demonstrates the benefits of using mixed methodology in future post-stroke research.
12 REFERENCES


107

Jennifer White

Exploring the Long-Term Experience of Psychological Morbidity in Community-Dwelling Stroke Survivors


