

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

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**BSc (Occupational Therapy)**

**Master of Medical Science**

**2008**

**University of Newcastle**

### **STATEMENT OF ORIGINALITY**

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Date: December 3, 2007

## **ACKNOWLEDGEMENTS**

I would like to acknowledge the support of my supervisors, Dr Lynette Mackenzie and Dr Parker Magin throughout this project. I would like to thank Lynette for being the first person to encourage me to undertake post-graduate study and for believing in my project. I would like to thank Parker for stepping into the role of supervisor at a later stage and embracing the project – he joined the project during the data analysis phase when I was uncertain and overwhelmed. I am grateful for his immense support and encouragement, which have helped me to maintain my vision and confidence in the outcomes. The knowledge he has imparted to me regarding qualitative research has been invaluable.

I would like to thank the participants who took part in the interviews. Their honesty and willingness to share about their lives was an inspiration. I never dreamed I could learn as much from them as I did.

I wish to express my appreciation to my colleagues for their support. I would specifically like to acknowledge Dr Michael Pollack and Dr Chris Levi who have enthusiastically supported my career within the Hunter Stroke Service. Special thanks to Louise Jordan and Lorna Davin for the professional and personal support they have lavished on me over these last few years.

Finally, I acknowledge my family for their constant love, support and encouragement and belief in me through all my academic efforts.

## **PAPERS PUBLISHED FROM THIS PROJECT**

The following papers from this project have been published in peer reviewed journals:

White, J., Magin, P., Mackenzie, L. & Pollack, M. (2007). "I cant": The occupational experience of stroke survivors in a community setting. A Qualitative Study. *Occ Therapy J Res in press* (Accepted 3.7.2007).

White, J., Parker, M., Attia, J., Pollack, M., Sturm, J. & Levi, C. (2007). Exploring post stroke mood changes in community dwelling stroke survivors: A qualitative study. *Arch Phys Med Rehabil in press*. (Accepted 19.11.2007).

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

***The undersigned co-authors contest that Jennifer White contributed to the aforementioned publications which form part of this thesis:***

Parker Magin

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Michael Pollack

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Jonathan Sturm

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## TABLE OF CONTENTS

STATEMENT OF ORIGINALITY .....	2
ACKNOWLEDGEMENTS.....	4
PAPERS PUBLISHED FROM THIS PROJECT .....	5
ABSTRACT .....	9
CHAPTER ONE: INTRODUCTION .....	10
1.1 Background.....	10
1.2 Research Aims.....	12
1.3 Context of Study .....	13
1.3.1 Stroke .....	13
1.3.2 The Impact of Stroke .....	13
1.4 Study Focus.....	15
1.5 Scope and Importance of this Study .....	15
1.6 Researcher's Background.....	16
1.7 Definition of Terms.....	18
1.7.1 Activity .....	18
1.7.2 Functioning.....	18
1.7.3 Goals .....	18
1.7.4 Health Related Quality of Life.....	18
1.7.5 Locus of Control .....	19
1.7.6 Occupation .....	19
1.7.7 Participation.....	19
1.7.8 Quality of Life (QOL) .....	19
1.7.9 Post Stroke Depression (PSD) .....	19
1.7.10 Rehabilitation.....	19
1.8 Synopsis .....	20
CHAPTER TWO: LITERATURE REVIEW .....	21
2.1 Introduction .....	21
2.2 Overview of Stroke.....	22
2.3 Impact of Stroke.....	22
2.4 Stroke Classification .....	23
2.5 Stroke Prevention and Acute Management .....	24
2.6 The Recovery Process.....	25
2.7 Rehabilitation Settings .....	27
2.8 Factors Influencing Transition to Community Living .....	28
2.8.1 Community Support.....	28
2.8.2 Social Support.....	29
2.9 Recovery .....	30
2.9.1 Maintaining Patient Priorities throughout Rehabilitation .....	30
2.9.2 Occupational Therapy Context.....	33
2.9.3 Quality of Life .....	35
2.9.4 Chronic Disease .....	36
2.10 Personal Influences on Recovery .....	37
2.10.1 Self-Efficacy .....	38
2.10.2 Post Stroke Mood Disturbance.....	38
2.10.3 Social Isolation .....	40
2.10.4 Stigmatisation.....	41
2.10.5 Adaption .....	42
2.10.6 Coping .....	44
2.10.7 Resilience.....	44
2.10.8 The Experience of Ageing and Stroke.....	45
2.10.9 Research Issues in Stroke .....	46
2.11 Key Issues to Emerge.....	46
CHAPTER THREE: METHODOLOGY .....	47

3.1	Chapter Overview .....	47
3.2	Description and Rationale for Study Design .....	48
3.3	Participants .....	50
3.3.1	Retrospective Cohort Study .....	50
3.3.2	Baseline Data from Cohort Study .....	50
3.3.3	Instruments used in the Cohort Study .....	51
3.3.4	Current Qualitative Study .....	52
3.3.5	Procedures .....	53
3.4	Field Notes .....	53
3.5	Data Analysis .....	54
3.5.1	Open Coding .....	54
3.5.2	Primary Coding .....	55
3.5.3	Axial Coding .....	55
3.5.4	Trustworthiness .....	56
3.5.5	Credibility .....	57
3.5.6	Transferability .....	57
3.5.7	Dependability .....	58
3.5.8	Confirmability .....	58
3.6	Ethics Approval .....	58
	CHAPTER FOUR: RESULTS .....	59
4.1	Characteristics of Participants .....	59
4.2	Identified Themes .....	61
4.2.1	Theme 1: Altered Participation in Life .....	62
4.2.2	Theme 2: Low Mood .....	64
4.2.3	Theme 3: Modulating Factors after Stroke .....	71
4.2.4	Theme 4: Experience with the Health System .....	75
4.3	Synopsis .....	83
	CHAPTER FIVE: DISCUSSION .....	84
5.1	Introduction .....	84
5.2	Overview and Discussion of Findings .....	84
5.3	Key Findings .....	85
5.3.1	Altered Participation in Life .....	87
5.3.2	Mood Changes .....	90
5.3.3	Modulating Factors after Stroke .....	93
5.3.4	Health System Experiences .....	95
5.3.5	Strengths and Contributions of Study Data .....	97
5.4	Limitations .....	99
5.5	Recommendations and Implications .....	100
5.5.1	Implications for Health Professionals .....	100
5.5.2	Rehabilitation Service Delivery Implications .....	103
5.5.3	Implications for Future Research .....	105
	CHAPTER SIX: CONCLUSION .....	107
	APPENDIX A: PUBLICATIONS FROM THIS STUDY .....	108
	A1 – “I Can’t”: The occupational experience of stroke survivors in a community setting. A Qualitative Study .....	108
	A2 - “Exploring Post Stroke Mood Disturbance” in community dwelling stroke survivors: a Qualitative Study .....	136
	APPENDIX B: PUBLICATION FROM LARGE COHORT STUDY Community-Dwelling Stroke Survivors: Function Is Not the Whole Story With Quality of Life .....	170
	APPENDIX C Interview Guide Questions .....	178
	Information Sheet .....	183
	Consent Form .....	186
	REFERENCES .....	188

## **ABSTRACT**

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

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

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

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

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

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

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