Examining the Nature of Resilience and Executive Functioning in People with Brain Injury and People with Multiple Sclerosis

Nivashinie Mohan

A thesis submitted for the Degree of Doctor of Philosophy at Flinders University,

Disability and Community Inclusion,

School of Medicine, Faculty of Health Sciences,

Adelaide, Australia

2010

## **TABLE OF CONTENTS**

# Chapter I

1	Statement of the Problem	.1
1.1	Introduction	.1
1.2	Definitions of resilience and executive functioning	.3
1.3	Rationale	.5
1.4	Aims and Outcomes	.8
1.5	Research and Documentation	.9

# Chapter II

2	Literatur	<b>e Review</b> 11
2.1	Introduc	<i>tion</i> 11
2.2	Resilien	<i>ce</i> 13
	2.2.1	A definition
	2.2.2	Resilience: A Historical Background15
	2.2.3	Protective factors
	2.2.4	Coping
	2.2.5	Mood states and resilient behavior
	2.2.6	Humour and resilience
	2.2.7	Disclosing positive emotions
	2.2.8	Fredickson's broaden and build theory of positive emotions
	2.2.9	Recent advances
	2.2.10	The relevance and clinical implications of resilience to practitioners

	2.2.11	Assess resilience as a developmental process	6
	2.2.12	Developing healthy perceptions of stressors	7
	2.2.13	Conclusion: Research on resilience	9
2.3	Executiv	ve functions	1
	2.3.1	Importance of executive functions	7
2.4	Trauma	tic brain injury4	9
	2.4.1	Introduction	9
	2.4.2	Neuropathology and causes of TBI	0
	2.4.3	Diagnostic criteria for Traumatic Brain Injury5	1
	2.4.4	Physical changes following TBI5	1
	2.4.5	Cognitive functions	2
	2.4.6	Impairments in Psychosocial Functioning following Frontal Lobe Injury6	0
	2.4.7	Mood disorders following a Traumatic Brain Injury	3
	2.4.8	Substance abuse and disability	8
	2.4.9	Identification and management of dual diagnosis	0
	2.4.10	Aspects of rehabilitation used in the intervention7	1
2.5	Multiple	e Sclerosis	5
	2.5.1	Epidemiology, Incidence and Prevalence of Multiple Sclerosis	5
	2.5.2	Etiology70	6
	2.5.3	Symptoms of Multiple Sclerosis70	6
	2.5.4	Fatigue7	8
	2.5.5	Pain and Multiple Sclerosis7	9
	2.5.6	Types of Multiple Sclerosis	9
	2.5.7	Diagnosis of MS8	1
	2.5.8	Treatment	2

2.5.9	Exercise and Multiple Sclerosis	83
2.5.10	Psychosocial Correlates of MS	84
2.5.11	Impairment of Cognitive and Executive functions in Multiple Sclerosis	87
2.5.12	Resilience for People with Multiple Sclerosis	88
2.5.13	Summary and conclusion	89

# Chapter III

3	Research	n Methodology	0
3.1	Introdu	ction9	0
3.2	Quantit	ative Methods9	2
3.3	Resilien	nce Scale9	3
3.4	Assessii	ng Executive Functioning9	4
3.5	Goal At	ttainment scaling9	7
3.6	The Ou	tcome Rating Scale9	8
3.7	Particip	pant Selection10	0
3.8	Particip	pant Demographic and Diagnostic Data10	1
	3.8.1	Mean age10	3
	3.8.2	Gender	3
	3.8.3	Education	4
	3.8.4	Employment10	5
	3.8.5	Types of Multiple Sclerosis	6
	3.8.6	Location of Brain Injury10	6
	3.8.7	Time since diagnosis10	)7

	3.8.8 Marital status1	07
	3.8.9 Children1	08
	3.8.10 Community Re- Entry Program1	.09
	3.8.11 The Multiple Sclerosis Society1	.09
3.9	Ethical Considerations1	10
3.10	Data collection points1	10
3.11	Analysis of Data1	12
	3.11.1 Wilcoxon Signed Rank Test1	13
	3.11.2 Mann - Whitney U Test1	13
	3.11.3 Spearman Correlation Coefficient1	13
3.12	Triangulation1	14
3.13	Reliability1	15
3.14	Validity1	16
3.15	Research Questions	17

# Chapter IV

4 Intervention	
Introduction	
4.1 Intervention Procedure	
4.2 Items of the intervention	
4.3 Structure of the bi weekly intervention sessions	

# Chapter V

5 H	Results		139
5.1	Case st	tudies	139
	5.1.1	Tina	141
	5.1.2	Leslie	163
	5.1.3	Betty	183
	5.1.4	Peter	200
	5.1.5	Rob	218
	5.1.6	Sarah	232
5.2	Resilier	nce Assessment Scores	247
5.3	Analysi	is of scores on the Resilience Scale	250
5.4	Executi	ive Functioning Assessment Scores	251
5.5	Analysi	is of scores on the Dysexecutive Questionnaire	253

## CHAPTER VI

6	Research Questions Answered
6.1	What is the relationship between measured resilience and executive functioning for all
	participants?254
6.2	Is there an improvement in resilience and executive functions after the intervention?258
6.3	Are there any group similarities or differences in the demonstration of resilient and
	executive functioning behaviours?
6.4	What is the evidence of resilient behaviours in the sample in this study?272

	of par	rticipants?	275
	6.5.1	Problem solving difficulties	277
	6.5.2	Social support	278
	6.5.3	Mood disorders	278
6.6	How do	pes having family/ spousal support influence resilience?	284
	6.6.1	Emotional support	284
	6.6.2	Practical support	287
	6.6.3	Strength of the family unit	288
	6.6.4	Religious and spiritual support	289
6.7	Does ur	nemployment compound the difficulties of TBI & MS and if so how?	290
6.8	What po	art does level of education play in coping with these conditions?	294
6.9	What is	the nature of social networks for all participants?	295
	6.9.1	Breaking of the social network	297
6.10	) To wh	at extent is denial a factor in coping with either condition?	300
6.11	To wh	at extent is age a factor in coping with either MS or TBI?	304
6.12	Since	people with frontal brain damage generally have impaired executive functioni	ng
	to who	at extent does a) training and/or b) mentoring compensate for executive	
	functio	oning	
	difficu	lties?	306
6.13	8 To wh	at extent do mood swings for either sample affect measures of executive	
	functio	oning and resilience?	307

6.5 What factors contribute to the resilience and effective executive functioning

# Chapter VII

71	Discussio	on3	310
7.1	Introdu	ction	310
7.2	Executi	ve functions and resilience	312
7.3	Social s	upport and networks	318
7.4	Mood st	tates and positive emotions	327
	7.4.1	High risk	330
	7.4.2	Coping and Resilience	331
7.5	Resilien	ace the norm?	339
7.6	Relearn	ing and reconstructing shattered selves	340
	7.6.1	Everyday Heroes	343

# Chapter VIII

8 Recommendations and Conclusion	
8.1 Limitations	345
8.2 Directions for future research	
8.3 Recommendations	
8.4 Conclusion	356
References	357

Appendix 1	Consent Form	447
Appendix 2	Ethics Approval Letter	449
Appendix 3	Letter of Introduction	450
Appendix 4	Participant Information Sheet	451
Appendix 5	Resilience Scale	453
Appendix 6	Wilcoxon Signed Rank Test	455
Appendix 7	Mann Whitney U Test	458

#### ABSTRACT

This study describes, identifies, measures and nurtures traits of resilience and executive functioning in two groups of participants, (a) ten with traumatic brain injury; 6 males, 4 females, (Mean Age = 42 years, SD =6.23) and (b) ten with Multiple Sclerosis, 3 Males, 7 Females (M =44, SD = 10.80). Participants who fulfilled the selection criteria underwent a six month individualized psychosocial intervention. The intervention was based on principles of person centred and cognitive behaviour therapy. Skill building exercises, problem solving training, appropriate management of mood disorders and support for building social networks were fundamental components of the intervention. Outcome data were collected using the Resilience Scale (Wagnild & Young, 1993), the Dysexecutive Functioning Questionnaire (DEX) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996), and Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) on three occasions; (01) baseline, (02) post intervention and (03) at six months follow up. Supporting data were obtained through case studies, medical records, psychological reports, interviews and participant observation. Statistical analysis of scores (Spearman Correlation Coefficient) indicates that there was a significant correlation between executive functioning and resilient behaviours. As resilience improved for the MS group, so did executive functioning abilities. Significant improvements in resilience scores post intervention (Wilcoxon Signed Rank) were reported by both groups. However, due to the severity of cognitive impairments in participants with TBI, an increase in DEX scores post intervention was not obtained. Despite low scores, significant behavioural changes were identified. Amongst them was the ability to set and persist at tasks, set goals, demonstrate insight and the ability to problem solve. Successful achievement of personal goals was dependent on the availability of support. Only then, were resilient behaviours more perceptible in both groups. Resilient behaviour was also dependent on mood states. When experiencing sustained personal equilibrium, (ie an

optimistic and resilient state) participants were better able to respond to feedback, make decisions and plan activities. Given the right circumstances and support, even the most impaired participants (impaired because of serious frontal lobe damage for people with TBI or people with primary progressive MS experiencing considerable pain and loss of mobility) were capable of resilient behaviour which in turn, was motivating for them and inspiring for their family and friends.

### SUPERVISOR'S CERTIFICATION

The researcher's supervisor confirms that he has approved all aspects of the research project detailed in this thesis, including the content of the literature review, the collection and analysis of data, reporting and the storage of data.

Supervisor:....

Dr Brian Matthews

### ETHICAL APPROVAL

The project titled: "Examining the nature and relationship of resilience and executive functioning in people with traumatic brain injury and multiple sclerosis has been granted ethical approval by the Social and Behavioural Ethics Committee of Flinders University, South Australia.

### DECLARATION OF AUTHENTICITY

I certify that this thesis does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: .....

Nivashinie Mohan

### **ACKNOWLEDGEMENTS**

To my Guru, Professor Roger Rees for giving me a dream. For turning my vision into reality. For taking me from the darkness of ignorance to the light of wisdom. It is not only words, it is a gratefulness felt by every fiber of my being – it is gratitude. You always said that completing a PhD is a journey. One which will change my life forever. I thank you for the journey and being instrumental in this change.

To, Dr Brian Matthews and Dr Michelle Bellon. For your guidance, support and unending encouragement. Thank you both for taking on this supervisory role. My heartfelt appreciation and gratitude.

To my family, Mohan, Saro, Thana, and Ko for rekindling the spark. I thank you with deep gratitude for lighting the flame within me.

For your guidance and wisdom, Jan Victory from the MS society. I thank you for your time and teachings.

But most of all, to my friends at the Community Re-entry Program and the Multiple Sclerosis society, who let me into their lives, and showed me the true meaning of resilience.

## LIST OF TABLES

Table 2.1	Characteristics of resilient behaviour	14
Table 2.2	Literature review matrix of Characteristics of Resilience	22
Table 2.3	Description of Protective factors	26
Table 2.4	Questions which can be used when assessing a client's schemas	38
Table 2.5	Executive functioning behaviours	43
Table 2.6	Methods which can be used to assess executive functions	46
Table 2.7	Executive functioning processes commonly difficult for people with frontal	
	lobe injury	48
Table 2.8	Strategies which facilitate attending behaviours	53
Table 2.9	Strategies to reduce orienting difficulties	55
Table 2.10	Strategies which facilitate language difficulties	56
Table 2.11	Strategies which promote self-awareness	57
Table 2.12	Types of memory	59
Table 2.13	Memory Rehabilitation Strategies	60
Table 2.14	Psychosocial difficulties in people with frontal lobe damage	62
Table 2.15	Structure which promotes errorless learning	73
Table 2.16	Symptoms of Multiple Sclerosis	77
Table 3.1	Characteristics of the Dysexecutive Syndrome measured by the DEX	
	Questionnaire (in question order)	96
Table 3.2	Steps used for Goal selection	98
Table 3.3	Participants' demographic and social data	102
Table 4.1	Items contained in the intervention	120
Table 4.2	Seven principles of problem solving	129
Table 4.3	Problem solving process	130

Table 4.4	Examples of the principles used in the intervention	138
Table 5.1	Tina's short term objectives, therapeutic intervention and goals	152
Table 5.2	Leslie's short term objectives, therapeutic intervention and goals	173
Table 5.3	Betty's short term objectives, therapeutic intervention and goals	192
Table 5.4	Peter's short term objectives, therapeutic intervention and goals	211
Table 5.5	Rob's short term objectives, therapeutic intervention and goals	225
Table 5.6	Sarah's short term objectives, therapeutic intervention and goals	240
Table 5.7	Total Resilience Scale Scores	248
Table 5.8	Resilience Scale categories for TBI participants	249
Table 5.9	Resilience Scale categories for MS participants	249
Table 5.10	DEX scores for all participants	251
Table 5.11	Dysexecutive Questionnaire scores for participants with TBI	252
Table 5.12	Dysexecutive Questionnaire scores for participants with MS	252
Table 6.1	Participants' correlation significance scores on the DEX and RS	254
Table 6.2	Characteristics of people who are regarded to be flexible	257
Table 6.3	Cognitive activities involved in executive functioning and compensating	
	strategies	258
Table 6.4	Benefits of participation in the intervention program	263
Table 6.5	Resilient behaviours	273
Table 6.6	Group conditions which contribute to depression in participants	
	with TBI or MS	280
Table 6.7	Individual conditions which contribute to depression in subjects	
	with MS or TBI.	282
Table 7.1	Observed adaptive and maladaptive coping behaviours	332

## LIST OF FIGURES

Figure 2.1	Protective factors which promote resilience	20
Figure 2.2	Frontal lobe umbrella: Executive functions and the relationship to	
	personality	44
Figure 3.1	Gender of both groups of participants	104
Figure 3.2	Levels of education for both groups of participants	104
Figure 3.3	Employment for both groups	105
Figure 3.4	Types of Multiple Sclerosis	106
Figure 3.5	Location of brain injury for TBI participants	107
Figure 3.6	Marital status for both groups of participants	108
Figure 3.7	Children for both groups of participants	109
Figure 3.8	Time line of data collection	112
Figure 5.1	Tina's strengths and protective factors	146
Figure 5.2	Tina's Outcome Rating Scale Scoring at 0, 2, 4 and 6 months of the	
	intervention	148
Figure 5.3	Tina's Resilience Scale Score	154
Figure 5.4	Tina's Dysexecutive Questionnaire scores	154
Figure 5.5	Leslie's protective factors and strengths	168
Figure 5.6	Leslie's Outcome Rating Scale scoring at 0, 2, 4, and 6 months of the	
	intervention	170
Figure 5.7	Leslie's Resilience Scores	177
Figure 5.8	Leslie's Dysexecutive Questionnaire Scores	177
Figure 5.9	Betty's protective factors and strengths	188
Figure 5.10	Betty's Outcome Rating Scale scoring at 0, 2, 4, and 6 months of the	
	intervention	190

Figure 5.11	Betty's resilience scale scores	194
Figure 5.12	Betty's Dysexecutive Questionnaire scores	194
Figure 5.13	Peter's protective factors and strengths	206
Figure 5.14	Peter's Outcome Rating Scale scoring at 0, 2, 4 and 6 months of the	
	intervention	208
Figure 5.15	Peter's Resilience Scale Scores	213
Figure 5.16	Peter's Dysexecutive Questionaire Scores	213
Figure 5.17	Rob's protective factors and strengths	221
Figure 5.18	Rob's Outcome Rating Scale scoring on 0, 2, 4 and 6 months of the	
	intervention	223
Figure 5.19	Rob's Resilience Scale scores	227
Figure 5.20	Rob's DEX scale scores	227
Figure 5.21	Sarah's protective factors and strengths	235
Figure 5.22	Sarah's Outcome Rating Scale score at 0,2,4 and 6 months of the	
	intervention	238
Figure 5.23	Sarah's Resilience Scale Scores	242
Figure 5.24	Sarah's Dysexecutive Questionnaire score	242
Figure 5.25	Mean resilience scale scores for both groups	250
Figure 5.26	Scores on the Dysexecutive Questionnaire (DEX) for all participants	253
Figure 6.1	TBI participant's resilience total scores at the three data collection points	259
Figure 6.2	MS participant's resilience total scores are three data collection points	260
Figure 6.3	TBI participants' Dysexecutive Questionnaire scale scores at three	
	data collection points	261
Figure 6.4	MS participant's Dysexecutive Questionnaire scale scores at three	
	data collection points	261

Figure 6.5	Mean total resilience scores for both groups at baseline, post intervention	
	and follow up	269
Figure 6.6	Mean scores on the DEX at baseline, post intervention and follow up	270
Figure 6.7	Implications of persistent unemployment	
Figure 6.8	Social networks for Leslie a participant with TBI	
Figure 6.9	Social networks for Sarah a participant with MS	

## IF....

IF you can keep your head when all about you Are losing theirs and blaming it on you, If you can trust yourself when all men doubt you, But make allowance for their doubting too; If you can wait and not be tired by waiting, Or being lied about, don't deal in lies, Or being hated, don't give way to hating, And yet don't look too good, nor talk too wise:

If you can dream – and not make dreams your master; If you can think – and not make thoughts your aim; If you can meet with Triumph and Disaster And treat those two impostors just the same; If you can bear to hear the truth you've spoken Twisted by knaves to make a trap for fools, Or watch the things you gave your life to, broken, And stoop and build 'em up with worn-out tools:

If you can make one heap of all your winnings And risk it on one turn of pitch-and-toss, And lose, and start again at your beginnings And never breathe a word about your loss; If you can force your heart and nerve and sinew To serve your turn long after they are gone, And so hold on when there is nothing in you Except the Will which says to them: 'Hold on!'

If you can talk with crowds and keep your virtue, ' Or walk with Kings – nor lose the common touch, if neither foes nor loving friends can hurt you, If all men count with you, but none too much; If you can fill the unforgiving minute With sixty seconds' worth of distance run, Yours is the Earth and everything that's in it, And – which is more – you'll be a Man, my son!

Rudyard Kipling