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SUBJECTIVE WELL-BEING IN MEN FOLLOWING NEUROSURGERY FOR ADULT ONSET EPILEPTIC SEIZURES

by

Martin P. Raffaele, B.A., GDP, MPhil (USyd)

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Faculty of Health Sciences
The University of Sydney
October 2014
STATEMENT OF ORIGINALITY

This thesis is my original work, and has not been submitted, in whole or in part, for a degree at this or any other university. Nor does it contain, to the best of my knowledge and belief, any material published or written by another person, except as acknowledged in the text.

28th October 2014

Martin Raffaele

APPROVAL OF THE HUMAN ETHICS COMMITTEE

The Human Research and Ethics Committee (HREC) of the University of Sydney granted approval for the survey and interview components of this research on 15 December 2011 (IRMA Project No: 2012/2468).
This thesis is dedicated to those closest to me for offering their support and strong belief that I was more than capable to complete this study. My goal to continue my tertiary education at The University of Sydney materialized in 2002, with the intent to offer greater understandings about epilepsy through lived experience studies. Supportive others never questioned my ability to achieve this.
ACKNOWLEDGEMENTS

I wish to thank the participants who offered their time to take part in the research project. Without their participation, the research would have been impossible.

I wish to state my highest gratitude to my supervisor, Professor Elias Mpofu, for his many hours of time, support and also belief in me to work to the thesis completion over the four years of study. I also wish to thank Professor Mpofu for his support for the Australian Post-Graduate Award scholarship, which supported my studies. I would like to also thank Professor Martin Mackey and Dr. Jennifer Smith-Merry, my Associate Supervisors for their time and support.

I wish to thank the University’s Disability Services Department for supplying all necessary computer programmes, including Kurzweil 3000, which allowed me to clearly read all relevant research documentation. I would have been considerably slowed down without the technology accommodations support.

I wish to thank Epilepsy Australia and Epilepsy Action, Australia, for their help with recruiting the participants for this study as well as their financial support to enable me to attend conferences relevant to my studies. My thanks also go to the International Bureau for Epilepsy (IBE) for their acknowledgement of the importance of my studies by awarding me the Outstanding Person with Epilepsy Award at the Ninth Asian and Oceania Epilepsy Congress in Manila, Philippines, in March, 2012.

The Faculty of Health Sciences provided an office both on the Cumberland and Camperdown Campuses, which allowed me to use a range of disability support programmes to advance my studies. The spacious office space protected me from major injury in the event of a seizure. These working spaces that the Faculty of Health Sciences provided accorded me a safe work environment, contributing to the successful completion of this study.
Abstract

Subjective Well-Being (SWB) is an individual’s personal evaluation of his or her life and also life satisfaction. It is an important indicator of the quality of the lived experience with disability. Determinants and qualities of SWB in men following neurosurgery for Adult Onset Epileptic Seizures (AOES) have not been investigated, despite the fact that SWB is a major indicator of their health-related quality of life (HRQoL). Biomedical interventions, including neurosurgery, are important for living with AOES. Often they are not enough in and of themselves for HRQoL with AOES. The lived experience as indexed by one’s SWB is a robust indicator of the wellbeing benefits from treatment for AOES. Neurosurgery is elective treatment for the control of partial seizure activity with the goal to enhance social and community participation with AOES. Lived experience with elective surgery for AOES is under-studied, although there is evidence to suggest that such studies would inform social and health support interventions to enhance HRQoL in people with AOES. Men with AOES are a special population in their risk for vulnerability to social perceptions by self and others that may restrict their participation in preferred roles.

This study aimed to determine how the SWB of men with AOES surgery is constructed around family relationships and health professional relationships, both medically and psychologically post-surgery. Other aims were to evaluate the perceived influence of social networks on SWB and determine the qualities of coping skills of men with AOES following elective surgery impact SWB.

Five individuals with AOES, all males, were the informants. This study applied an in-depth, semi-structured interview process with each of five male participants to investigate how their SWB was affected by elective surgery for AOES. It sought to address the questions how (a) family relationship wellbeing is impacted for those with AOES, (b) health rehabilitation consultation relations may change post-surgery for AOES, (c) participation in social networks is influenced and (d) post-surgery internal perception and coping strategies influence SWB. The data were thematically analysed using a hermeneutic and interpretive phenomenological analysis approach to explore emergent meanings from the rich description prompted by those questions.

Findings suggest that men with AOES and elective neurosurgery experience both resources for and obstacles to SWB within relationships in the family, health and social
network environments. Within family settings, they experience respect as a resource for SWB whereas marginalization lowered their sense of SWB. Positive resources for SWB within health consultation included their own knowledge AOES from lived experience and the alliances they achieved with provider health professionals. Social network resources for SWB included engagement with and participation of disability support organizations which recognized their lived knowledge of AOES and enabled access to resources for participation in the community.

These findings lead to the conclusion that personal agency explains SWB among men with AOES and elective neurosurgery in that the more proactive the individual is in addressing barriers to participation, the greater his SWB. This effect is likely explained by the individuals’ perceived and actual sense of control over their social outcomes across contexts of participation.

Implications of the findings suggest rehabilitative psycho-education for the person with AOES, family members and the social support network important for SWB with AOES. An inclusive psycho-education programme can add to competencies for social and community participation, which would raise SWB with AOES and surgery for it. A conceptual model in which external and internal perception factors are considered appears to explain the direct effects of health supports on SWB in men with AOES following neurosurgery.
**TABLE OF CONTENTS**

**DECLARATIONS** ........................................................................................................ii

**ACKNOWLEDGEMENTS** ...........................................................................................v

**ABSTRACT** ..................................................................................................................vi

**CHAPTER 1: Introduction**

- **The Study Purpose** ................................................................................................... 1
- **Personal and Insider Experience Background** ......................................................... 1
- **Personal Chronology** ............................................................................................... 2
- **Post-Surgery Experiences** ....................................................................................... 4
- **Subjective Well-Being** ............................................................................................ 5
- **Real World Aspects of SWB** .................................................................................. 6
- **The Central Role of Emotional Regulation in SWB** .............................................. 6
- **Epilepsy** ................................................................................................................... 7
- **Seizure Types** ......................................................................................................... 7
  - **Focal Seizure** .......................................................................................................... 8
  - **Generalised Seizures** .............................................................................................. 9
- **Education about AOES** ........................................................................................ 9
- **Psycho-Behavioural Sequalae of AOES** ............................................................... 10
- **Research on SWB and AOES** .............................................................................. 11
- **Relationships Impact with AOES** ...................................................................... 11
<table>
<thead>
<tr>
<th>Subject</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of Frequency of Seizures</td>
<td>12</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>17</td>
</tr>
<tr>
<td>Conceptual Model</td>
<td>17</td>
</tr>
<tr>
<td>Family Environment</td>
<td>18</td>
</tr>
<tr>
<td>Professional / Consultant Relationship</td>
<td>20</td>
</tr>
<tr>
<td>Social Networks</td>
<td>21</td>
</tr>
<tr>
<td>Self-Environment</td>
<td>21</td>
</tr>
<tr>
<td><strong>Research Objectives</strong></td>
<td>23</td>
</tr>
<tr>
<td><strong>Research Questions</strong></td>
<td>23</td>
</tr>
<tr>
<td><strong>Significance of Study</strong></td>
<td>24</td>
</tr>
<tr>
<td>Practical Significance</td>
<td>24</td>
</tr>
<tr>
<td>Methodological Significance</td>
<td>24</td>
</tr>
<tr>
<td>Theoretical Significance</td>
<td>24</td>
</tr>
<tr>
<td><strong>Limitations and Delimitations</strong></td>
<td>25</td>
</tr>
<tr>
<td><strong>Definition of Terms</strong></td>
<td>25</td>
</tr>
<tr>
<td>Case study</td>
<td>25</td>
</tr>
<tr>
<td>Subjective Well-Being (SWB)</td>
<td>26</td>
</tr>
<tr>
<td>Seizures</td>
<td>26</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>26</td>
</tr>
<tr>
<td>Adult-Onset Epileptic Seizures (AOES)</td>
<td>26</td>
</tr>
<tr>
<td>Neurosurgery</td>
<td>26</td>
</tr>
</tbody>
</table>
# Table of Contents

**Conclusion**................................................................................................................... 27

**CHAPTER 2: Philosophy and Psychological Aspects** 28

**Introduction**.................................................................................................................. 28

Cost of Social Stigma Post-Surgery................................................................................ 28

Cost of Discrimination...................................................................................................... 30

Cost of Denial................................................................................................................... 30

The History of Epilepsy and Surgery............................................................................... 31

Temporal lobe epilepsy (TLE).......................................................................................... 33

*Symptoms Associated with a Temporal Lobe Seizure*.................................................. 33

*Temporal lobe seizures (TLS): Symptoms associated with a focal seizure*.................. 33

*Pre-Ictal Period*.............................................................................................................. 34

*Pre-ictal physical symptoms*.......................................................................................... 34

*Pre-ictal psychological symptoms*................................................................................ 35

*Peri-Ictal Period*.............................................................................................................. 35

*Ictal Period*.................................................................................................................... 36

Treatment through surgery.............................................................................................. 36

*Chronic illness plasticity*............................................................................................... 37

*Post-neurosurgery plasticity*........................................................................................ 37

Treatment and Management of Seizure Activity Post-surgery........................................ 38

*Epilepsy Medication Post-surgery*................................................................................. 39

*Rehabilitation Therapy*.................................................................................................. 40
<table>
<thead>
<tr>
<th>Table of Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative treatments:</td>
<td>41</td>
</tr>
<tr>
<td>Atkins Diet:</td>
<td>41</td>
</tr>
<tr>
<td>Ketogenic diet:</td>
<td>42</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>43</td>
</tr>
<tr>
<td><strong>CHAPTER 3: Subjective Well-Being and Environmental Aspects</strong></td>
<td>44</td>
</tr>
<tr>
<td><strong>Introduction</strong></td>
<td>44</td>
</tr>
<tr>
<td>Description of Elements of Subjective Well-Being:</td>
<td>45</td>
</tr>
<tr>
<td><em>Happiness</em>:</td>
<td>45</td>
</tr>
<tr>
<td><em>Life-satisfaction</em>:</td>
<td>45</td>
</tr>
<tr>
<td><em>Fulfilment</em>:</td>
<td>45</td>
</tr>
<tr>
<td><em>Self-perception</em>:</td>
<td>45</td>
</tr>
<tr>
<td>The Relationship between SWB and AOES:</td>
<td>46</td>
</tr>
<tr>
<td>Environments:</td>
<td>49</td>
</tr>
<tr>
<td><em>Family Environment</em>:</td>
<td>50</td>
</tr>
<tr>
<td><em>Social Support through Long-Term Intimate Relationships</em>:</td>
<td>50</td>
</tr>
<tr>
<td><em>Sexual Dysfunction and the Amygdala Post-surgery</em>:</td>
<td>51</td>
</tr>
<tr>
<td><em>Health Environment</em>:</td>
<td>53</td>
</tr>
<tr>
<td><em>Social Network Environment</em>:</td>
<td>53</td>
</tr>
<tr>
<td><em>Disability Identity</em>:</td>
<td>54</td>
</tr>
<tr>
<td><em>Self-Environment</em>:</td>
<td>54</td>
</tr>
<tr>
<td>Individuals Perceive SWS Differently, Based on Personal Perception:</td>
<td>54</td>
</tr>
</tbody>
</table>
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Related Quality of Life</td>
<td>55</td>
</tr>
<tr>
<td>Psychological Trauma Arising from Surgery</td>
<td>56</td>
</tr>
<tr>
<td>Depression and Mood Disorders</td>
<td>57</td>
</tr>
<tr>
<td>Labelling and Stigma</td>
<td>58</td>
</tr>
<tr>
<td>Problems of Stigma as a Result of Labelling</td>
<td>58</td>
</tr>
<tr>
<td>Stigma and Its Psychological Effects</td>
<td>60</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>61</td>
</tr>
<tr>
<td><strong>CHAPTER 4 Methodology</strong></td>
<td>62</td>
</tr>
<tr>
<td><strong>Introduction</strong></td>
<td>62</td>
</tr>
<tr>
<td>Phenomenology or Grounded theory</td>
<td>62</td>
</tr>
<tr>
<td>Research Design</td>
<td>64</td>
</tr>
<tr>
<td>Phenomenological case study approach</td>
<td>64</td>
</tr>
<tr>
<td>Case Study</td>
<td>65</td>
</tr>
<tr>
<td>A Multiple Case Study</td>
<td>66</td>
</tr>
<tr>
<td>The Interpretive Phenomenological Analysis</td>
<td>67</td>
</tr>
<tr>
<td>Insider Perspective</td>
<td>68</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>69</td>
</tr>
<tr>
<td>Trustworthiness in Qualitative Studies</td>
<td>69</td>
</tr>
<tr>
<td>Pilot Study</td>
<td>69</td>
</tr>
<tr>
<td>Goal of Pilot Study</td>
<td>70</td>
</tr>
<tr>
<td>Pilot Study Structural Guide</td>
<td>70</td>
</tr>
</tbody>
</table>

*Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures*
# Table of Contents

Sampling Frame for the Pilot study................................................................. 73

Social Resonance............................................................................................. 73

Participants for pilot study............................................................................. 73

Establish Networks for Participant Recruitment......................................... 74

Participating centres/agencies....................................................................... 74

Recruitment Procedures.................................................................................. 74

*Disability/Epilepsy newsletter and magazines*............................................. 74

*Sydney-based community centres*............................................................... 75

Snowballing..................................................................................................... 75

*Results of procedures*.................................................................................. 75

The Credibility and Trustworthiness of the Data............................................ 75

Pilot Study Data Analysis............................................................................... 76

Key Lessons from the pilot study................................................................. 76

Main Study..................................................................................................... 79

*Design*.......................................................................................................... 79

*Participants and Setting*............................................................................. 83

*Age*............................................................................................................... 83

*Type of Epilepsy*......................................................................................... 83

*Living arrangements*.................................................................................. 83

*Healthcare relationships*............................................................................ 83

Main Study Data Analysis............................................................................. 84
## Table of Contents

**Conclusion** ........................................................................................................... 84

**CHAPTER 5: Results** ......................................................................................... 85

**Introduction** ........................................................................................................ 85

Changes in family relationships post-surgery ......................................................... 85

**Role Positioning** ................................................................................................ 87

*Marginalization* ....................................................................................................... 87

*Distancing of companionship* ............................................................................... 88

*Relationship finder and nurturer* ......................................................................... 89

*Exclusion by family of origin* ............................................................................... 89

*Dependency* ........................................................................................................... 91

*Overprotection and indebtedness* ......................................................................... 92

*Transportation* ....................................................................................................... 93

*Financial* ................................................................................................................. 93

**Role Enmeshment** .............................................................................................. 95

*Spouse – Child* ...................................................................................................... 95

*Parent – Child* ....................................................................................................... 96

*Adult – Child* ......................................................................................................... 96

**Responsibility** ..................................................................................................... 97

*Accountability* ...................................................................................................... 97

*Duty to care* .......................................................................................................... 98

*Decision-making* ................................................................................................. 99
Changes in Health Professional / Consultant relationships post-surgery .................. 100

Perceived Change in context of Professional/Consultant relationships ................. 102

Neglect ................................................................................................................. 102

Expertness .......................................................................................................... 103

Support ................................................................................................................. 105

Time availability .................................................................................................. 105

Understanding and Empathy ............................................................................. 107

Responsibility of Health Professional / Consultant ............................................ 109

Adapt communication style ............................................................................. 109

Self-care ................................................................................................................. 110

Decision-making support .................................................................................. 111

Changes in Social Network Relationships Post-surgery .................................... 112

Social Affiliation ................................................................................................. 112

Social Exclusion / Inclusion ................................................................................ 114

Collapsed social network ................................................................................. 114

Neighbourhood collaboration ........................................................................... 116

Work-place engagement .................................................................................... 116

Education Responsibility .................................................................................... 117

Epilepsy Support Groups and Communities ...................................................... 118

Support education ............................................................................................... 119

Show respect for people’s rights ........................................................................ 119
# Table of Contents

Reduce the risk of discrimination ................................................................. 120

Increase the community quality of life ...................................................... 120

Social Labelling ...................................................................................... 120

*Stigma* ................................................................................................. 121

*Positive Labelling and Community Support* ............................................ 122

Coping Strategies to Enhance the Participants’ SWB .................................. 123

Cognitive Coping Strategies ..................................................................... 126

*Cognitive Reconstruction* ..................................................................... 126

*Threat Minimization* .......................................................................... 126

*Emotional Expression* ......................................................................... 127

*Wish-fulfilling Fantasy* ......................................................................... 128

*Self-blame* ........................................................................................ 128

Behavioural Coping Strategies ................................................................. 129

*Information-seeking* ......................................................................... 129

Conclusion ............................................................................................... 131

**CHAPTER 6: Discussion and Conclusion** ............................................. 133

*Introduction* .......................................................................................... 133

Quality of Immediate and Extended Relationships .................................. 133

*Role Positioning* ................................................................................ 133

Changes in Health Professional / Consultant Relationships Post-surgery .... 135

Changes in Social Network Relationships Post-surgery .......................... 137
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Affiliation</td>
<td>137</td>
</tr>
<tr>
<td>Coping Strategies Effects on SWB</td>
<td>138</td>
</tr>
<tr>
<td><strong>Information Seeking Actions</strong></td>
<td>139</td>
</tr>
<tr>
<td><strong>Cognitive restructuring</strong></td>
<td>139</td>
</tr>
<tr>
<td>Modified Conceptual Model</td>
<td>140</td>
</tr>
<tr>
<td>Cultural Norms and Gender Role Identity</td>
<td>142</td>
</tr>
<tr>
<td>Social Identity and Social Stigma</td>
<td>143</td>
</tr>
<tr>
<td>Social Network Effects</td>
<td>144</td>
</tr>
<tr>
<td><strong>Limitations of the Study</strong></td>
<td>144</td>
</tr>
<tr>
<td>Recommendations</td>
<td>145</td>
</tr>
<tr>
<td>Rehabilitation Implications</td>
<td>148</td>
</tr>
<tr>
<td>Family participation</td>
<td>149</td>
</tr>
<tr>
<td>Health professional with Patient Oriented Care</td>
<td>149</td>
</tr>
<tr>
<td>Social Support is Important</td>
<td>150</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>150</td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td>151</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>152</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>197</td>
</tr>
<tr>
<td>Appendix A: Definition of terms used in the thesis</td>
<td>197</td>
</tr>
<tr>
<td>Appendix B: Participant Consent Form</td>
<td>203</td>
</tr>
</tbody>
</table>
Table of Contents

Table 4.2 Pilot Study Structural Guide ................................................................. 71
Table 4.3 Pilot Study Participant Summary ......................................................... 72
Table 4.4 Strategy for recruiting participants for the pilot study ......................... 77
Table 4.5 Interview Guild .................................................................................. 78
Table 4.6 Main Study Participant Demographic Summary ................................. 81
Table 4.7 Main Study Participant Social Network Summary ............................... 82
Table 5.1 The impact of role positioning and responsibility in the family Environment .............................................................................................................. 86
Table 5.2 Illustrative Statements on role marginalization .................................... 87
Table 5.3 Illustrative Statements on role positioning ............................................ 92
Table 5.4 Illustrative Statements on role enmeshment ........................................ 95
Table 5.5 Illustrative Statement on Responsibility ............................................... 97
Table 5.6 The impact of role positioning and responsibility in health relationships on SWB ................................................................. 101
Table 5.7 Illustrative Statements on neglect ....................................................... 103
Table 5.8 Illustrative Statement on role support ............................................... 105
Table 5.9 Illustrative Statement on responsibility of health professional/ consultant 109
Table 5.10 Illustration of how the effects of relevant social networks influenced the participants’ SWB ......................................................................................................................... 113
Table 5.11 Illustrative Statement of exclusion/inclusion in a social affiliation ....... 114
Table 5.12 Illustrative Statement on education responsibility ............................. 118
Table 5.13 Social Labelling ................................................................................. 121
Table 5.14 The coping strategies of Personal Environment on Subjective Well-Being .... 124
Table 5.15 Cognitive coping strategies of participants ............................................. 125

Table 5.16 Behavioural coping strategies of participants ........................................ 129
## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>AED</td>
<td>Anti-epileptic Drugs</td>
</tr>
<tr>
<td>AOES</td>
<td>Adult Onset Epileptic Seizures</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychology Association</td>
</tr>
<tr>
<td>ATRA</td>
<td>American Therapeutic Recreation Association</td>
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<tr>
<td>BMI</td>
<td>Brain and Mind Institute</td>
</tr>
<tr>
<td>CBI</td>
<td>Chronic Brain Injury</td>
</tr>
<tr>
<td>GBS</td>
<td>Guillain-Barre’s syndrome</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CID</td>
<td>Chronic Illness and Disease</td>
</tr>
<tr>
<td>CNS</td>
<td>Central Nervous System</td>
</tr>
<tr>
<td>CPS</td>
<td>Complex Partial Seizures</td>
</tr>
<tr>
<td>CRS</td>
<td>Commonwealth Rehabilitation Service</td>
</tr>
<tr>
<td>CT</td>
<td>Computed Tomography</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalography</td>
</tr>
<tr>
<td>EFE</td>
<td>Extended Family Environment</td>
</tr>
<tr>
<td>EISG</td>
<td>Epilepsy Inner-City Support Group</td>
</tr>
<tr>
<td>GPS</td>
<td>General Partial Seizures</td>
</tr>
<tr>
<td>GS</td>
<td>Generalised Seizures</td>
</tr>
<tr>
<td>HRQOL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>IDD</td>
<td>Intercital Dysphoric Disorder</td>
</tr>
<tr>
<td>IFE</td>
<td>Immediate Family Environment</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>JECA</td>
<td>Joint Epilepsy Council of Australia</td>
</tr>
<tr>
<td>LTL</td>
<td>Left Temporal Lobe</td>
</tr>
<tr>
<td>MR</td>
<td>Multidisciplinary Rehabilitation</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
</tr>
<tr>
<td>PCRM</td>
<td>Physicians Committee for Responsible Medicine (America)</td>
</tr>
<tr>
<td>PGS</td>
<td>Primary Generalised Seizures</td>
</tr>
<tr>
<td>PTL</td>
<td>Partial Temporal Lobectomy</td>
</tr>
<tr>
<td>PWE</td>
<td>People With Epilepsy</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>RTL</td>
<td>Right Temporal Lobe</td>
</tr>
<tr>
<td>SGS</td>
<td>Secondary Generalised Seizures</td>
</tr>
<tr>
<td>SPECT</td>
<td>Single Photon Emission Computed Tomography</td>
</tr>
<tr>
<td>SWB</td>
<td>Subjective Well-Being</td>
</tr>
<tr>
<td>SPS</td>
<td>Simple Partial Seizure</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>TLE</td>
<td>Temporal Lobe Epilepsy</td>
</tr>
<tr>
<td>TLS</td>
<td>Temporal Lobe Seizures</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Chapter 1

Introduction

The Study Purpose

The exploration of subjective well-being (SWB) in men following neurosurgery for adult onset epileptic seizures (AOES) is the focus of this study. The study addresses the knowledge gap about the health and well-being with a debilitating neurocognitive disorder within everyday social contexts. Neurosurgery is used as a means of controlling AOES when the chronic illness is untreatable through medication alone. Its effects on quality of life with AOES are unknown. The term, onset in this research refers to the time or age at which seizure activity commenced.

The study reports on the lived experiences with AOES of five males. Each case study illustrates the post-surgery issues that the person with AOES experienced in significant health related environments. The environments include: Family, Professional/Consultant and Social Networks. Participants reflected upon their post-surgery recovery process and what effect the external perception of these three environments has on their SWB. In most cases, the effects were personal to the individuals, although some common elements were apparent.

Personal and Insider Experience Background

I am an individual who has experienced two left hemisphere partial temporal lobectomy (PTL) procedures as a means to reduce adult onset epileptic seizures (AOES). The main motivation for conducting this research derives from my strong interest in the neurological condition, epilepsy and its impact on quality of life. My interest became evident following my second neurosurgical procedure in 2000. After my first left PTL procedure in 1998, I began participating with the Epilepsy Inner-city Support Group (EISG). My experience and knowledge about SWB in individuals living with AOES increased as the result of my participation with this community support group. I became aware of there being similarities of SWB in adult male members who have epilepsy and had experienced similar medical procedures to control seizure activity.
Chapter 1: Introduction

Personal Chronology

At the age of 19 years I began to unknowingly experience adult onset epileptic seizures (AOES) (see Table 1.1 for chronology). It was not until December of 1990 that my fiancé, who had witnessed the onset on several occasions, brought this to my attention. Although I had been experiencing a number of Complex Partial Seizures (CPS), at least once a month for a period of around one year, my fiancé appeared not to be bothered. A near fatal car accident, resulting from the experiencing of a seizure whilst driving, was to change my attitude towards AOES. I experienced many negative emotions, including fear, frustration and jealousy as a result of the diagnosis and lack of education on the condition.

At 24 years of age, following a long list of neurological testing, it was suggested by my neurologist that I undergo an anterior temporal lobectomy. This form of neurosurgery is conducted to remove the hippocampus as a means to strongly reduce irregular neuronal activity causing uncontrolled AOES to occur. The decision made upon whether to ensue with the surgery was strongly influenced by a lack of knowledgeable support when considering the physical and psychological effects of the elective procedure pre-surgery.
Table 1.1 Incidents relating to my epilepsy and neurosurgery

<table>
<thead>
<tr>
<th>Year</th>
<th>Incidents Relating to My Epilepsy and Neurosurgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>Diagnosed with adult onset complex partial seizure (CPS) at Royal Prince Alfred Hospital (RPAH) following eight months of investigation</td>
</tr>
<tr>
<td></td>
<td>Lesions were evident on the hippocampus of the left hemisphere temporal lobe</td>
</tr>
<tr>
<td></td>
<td>Education and counselling was not provided on the condition and how it would affect my life</td>
</tr>
<tr>
<td>1993-1994</td>
<td>18 months of neurological testing was performed (including 14 days of 24-hour examination/observation)</td>
</tr>
<tr>
<td></td>
<td>Left hemisphere partial temporal lobectomy (PTL) was recommended to control seizure activity at RPAH</td>
</tr>
<tr>
<td></td>
<td>Education and counselling relation to the condition and operation were was not provided</td>
</tr>
<tr>
<td></td>
<td>I chose not to undertake the neurosurgical procedure</td>
</tr>
<tr>
<td>1997-1998</td>
<td>Two years of neurological testing was performed (including 21 days of 24-hour examination/observation)</td>
</tr>
<tr>
<td></td>
<td>Partial temporal lobectomy (PTL) was recommended for control of seizure activity at Prince of Wales hospital (PWH)</td>
</tr>
<tr>
<td></td>
<td>Chose to undertake the neurosurgical procedure</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation was not provided</td>
</tr>
<tr>
<td>2000</td>
<td>Long period of neurological testing was performed</td>
</tr>
<tr>
<td></td>
<td>Seizure activity recommenced</td>
</tr>
<tr>
<td></td>
<td>Examinations found that the 1998 procedure was incomplete</td>
</tr>
<tr>
<td></td>
<td>Chose to follow recommendations, and underwent a second left hemisphere PTL at PWH</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation was not provided</td>
</tr>
<tr>
<td></td>
<td>Further seizure activity commence within a month following the neurosurgery</td>
</tr>
<tr>
<td>2001</td>
<td>A Further Period of test were performed at PWH</td>
</tr>
<tr>
<td></td>
<td>Lesions were located on the right hemisphere temporal lobe</td>
</tr>
<tr>
<td></td>
<td>A further PTL procedure was analysed as not optional as the resection would reduce memory capacity to 15 seconds in duration</td>
</tr>
</tbody>
</table>

A number of unanswered questions resulted in both my wife and I experiencing considerable anxiety: (1) would the result of the operation leave me with significant cognitive damage? (2) Would the surgery cause me to become even more embarrassed...
when in general society? The fear of the unknown, mostly due to a lack of psycho-
education about these issues, encouraged poor SWB. This confusion strongly influenced
my decision not to experience the elective surgery procedure at that time.

For a period of eight years I took every possible antiepileptic medication available at
that time. Combinations of up to three medications, at higher than recommended doses,
were trialled, with the inability to terminate seizure activity resulting in poor SWB. In
actual fact, the frequency of seizures increased to seven diurnal CPSs each week, with
nocturnal activity remaining unregistered. In 1998, a neurologist suggested that I
experience a Partial Temporal Lobectomy (PTL) to reduce the seizure activity. It was at
this time I chose to undergo the procedure, conducted in August 1998, with the belief
that it would positively impact my quality of life and result in greater SWB.

**Post-Surgery Experiences**

I experienced a period of 10 months remission from seizures post-surgery, and greater
SWB. However, CPS activity returned following the withdrawal of Neurontin
(gabapentin) at this time. This is a well known side-effect that is experienced for a short
period when a medication such as Neurontin is being removed from the blood system
(Beran, et al., 2001; Scheinfeld, 2003). Following an extended period of CPS, with an
increase in frequency a second long period of neurological examinations was performed
at The Prince of Wales Hospital (PWH), Sydney, Australia. Results indicated that the
previous elective PTL procedure had failed to remove an adequate proportion of the
damaged tissue. Subsequently, a second operation was recommended and performed in
October 2000 to successfully complete this left hemisphere PTL.

In mid-2001 I commenced experiencing an increased number of seizures. Further
examination was to determine that this irregular neuron activity was the result of right
temporal lobe lesions. A neurologist advised that the same operative procedure would
not be recommended within the right hemisphere as the result would be the inability to
retain memory beyond a short-term period of approximately 15 seconds in duration.
Following this diagnosis, I sought to attain further relevant knowledge about epilepsy
and the frequent difficulties experienced as the result of this chronic illness. Thus, I
choose for my graduate studies to focus on lived experience of people with AOES.
Chapter 1: Introduction

The need for research on the SWB in men with AOES and elective surgery has been identified by a number of neuro-epileptic specialists as a topic that lacks adequate research time and findings (Austin, 2011; Bellon, 2011; Holmes, 2010). A case study approach would meet the need to explore lived experiences influencing SWB with AOES and elective surgery. In the following sections quality of SWB and social health with AOES are considered as background to the conceptual model and research questions for this study.

Subjective Well-Being

Subjective well-being (SWB) in a person’s life is based on both emotional and cognitive evaluations, including feelings of happiness, peace, fulfilment, and self-perception (Diener, Oishi & Lucas, 2003). Self-perception is an aspect of SWB that is often assessed. SWB is an individual’s personal evaluation of their life or experienced quality that has influenced this. It is often influenced by life coping / adjustment skills or how a problem is perceived by the individual (Krause & Broderick, 2004; Nelson, 2001). Diener and Ryan (2009) characterised SWB to include self judgements, feelings about self-perception, interest, and engagement. Affective reactions such as joy and sadness to life events are self-evaluations made by the individual. Other outcomes may be measured by objective external criteria, such as whether the individual is in a personal relationship (Nelson, 2001).

This research focuses on four SWB domains in men with neurosurgery for AOES; Physical Well-Being; Social / Family Well-Being, Emotional Well-Being, and Functional Well-Being. These aspects are important because they influence social participation for people with a health condition (Webster, Cella & Yost, 2003). The World Health Organization (WHO) International Classification of Functioning, disability and health (ICF) considers participation in preferred action ties and environments to be the essence of healthy living. The ICF categorises disability as a complex phenomenon to which internal and external social environments are fundamental.
Lived experience with AOES would be impacted not only by the physical health aspects, but also the social environmental context. These ICF considerations background the questions for this study, the findings and related discussion.

**Real World Aspects of SWB**

SWB has real world consequences. For instance, a person with greater SWB is more likely to gain a promotion in the workplace than another with poor SWB (Clayton & Chubon, 1994; Lee & McCormick, 2004). Similarly, a person who experiences more satisfaction in the workplace is more likely to experience greater SWB (Diener, Nickerson, Lucas & Sandvik, 2002; Lee & McCormick, 2004). A man with poor SWB is more likely to lose employment than another with good SWB (Michalos, 2008). A person with greater SWB is more likely to attain new employment faster (Clark, 2003). Diener and Ryan (2009) reported couples with greater SWB as more likely to experience a strong relationship. They also claimed that those who enter a relationship with poor SWB are more likely to witness their relationship dissolve. When the chronic illness of AOES develops, with SWB might suffer from stress developing in the personal relationship.
The Central Role of Emotional Regulation in SWB

The correlations of pleasant emotions that are associated with SWB have received research attention (Kämpfe & Mitte, 2010). For instance, the level of psycho-education and financial stability one attains often influences greater SWB (Diener & Ryan, 2009; Michalos, 2008). People with higher goals set larger, more strenuous objectives of attainment that often result in greater SWB (Diener & Biswas-Diener, 2003).

Greater SWB is often influenced by social group participation. In general, people who live in more accepting social environments experience higher SWB. This may be the result of experiencing a sense of personal freedom, gaining new knowledge and enjoying life to the full (Diener & Ryan, 2009). Not allowing past negative social experience to influence present and future decision making also heightens SWB. The converse is also true (Diener & Biswas-Diener, 2003). For a number of individuals with AOES, the choice to experience neurosurgery often results from the expectation to have higher SWB and greater personal fulfilment.

Epilepsy

Epilepsy is the leading neurological disorder experienced world-wide, historically the chronic illness has failed to be knowledgably understood or accepted in all societies (Räty, Wilde-Larsson & Söderfeldt, 2003). The stigma associated with epilepsy allows even occasional seizures to have serious personal and social effects that most often result in poor SWB (Jacoby, 2002; Wheless, 2006).

Seizure Types

Epilepsy is a chronic illness that is characterized by seizures that result from irregular neurological nerve activity (Téllez-Zenteno, Dhar & Wiebe, 2005). An imbalance of regular nerve activity causes the individual with the condition to experience a seizure. There are two major forms of seizures; a Focal seizure and a Generalised seizure (Figure 1.2).
Focal Seizures

Focal seizures result from irregular neurological activity commencing from a single (partial) region in the brain (Mosby’s dictionary, 2009). The forms of seizure activity that can be controlled by neurosurgery are focal seizures. This is most often the result of scar tissue forming on the hippocampus, located within the temporal lobe. The hippocampus allows for memory to be saved and accessed (Schachter & Andermann, 2008).

The focal forms of seizure activity are Simple Partial Seizures (SPS) and Complex Partial Seizures (CPS). The SPS commence from a focal point of the brain, lasting for up to 30 seconds in length. When experiencing SPS, the person maintains consciousness as the irregular neurological activity remains within the epileptogenic zone of its commencement. The person with SPS will experience an aura; in most cases being an unusual smell or taste (Blume, 1997).

The CPS can last from one to five minutes in length. At this time, irregular neurological discharge that commenced within an epileptogenic zone then spreads to motor areas. The CPS is commonly physically observed as spasmodic movement commencing in the hand, face, or feet. The disturbance may then spread to the lower part of the motor strip controlling mastication (Mosby’s dictionary, 2009). This may result in the experiencing of secondary generalised seizures, including a loss of consciousness uncontrollable shaking / convulsions occurring. When seizure activity is isolated to a specific focal point, it is possible for a neurosurgical procedure, such as a partial temporal lobectomy.
(PTL) to be performed as a method to reduce this irregular activity (Ko & Ramsay, 2013).

**Generalised seizures**

There are six forms of generalised seizures (GS); Absence, Myoclonic, Tonic, Clonic, Tonic-Clonic, Atomic. The irregular neuro-activity that stimulates GS does not originate from a single epileptogenic zone, with activity generating from both hemispheres. When experiencing an absence seizure, the patient can lose consciousness for up to 20 seconds, giving the impression that s/he is “staring into space”. When experiencing a myoclonic seizure, one side of the body will lose complete muscular strength, causing the body to fall. The patient remains conscious and will often hide this by saying, “I just tripped.” When experiencing the following seizure type, Tonic, Clonic, Tonic-Clonic, and Atomic, the patient will lose consciousness and fall (Mosby’s dictionary, 2009).

**Education about AOES**

Limited time has been dedicated to education about AOES in all environments, including family, professional / consultant, and social network societies. A small number of research projects have focused on the psychosocial effects that this chronic illness has upon relationships in all environments and overall SWB. Research by Famularo, Fenton, Kinscherff, Barnum, Bolduc, et al. (1992) focused on whether neurocognitive factors played a unique and significant role in predicting delinquent behaviour in groups at high risk, inner-city adolescents. Research by Zinkus and Gottlieb (1983) found that juvenile delinquents with severe auditory processing difficulty and speech disorders will often experience overall negative social judgement, frequently resulting in anti-social activity.

One of the major causes of the increase in negative social judgement towards people with AOES is often the result of a misinterpretation of the symptoms (Famularo, et al., 1992). These misperceptions include drug abuse, bi-polar disorder, dementia, and schizophrenia (Mirsattari, Gofton & Chong, 2011). The misconceptions may exacerbate the impact on SWB (Lucas, Dyrenforth & Diener, 2008). The accusations of the observer may confuse the individual who was unaware of experiencing AOES; resulting in actions of withdrawal and poor SWB being experienced.
Psycho-Behavioural Sequalae of AOES

The temporal lobes are involved in the primary organisation of sensory input (Corkin, Amaral, González, Johnson & Hyman, 1997). Selective attention to visual or auditory input is common with damage to either of the temporal lobes. Most individuals with temporal lobe lesions experience complications recalling words and images, and placing these into categories (Bell, Lin, Seidenberg & Hermann, 2011). For instance, an individual with temporal lobe lesions may be shown the image of a fork but is unable to collaborate and repeat the word that is the title of this implement. Lesions pertaining to the left temporal lobe often affect recognition of visual content, such as the recall of a facial image. This potentially affects the social life of the participant, as he is often unable to identify another individual he recently met and address them by name. Although the second person may consider themselves to be an acquaintance, they may often be offended that the individual with epilepsy is unable to recall their name. This will most often result in poor SWB for the individual with epilepsy, causing further discomfort when they next meet. This will often influence the individual to fear new relationships, resulting in social isolation.

An individual with AOES will often experience symptoms that include poor word recognition, decreased recall of verbal information, and speech perception. Premature, uneducated judgement by social environments based upon their perception about the cause of these speech deficits may often lead to incorrect judgement, including the intellectual level of the individual. This may often psychologically affect the individual with epilepsy, creating poor SWB, and leading to the discomfort when correlating with members of relevant social environments. This will often influence the individual’s comfort when participating in all social environmental activities. Lesions pertaining to the right temporal lobe often affect the setting and attaining of single goals.

A loss of self-consciousness when participating in community environments is often experienced as a result of right temporal lesions (Ropper & Victor, 2008). These individuals often experience difficulty with the recall of rhythm of speech and music, resulting in an inability to discriminate or retain melodies. It is the surgical removal of the hippocampus in one of the temporal lobes that is most often typically elected to control AOES when combinations of anti-convulsive medications have been incapable of doing so.
Research on SWB and AOES

Four main areas of research of living with AOES include family life, professional/consultant communication, involvement in general social activities, and self-environments. This study focuses on how the SWB of a man with neurosurgery for AOES has been affected when he is establishing a place in relevant social environments post-surgery. What psychological difficulties does he face when conducting these actions? These are considered next.

Relationships Impact with AOES

Relationships could flourish with social support or deteriorate if unsupported. A study by Carran, Kohler, O'Connor, Cloud, and Sperling (1999) reported that people who experience the full termination of AOES post-surgery encounter greater SWB. The researchers claimed that individuals whose seizure activity fully terminated were more likely to find a partner to marry, or chose to divorce their present partner than the individuals continuing to experience AOES. The researchers asserted with greater SWB arising full seizure control, a number of the participants felt no longer dependent upon their partner’s input when making a decision that they felt would benefit their relationship.

Poor SWB may also result from negative self-judgement (Carran, et al., 1999). In a number of cases, the elective surgery procedure is perceived by the individual as a means to restore their pre-AOES existence rather than a process that offers the proficiency to establish new social environments. In such cases, the individual is required to not only establish and attain future goals, but also cope with the stigma and labelling which has resulted from the negative judgement of past societies.

Schachter (2007b) claimed there to be a number of difficulties children with epilepsy often experience, including rejection and isolation by peers in the school environment. Schachter (2008a) asserted that women with AOES experienced problems with family planning, fertility and sexuality participation. Further research conducted by Schachter and Andermann (2008) focused on the difficulties of social perception by participants from 21 countries around the world. Their findings suggested that a lack of social acceptance of epilepsy is common on a world-wide level. Unfortunately, research
studies about men with epilepsy and the effects on external social environments have not been conducted until now.

Carran, et al. (1999) found that a number of male participants often sought to attain a dominant role within this environment. If the relationship was unable to abide to these changes, greater SWB may influence a number of participants to dissolve the relationship with the desire to establish a new identity that does not require such support. The researchers also reported in the traditional relationship, where the male holds a more decisive role in a partnership, the participants whose seizure activity was controlled as a result of neurosurgery most often preferred to remain in positions of control. Employment is important to personal relationships. By attaining employment, the individual is once again able to create financial stability and regain the primary role he once held in the immediate family environment (IFE) prior to the neurosurgical procedure. In a number of Western countries similar to Australia, financial support is offered to individuals with AOES by the Commonwealth Government in the form of a disability support pension (DSP). In most cases, the individual’s chronic illness inhibits his/her ability to gain and maintain employment.

**Effects of Frequency of Seizures**

The frequency of seizures has been recognised by a large number of researches as influencing the SWB of men with AOES (Kellett, Smith, Baker & Chadwick, 1997; Poochikian-Sarkissian, Sidani, Wennberg & Devins, 2008; Wheless, 2006; Wilson, Bladin & Saling, 2001; Wilson, Wrench, Saling & Bladin, 2008). Kellett et al. (1997) gathered retrospective postal research data from 94 participants who had undergone neurosurgery between 1986 and 1994. The participants were separated into two groups based on the frequency of seizures experienced over the period of one year; less than 10 seizures a year, or at least 10 a year. The research measured the levels of depression, anxiety, impact, effect on balance, mastery, and self-esteem experienced by each participant. These were then compared to those of other participants. The study claimed that individuals who were free of seizure activity experienced greater SWB than others whom continued to experience seizures. The researchers asserted that poor SWB was more evident in participants whom experienced at least 10 seizures over a yearly basis. Personal agency has also been associated with higher SWB post-surgery.
Poochikian-Sarkissian et al. (2008) reported participants experiencing greater seizure control post-surgery often perceive themselves as gaining a higher level of control over pertinent environments, resulting in greater SWB and psychosocial outcomes. This study will investigate the role of perceived control in the management of post-surgery AOES. This will provide stronger understanding about how all environments affect the SWB of men with AOES post-surgery. Many individuals in all social environments, including medical societies label a resective procedure, such as a partial temporal lobectomy (PTL) as a method to cure epilepsy. As a result, their judgement of the participants' physical and emotional post-surgery activity is based upon psychological stability and earnest to achieve new goals.

Wilson, et al. (2001) reported that a number of individuals whose epilepsy is cured by neurosurgery often experience difficulties starting a new life as a person who is seizure free. The researchers claim that the participant may often build an identity based around their chronic illness, and therefore the cure leaves a gap in their internal perception. This study indicates that assertions such as these may result in poor SWB when these findings are easily attained by relevant participants. Ethnographic research has revealed significant insight about living with AOES.

Schachter (2007a) reported on the effects of living with epilepsy from interviews with health care professionals who work with both patients with epilepsy and others closest to these patients. Research up until this point has failed to discuss the impact on the wellbeing of men, and particularly their role as fathers and husbands, and also their place in other social groups. Other matters that have lacked significant research attention include participation in family planning, fertility and sexual ability. Further research is required to fill this gap by examining how men with neurosurgery for AOES may be affected by the condition.
Table 1.2 Epilepsy, Seizure types and effects of personal and social functioning

<table>
<thead>
<tr>
<th>Authors</th>
<th>Object in Focus</th>
<th>Participants</th>
<th>Region</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Espinola-Nadurille, Crail-Melenda, &amp; Sanchez-Guzman (2014)</td>
<td>Stigmatic experiences of PWE</td>
<td>25 people -10 PWE -10 carers -5 physicians</td>
<td>Mexico</td>
<td>Qualitative</td>
<td>- Epilepsy was attached to a powerful stereotype that includes notions of contamination, danger, sin, divine punishment, supernatural forces, and madness. - Internalized, interpersonal, and institutional stigma prevents PWE from participating in school and employment and reduces their opportunities to establish peer and couple relationships. - Mexican's overt impunity of structural discrimination towards PWE shows a lack of available legal resources that protect their human rights.</td>
</tr>
<tr>
<td>Hasan, et al. (2010)</td>
<td>Understanding Epilepsy</td>
<td>382 Chinese people</td>
<td>Malaysia</td>
<td>Qualitative, Cross-sectional descriptive</td>
<td>- People with Epilepsy are socially discriminated due to the negative public attitudes, misconceptions and false beliefs. - 74.6% respondents, 16.2% believed epilepsy is a type of mental illness. - Majority 90.8% accepted that POW can become useful members of the society. - Only 16% would to marry people with Epilepsy - Prejudice and discriminatory behaviour towards people with epilepsy was commonly reported</td>
</tr>
<tr>
<td>Poochikian-Sarkissian et al (2008)</td>
<td>Effects of frequency of seizures</td>
<td>145 patient with PWE</td>
<td>Canada</td>
<td>Qualitative</td>
<td>- Seizure freedom, whether achieved by surgical or pharmacological treatments, was associated with maximal reduction of illness intrusiveness. - Increased illness intrusiveness correlated signficantly with decreased QOL and increased depressive symptoms. - Illness intrusiveness is an important determinant of the psychosocial impact of epilepsy and its treatment. - Effective pharmacological or surgical treatment may reduce illness intrusiveness in epilepsy. - Health care providers should consider multifaceted interventions to reduce illness intrusiveness and, thereby, improve QOL.</td>
</tr>
<tr>
<td>Schachter (2008)</td>
<td>Relationship impacts with AOES</td>
<td>Documents experience of female patients over 30 years</td>
<td>USA</td>
<td>Qualitative</td>
<td>- Women with AOES experienced problem with family planning, fertility and sexuality participation.</td>
</tr>
</tbody>
</table>
Table 1.2 Epilepsy, Seizure types and effects of personal and social functioning (continue)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Object in Focus</th>
<th>Participants</th>
<th>Region</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schachter (2007a)</td>
<td>Relationship impacts with AOES</td>
<td>Documents experience of health care professionals over 30 years</td>
<td>USA</td>
<td>Qualitative</td>
<td>-Health care professional failed to discuss the wellbeing with the patients</td>
</tr>
<tr>
<td>Schachter (2007b)</td>
<td>Relationship impacts with AOES</td>
<td>Documents experience of child patients over 30 years</td>
<td>USA</td>
<td>Qualitative</td>
<td>-Children experience a number of social difficulties including rejection and isolation by peers in the school environment.</td>
</tr>
</tbody>
</table>
- Denial is a relatively common response in the self, creating poor self-possession. 
- Rehabilitation must include developing a new self-concept, acceptance and strength to deal with negative societies. |
- Results indicated those with Low IQ are at highest risk for poor self-concept. 
- Discrimination affects SWB and QOL |
| Wilson, et al. (2001) | Post-surgery results | Documents the clinical phenomenology of PWE | Australia | Qualitative       | -Acceptance and adjustment to seizure control primarily depends on the patient's capacity to discard roles associated with chronic epilepsy and to learn to become well, which can be difficult. 
- This syndrome comprises psychological, affective, behavioural, and sociological features. |
| Carran, et al. (1999) | Relationship impacts with AOES | 430 epilepsy surgery patients | USA    | Qualitative      | -Marital rates were lower than expected in men. 
- Men with onset of epilepsy by age 11 years were less likely to be married than men whose seizures began after age 11 or women whose seizures began at any age. 
- Men and women with temporal lobe epilepsy had higher marriage rates than those with extra-temporal lobe epilepsy. 
- More than 4 years after epilepsy surgery (n = 190), patients who had no recurrent seizures were more likely to change marital status (28 of 124, 23%), than those who had recurrent seizures (five of 66, 8%). 
- Most men who married were employed (77%), whereas women who divorced were usually unemployed (67%). |
Table 1.2 Epilepsy, Seizure types and effects of personal and social functioning (continue)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Object in Focus</th>
<th>Participants</th>
<th>Region</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Gordon, & Sillanpaa, (1997) | Social Judgement             | 1043 adults living in Italy, Germany, Finland and Denmark | UK      | Qualitative | - Epilepsy remains a hidden disorder with ignorance, prejudice, superstition, stigma and discrimination.  
- Social attitude towards people with Epilepsy will be a factor of great important in that person’s life. |
| Kellet et al., (1997)     | Effects of frequency of seizures | 94 patients with PWE                             | UK      | Qualitative | - Individuals who were free of seizure activity experience greater SWB than others whom continued to experience seizure. |
Statement of the Problem

The research will investigate SWB in men with neurosurgery. It focuses on how emotions are controlled or expressed by each participant in relevant social relationships; such as those within the Family, Professional/Consultant, and Social network environments. How emotional reactions and self-judgement can affect SWB, influencing the ability to gain and maintain relationships in all environments depends on the interpretation of the social action. A qualitative case study approach has been chosen to understand SWB in men following surgery on males with AOES.

Case study is a methodology that is commonly used in many fields of research; health science, social work, psychology, and sociology. A Case study can be conducted from within several theoretical frameworks, such as post-modern and critical (Merriam, 1988). By using case study methods, the researcher relies on the individual voices of people within the social group under investigation. The growing interest in social science research can be considered the starting point for gaining an understanding of a range of experiences people with epilepsy encounter (Noor, 2008). The Conceptual Model (Figure 1.3) is the preliminary schematic structure, in the IPA paradigm from which the chosen research questions are developed to guide general discussion and conducting interviews for this study.

Conceptual Model

The conceptual model (Figure 1.3) proposes the following social environments influence on SWB: Family, Professional/Consultative, Participation, and Personal. The social dynamics associated with each of these environments is explained next.
Family Environment

The importance of primary support in the IFE following neurosurgery was addressed by Mikati, Comair, Ismail, Faour, and Rahia (2004). These researchers reported that regardless of the level of seizure control, most participants are greatly dependent upon the support of the IFE for at least one year post-surgery. This included emotional support when making decisions that the result would affect this environment in either a negative or positive manner. Mikati, et al (2004) claimed that support within the IFE
Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures

provided the participant with stability by creating a sense of belonging; resulting in greater SWB. SWB is also influenced by the social stigma that often arises in the extended family environments (EFE).

As the result of a lack of necessary education, the resection is often recognised as one that cures AOES. The acknowledgement that the EFE offers the individual is most often based upon post-surgery achievements. Therefore, the support that is offered by members of the EFE post-surgery is often influenced by the level of relevant medical activity and the speed by which the individual is capable to attain future goals. These include employment, and creating financial stability for the IFE post-surgery. The disrespect that regularly arises from this judgement is often a diminishing factor that influences poor SWB.

Immediate family support is necessary when dealing with social judgement and its effect on SWB. If the participant feels that he is not pressured to attain goals at a faster pace than he is capable, both physically and emotionally, SWB will increase. The participant may feel more comfortable taking part in general social activities, reducing the effect of stigma.

The study by Mikati, et al., (2004) focused upon Middle-Eastern sample, offering an important overall understanding of how individuals whom are followed neurosurgery are affected when strong family support and social acceptance is provided. Overall, SWB positively increased. However, dependency on family increased following surgery, regardless of the outcome.

The present study focuses upon Australian men to provide a broader understanding on SWB in men of Western backgrounds following elective neurosurgery for AOES. Poor SWB may also result from the judgements made by significant others, including workplace colleagues.

Poor SWB may be significant when rejection occurs within the work-place society. In many cases, the consequence includes financial hardship for the individual and others. In a number of cases, this financial instability is accompanied by stigma, including labelling the individual as lazy, irresponsible, and incapable of accepting change.

The opinions of both the wife/partner and child/children, and how they relate to the individual may have a strong influence on SWB. The strength of the relationship a male
with AOES holds with his partner following the elective surgery influences SWB. This could also be the case if the individual has children. How these two social entities communicate in relation to the individual’s condition also influences the immediate family bond. Published data that focuses on how a relationship between a father with epilepsy and his children is limited (Sare, Rawnsley, Stoneman & Duncan, 2007), but the effect on a man’s SWB following AOES and neurosurgery is presently unavailable. Schachter (2007b) has examined the difficulties that may occur in this form of relationship when a child has epilepsy, but not in men with AOES. The research will explore the influence on SWB on men with AOES following neurosurgery and of their relationships with partners or significant others, such as the EFE.

The individual’s experience of AOES and neurosurgery may often impact EFE relationships. For instance, if the partner’s family has a negative reaction towards the individual based upon AOES and neurosurgery, anger and disrespect can often be expressed by all involved. Suggestions of a better life being possible away from the individual may also influence disruption in the IFE. How the individual perceives the strength of his relationship with his EFE, and that held between both EFE may also strongly affect SWB. The relationship held post-surgery with medical professionals and consultants may often affect SWB.

**Professional / Consultant Relationship**

The post-surgery relationships held with members of the specialist/consultant environment are often very important for their patient’s SWB (Schachter, 2008c). For many individuals, difficulty is often experienced when consulting their neurologist or visiting the hospital where the elective surgery was performed. If there is a poor relationship held between the professional and the patient, the individual may often experience insecurity and anxiety. As a result, the consultation period with the professional may often be shortened, with the individual failing to gain answers to questions that had planned to be asked prior to entering. Due to a lack of gained knowledge, being the consequence of poor communication with relevant members of the medical environment, poorer SWB often results. This may lead to an increase in the psychological symptoms of anxiety and depression experienced by the individual post consultation.
Anxiety and depression may often be experienced by the individual when confusion is experienced about the cause of symptoms, including continuing AOES post-surgery. The lack of necessary knowledge held by the individual about what may be the cause of their increased seizure activity and emotional displacement will most often encourage poor SWB in other external social environments, such as the IFE.

Inadequate support for men with AOES by members of the medical environment may often affect IFE relationships. However, if the individual is able to maintain a strong relationship with the neurologist and adequate knowledge is gained, he is likely to experience greater SWB, which may strengthen stability post-surgery regardless of whether full seizure control is attained. The level of SWB experienced when present in social networks post-surgery is also often influenced by communication and education.

**Social Networks**

The quality of SWB that men with AOES experiences post-surgery when participating in the activities of general societies is often influenced by stigma and labelling. The individual’s choice to take part is often influenced by external perception. The individual may often judge whether he can confidently establish a position in either past or future social networks based upon this, with negativity often resulting in social isolation. The effect on SWB may alter over time, depending on how the participant perceives the success of the surgical procedure. If the participant feels that the operation has allowed him to participate in general social activities, such as driving, going out and playing sport without fearing social judgement, he is most likely to experience greater SWB. Employment or participation in the work-place environment following the surgical procedure will often influence greater SWB. A number of individuals suggest that with greater SWB as the result of successful work-place activity, an increase in positive internal perception is experienced in the self-environment.

**Self-Environment**

Self-environment refers to personal or self-acceptance (Moos & Holahan, 2007). Self-deception can also be recognised as internal perception. This includes self-regulation and the coping skills the individual uses when addressing circumstances that affect SWB (Cuddy, Fiske & Glick, 2008).
Difficulties may often arise in men whom develop sexual dysfunction as a result of AOES. Commonly, men with AOES experience hyposexuality, erectile dysfunction, or sexual anorexia (Smaldone, Sukkarieh, Reda & Khan, 2004). Consequently, people with AOES may enter relationships fearing embarrassment and rejection (Silveira, de Souza, Carvalho & Guerreiro, 2001). However research by Bauer, Stoffel-Wagner, Flugel, Kluge, Schramm, Bidlingmaier, et al., (2000) found that hypersexuality may result following the elective temporal lobectomy procedure.

Bauer, et al. (2000) conducted research on 22 men with epilepsy, aged 25 to 48 years. The participants’ hormonal levels were investigated prior to the PLT procedure, with a follow up three, six, and twelve months assessment post-surgery. Following neurosurgery, 14 of the 22 participants (63.6%) achieved total seizure control. These 14 participants entered the second stage of analysis. The researchers noted that prior to the surgery the participants experience hyposexuality as a result of hormonal deficiency. Following a strong reduction in seizure activity as a result of the surgery, the researchers found that seven of the 14 participants (50%) demonstrated an increase of hormonal production. These led to increased hypersexuality; an increase in the desire and performance of sexual activity, influencing greater SWB. Bauer, et al. (2000) concluded their research by stating “Successful temporal lobe epilepsy surgery may lead to a normalization of serum androgen concentrations in men with epilepsy” (Bauer, et al., 2000).

The self-environment is most often influenced by the state of the individual’s internal perception. These include issues such as self-worth and self-confidence, and the effect on SWB. There is no true academic knowledge about the self-connection or the understanding one has of the personal emotions that a man with AOES experiences following neurosurgery.

As with any relationship, the connection the individual has with his inner-self influences SWB. This is a individual that often fails to be adequately addressed due to a lack of personal understanding on the part of relevant researchers. An explanation of the psychological state of self-connection can be provided by a male researcher who has also experienced this condition. My personal experience with both this condition and neurosurgery will allow my research to provide a stronger understanding about how the SWB of the participants is affected as a result of self-awareness and explanation.
An analysis of how SWB in these men is influenced by the environment over time will assist in understanding how actions, such as rehabilitation can influence the psychological and psychosocial recovery following neurosurgery for AOES. By adopting a case study research method of analysis to identify changes that occur in these five environments, this study will provide further knowledge than is currently available.

**Research Objectives**

1. Determine the influence of family relationships on SWB of men with AOES following elective surgery.

2. Evaluate how quality of perceived medical professional / consultant relationships influence SWB of men with AOES following relevant elective neurosurgery.

3. Evaluate the perceived influence on SWB in men with AOES of social networks in which they participate.

4. Determine how the self-regulation coping skills of men with AOES following elective surgery influence their SWB.

**Research Questions**

1. What aspects of family relationships influence SWB in individuals with elective neurosurgery for AOES?

2. How do professional / consultant relationships influence SWB in men with elective neurosurgery for AOES?

3. How do nominated social networks influence SWB in men with AOES following elective neurosurgery?

4. What coping strategies do men with elective neurosurgery for AOES use to enhance SWB?
Significance of Study

There are three major potentially significant contributions to be made by this study: practical, methodological, and theoretical.

Practical Significance

The results of the investigation could be beneficial for further research about SWB in men with neurosurgery for AOES. The lack of education in many societies on AOES often results in the observer of AOES recognising symptoms, such as convulsions being due to drug abuse. As limited research has been conducted in relation to this topic, the findings that this study provides will offer a foundation upon which rehabilitation for men with AOES and elective surgery can be asserted to achieve full community inclusion.

Methodological Significance

The study will demonstrate the potential of employing a case study approach to understand SWB in men with AOES. A number of researchers have noted that the best means for gaining an understanding of another person’s subjective experience is through a narrative process, allowing the individual to tell their stories (Anderson, 2006; Okun & George, 1984; Strauss, 1994). Strauss (1994) wrote about his struggle in dealing with the inadequacies of a mental health system that fails to provide adequate attention to the subjectivity of people with schizophrenia. He claimed:

it may be possible that the story, with its capacity to combine subjective and objective aspects of experience in a temporal context, may be the optimal organizing structure for a science of psychiatry. (Strauss, 1994, p. 104)

The narrative allows for interpretive or constricted knowledge of each case study to be gained, and what now matters most to people in their lives (Anderson, 2006).

Theoretical Significance

An interpretive phenomenological analysis (IPA) is a paradigm that focuses on both meanings and experiences of human beings (Denzin & Lincoln, 2005). IPA is phenomenological in that it is concerned with exploring experience in its own terms.
Chapter 1: Introduction

The IPA paradigm is to be adopted to understand the SWB in men with elective neurosurgery for AOES. This phenomenological approach involves a detailed examination of the individual’s life-world (Smith, Flowers & Larkin, 2009). The process attempts to explore the personal experiences of the individual and is concerned with his perception or account of the object or events, as opposed to an attempt to create an objective statement of the object or the event itself (Fade, 2004; Smith & Osborn, 2003). The IPA paradigm is important to this study because it assumes that there is no single social reality (Braun & Clarke, 2006). Instead, social reality is regarded as ambiguous because each individual understands his own social realities as a result of his personal experiences and his ways of reasoning (Connelly & Clandinin, 1988; Miles & Huberman, 1994).

Limitations and Delimitation

Limited research in this specific area means that I have also had to examine sources of literature that have researched those with epilepsy under different circumstances, and research conducted on other chronic illnesses that focus on the same results. This cross-comparison literature reviews offer valuable information to support this study. These topics include: overall SWB in adults with epilepsy, to gain a general understanding of the difficulties that come with firstly experiencing seizures at this age (Scambler, 1989); the SWB in men with neurosurgery for cancer, spinal cord injury, and cranial nerve injury (Elger & Elger, 2001), by offering an understanding of the psychological difficulties experienced post-surgery (Thorbecke, 2001), when re-establishing themselves in all social environments following surgery (Ponsford, Sloan & Snow, 1995; Shorvon, 2004).

Definition of Terms

Case Study

The Case Study highlights in depth contextual analysis of a restricted number of experiences or conditions and their relationships (VandenBos, 2007). Yin (2009) defined case study as an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used.
Subjective Well-Being (SWB)

Subjective well-being can be simply defined as the individual’s current judgement about his or her overall quality of life and happiness (VandenBos, 2007). Such an evaluation is often expressed in affective terms; when asked about subjective well-being, participants will limit their response and often say, “I feel good” (Schwarz & Strack, 1999). Subjective well-being is thus, at least in part, a proxy for a global affective evaluation.

Seizures

A seizure is a hyperexcitation of neurons in the brain leading to abnormal electric activity that causes a sudden, violent involuntary series of contractions of a group of muscles (Mosby’s dictionary, 2009, p. 1677).

Epilepsy

A chronic illness will characterised by recurring episodes of convulsive seizures, sensory disturbances, abnormal behaviour, loss of consciousness, or all of these. Come until all types of epilepsy is an uncontrolled electrical discharge from the nerve cell of the cerebral cortex (Mosby’s dictionary, 2009, p. 655).

Adult-Onset Epileptic Seizures (AOES)

Adults (18 years or above) may develop epilepsy, experiencing seizures as a result of strokes, tumours, abscesses, brain trauma (either as a child or in adulthood), encephalitis or meningitis, uremia, and many other illnesses. In many instances, the underlying cause is not determined (Taber, 2009, p. 2094).

Neurosurgery

A specialised medical surgical procedure specialty concerned with the prevention, diagnosis, treatment and rehabilitation of disorders that affect the entire nervous system including the brain, spinal cord, cranial nerve, or peripheral nerves (Taber, 2009, p. 1580).
Conclusion

This research focuses on the SWB in men who require neurosurgery to control AOES. This research is important because SWB is sensitive to anguish in several environments of living (Ohaeri, Awadalla & Gado, 2009). These relationships are categorised as three environmental realms: Family; Professional / Consultant; Social Networks. Additionally, whether SWB in the male with AOES differs, depending on the period of time following the elective surgery? Four research questions have been constructed to answer the effects on SWB in men with elective neurosurgery for AOES (Schachter, 2008a; Schachter, 2008b; Schachter, 2008c; Schachter & Andermann, 2008; Schachter, Holmes & Trenité, 2008).

Many researchers have focused on the SWB in adults with neurosurgery for epilepsy, using both qualitative and quantitative research methods. This research is offering a different perspective on this subject. The open-ended interview structure allows for predetermined questions and also encourages questions to be asked by the participant during the interview process. A mode of four phases demonstrates how the difficulties that men with AOES experience in different social environments impact SWB.
Chapter 2

Physical and Psychosocial Aspects

Introduction

For many centuries, cultures have acknowledged the chronic illness of epilepsy as one that is difficult to treat, with surgery attempting to control the condition as far back as 2000BC. The location of scar tissue and the form of seizure activity an individual experiences is what determines the possibility of surgery, making only a small number of individuals eligible for a surgical procedure. This chapter looks at those who experience focal seizures originating from damage in the temporal lobe (TLE). An explanation of the seizure types and symptoms that individuals with TLE experience prior to surgery, and in many cases post-surgery is provided to form a better understanding of why surgical treatment is considered, and the possible physical and psychological consequences of this procedure. The chapter also discusses the additional post-surgery treatment often adopted, including diets and the social costs that may arise as the result of surgery.

Cost of Social Stigma Post-Surgery

When addressing most cognitive illnesses, the number of negative social stigmas that can encourage greater affective costs to the individual is often the result of a lack of general education on the condition. Hasan, et al. (2010) reported the education level of the general community on epilepsy is very limited, resulting in the subject experiencing large emotional burdens. Limited knowledge about AOES is presently current in all societies. As the chronic illness affects not only the self-environment but also relevant external social environments, further research as to the cost on the subject is necessary. Many people show difficulty when facing an individual who exhibits unusual physical, cognitive and affective behaviours, often resulting in inaccurate judgements (Halasz, 2007, May 7, pers comm.). Austin (2011, February 12, pers. comm.) indicated that the SWB of the patient post-surgery is a topic that is very much understudied, strongly encouraging the need for research in this area. Health specialists have dedicated very little time to educating society on the condition of AOES. Social understanding about how the lack of knowledge on AOES can encourage poor SWB is
necessary. Knowledge of the affective consequences of stigma that an individual may experience within the social network is also an important issue that requires further investigation.

Kirk (2005) reported that what often influences the cost of social stigma is the context in which a medical condition is diagnosed. Consequently, the development of labelling and stigma in all social environments may also see the subject encounter high psychological costs. The subject may experience this following neurosurgery, influencing poor SWB (Raffaele, 2009). Within a short period of time post-surgery the subject is often encouraged to resume participation in many social groups in which he participated prior to experiencing AOES. The expectation is for the subject to take part in all normal activities, including the recommencement of employment, as the assumption is that the ‘broken part of the frame’ has now been repaired. Due to a combination of the physical, cognitive, and assertive effects of surgery, the subject is often psychologically incapable of performing at that time. Health professionals often label the individual as one who now fears the burden of normality that arises from full seizure control. They believe the individual may often continue to identify with the earlier persona as a means to avoid normality (Wilson, et al., 2001).

There is evidence to suggest that many people respond negatively when told a family member or friends with epilepsy requires elective neurosurgery to assist to control frequent seizure activity. In reality, members of most social environments find it more difficult to deal with a neuropsychological illness than many other illnesses (Myers, 2004). Bjorklund’s (1998) autoethnographic paper reflects upon the psychosocial stigma that resulted from his misdiagnosis with schizophrenia, which had a devastating effect on SWB. He hoped to increase awareness of the serious psychosocial implications experienced by those who do not yet have an accurate understanding of the diagnosis because of inadequate education. Bjorklund (1998) requested that those within the professional/consultant environment not simply adopt immediate assumptions of what one is capable of achieving because of developing schizophrenia (Raffaele, 2009). It is the authors experience that by merely basing diagnosis on medical knowledge gained while studying at a tertiary level, without at least questioning why for some individuals past treatment plans have not worked, this will often cause further disruption to occur in relevant social relationships. For many patients, they may face these problems because of neurosurgery for AOES.
Cost of Discrimination

VadenBros, (2007) stated that discrimination results following the ability to distinguish between the persons or objects that differ quantitatively or qualitatively from others. In conditioning, it is following the learning of differential reinforcement or differential conditioning techniques that this is usually established. Differential discrimination of those with a medical condition is usually the behavioural manifestation of prejudice and therefore can involve negative, hostile and injurious treatment.

Engel, et al. (2007) identified there to be few other chronic illnesses that evoked more negative emotional reactions in social networks than epilepsy. They claimed that throughout history, members of almost every cultural environment have negatively judged those with epilepsy because of assumptions about why they developed the condition and leading to severe discrimination (Raffaele, 2009). Engel, et al. (2007) claimed this to be second only to that incurred by leprosy. “Epilepsy remains a hidden disorder with ignorance, prejudice, superstition, stigma and discrimination” (Gordon & Sillanpaa, 1997), shown towards the individual with this chronic illness. Buelow, et al. (2003) reported that individuals might experience discrimination in many social environments because of elective neurosurgery. This will often influence the level of stigma and isolation shown towards the participant, further lowering SWB. There is still opportunity for changing the attitude of others towards the participant. Many participants use denial as a means to prevent discriminative treatment.

Cost of Denial

“One of the primitive defence mechanisms involving rejection of negative thoughts, feelings or behaviours is denial. It differs from lying in that the person, at least partially, believes his/her own distortion (Raffaele, 2009, p.33).” VadenBros, (2007) claimed that forms of denial often result from the refusal to concede the condition such as epilepsy as chronic illness, which often has a great monetary and fertility cost. Denial is an unconscious process that functions to resolve emotional conflict or reduce anxiety. Whiteneck, Gerhart and Cusick (2004) claimed that denial permits the rejection of the full reality and responsibility of a diagnosis. When present in most communities, the cost of denial may result from the individual being categorised as one who is limited in activity. This may be influenced by factors that include the inability to recognise personal weaknesses, or acknowledge awareness of their actions. Schachter, Holmes and Trenité (2008) claimed that this can place the
individual in high risk situations leading to social judgement, triggering unhappiness, low self-perception and poor life-satisfaction (Raffaele, 2009).

**The History of Epilepsy and Surgery**

Descriptions of seizures are traceable as far back as civilisation itself. As early as “in antiquity, seizures were felt to occur as a consequence of supernatural forces” (Hunt, Morrow, & Craig, 2007). Recorded references to epileptic activity date back roughly 12,000 years; however, describing the condition as a mental disease (van Koppen, 2004).

Evidence of the diagnosis of epilepsy was first found on a Cuneiform tablet in Babylon, compiled c.700 BC. Large parts of a series of the tablets were dedicated to the diagnosis of Sakikku (all diseases). The tablets are presently held in the British Museum, London, and classify seizures as being ‘The Falling Sickness’ (Hunt, Morrow & Craig, 2007). Kinnier Wilson and Reynolds, a translator of Ancient languages interpreted the Cuneiform text on epilepsy thus:

> If the possessing demon possesses him many times during the middle watch of the night, and at the time of his possession his hands and feet are cold, he is much darkened, keeps opening and shutting his mouth, is brown and yellow as to the eyes...
> It may go on for some time, but he will die. (1990, p. 191)

The ancient Greeks developed medical schools for the observation of conditions in 700BC. As with the Babylonians, the concept of epilepsy mostly derived from a religious notion of possession; to be seized by spirits. In a number of ancient cultures, epilepsy was thought to be a mental disturbance caused by supernatural intrusion. Epilepsy was viewed as a “sacred disease” by the ancient Greeks as it was believed to have been created by the gods (Chiu, 2000). The term, ‘epilepsy’ derives from the Latin *epilēpsia*, and from the Greek *epilambanein*, meaning to attack or to seize.

By the beginning of the Early Medieval period, demonic concepts of epilepsy were to prevent seizure through spiritual purification. A strong connection was set between sin and seizure (Magiorkinis, et al., 1992). A number of articles have noted that individuals with epilepsy at that time believe the seizures they experienced were the result of religious intervention, particularly as the feeling perceived involved a loss of consciousness and self-perception, as with the temporal lobe epilepsy (TLE) (Devinsky & Lai, 2008; Saver & Rabin, 1997; Waxman & Geschwind, 1975). This was to continue for many hundreds of years.
In the 13th century, in Europe, following the observation of generalised seizures, Avicenna also believed that this form of irregular brain activity was due to neurological damage. He believed that this affected the frontal lobe activity, making it impossible for the person affected to remain standing upright (Bennetta & Hacker, 2002).

By the beginning of the Early Modern period, the concept of epilepsy was marked by the new factors of autonomy. It was now believed that the cause of different types of seizures were the result of the places where damaged tissue lay. This resulted in previous methods of medical care to be questioned and abandoned (Bennett, 1992).

Although first suggested by Hippocrates in the 5th century B.C., the concept of epilepsy as a brain disorder only began to take root in the 17th and 18th centuries (Reynolds & Trimble, 2009). Thomas Willis (1621-1675 AD) enounced the theory that epilepsy results from a chemical imbalance. Willis believed that muscular movement was caused by the mixture of two vitriolic chemicals in the muscle tissue (Larne, 2008). One of the major advances of the 18th century was the beginning of the use of crude chemical preparation to treat epilepsy, even though many of them were not based on physiological or chemical footing (Magiorkinis, Sidiropoulou, & Diamantis, 1992).

In the early 20th century, surgeries were designed to improve insufficiency of the cerebral circulation, which was recognised as having the potential to initiate seizures. By the middle of the 20th century, the term temporal lobe epilepsy (TLE) was widely utilised and much of the subsequent understanding of this disorder was based on pre-surgical studies of intractable cases. The development of methods of examination, including Electroencephalography (EEG) in 1938, Computed Tomography (CT) in 1973, Magnetic Resonance Imaging (MRI) in 1977, and Single Photon Emission Computed Tomography (SPECT) in 1983 strongly influenced the isolation of the individual’s epileptogenic zone and eligibility for neurosurgery. The most frequent neurosurgical method performed to control AOES is the partial lobectomy procedure. All participants in this study experienced this procedure.

Epilepsy is now thought to be a diverse family of disordered brain conditions that results from irregular neurological nerve activity (Téllez-Zenteno, Dhar & Wiebe, 2005). Epilepsy cannot be categorised as a single condition, but having in common an abnormally increased disposition to seizures (Fisher, et al., 2005). Many researchers have stated that the onset of the seizure must be unprovoked and not the result of a high intake of alcohol or drugs.
Temporal lobe epilepsy (TLE)

Temporal lobe epilepsy is the most common form of epilepsy, with approximately 65% of individuals with the chronic illness experiencing this disorder (Bagla & Skidmore, 2011). As each temporal lobe is responsible for both similar and varied functions, seizure symptoms resulting from a lesion in either temporal lobe may vary greatly (Beleza & Pinho, 2011). In most cases, abnormal shaking occurs on the opposite side of the body (Shulman, 2000).

A participant with TLE frequently experiences reduced retention of visual or auditory input. Left temporal lobe lesions often affect recognition of visual content, including the recall of facial images. Lesions pertaining to the right temporal lobe can also result in decreased recall of aural and visual content, including speech perception. Overall, the temporal lobes are responsible for the primary grouping of sensory input (Corkin, Amaral, González, Johnson & Hyman, 1997). Most participants with temporal lobe lesions experience complications categorising words or images; left temporal lesions distract recognition of words, and the right temporal lesions cause a loss of self-consciousness when communicating in social network situations (Ropper & Victor, 2008).

The retention and recall of events is highly associated with the temporal lobes. Lesions pertaining to the right temporal lobe often interrupt the recall of non-verbal material, decreasing the recognition of tonal sequences, music and drawings (Svoboda, 2004).

**Symptoms Associated with a Temporal Lobe Seizure**

Complex partial seizures occur in a three period formation: pre-ictal, ictal and post-ictal denoting before, during a convulsion and following the shaking. Although other types of seizures have a different symptomatology, which lists seizure symptoms, refers specifically to the type of seizures experienced by the participants in this study - temporal lobe seizures.

**Temporal lobe seizures (TLS): Symptoms associated with a focal seizure**

A participant with temporal lobe epilepsy will most often experience focal seizures (Panayiotopoulos, 2010; Soeder, et al., 2009). The temporal lobes have limbic systems that influence emotional and social functioning, and determine exclusion. The regions are responsible for judgement and reasoning, and personal functions, therefore any disorders, such as a stroke or other head-trauma affecting these areas often creates behavioural...
problems (Devinsky, 2008a). Controversy is expressed over whether people with epilepsy (PWE), who experiences complex partial seizures, encounters a high level of emotional fluctuation based solely on the seizure type, or whether pre-established psychotic diseases contribute to these (Kanner, 2000).

A focal seizure is irregular neuro-electrical disturbance that originates in an epileptogenic zone in the brain (Maccotta, et al. 2013). During a focal seizure, irregular limbic movement, sensations, feelings or emotions may occur. Focal seizures where the individual remains conscious are titled simple focal seizures. When the irregular neurological activity passes this region, and transfers throughout the brain, the focal seizures become complex. The individual will always lose consciousness as the result of the complex focal seizure (Fisher, et al., 2005).

**Pre-Ictal Period**

The pre-ictal period results from an increase in irregular neurological activity in the epileptogenic zone of the brain. The pre-ictal period can result in physiological phenomena such as prodromal symptoms, which commence only minutes or as long as days prior to the ictal period (Delamont, Julu & Jamal, 1999). Migraines, Reflux and diarrhoea, resulting from an imbalance in neurotransmission may often be what the individual experiences at this time (Cianchetti, Pruna, & Ledda, 2013).

**Pre-ictal physical symptoms**

Research conducted in a number of Western cultures found during the pre-ictal period an increase of high serotonin levels in the gut may lead PWE to begin to experience reflux and diarrhoea. This may often commence one day prior to the ictal period. There is also widespread agreement among individuals with epilepsy and clinicians alike that some situations are conducive to seizures (Lambert, 2001), including sleeplessness, frustration, and weakness. Boylan (2002) found that 63-72% of PWE identify characteristic changes in personality during the pre-ictal period. Researchers state that resulting from an imbalance in neurotransmitters, including serotonin and GABA, PWE will also experience diarrhoea during the post-ictal period (Verderber, Verderber & Sellnow, 2008).

Although most researchers are in consensus with literature that states the symptoms and actions of PWE prior to a seizure, a number of researchers feel more time is needed to
observe the period leading up to the seizures, which can be up to two days (Delamont & Walker, 2011; Engel & Pedley, 2008).

**Pre-ictal psychological symptoms**

For the observer, pre-ictal characteristic changes in personality of the individual with AOES are harder to distinguish or describe than those of the peri-ictal, ictal, and post-ictal periods (Schachter, Richman, Loder & Beluk, 1995). This is often because the observer categorise the emotion simply as general or anxiety (Schöndienst & Reuber, 2008).

As the result of reduced GABA levels, during the pre-ictal period the participant experiences characteristic changes, such as an increased sense perception or noticing an increase in actions such as sweating. Due to an increased effect of serotonin, impulsivity and obsessive behaviour may also be an indication that the pre-ictal period is being experienced (Davidson, Dorris, O’Regan & Zuberi, 2007). Poor frustration tolerance is also visible in relation to social response. As it is a condition one often feels, the individual may need to conceal from others the psychosocial effects in addition to the neurological condition itself (Shukla, et al., 2008). Conflict about the validity of the existence of this phase is apparent in the literature and the phenomenology of mood disorders in epilepsy remains controversial. Controversy frequently arises about whether fluctuations in mood are truly the result of pre-ictal neurological activity, or whether an independent psychological phenomenon is the cause (Mula, et al., 2010).

Research has suggested that a subgroup of individuals may develop an affective syndrome, often titled “inter-ictal dysphoric disorder (IDD)” (Blumer, Montouris & Davies, 2004). Mula, and Monaco (2011) claimed that a number of the behavioural changes that transpire during the ictus period need to be registered so a precise distinction between "true" psychiatric phenomenology and peri-ictal phenomena could be established.

**Peri-Ictal Period**

The peri-ictal period of a CPS is a period of approximately 30 seconds leading up to the ictal period. The peri-ictal period recommences following the period of convulsions (ictal), continuing for up to one hour in duration. It is at this time that automatism symptoms are experienced (Janszky, et al., 2007). Greater acknowledgement and comprehension of the peri-ictal period is clinically important and the creation of a method to understand the basic
mechanisms underlying mood changes through the peri-ictal period and the substrates of, emotion, volition, cognition and consciousness is necessary (Prueter & Norra, 2005). Many medical professionals prefer the term peri-ictal, as it defines the parameters of the seizure, and determines when a seizure has ended (Mula & Monaco, 2011).

Ictal Period

The ictal period can range from one minute to five minutes in duration. It is at this stage that the irregular nerve activity progresses out of the epileptogenic zone as the result of an imbalance in neurotransmitters (Bacci, Sancini, Verderio, Armano, Pravettoni, et al., 2002). When experiencing a focal seizure, PWE may encounter uncontrolled convulsive activity for the duration of this period (Toy, Simpson, Pleitez, Rosenfield & Tintner, 2008).

Treatment through surgery

The temporal lobectomy, the most common surgical procedure performed for epilepsy, is the removal of the portion of the temporal lobe causing focal seizure activity. In most cases, the resection involves a moderate portion of the brain, approximately 5cm in length (Badawy & Jackson, 2012). These procedures include the partial removal of the amygdala and hippocampus (Amygdalahippocampectomy), or the full removal of the lobe (Anterior Temporal Lobectomy: van Mierlo, et al., 2011).

A partial temporal lobectomy (PTL) is the most frequent neurosurgical procedure performed on individuals who experience CPS and is the most successful type (von Lehe, et al., 2006). Research conducted in Western cultures found approximately 85% of patients who undergo a PTL experience a great improvement in seizure control, 65% of patients no longer experience seizures and 20% continue to experience a reduced frequency of CPS or secondary generalised seizures (SGS) (Bonilha, Martz, Glazier & Edwards, 2012). The frequency of these seizures for this 20% of patients reduces by more than 90% post-surgery (Weiner, 2004). Approximately, 15% of patients will see no worthwhile improvement. Most patients need to continue taking antiepileptic medications, but usually at a lower dosage (Téllez-Zenteno, Dhar & Wiebe, 2005). Nevertheless, the side effects of a PTL on emotional behaviour regulation would be significant in its effect on SWB. Following a PTL, some patients still experience SPS, in which auras or sensations such as unusual smell or taste is experienced for a period of 10-30 seconds in duration (Weiner, 2004).
**Chronic illness plasticity**

Chronic illness is a condition that has been present, either continually or off and on, for at least three to six months, the period depending on the condition. Over a period of up to a year, the individual may unintentionally recall the physical memory of the experience and unconsciously choose to experience the chronic pain once again. The diagnosis of neuroplasticity occurs when the acute pain experienced by the individual progresses into chronic pain (Medical MultiMEDIA Group, 2009).

The primary goal of rehabilitation for assisting an individual with chronic illness to do with the central nervous system (CNS) is to develop a programme that is most suitable to their social environments (VandenBros, 2007). CNS plasticity is often classified as a method that is inadequate for treating individuals with neuropsychological deficits (Forget, Lippé & Lassonde, 2009). The need for co-active involvement between the participant and therapist is necessary for developing a suitable rehabilitation programme post-neurosurgery (Wilson, 2003). Unlike the medical treatment provided by a professional/clinician, a rehabilitation programme to develop plasticity is a process in which the participant plays an active role. The interaction of counsellors working together with other health-care professionals may assist in achieving a more optimum level of physical, social, psychological, and vocational functioning post-surgery (Gilbert, 2012)

**Post-neurosurgery plasticity**

It is recognised that rehabilitation helps individuals who experience a physical disability as the result of widespread functional and structural plasticity (Nudo, 2003). The primary reason for the success of rehabilitation lies in the plasticity of the CNS. Plasticity of a nervous system makes it possible to separate regions of the brain and to learn and register new experiences (Gilbert, 2012). “Neural plasticity is the ability of the nervous system to change in response to experience” or environmental situations post-surgery (Reynolds, Lane, & Richards, 2010). As a result of constant successive activity a change in reactivity of the CNS and its components is achieved (VandenBros, 2007).

Chiappedi, M., & Bejor, M. (2010) claimed that physical injury can change the way one’s brain works and even its shape, if an appropriate length of time and intensity is offered by rehabilitation. Methods to develop the plasticity of the CNS were trialled on children with chronic brain injury, with the hope of increasing chronic illness control. The possible
consequences of long-term rehabilitation treatment are that the process may alter the neurological process of the individual through CNS plasticity.

**Treatment and Management of Seizure Activity Post-surgery**

The aim of the main treatment for epilepsy post-surgery, namely anti-epileptic drugs (AEDs), is to maintain the reduced frequency or severity of epileptic seizures attained through neurosurgery. This is often in the setting of significant side effects (VandenBos, 2007). The classification of remission post-surgery is set according to patient perceptions following five years of seizure freedom, either on or off treatment (Stokes, Shaw, Juarez-Garcia, Camosso-Stefinovic & Baker, 2004). However, a person in remission still lives with the uncertainty of whether they may experience a seizure in the future. These circumstances place limitations upon the individual when present in social networks, including the workplace, influencing low SWB.

National Institute of Clinical Excellence Epilepsy guidelines (NICE, National Institute for Health and Clinical Excellence, 2012) recommend treating psychological issues that may arise as a result of epilepsy with therapy such as cognitive behavioural therapy (CBT), relaxation or biofeedback, in conjunction with anti-epileptic medication. The NICE guidelines state this is an important method to control seizure activity. They claim that psychological interventions “may be associated with an improved quality of life for some individuals” (NICE, 2012, p. 27).

The NICE guidelines (Meijer, Verloop & Beijaard, 2002) focus principally upon seizure control and securely classify epilepsy within a medical model. This model projects that seizure control alone would affect the quality of life and general wellbeing of individuals with epilepsy. However, evidence has revealed that neither the frequency of seizures nor the type can be solely associated with quality of life. Bishop and Allen (2003, p. 227) state that “the impact and consequences of epilepsy cannot always be understood as resulting directly or logically from the occurrence of seizures.” Many issues can impact upon the participant as a result of past physical and cognitive effects of seizures. The fear of future consequences post-surgery will often negatively influence happiness, self-perception, fulfilment and life-satisfaction (Wilson et al., 2007). In many cases, where the sole focus of surgery is the control of seizure activity, this leads to the ignoring of the emotional and psychosocial impact of the chronic condition and surgery. When an individual experiences seizures post-surgery,
societal and cultural support, both physical and emotional, is necessary when treating and managing epilepsy as a chronic illness.

**Epilepsy medication post-surgery**

Research conducted in Western cultures found approximately 20% of the patients in who undergo a PTL are not required to take antiepileptic drugs (AED) post-surgery to attain and remain seizure-free (Schiller, Cascino, So, & Marsh, 2000; Tellez-Zenteno et al., 2007), increasing SWB. In theory, the consideration of postsurgical success relates to seizure control and is therefore dependent on the preoperative identification and resection of the epileptogenic zone. Although no single observation technique can specifically identify the epileptogenic zone, accurate identification is the desired surgical pre requisite (Andrade, 2009). Medical professionals define an individual’s suitability for surgery by identifying the epileptogenic zone in the brain (Spencer, & Huh, 2008). The driving motivation is that the use of various tests has independent value in terms of localising the zone. An independent evaluation from each study and consideration of the results of a combination of relevant testing provides confidence in the localisation of the zone. The likelihood of the individual experiencing further seizure activity post-surgery may be the result of more than one factor (McIntosh & Berkovic, 2006), including increased emotional stress levels, encouraging low SWB.

Studies conducted in Western cultures found approximately 50% of patients experience seizure activity following a long period of remission post-surgery (Foldvary, et al., 2000). These seizures suggest the return may be due to more than one cause. A pattern of persistent and frequent post-operative seizures may suggest incomplete removal of the preoperative epileptogenic zone (McIntosh, et al., 2004). Furthermore, a pattern of extended seizure freedom followed by occasional seizures may also suggest a further undetected epileptogenic zone. The second temporal lobe may have an underlying low-grade epileptogenic zone as the result of the surgical procedure to remove the initial lobe responsible for previous frequent seizures (McIntosh & Berkovic, 2006). The last 20-years have also recognised that the quality of the surgical outcome also relies on the post social and psychological effects on patients, illustrating the need for post-surgery counselling.


**Rehabilitation Therapies**

Recent clinical studies have shown seizure reduction should not be considered the only objective of a lobectomy procedure. The aims of rehabilitation are to maximize a patient’s skills to participate in all relevant social settings (Bishop, 2004). The word ‘rehabilitation’, comes from the Latin term *rehabilitare*. Rehabilitation is the process that centres on the restoration of an individual’s well-being, independence, and level of functioning following injury, trauma, or a developed physical or mental illness, disability, or impairment to the maximum possible unit (VandenBos, 2007). There are various types of rehabilitation available. Counselling psychology focuses on facilitating personal and interpersonal functioning across the lifespan (VandenBros, 2007). Factors of this method include rehabilitation, social, music, educational, vocational and recreational health.

Rehabilitation psychology provides interventions for individuals with a chronic illness such as epilepsy, an opportunity to achieve “personally fulfilling, socially meaningful, and functionally effective interaction” (Banja, 1990, p. 615). Social counselling includes processes of either direct management of personal and social problems, or the planning or practising of programmes that benefit the participant’s social network (VandenBros, 2007). Music counselling as a means to develop brain plasticity includes the use of singing to address speaking and voice quality, rhythmic stimulation to encourage movement and walking and the use of music improvisations to address emotional (Thaut & McIntosh, 2010).

Educational counselling is a process focusing specifically on providing advice and assistance to students in the development of their educational plans, choice of appropriate courses, and the choice of college, technical school or university (Yahanpath, Neal, & McCormack, 2013). Vocational rehabilitation is structured on a variety of rehabilitation methods, including vocational counselling, pre-employment training, assisting the individual to attain employment, and job support (Caplan, Fadyl, & Mcpherson, 2009).

Recreational therapy is classified as “...a treatment service designed to restore, remediate and rehabilitate a person’s level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restriction to participation in life situations caused by an illness or disabling condition” (American Therapeutic Recreation Association [ATRA], 2009). Psychoeducation is a process designed to offer understanding to individuals with physical, cognitive and affective health issues as
the result of surgery and to offer their families knowledge about the condition and their role in helping to care for the individual (Reid, Lloyd & de Groot, 2005). Often psychoeducational training involves participants with anxiety disorder, clinical depression, psychotic illness, and schizophrenia (Donker, et al., 2009, Nasr & Kausar, 2009).

**Alternative treatments**

Following neurosurgery, many individuals with epilepsy may often pursue alternative treatments, such as fasting and dieting as a means to influence seizure control, which can encourage higher SWB. Evidence as far back as the Hippocratic Corpus, *On The sacred Disease* (c.400BC), shows that individuals who are prone to seizures have practised fasting with a desire to cure seizures. Research interest in dietary methods to control seizures lowered in the 20th century with the development of electrical brain testing. However, researchers in the 21st century (Kang, et al., 2007; Kossoff, Rowley, Sinha & Vining, 2008; Nordli Jr, et al., 2001; Smith, Politzer, MacGarvie, McAndrews & del Campo, 2011) are once again interested in the efficacy of a modified version of the Ketogenic diet and Atkins diet. People on this diet have experienced a percentage of reduced seizure activity when resective procedures, such as a temporal lobectomy and/or anti-epileptic drugs (AED) have failed to control the irregular neuron activity.

Kossoff, et.al., (2006), claimed both the Atkins and Ketogenic diets can strongly contribute as optional treatments of seizure activity post-surgery. With the intent to reduce seizure activity, both diets restrict the consumption of carbohydrates, such as bananas and bread, and increase the consumption of foods containing high levels of fats (Verrotti, D'Egidio, Agostinelli & Gobbi, 2012).

**Atkins Diet**

The present day Atkins diet consists of a food consumption balance of 60% fat, 30% protein, and 10% carbohydrates (Kang, et al., 2007). Freeman, Kelly, Freeman (1996) believe that the success of seizure control is influenced by the higher ratio of fats and protein to carbohydrate consumption. The procedure has been question by a number of researchers.

In 2003, the American Physician's Committee for Responsible Medicine (PCRM) in a report on the Atkins diet claimed that this food plan could lead to an increased risk of further chronic illness and health problems following neurosurgery. The PCRM reported that dietary
practices might lead to cardiac problems, including an increased likelihood of a heart infection, and gastrointestinal problems, such as regular diarrhoea and stomach ulcers. The Atkins diet is recommended mostly for adults with epilepsy, when seizure activity is not fully controlled by surgery and medication alone (Abou-Khalil, 2009). However, the diet is not recommended to replace the consumption of medication.

**Ketogenic diet**

The ketogenic diet is a high-fat, adequate-protein, low-carbohydrate diet that in medicine is used primarily to treat difficult-to-control (refractory) epilepsy in children (Abou-Khalil, 2009). The focus of this diet is to influence the burn fats rather than carbohydrates to empower body activity. Normally, body energy is fuelled by glucose, a conversion of carbohydrates contained in food. Glucose is then transported around the body and is very important for increased brain function (Bough & Rho, 2007). Because of the diet, ketone bodies replace glucose as an energy source in the brain. Researchers have noted ketosis, resulting from the increased level of ketone bodies in the blood, is a state that reduces the frequency of epileptic seizures (Freeman, Kossoff, & Hartman, 2007). The Ketogenic diet is recommended mostly for children experiencing uncontrolled seizure activity. It is also recommended that participants of this diet do not rely solely upon it as a means for seizure control. It has been noted that a number of participants experience increase aspects of SWB, including confidence and self-esteem (Bough & Rho, 2007).

Kossoff, et al., (2006) however questioned whether the necessary increased production of ketone bodies, produced by the liver to avoid draining of protein stores in the body muscles, would place the individual in greater danger of developing kidney stones and immune infections. A further argument is that these dietary restrictions are likely to lead to heart disease and other ailments (Carrette, et al., 2008).

Further suggestions to control seizure activity have been the consumption of natural herbs, such as green tea, containing the amino acid of L-Theanine. For many centuries, Asian cultures have argued that its consumption works as a relaxant to control irregular neurological activity (Nobre, Rao & Owen, 2008). This is similar to the effect GABA has on neuron-accelerants, such as dopamine and serotonin, reducing irregular central nervous system activity, and lessening the chance of experiencing convulsions in a seizure (Yamada, et al., 2005).
Chapter 2: Physical and Psychological Aspects

Conclusion

Historical writing has shown that epilepsy has been observe as an illness for over 12,000 years, with Cuneiform tablets stating treatment through surgery attempted as a method to control the chronic illness. As seizures are the most commonly experienced neurological chronic illness worldwide, with 5% of individuals experiencing these, and 0.5% later diagnosed with epilepsy because of continuing to experience them, greater understanding is necessary on the chronic illness. This includes research on specialised care, such as neurosurgery to control the condition. Greater knowledge is required on all the forms of epilepsy, and the relative forms of treatment practiced to reduce activity. A higher level of understanding of the physical and psychological aspects that the illness and treatment has on individuals is also necessary. Research is necessary for not only those experiencing focal seizure activities, which surgery is an option when other forms of treatment have not been successful, but also other forms of partial and generalised seizure activity. Additionally, greater understanding is necessary on the post-surgery effects on the SWB of individuals with AOES, with this study looking at men. Understanding the full period over which a seizure is experienced, with the convulsive activity being only a couple of minutes of the up to three day episode can create greater support for these men when present in all family, medical, and social network environments.

It is important to understand and practice all forms of rehabilitation counselling, including psycho-education post-surgery. It is also important for research to focus on the possible social cost, monetary cost, and mortality that may result from the surgical procedure when necessary forms of support fail to be provided. The following chapter will discuss rehabilitation and the possible methods that may assist an individual following a neurosurgical procedure.
Chapter 3

Subjective Well-Being and Environmental Aspects

Introduction

Subjective Well-Being (SWB) is a hypernym, which is made up of a group of separable components, including happiness, self-perception, fulfilment, and life-satisfaction. Diener and Biswas-Diener (2003, p. 2) stated SWB to be “satisfaction with life domains such as marriage, work, income, housing, and leisure; feelings of positive; experiencing infrequent feelings of negative affect (such as depression, stress, and anger); and judgement of one’s life to be fulfilling and meaningful.” Thus, SWB refers to a balance of an overall sense of well-being including both physical and psychological elements that are relatively permanent rather than temporary (Diener & Tov, 2007). In this study, the emotional factor of SWB includes how regularly a participant experiences positive emotions, such as happiness, while the cognitive factor includes the participant’s judgment of self-perception. Health, a feeling of fulfilment and external social all judgement influence Self-perception (Fuhrer, 2000).

Diener and Tov (2007) categorised SWB as subjective in nature, conceiving it as the experience of the individual, which differs from other global measures of well-being, such as quality of life (QOL). They stated that research originally focused on the causes of well-being, but recently has focused on the consequences of SWB, particularly whether high levels of SWB are beneficial to effective functioning, or alternatively, whether they hinder success. Evidence continues to develop that suggests happiness, fulfilment and self-perception have significantly improved SWB within the four areas, health-care, stability, employment and income, and benefits relationships within an individual’s societal network (Diener & Biswas-Diener, 2002; Lyubomirsky, King & Diener, 2005). SWB is also characterised by the fulfilment of needs.

Everything individuals have or do not have, do or do not do, and wish or not wish has a hidden and clear impact to how they perceive QOL (Fuhrer, 2000). As the desire of most individuals is to live with a balanced sense of SWB, it is important for them to understand what signifies and inspires the desire for a “good life” on an individual level (Hagerty, et al., 2001).
Description of Elements of Subjective Well-Being

**Happiness**

Happiness is emotional joy, gladness, satisfaction, and well-being (VandenBros, 2007, p. 429). Ryan and Deci (2001) found that one’s focus on the quality and state of happiness in terms of pleasure achievement and the avoidance of grief often strongly influences SWB. Self-realization influences the level at which an individual can attained complete harmony. A study by Diener & Seligman, (2002) found the happiest 10% of college students to engage in significant social activity.

**Life-satisfaction**

Life-satisfaction is the degree to “which a person finds life rich, meaningful, full, or high quality” (VandenBros, 2007, p. 539). Many typecasts have been developed to classify the life satisfaction of an individual in comparison to his/her social grouping. Improved life satisfaction is often a goal of equality, especially for those following neurosurgery for AOES. The Diener and Seligman’s (2002) study reported social participation to predict life satisfaction.

**Fulfilment**

Fulfilment is the actual or felt satisfaction of a need or desire, or the attainment of aspirations (VandenBros, 2007, p. 392). Diener and Seligman (2002) claimed a rich and fulfilling social life and a network of close social support with family and friends as being strongly correlated with SWB. What an individual often gains initially when he/she believes a potential goal is now achievable are feelings of fulfilment. Work availability and social acceptance predicts the level of SWB only if the individual's needs are fulfilled (Gröpel, & Kuhl, 2009). Further fulfilment when goals are actually achieved following performing and completing necessary actions is often experienced (Ryan & Deci, 2001).

**Self-perception**

Self-perception is a method by which individuals perceive themselves, or the physical, cognitive and emotional characteristics upon which the self is founded (Diener, 2000). Such a perception may contain genuine self-knowledge with various degrees of distortion (VadenBros, 2007). Ryan and Deci (2001) reported that feelings of self-
perception, such as pleasure, contentment, or gladness are elements that influence overall SWB.

Table 3.1 Elements verses Context of SWB

<table>
<thead>
<tr>
<th>Elements of SWB / Contexts</th>
<th>Happiness</th>
<th>Life-satisfaction</th>
<th>Fulfilment</th>
<th>Self-perception</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Environment</strong></td>
<td>Happiness when in the Family Environment</td>
<td>Life-satisfaction when in the Family Environment</td>
<td>Fulfilment when in the Family Environment</td>
<td>Self-perception when in the Family Environment</td>
</tr>
<tr>
<td><strong>Health Environment</strong></td>
<td>Happiness when in the Health Environment</td>
<td>Life-satisfaction when Health Environment</td>
<td>Fulfilment when in the Health Environment</td>
<td>Self-perception when in the Health Environment</td>
</tr>
<tr>
<td><strong>Social Network activity</strong></td>
<td>Happiness when present in the Social Network</td>
<td>Life-satisfaction when present in the Social Network</td>
<td>Fulfilment when present in the Social Network</td>
<td>Self-perception when present in the Social Network</td>
</tr>
</tbody>
</table>

The Relationship between SWB and AOES

Mrabet, Mrabet, Zouari and Ghachem (2004) noted emotional stability to be the state that enables a person with epilepsy (PWE) to have appropriate feelings about common experiences and act in a culturally appropriate manner. The emotional stability of a person with AOES is often self-measured; based on the stability the individual perceives to be able to create not only within him or herself, but also in those closest to them (Reynders, 2008).

Gilliam (2003) said research evaluating facets of SWB, such as self-perception, QOL, and disability in epilepsy, have revealed that the scale of adverse effects of seizure frequency on many facets of SWB including health status is equal to that seen with diabetes mellitus and active cardiovascular disease. He claimed research of patient-oriented comprehensive outcomes post-surgery specified rehabilitation positively affects an extensive range of SWB (Gilliam, 2003). Markand, et al. (2000) reported observing an improvement in the SWB of 53 people as the result of achieving a seizure-free status following neurosurgery to control temporal lobe epilepsy.

Markand, et al. (2000) claimed that when a person does not experience complete termination of seizure activity post-surgery, their self-perception or social status would often lead to a poorer SWB. As a result, emotional instability may often lead to frustration, negativity, and guilt. Because of depression, or similar medical disorders, the individual may experience inflated jealousy, fear of competition, and diminished
accountability, leading to poorer SWB (Ohaeri, Awadalla & Gado, 2009). A goal of this study is to understand these behavioural affects and their consequence on SWB.

The SWB in PWE who have undergone neurosurgery most often differs from those whose AOES is controlled conservatively by taking antiepileptic medications (Vickrey, et al., 2000; Wilson, Wrench, Saling & Bladin, 2008). Vickrey, et al., (2000) reported that greater than 50% reduction in seizure activity results in improved SWB. They found variable effects of medication and depression seem to have a strong influence on SWB in men with epilepsy, independent of the frequency that seizures are experienced. In most cases it was found that individuals whose seizure activity was controlled with anti-convulsive medication alone experience greater happiness, self-perception and life-satisfaction, resulting in stronger emotional stability. It is the author’s experience that when AOES are controlled, participants are more likely to experience greater SWB.

Wilson, Wrench, Saling and Bladin (2008) reported that the seizure activity a participant experiences and the seizure frequency post-surgery often influences self-worth, resulting in varied levels of SWB. It may be assumed that each individual with AOES who undergoes elective neurosurgery wishes for full seizure control to result post-surgery. The participant’s ability to psychosocially deal with these results may strongly influence SWB. Wilson, Bladin and Saling (2001) reported patients with AOES experience more difficulty in most environments as a result of stigma and labelling, affecting how the participant evaluates self-perception, life adjustment, or ability to solve problems in the family environment; often leading to hyposexuality. They claimed that of those who experience complete control of seizure activity, 50% experience improved sexual function. McLachlan, et al., (2004) reported that people who experience a partial temporal lobectomy attained higher SWB and QOL than others whose intractable seizure activity was controlled by taking medication alone. However, they claimed the individual was most likely to become reclusive post-surgery when seizure activity was not fully controlled. It is the author’s experience that the individual will often choose to remain isolated from social network activity, fearing judgement of their continuing seizure activity. Lambert (2001) reported that social isolation might lead to the individual choosing to live in an environment structured around fantasy. She claimed to have observed individuals feeling more comfortable.
when isolated from the social network, as this encouraged a feeling of protection from their judgement and they were less likely to be the focus of social ridicule.

It is the author’s experience that to stabilise SWB following the surgical procedure, it is necessary to face psychosocial difficulties that arise from AOES action. Whether seizure activity terminates or continues post-surgery, the implementation of psychological counselling will allow the health professional to address the psychosocial difficulties that may continue to be experienced, poorly influencing SWB. To comprehend all the individual effects on SWB, further research is necessary. Following this, a greater understanding of the difficulties men with AOES experience will be available, encouraging the further development of methods to increase SWB post-surgery.

It is the author’s experience that the need for necessary counselling both at a medical and social level is important to ensure reactions such as these do not lead to low SWB. Further research to provide understanding about the level of importance an individual with AOES feels towards counselling during a structured rehabilitation period is also necessary. By doing so, health professionals will gain further understanding about how to interpret the information an individual with AOES provides from a first person perspective. The development of post-surgery rehabilitation based on the independent needs of each individual will strongly influence stability and greater SWB.

It is the author’s experience that those closest to the person often fail to anticipate the level of emotional support required post-surgery. Pengelley and Hasserjian (2003) claimed that without adequate psychoeducation for both members in a personal relationship, a lack of necessary support might often fail to be present, leading to a significant weakening of the relationship. When the individual is a parent, it is also necessary that their child/children take part in post-surgery psychoeducation for the overall well-being of the IFE (Allotey & Reidpath, 2007). Further qualitative studies are necessary for greater understanding about the effects of AOES on primary relationships post-surgery (Fisher, et al., 2000).

A small number of research papers on the topic of SWB in males with AOES in relation to how the onset of this chronic illness affects marital status have been published (Carran, Kohler, O'Connor, Cloud & Sperling, 1999; Wada, et al., 2004). The
study by Wada, et al. (2004) focused on 278 Japanese patients (142 men and 136 women) of which 66 of the male participants had been married. Thirteen men reported AOES was the central cause of their divorce. The researchers also found that due to the level of strain AOES placed on the relationship, there was a strong association between the absence of employment and the decision to divorce. In a number of cases, with the removal of the left hemisphere amygdala, the individuals were afraid to make decisions that included the well-being of those closest to him, resulting in further psychological difficulties, including anxiety and depression (Carran, et al., 1999).

**Environments**

Figure 3.1 depicts the environmental reaction that influences Social perception both External and Internal. As the interviewing of social network members about their perception of an individual with AOES rarely takes place, the participant’s perception of the social reaction is often what the researcher considers.

![Figure 3.1 Environments of Social Reaction](image-url)
Each of the external environments, Family, Medical and Social Network influences SWB of men with AOES. Additionally, self-perception of the individual with AOES also influences SWB, influencing Physical Affective and Psychological Affect. Only limited data could be attained from the participants in this study as each individual experienced some absences in memory. This has been both the result of the PTL and the seizure activity participants experienced up until that time, and in some cases following the procedure.

**Family environment**

Family environment as a social group consisting of individuals affiliated by blood or by marriage, adoptive, or other personal bonds (VadenBros, 2007). Although the family has been a fundamental social unit of most human societies, its form and structure has varied widely, including long-term intimate de facto relationships.

**Social Support through Long-Term Intimate Relationships**

There is evidence to suggest that associated support through marriage or other long-term intimate relationships is one of the strongest influences on better health outcome for a man with AOES (Kanner, 2006; Scicutella & Ettinger, 2002). An individual with AOES is more likely to feel secure within the IFE, and less likely to fear physical injury while experiencing a seizure. Elliott, Charyton, McAuley and Shneker (2011) argued that with this security, the individual was more likely to attain necessary academic education and maintain employment. According to Suurmeijer, Reuvekamp & Aldenkamp, (2001), psychosocial factors are more likely to create negative SWB than clinical ones, such as seizure frequency.

Burman and Margolin (1992) reported that as a specific source of social support, marriage might increase the person’s ability to cope when participating in social network activities, including friendships and at work. Robles, Slatcher, Trombello, McGinn (2013) argued that this was the result of adequate support gained in the immediate family environment, enhancing the individual’s capacity to deal with the chronic illness. It is the author’s experience that an individual with AOES is more likely to experience greater SWB post-surgery when positioned within a supportive personal relationship.
Kiecolt-Glaser and Newton (2001) further supported the idea that married people with AOES experience greater physical, cognitive and affective health, and therefore social support through marriage may be particularly important for the patient. What requires consideration at this stage is that often subjects who mostly live within secure marriage environments are the ones that these studies base their findings upon. In contrast, Elliott, Charytonc, McAuleyd, and Shneker, (2011) reported participants who continue to experience AOES activity are less likely to remain married. As a result, the continual experience of seizure activity following surgery is more likely to have a negative effect on SWB (Kobau, et al., 2004).

A large quantity of research focusing on marital status and SWB has identified a number of theories that address the protective effects of the IFE. However, researchers such as Elliott, Lu, Shneker, Moore, and McAuley, (2009) have identified marital relationships that include an individual who continues to experience adult seizures is less likely to maintain stability. Limited economic and material means is what often influences the result. It is considered that the individual who is unable to maintain financial stability following the PTL often holds a less significant position in the personal relationship (Elliott, Charyton, McAuley & Shneker, 2011).

**Sexual Dysfunction and the Amygdala Post-Surgery**

Sexual Dysfunction is a variety of differences in emotional related behaviour after surgery based on gender, with women retaining greater and more vivid memories for emotional events due to a larger left temporal lobe (Canli, Desmond, Zhao, & Gabrieli, 2002). Neuroimaging has found that the right amygdala is most often larger in men, containing relatively high concentrations of sex hormone receptors. As a result, men are more likely to have a greater sexual drive post-surgery because they use visual perception to trigger sexual memory more often (Goldstein, et al., 2001).

Hamann (2005) reported an association “...between the size of the amygdala in patients with epilepsy and sexual drive.” Baird, Wilson, Bladin, Saling and Reutens (2007) claimed, “...a patient with greater residual amygdala size post neurosurgery attained greater sexual drive and motivation.” Goldstein, et al., (2001) found the individual is more likely to experience a lower level of sexual function post-surgery when the epileptogenic zone is located in the right temporal lobe.
Chapter 3: Subjective Well-being and Environmental Aspects

The primary role of the “amygdala is the formation and storage of memories associated with emotional events” (Amunts, et al., 2005). Blair, Schafe, Bauer, Rodrigues, and Ledoux (2001) reported that under regular circumstance, when experiencing fear, sensory stimuli reach the amygdala and an association with memories of the stimuli is developed. The researchers claimed that those with larger left amygdala experience greater and more complex social networks. They found participants with a dominant left temporal lobe were able to make more accurate personality judgments about other persons they had previously met.

Baird, et al. (2007) reported that the removal of the left or right amygdala might often result in high socio-emotional discomfort becoming easily apparent. A number of researchers have noted individuals are often not motivated to re-join their social network post-surgery (Brierley, Medford, Shaw & David, 2004; Cristinzio & Vuilleumier, 2007; Elger, Helmstaedter & Kurthen, 2004; Tanriverdi, Poulin & Olivier, 2008). Tanriverdi et al. (2008) said a lack of motivation resulted from an inability to comprehend emotional or social nuances, resulting in little or no interest in social network interaction, and persistent attempts to avoid contact with others or flee if pursued. Due to feelings of negative SWB initially resulting from AOES, a participant is likely to withdraw both physically and psychologically when approached (Olson, Plotzker & Ezzyat, 2007). Carran et al. (1999) claimed AOES often has a strong negative effect upon marriages, and the termination of seizure activity creates greater stability or new opportunities for changes in social relationships.

Herzog, et al. (2010) reported hyposexuality is one of the most frequent dysfunctions experienced by men with AOES, with a greater effect on those who experience a PTL in the right hemisphere. They found that up to 67% of participants with AOES who experience focal seizures are likely to encounter erectile difficulties, especially originating from the temporal lobe. Hellmis (2008) has also noted that the amygdala has extensive anatomic connections with the arcuate and preoptic nuclei, negatively influencing the regulation of gonadotropin releasing hormone. Bauer, et al. (2000) found that the percentage of hypersexuality increased in participants following a left hemisphere partial temporal lobectomy.

Lambert (2001) reported a raise in sex hormone binding globulin and reduced free testosterone will often transpire in men with AOES post-surgery, resulting in increased
hypersexuality. The researcher claimed this demonstrates that on average, men who undergo an elective PTL for AOES do experience an improved sexual performance after the temporal lobectomy. Based on these results, successful clinical and surgical treatment for AOES influences better seizure control and sexual function post-surgery. Bauer, et al. (2000) claimed that the judgement of individuals in the social network might also influence the individual’s hyposexuality post-surgery.

This qualitative study attempts to fill this gap by providing more detailed knowledge on how a participant’s sexual activity is post-surgery affected. Questions asked of the subjects address these issues and offer understanding about the importance of discussing topics such as sexual dysfunction during the necessary rehabilitation period with a medical professional, such as a psychiatrist.

**Health Environment**

Individuals when consulting health professionals about specific post-surgery effects and treatment may often experience impediment. In many cases, only general knowledge about possible surgical effect (Lindsey, 2002), such as basic percentages on the likelihood of experiencing a seizure post-surgery, is all that they receive. What this can often lead to is the individual being unable to recognise the symptoms that are influencing their happiness, self-perception, fulfilment, and life satisfaction accurately (Gilliam, et al., 1999). The individual may often only see a clinician and a neurologist occasionally post-surgery, often judging the specialist as being most credible for attaining knowledge on their chronic condition and possible post-surgery effects (Dunn, & Burcaw, 2013).

**Social Network Environment**

Paton, Belova, Morrison and Salzman (2006) reported that because of the attitudes and lack of education of relevant members within the social networks, an individual often experiences an imbalance of fear and insecurity arising from anxiety. McDannald, Kerfoot, Gallagher and Holland (2004) claimed that the individual often fears social reactions post-surgery because of an emotional imbalance resulting from the removal of the amygdala. They asserted that this cognitive effect, which may have been present pre-surgery, often impairs the person’s ability to attain and express emotions when present in the social network environment. Amunts, et al. (2005) declared that this was
a form of classical conditioning of emotional responses often experienced by the individual when addressing others in general conversation. As a result, all participants will most often experience emotional instability. It is the author’s experience that the support of epilepsy support groups, meeting with both a counsellor and other individuals with similar physical and emotional experiences may allow the individual to find positive identity within one’s chronic illness.

**Disability Identity**

Disability identity can be defined by the situation where individuals who experience a similar chronic illness feel affinity, or even solidarity when in each other’s presence (Putnam, 2005). Studies have found similarities in beliefs and understandings among participants who experience similar disabilities towards rehabilitation, medical needs, employment experiences and general social understanding (Barnartt & Scotch, 2001; Dunn & Burcaw, 2013). Olkin and Pledger (2003, p.203) wrote:

> Although it might be hypothesized that disability identity and feeling a part of a disability community are buffers against the stresses of being an oppressed minority, this has not been directly examined…. Is disability identity a buffer against… disability-specific hassles?

**Self-Environment**

Self-environment is strongly based upon one’s self-perception and self-monitoring (VadenBros, 2007). Self-perception is the view of oneself or of any of the mental or physical attributes. Self-monitoring is the method used by behavioural management in which the individual keeps a record of their behaviour. Fisher, et al., (2000) noted that self-monitoring is a personal trait reflecting an ability to modify behaviour in response to situations or pressures, opportunities, and norms. ‘High self-monitors’ are typically more in tune with the demands of the situation, whereas low self-monitors tend to be more in tune with internal feelings.

**Individuals Perceive SWB Differently, Based on Personal Perception**

An individual with elective neurosurgery for AOES often perceives SWB differently from others (Johnson et al., 2007). This may also depend upon the period that has passed post-surgery and methods of self-regulation and coping skills. Recent methods of analyses adopted by researchers to assess a patient in the self-environment include the FACIT-SP-12. There is evidence to suggest the choice to adopt quantitative
instruments, such as the FACIT–SP-12 to question whether SWB has increased over time is needed (Johnson, et al., 2007; Lin & Bauer-Wu, 2003). The FACIT–SP-12, is comprised of multiple choice questions, providing participants with a five point Likert-like scale of 0 (not at all) to 4 (very much), covering 12 items and was developed as an overall index of SWB. As little research has involved those with AOES post-surgery, the study will reflect on studies of the SWB of patients with cancer to assess the self-environment.

When adopting the FACIT–SP-12, Johnson, et al., (2007) reported that SWB in cancer patients decreases post-surgery, with only the item relative to spirituality staying consistent over the 12-month longitudinal study. They claimed that of the other factors, such as inner harmony, peacefulness, and a sense of comfort and strength, suggested that the participant’s assessment of SWB changes over time, influenced by their condition. Johnson, et al. (2007) claimed that some aspects, due to a lack of support and education for the individual, topic such as the control of their medical conditions, are commonly self-defined, poorly influencing SWB.

The Lin and Bauer-Wu’s (2003) report on clinical care claimed that as SWB is a complex concept that has a probability for changing over time, one must acknowledge this when researching the topic. Although a one off evaluation of SWB provided valuable information, more detailed inquiry methods are necessary to be used over time to assess and assist the individual requirements of participants.

The specific term, quality of life (QOL) is mostly used for study outcomes in which at least three domains (major dimensions) of life have been evaluated (e.g., physical, social, emotional) (Starling, 2010). Alternatively, the more narrow term health-related quality of life (HRQL) is used to describe measurement of characteristics most likely to be affected by health status (Osaba, 1994). Therefore, HRQoL can be distinguished from QOL as it concerns itself primarily with those factors that fall under the purview of health care providers and health care systems (Wilson, & Cleary 1995)

**Health Related Quality of Life**

Health-related quality of life (HRQoL) is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses
on the impact health status has on quality of life (Till, Osoba, Pater, Young, 1994; Ware, 1994). Schipper, Clinch, and Powell (1990) defined HRQoL as the “functional effects of an illness and its consequent therapy upon a patient, as perceived by the patient”. It is important to emphasise that these are the impairments that patients themselves consider important (Walker & Avant 2005).

Over the last 10 years, there has been growing interest in research measuring HRQoL in participants with AOES following neurosurgery. Elsharkawy, et al., (2009) focused on the long-term outcomes and predictors of the HRQoL in a large group of clients who underwent elective neurosurgery for refractory extratemporal epilepsy. The data from Elsharkawy, et al., (2009) found that 87 participants indicated their “relationships between the duration of seizure freedom and QOL subscales were mainly non-linear.” The analysis showed that following neurosurgery, issues including seizure freedom, the levels of antiepileptic medications still required and their side effects, medical comorbidities and independence to perform actions such as driving a car influence QOL. Furthermore, the presence of post-operative seizure activity lowered QOL in participants. Mikati, et al. (2004) found that clinical care was important for the individuals, with its absence often leading to emotional and psychological trauma.

**Psychological Trauma Arising from Surgery**

Three factors are associated with psychological trauma arising from surgery. These are that:

1. It was unexpected.
2. The patient was unprepared.
3. The patient could not have acted in any way to prevent this from happening.

For patients post-surgery, affective trauma can result from events such as the breakup of a significant relationship. A patient encountering the unexpected results of neurosurgery may experience humiliation or deep disappointment. The individual may discover further unexpected difficulties relating to the AOES for which further surgery is not an option (Harroud, Bouthillier, Weil, & Nguyen, 2012). For instance, if it were later found that lesions progressed to the second temporal lobe of a patient, causing further seizure activity, the same surgical procedure would not be an option. This is because the patient would already be dependent upon the second temporal lobe to perform the actions of both lobes (Summerville, 2002, pers. comm.). Although one may
not anticipate these situations and similar others as likely to occur, such circumstances may lead to the patient experiencing further psychological trauma (Harroud, et al, 2012).

How physical, cognitive and affective trauma are distinguished often depends on the speed and frequency with which that upset is triggered, how intensely threatening the source of upset is, and how long it takes to maintain emotional stability following the incident. For a patient who fails to receive adequate post-surgery rehabilitation, emotional trauma based on the high level of suffering experienced as a result of AEOS may develop, having a higher psychological effect on the individual. Suicide may occur post-surgery, even when patients report excellent seizure control (Hamid, et al., 2011).

**Depression and Mood Disorders**

Men with epilepsy are most at risk for developing depression, with factors such as age of onset, the location of the epileptogenic zone, seizure type and frequency, and duration of the chronic illness influential (Trimble, Ring & Schmitz, 2000). Gaitatzis, Trimble and Sander (2004) claimed that of a group of 100 patients with cryptogenic epilepsy and normal intelligence, health professionals diagnosed 3% of participants with depression and a further 3% with dysthymia. Depression is a relatively frequent comorbid psychological disorder in chronic epilepsy, with an average 30% lifetime prevalence among persons with epilepsy (Richardson, et al., 2007). Glosser, Zwil, Glosser, O’Connor and Sperling (2000) maintained of patients who experience a PTL, 27.1% will experience depression pre-surgery and 24.9% post-surgery. Hermann, Seidenberg and Bell (2000) reported that patients who continue to experience seizures post-surgery, 43% are at risk of developing depression. This results in higher levels of suicide (Rayner & Wilson, 2012). Téllez-Zenteno, Patten, Jette, Williams, and Wiebe, (2007) claimed individuals with epilepsy were also more likely to report lifetime anxiety disorders or have contemplated suicide.

Gaitatzis, Trimble, and Sander, (2004) reported that patients with TLE contemplate suicide 25% more often than those within the general population. Further research has shown that 30% of men with AOES contemplate suicide within the first three months post-surgery as the result of depression (Pompili, Girardi, Tatarella, Angeletti & Tatarella, 2006). This is often the result of a lack of adequate rehabilitation, including psychoeducation for both the patient and those closest to them (Rayner & Wilson,
2012). Inadequate support may leave a patient open to experiencing further trauma not associated with the present condition, leading to labelling and stigma.

**Labelling and Stigma**

Originating in sociology and criminology, labelling theory focuses on the oral tendency of majorities to negatively label minorities or those seen as deviant from what is thought to be normal (VandenBros, 2007). Labelling is frequently associated with the concept of a self-fulfilling prophecy and with stereotyping. Therefore, sociologically, the social manifestation of a label is not restricted to institutional contexts. The behavioural issues suggest some individuals are at risk of labelling. Low SWB is more likely to influence the behaviour patterns the participant experiences, which are often associated with the neurological procedure rather than discomfort in most social environments (Raffaele, 2009).

**Problems of Stigma as a Result of Labelling**

Stigma is a mark of disgrace that sets a person apart. When a person is labelled by their illness, they are seen as part of a stereotyped group. Negative attitudes create prejudice, which leads to negative actions and discrimination (Link & Phelan, 2001). Stigma originally referred to the presence of bodily signs that exposed something unusual or bad about the moral status of individuals (Prior, Wood, Lewis & Pill, 2003). In Goffman’s (1963) book titled “Stigma”, the author was the first researcher to acknowledge this term as one with a multitude of connotations and definitions. The mere existence of a diagnostic labelling, even when any covert sign of cognitive illness is absent, is often sufficient to draw out stigma (Link, Cullen, Struening, Shrout & Dohrenwend, 1989; Link, Mirotznik & Cullen, 1991). Assumptions about the way a person with a certain mental illness, such as Down’s syndrome, appear are common in all societies. However, as the symptoms of epilepsy are often either misunderstood or ignored, the individual with this chronic illness mostly fails to live up to the social expectations of ‘what is normal’, and “…he is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribution is a stigma, especially when its discrediting effect is very extensive” (Goffman, 1963, p.3).

Scott (1961) reported that this ‘deviant labelling’, that general society places on those with a disability does in fact lead to ‘secondary deviance’. He claimed the powerless
labelled participant might adopt the meaning of this deviancy and begin to exhibit symptoms and behaviours that will lead to social isolation. Deviant labelling rapidly increases when the quality of the condition influences SWB. “Stigma commonly results from a transformation of the body, labelling, a blemish of the individual character, or membership of a despised group” (Goffman, 1963, cited Raffaele, 2009), leading to low SWB. Building upon this definition by Goffman (1963), Link and Phelan (2001) defined stigma as existing when a person is identified by a label, which sets the person apart and links the person to undesirable stereotypes that result in unwarranted treatment and discrimination. “Stigma will often upset social interaction, and is managed by controlling the flow of information about real or imagined discreditable qualities in face-to-face encounters” (Green & Sobo, 2000). If enacted while in isolation from others much deviant behaviour can be hidden (Hubel, 2010). However, if neurosurgery does not result in the control of AOES, this is often not the case. Consequences of labelling and stigmatisation will often lead to low SWB if by AOES the individual is identified (Baral, Karki, & Newell, 2007).

There have been many published documents which address complex focal seizures and the problems a father might experience when he has a child with epilepsy. However, little documentation covers the effects of fertility and parenting for a man with epilepsy. Sare, Rawnsley, Stoneman, and Duncan (2007) report that within the 10-year period leading up to 2007, more than 1000 publications on the topic of women with epilepsy and pregnancy occurred. These articles focused on topics such as the effects of anti-epileptic medications on pregnancy, fertility and attitudes towards motherhood. The authors claimed that they were unable to find any articles that directly focused on men with AOES and their attitudes towards fatherhood. Sare, et al. (2007) reported that for most individuals, AOES adversely affected self-esteem and quality of life. Although the research by Sare, et al. (2007) discussed the effects on fatherhood when a man has epilepsy, it failed to consider a father who develops AOES and postsurgery effects. The lack of adequate research on this topic may allow problems to occur in the family environment because of lack of education (Raffaele, 2009).

A lack of education as to why a person exhibits emotional changes, such as symptoms of depression, regression and reclusion may cause problems for the home environment. As this may result in stigmatisation occurring towards the partner/father with AOES,
the individual may feel he has not a choice but to perceive and present his identity based on family judgement. This may include a need to disguise and admit to the stigmatised feature or attribute, and work hard to minimise its significance (Thomas, 2007).

**Stigma and Its Psychosocial Effects**

In general, psychosocial effects describe the feelings and reactions experienced by individuals when their overall capability to explain what they experience, such as when experiencing a CPS, is based on a third person’s observations (Raffaele, 2009). Smart (2001) reported this often leads to less than appropriate social interaction, contact, and experience with peers, which may lead to negative psychosocial effects. These may include a poor sense of identity, frustration and stress. The additional stresses that individuals with a disability experience through labelling often see them becoming more vulnerable to psychosocial problems (Smith, & Osborn, 2003).

Jacoby (2002) suggested the difficulties participants tend to experience following elective neurosurgery, such as fear, lack of power and traumatic states are generally a result of low SWB. When conducting this research, I feel the understanding of effects would be of great benefit for these men and those closest to them. This understanding would also assist pre-service community health students who on the completion of their degree would be working with these men and their families in the field of medicine. Similarly, this knowledge would be extremely beneficial for counselling and psychology students.

The participant tends to elicit negative, harsh, and conflicting interactions from his partner, which may influence negative reactions from children (Carran, et al., 1999). These participants often encounter problems with social interactions and experience social rejection and isolation (Morrell, 2002). As a result, a noticeably negative flow of reactions and feedback from society may be recalled when questions regarding social reactions are asked of these men (Barry, et al., 2008). Whiteneck, Gerhart & Cusick (2004), “indicate individuals with brain injury report a range of environmental barriers and obstacles that limit their societal participation and SWB.”
Conclusion

This chapter provided a description of the elements of SWB, including happiness, life-satisfaction, fulfilment and self-perception. The chapter also reflected on the relationship between AOES and SWB. The chapter discussed relationships within the four social environments relevant to the participant in this study, Family, Health, Social Networks, and Personal. The chapter also discussed the physical and emotional effects that may result for the individual following the PTL procedure such as, sexual disfunction resulting from the removal of the amygdala. Health related quality of life and psychological traumas that may arise post-surgery were also discussed. Additionally, the effect of labelling and stigma, and the cost on the individual’s SWB was also covered. The following chapter will focus on these specific research questions, discuss the research constructed and the methodology and methods chosen and outline the research process.
Chapter 4
Methodology

Introduction

This chapter discusses qualitative research methods employed in this study: case study and a phenomenological approach. It also presents the research design aligned to the research objectives. The chapter also discusses the procedures and results of the pilot study implemented to trial the data collection procedure and measurement.

This is a qualitative study to access the live experience with AOES following elective neurosurgery. Lived experience is essentially about subjective well-being (SWB) and in a unique sample, amenable for study using qualitative inquiry. This can be done through qualitative research methods; however there are a number of qualitative research methods approaches that can be introduced to collect and interpret relevant data, such as phenomenology or grounded theory.

Phenomenology or Grounded theory

Phenomenological inquiry is most aligned with lived experience studies (Smith & Sparkes, 2009; Starks & Trinidad, 2007; Dey, 1993). It can be differentiated from grounded theory, which is more suitable for studies to sociology (see Table 4.1). Interpretive phenomenological analysis (IPA) is the primary approach for this study (See also research design section page 64). Table 4.1 shows the commonality between phenomenology and grounded theory.
Table 4.1 Similarities and differences between phenomenology and grounded theory

<table>
<thead>
<tr>
<th>Commonality</th>
<th>Phenomenology</th>
<th>Grounded theory</th>
<th>This study (IPA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>History</td>
<td>European philosophy</td>
<td>Sociology</td>
<td>Health Sciences</td>
</tr>
<tr>
<td>Philosophy</td>
<td>There exists an essential, perceived reality with common features</td>
<td>Theory is discovered by examining concepts grounded in the data</td>
<td>PWE with neurosurgery for AOES perceived reality with social environments</td>
</tr>
<tr>
<td>Goal</td>
<td>Describe the meaning of the lived experience of phenomenon</td>
<td>Develop an explanatory theory of basic social processes</td>
<td>Describe the SWB of PWE’s lived experiences post-surgery</td>
</tr>
<tr>
<td>Methodology</td>
<td>“What is the lived experience of [the phenomenon of interest]?”</td>
<td>“How does the basic social process of [X] happen in the context of [Y environment]?”</td>
<td>“What is the SWB of men following neurosurgery for AOES?”</td>
</tr>
<tr>
<td>Sampling</td>
<td>Those who have experienced the phenomenon of interest</td>
<td>Those who have experienced the phenomenon under different conditions</td>
<td>Men who have experienced neurosurgery to control AOES.</td>
</tr>
<tr>
<td>Data collection</td>
<td>Observe participants in the context where the phenomenon is experienced</td>
<td>Observe participants where the basic social process takes place</td>
<td>Interviewing men with AOES who have experienced neurosurgery</td>
</tr>
<tr>
<td>Interviewing</td>
<td>Participant describes experience; interviewer probes for detail, clarity</td>
<td>Participant describes experience; interviewer probes for detail, clarity</td>
<td>Participant describes experience; interviewer probes for detail, clarity</td>
</tr>
<tr>
<td>strategies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analytical</td>
<td>Identify descriptions of the phenomenon; cluster into discrete categories;</td>
<td>Open axial, selective coding: Examine concepts across their properties &amp; dimensions; develop an explanatory framework that integrates the concepts into a core category</td>
<td>Identify descriptions of the SWB; cluster into discrete categories; taken together, these describe the principle and structure of the experience of men with AOES</td>
</tr>
<tr>
<td>methods</td>
<td>taken together, these describe the “essence” or core commonality and structure</td>
<td></td>
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<td>of the experience</td>
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<tr>
<td>Role of analyst’s</td>
<td>Bracket views</td>
<td>Bracket views</td>
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<td>view</td>
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<tr>
<td>Audience</td>
<td>Clinicians, practitioners &amp; others who need to understand the lived experience of the phenomenon of interest</td>
<td>Researchers &amp; practitioners who seek explanatory models upon which to design interventions</td>
<td>The family, medical, and social network environments of men with neurosurgery for AOES</td>
</tr>
<tr>
<td>Product</td>
<td>A thematic description of the pre-given “essences” and structures of lived experiences</td>
<td>Generate theory from the range of the participants’ experience</td>
<td>The thematic descriptions of factors that impact the SWB in men following neurosurgery for AOES</td>
</tr>
</tbody>
</table>

Research Design

This research applies IPA to study subjective well-being in men following neurosurgery for adult onset epileptic seizures. First, phenomenology is useful to characterise experiences by individuals (Draucker, 1999; Geanellos, 1998; Maggs-Repport, 2000; Moran, 2000; Orbanic, 1999; Swanson & Wojnar, 2004). It uses in-depth interview and other tools to capture live experiences perspective (Husserl, 1970). Phenomenology is both a philosophy and a group of research methods that focus on exploring and understanding human experience (Smith, et al, 2009). To comprehend the meaning of a participant’s experience, a number of researchers use phenomenology to focus on a concrete experiential account grounded in everyday life, (Langdridge, 2007). IPA is a sub-approach of phenomenology which “focused the subjectivity of reality, continually pointing out the need to understand how humans view themselves and the world around them” (Willis, 2007, p. 53).

A significant value for phenomenological philosophy is it engages the researcher with a large supply of qualitative information about how to examine and comprehend the lived experiences of the participant (Fade, 2004; Smith & Sparkes, 2009). A number of IPA researchers have worked in health and are usually interested in exploring the lived experience of longer term disruptions to physical, cognitive and affective health (Cassidy, Reynolds, Naylor & De Souza, 2011; Larkin, Watts & Clifton, 2006; Smith, Flowers & Larkin, 2009).

Phenomenological case study approach

The phenomenological case study approach is appropriate for investigating either single cases, or a deliberate number of chosen participants. Single-case studies are able to identify issues that illustrate errors and system failures and to illuminate or draw attention to ‘different’ situations. However, positive inferences may be harder to attain without a small sample of participants (Langdridge, 2007; Fade, 2004). In multiple participant research, the strength of analytical findings quickly increases once factors are located in more than one participant. It is important to distinguish between statistical and qualitative validity: phenomenological research can be vigorous in signifying the presence of factors and their results in individual cases (Moustakas, 1994). However, caution is necessary when suggesting the extent in relation to the population from which the participants or cases were taken (Biggerstaff & Thompson, 2008).
Adopting a phenomenological approach into the case study will benefit to identify the experiences of five participants and emphasise the importance of personal perspective and interpretation in this study. The case study will offer the understanding of subjective experience, gaining insights into people’s motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom (Eatough, & Smith, 2008; Lester, 1999).

Using a phenomenological approach to single cases or selected samples can be an advantage in indicating the presence of factors and their effects in individual cases, but must be careful when suggesting their extent in relation to the population from which the participants or cases were drawn (Lester, 1999). For this study, the participants had been chosen carefully in order to identify phenomena of subjective well-being of men who have experience surgery for AOES. Phenomenological methods and case studies are particularly effective at bringing to the fore the experiences and perceptions of each participant from his own perspectives, and therefore at challenging structural or normative assumptions. Adding the interpretative phenomenological dimension this research, enabling it to be used as the basis for practical theory, allows it to inform, support or challenge policy and action (Cassidy, Reynolds, Naylor, & De Souza, 2011; Smith, Flowers, & Larkin, 2009; Larkin, Watts, & Clifton, 2006).

**Case study**

A case study is a form of qualitative research that focuses on understanding the specific concerns/issues of a group of participants in one particular context. The case study research method places emphasis on the exploration and description of the social circumstances of each participant or research site (Davidson, Neale, & Kring, 2004).

Case studies typically explore the interaction of all variables with the aim to offer a broad understanding of a condition or event (Stake, 1995). Through a process often labelled as ‘think description’, one can attain this form of comprehensive knowledge. Think description is comprised of an in-depth description of behavioural action(s) being assessed, the circumstances under which they are employed, the characteristics of the participants, and the social environment(s) in which they are placed. Think description also includes an interpretation of demographic and descriptive data such as values, norms, and the fixed attitudes of social environments (Yin, 2003).
Case study research on a small number of cases is appropriate when the population being studied, such as that in this research, is limited. When numbers of participants limits a study, the researcher must strike a balance between keeping a focus on the investigation of issues and avoiding undue influence by the researcher (Caelli, 2001). When interviewing participants that have a strong personal understanding of the topic, it is important for the researcher to establish strong rapport and empathy in order to gain detailed information (Goddard, et al., 2008).

A multiple case study

A multiple case study approach to data analysis is adopted when a number of case studies are brought together to understand the impact on each participant in their own environments (Zach, 2006). Each case contributes to clarifying the phenomenon exhibited in those cases (Stake, 2006). The approach increases the authenticity of the research through the implied “replication logic” inherent in its design (Yin, 2009). Replication logic is an approach that uses theory to determine other cases by which the findings of one case can be corroborated (Tsoukas, 2009). This replication logic is similar to the one employed in multiple experiments when a significant finding from a single experiment is discovered and then an effort to immediately replicate this finding in another experiment is enacted (Yin, 2009).

Multiple case studies provide an understanding of what the participant in each case study has individually experienced, also providing an interpretive context for other cases (Yin, 2009; Baxter, & Jack, 2008). As each participant is different, the main purpose of using the multiple case study construct is to understand the detail and experiences associated with each case without necessarily expecting the same findings. This enables the researcher to highlight the distinctiveness and uniqueness of individual cases (Stake, 2006). The selected cases could be analysed as independent studies written by different researchers or as predesigned parts of a single study. In either circumstance, each case may be categorised as an independent study whilst also recognising commonalities (Yin, 2009). An intensive case study approach with a small number of participants makes for a comprehensive understanding of the phenomena under study. Qualitative interviews are able to capture the richness of information from isolated case studies.
The Interpretative Phenomenological Analysis

An Interpretative Phenomenological Analysis (IPA) paradigm is utilised for interpretation of qualitative data when the focus of the study is to understand the life experiences of an individual, how he or she interprets these and what significance those experiences hold for him/her (Biggerstaff & Thompson, 2008; Smith, 2004). The IPA paradigm helps interpret the structure of experiences, how people engage with and understand these experiences in relation to themselves. This provides a greater knowledge of how people perceive their lives in relevant social environments (Lincoln & Guba, 2000).

A central concern of IPA is to understand how the world appears to the individual, in other words the subjective experiences of the participant (Smith, 2004). Categorised as a phenomenological psychology, IPA is qualitative in nature, focusing on understanding meaning from narrative accounts by participants (Denzin & Lincoln, 2005). In order to explore what is sometimes titled “the lifeworld of the individual”, through IPA the participants are able to illustrate their views of reality, enabling an understanding of the participants’ lived experiences (Eatough & Smith, 2006).

Applying IPA theory to this study acknowledges the participants have more knowledge about their experience of AOES post-surgery than the researcher does. Learning is not merely the incorporation and adaptation of the new knowledge gained through observation and questioning, but also the process by which the researcher incorporates his or herself into this knowledgeable community. Fade (2004) supports this theory by pointing out the foundation of IPA is based on the theory that the researcher is to gain an insider perspective of the phenomenon being studied, whilst acknowledging the researcher is the primary analytical instrument. Reflexivity is viewed as a possible tool for enabling the researcher to formally acknowledge his interpretative role, rather than as a fundamental technique for eliminating bias (VandenBos, 2007). IPA is assistive for attaining an insider perspective on the lived experiences of individuals.

However, as the SWB experience post neurosurgery differs from one AOES participant to the next, each case will be analysed individually in relation to the four social environments set out in chapter 1; Family, Health Professional/Consultant, Social Network, and Self environments. This will assist the researcher to attain a perception of the psychosocial effects in each social environment. Overall, IPA focuses on the personal experiences of each
participant, which can build knowledge about AOES post-surgery and the effects on SWB because of social reaction to the experience. The Illness Narrative is often adopted to comprehend the first-person conception and experiences (Smith, et al., 2009). Overall, the research focuses on the personal experiences of each participant, upon which greater understanding can be built about the post-surgery experience of men with AOES and the effects on their SWB and the factors impacting upon it.

**Insider Perspectives**

This study examined an ‘insider’s perspective’ on men following neurosurgery to control AOES to explore how the expectations and judgement of relevant social environments influenced their SWB. Insider perspectives refer to the perspective(s) of the individuals from whom researchers seek to understand phenomena or concepts (Liamputtong, 2010; Silverman, 2006). The insider perspective is important to qualitative research objectives as it allows researchers to explore concepts and conceptualisation from the research participants own perspective(s) (Thorne, 2006), especially when adopting the phenomenology to describe what all participants have in common, as they experience a phenomenon (e.g., grief, anger). The insider perspective is the reflection of the participants’ experiences. What they experienced and how they experienced it (Moustakas, 1994). According to the concepts of Edmund Husserl (1859 – 1938), a phenomenological approach is based on studying people’s experiences as they are lived every day, viewing these experiences as conscious (van Manen, 1990), and arriving at a description of the essence of these experiences, not explanations or analyses (Moustakas, 1994). This is the reason why the insider perspective of my own experience was important.

Conducting research in this atmosphere, it is important that the participants have trust in the researcher. This trust comes from the shared experiences between participants and the person who is interviewing them. In the world of epilepsy, there is no way that people who have never had the condition can imagine what it feels like when someone has a seizure. Just looking or studying a video recording of someone’s seizure or reading from the medical textbook are not enough. It is difficult to explain the emotional experience before and after a seizure to anyone, especially to people who do not have epilepsy, because it does not make any sense to the typical person. For example it is difficult to describe the fear or embarrassment felt by an individual when they have a seizure in front of other people or in public, unless you are the one who has a direct experience of the phenomena. The
experiential knowledge of the ‘insider perspective’ provides a level of understanding which breaks down the participant/researcher divide which enables more effective communication of experience.

The insider perspective of the researcher upon this phenomenon is a special and important part of this study and significantly impacts on the interpretation of the results. The insider perspective allowed the researcher to understand the feeling and situations, even though the researcher may not have directly experienced the circumstances that participants had mentioned.

**Ethical considerations**

The Human Research Ethics Committee of the University of Sydney approved the study. A Participant Consent form that included details of the project, of the researcher, assurances of confidentiality, and for the use of apparatus such as an MP3 player to record the interviews was signed before commencement of each interview and observation. During this study, all the participants were aware they could withdraw from the study at any time. For anonymity and confidentiality, each participant's identity was hidden by the use of a pseudonym.

**Trustworthiness in Qualitative Studies**

Attaining trustworthiness was an important goal in this study. The reason for doing so was to reinforce that the findings attained from the interview process were in fact valuable to the study as a whole. The four issues that contribute to attaining trustworthiness are credibility, transferability, dependability, and conformability. These were attained through the recruitment and the conducting of a pilot study, where structure and content was tested. All interviews followed the structure described below.

**Pilot Study**

In order to ensure the study protocol was viable, a pilot study was conducted prior to the main study. Due to there being a limited number of males who have experienced the onset of AOES and surgery to control the chronic illness, the pilot study consisted of only two participants. The pilot study trialed the research protocol to be used when conducting the main study. This included the establishment of networks, appraising accessibility, trustworthiness and the modification of notable issues. According to Van Teijlingen, Rennie,
Hundley and Graham (2001) “advantages of conducting a pilot study is that it might give advance warning about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate or too complicated” (p. 1). As such, the goals of the pilot study were to:

**Goals of Pilot Study**

1. Establish the networks in which to locate possible male participants with Adult Onset Epilepsy Seizures (AOES).

2. Assess the cognitive and procedural accessibility of the interview guide.

3. Assess the credibility and trustworthiness of data from the interview guide for understanding constructions of Subjective Well-Being (SWB) of men with AOES.
   a. Explore whether the SWB of the primary participants is appropriate in relation to their public, social environments (credibility).
   b. Assess whether the data collected through the interview guide can be found in similar populations of people with AOES who have not had neurosurgery (transferability).
   c. Assess whether the data collection, data analysis and theory generation processes of the study are consistent and repeatable (dependability)

4. Anticipate and amend any logistical and procedural issues or limitations related to the study.

**Pilot Study Structural Guide**

Prior to commencing the pilot, the following criteria were established to identify eligible participants and methods of recruitment (Table 4.2). Participants were required to be male. Their presently age was to be at least 21-years; the participant had to have developed epilepsy after 18-years and had undergone neurosurgery with the intention to reduce seizure activity. The participant was required to be capable of understanding and speaking English without the assistance of an interpreter. The pilot protocol included semi-structured interviews which would involve one to one interviews. Audio recording would be made of each interview, with the option for post-interview telephone communication (Table 4.2).
Table 4.2 Pilot Study Structural Guide

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Recruitment</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Male over 21-years of age</td>
<td>-Advertise on Epilepsy organisations websites</td>
<td>-Semi-structured interview</td>
</tr>
<tr>
<td>-Developed epilepsy after 18-years</td>
<td>-Advertise in Epilepsy Journals</td>
<td>-One to one interviews</td>
</tr>
<tr>
<td>-Have undergone surgery for epilepsy</td>
<td>-Snowballing/word of mouth</td>
<td>-Audio recording made of each interview</td>
</tr>
<tr>
<td>-Understand and speak English</td>
<td>-Advertise on social networking</td>
<td>-Some post-interview telephone communication</td>
</tr>
</tbody>
</table>
Table 4.3. Pilot Study Participant Summary

<table>
<thead>
<tr>
<th>Pilot Case Study</th>
<th>Present Age and Status</th>
<th>Age of Onset</th>
<th>Age and status at procedure</th>
<th>Focal point</th>
<th>Sexual Drive</th>
<th>Living Arrangements</th>
<th>Medical Consultations Post-surgery</th>
<th>Post-Surgery Rehabilitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam</td>
<td>27 Single</td>
<td>24</td>
<td>24 Dating</td>
<td>Pituitary Gland</td>
<td>Strong Desire</td>
<td>Living alone Rented apartment</td>
<td>Clinician Neurologist &gt; 5 times a year</td>
<td>No</td>
</tr>
<tr>
<td>Tim</td>
<td>53 Married</td>
<td>18</td>
<td>47 Married</td>
<td>Left Temporal Lobe</td>
<td>Strong Desire</td>
<td>Living with IFE Owned accommodation</td>
<td>Clinician Neurologist Psychiatrist General Psychologist &lt;5 times a year</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Sampling Frame for the Pilot study

The sampling frame comprised adults living with AOES post neurosurgery within Australia. Adult males with AOES were recruited with the assistance of community support groups, disability newsletters, magazines and snowballing/word of mouth. Major epilepsy support associations, Epilepsy Australia, and Epilepsy Action, Australia were contacted and their assistance was requested. The sampling frame for this study was inclusive of a variety of living arrangements embracing individuals who presently reside with an extended family, or who live alone.

Social Resonance

In order to ensure the participants were the focal point of analysis and theory, social resonance was continually sought and usually achieved. Social resonance refers to the state of being that occurs when individuals engaged in face-to-face communication feel strongly connected. Adopting this social psychological notion of rapport allows the participants to comfortably discuss the psychosocial effects experienced as a result of levels of SWB.

Participants for pilot study

Table 4.3 provides short profile demographics of the participants who took part in the pilot study. Two men with neurosurgery for AOES participated in the pilot study; Sam aged 27-years and Tim aged 53-years at the time of the interview. The two participants developed seizures in their adult years. Sam was 24 years and in an intimate relationship at the time of surgery for AOES. Tim was 47 years of age and married. The focal point of surgery on Sam was Pituitary gland and Tim was the left temporal lobe. Sam is presently living alone in a rented apartment. Tim is living with his wife and three of his children in a house they own. Both participants reported experiencing strong sexual desires, however only Tim is in regular practice. Sam has consulted a clinician and neurologist post-surgery and is now visiting these medical professionals less than five times a year in total. Tim has consulted a clinician, neurologist, psychiatrist, and general psychologist post-surgery. Tim continues to visit three of these medical professionals more than five times a year in total. Only Tim was provided with post-surgery rehabilitation.
Establishing Networks for Participant Recruitment

In order to ensure the success of this study it was important to establish networks for the recruitment of eligible participants (see Table 4.4). As such, four strategies for data collection were piloted. These included the request for participants from firstly, participating centres/agencies in Australia, secondly, Disability/Epilepsy newsletter or magazines, and thirdly, the Sydney-based community centres or advocacy groups. In addition, the ‘snowballing’ recruitment technique was practised.

Participating centres/agencies

Major epilepsy organizations in Australia were identified through a Google search. The researcher telephoned The Epilepsy Foundation, Epilepsy Australia, Epilepsy Action and requested their assistance in finding volunteer participants for the project.

Recruitment Procedures

Similar to the methods by which data were collected for the pilot study, a purposeful sampling strategy was employed to recruit participants for the main study (see Table 4.4). The pilot study revealed that participants were widely distributed and relatively inaccessible hence, the main study sought recruitment of participants from a number of states in Australia in order to enhance the possibility of finding members of the target population. Participants were recruited through advertisements published in bulletins, through advocacy groups and disability focused newsletters and webpages.

As the researcher was formerly the co-ordinator of the Inner-city Epilepsy Support Group in coordination with Epilepsy Action, Australia details of this project were also forwarded to the coordinator of the support organisation and informal permission was received to ask relevant clients if they were interested in participating.

Disability/Epilepsy newsletter or magazines

The researcher performed a search through Google in Australia for major disability newsletters or magazines that catered to people with epilepsy. Those that publish material for general viewing in Australia were shortlisted. The researcher then contacted each newsletter and requested their participation in the study.
Two organisations placed information about this study within their Research section (see Appendix F). The Epilepsy Foundation of Victoria, a sister organisation of Epilepsy Australia, also assisted in the recruitment of participants by placing an advertisement in a relevant journal (see Appendix G). This meant only those people who were eligible and interested contacted the researcher and there was a degree of comfort and security provided to those expressing an interest because they trusted the organisations involved.

**Sydney-based community centres**

The researcher also communicated with community and advocacy groups/centres that catered specifically to people with Epilepsy and those closest to them. As there was only a small number of Sydney-based groups and centres interested in recruitment, additional organisations across Australia were contacted.

**Snowballing**

Snowballing enlistment was carried out at the end of a participant’s interview. This procedure consisted of the researcher asking each participant if they knew of somebody who also met the eligibility criteria of this study and whether they would be willing to give that person a copy of the participant information sheet (Appendix C). The researcher was not aware of the identity of this second person prior to the contact of the new potential participant. Additionally, the initial participant (informant) was not made aware of whether the second person chose to participate in the project following our communication.

**Results of procedures**

Two participants were located with the assistance of Epilepsy Australia, and Epilepsy Action, Australia. Procedural access to the interview was achieved by offering the participant a number of optional locations where they could take part in the study through face to face interviewing. Both interviews were conducted at the residential address of both participants.

**The Credibility and Trustworthiness of the Data**

When constructing the research procedure and pilot study interview guide, questions relating to three external social environments; the Family, Professional/Consultant, and Participation were considered (Table 4.5). To ensure the issue of credibility was initially addressed, each of the potential research participants was asked a small number of questions via telephone to
determine whether their participation would be credible for this study. Trustworthiness was established on issues including their chronic illness, methods of treatment, including surgery, present health status and present social status.

**Pilot Study Data Analysis**

After the interviews were transcribed verbatim the pilot study data were analysed using a line by line analysis (Luborsky, 1994). According to Luborsky (1994), “line-by-line analysis” is comprised of the thorough reading of transcripts, followed by a division of the data into significant analytical entities (segmenting the data). Once meaningful segments (founded on meaningful themes in this instance) are identified, these are then coded. For the objective of the pilot study, this was adequate for attaining topical responses, direct and emotional statements and discourse markers.

**Key Lessons from the pilot study**

Consistent with the aims of the pilot study, networks identified enabled the recruitment of relevant participants. However, relatively few volunteers were identified by the various agencies for participation in the pilot study, with only two of these individuals being likely to participate in this study in Australia. While participation in the pilot study may have been limited it was still accessible. Both participants found the majority of the interview guide easy to understand and answer. Further, the pilot study confirmed the interview guide accessed data relevant to the focus of this research project.

The pilot study used a set of semi-structured questions (Appendix D). Through the process of conducting the pilot study, structural changes were made to the interview guide and the analytic process for the main study. These modifications were made by developing more structured questions. These modifications were made in order to assist cognitive and procedural accessibility, clarity and reduce confusion about question meaning. The trustworthiness of the study was determined by assessment of the credibility, transferability, and dependability of the interview guide.
Table 4.4 Strategy for recruiting participants for the pilot study

<table>
<thead>
<tr>
<th>Steps</th>
<th>Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Participants will be asked if they knew someone who could be included in the sampling frame (x =0)</td>
</tr>
<tr>
<td>2</td>
<td>Giving the participant a copy of the Snowball Participant Information Sheet</td>
</tr>
<tr>
<td>3</td>
<td>The participant gives the Snowball Participant Information Sheet to someone they know</td>
</tr>
<tr>
<td>4</td>
<td>The individual the participant gives the Snowball Participant Information Sheet to contacts the researcher</td>
</tr>
</tbody>
</table>
Table 4.5 Interview Guide

<table>
<thead>
<tr>
<th>Questions/Discussion:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction:</strong></td>
</tr>
<tr>
<td>• Some people would say that a way a man with adult onset epileptic seizures following surgery sees himself in all social environments is made up of a variety of different things. I’d like to ask you a few questions about some of these factors.</td>
</tr>
<tr>
<td><strong>Grand Tour:</strong></td>
</tr>
<tr>
<td>• Tell me about your views about SWB post-surgery.</td>
</tr>
<tr>
<td>• Tell me what comes to mind.</td>
</tr>
<tr>
<td>• There is no importance to what comes first.</td>
</tr>
<tr>
<td>a) If participant generates concepts, probe concepts</td>
</tr>
<tr>
<td>b) If they feel differently ask them why.</td>
</tr>
<tr>
<td><strong>Family:</strong></td>
</tr>
<tr>
<td>• Generally unrest can occur in the family environment following neurosurgery. What do you think about that? When you are in the family environment:</td>
</tr>
<tr>
<td>a. How happy do you feel?</td>
</tr>
<tr>
<td>b. How peaceful are you?</td>
</tr>
<tr>
<td>c. What would you say is the quality of your self-perception?</td>
</tr>
<tr>
<td>d. How fulfilled do you feel?</td>
</tr>
<tr>
<td><strong>Medical:</strong></td>
</tr>
<tr>
<td>• When people think about their epilepsy post-surgery they may often think about their neurologist and medical consults, and the level of care and support they received after the operation. What do you think that means? When you are round medical professionals and consults:</td>
</tr>
<tr>
<td>a. How happy do you feel?</td>
</tr>
<tr>
<td>b. How peaceful are you?</td>
</tr>
<tr>
<td>c. What would you say is the quality of your self-perception?</td>
</tr>
<tr>
<td>d. How fulfilled do you feel?</td>
</tr>
<tr>
<td><strong>Public:</strong></td>
</tr>
<tr>
<td>• Little information about epilepsy is present in general societies. How do you think that could influence their judgement? When you are in general social environment:</td>
</tr>
<tr>
<td>a. How happy do you feel?</td>
</tr>
<tr>
<td>b. How peaceful are you?</td>
</tr>
<tr>
<td>c. What would you say is the quality of your self-perception?</td>
</tr>
<tr>
<td>d. How fulfilled do you feel?</td>
</tr>
</tbody>
</table>
Credibility was achieved using the ‘member check’ technique. Also known as an information feedback technique (Harper, & Cole, 2012), participants of the pilot study spontaneously used terms consistent with SWB and neurosurgery located in the interview guide.

Transferability was achieved through the provision of evidence of the analytic process, which may allow other researchers to repeat the protocol. Alternatively, other researchers may utilise the procedure described in this study to analyse data from other research exploring similar concepts in relation to post-surgery neurosurgical disorders.

Dependability of the data collection, analysis, production and the level to which the study's findings are supported were ensured by an independent audit of the research methods by a competent peer.

The results from the pilot study confirmed that the conceptual framework, procedures and data collection techniques for this research met the standard expectations of credibility, transferability, dependability and trustworthiness. Based on the pilot study the main project was adapted to include amendments to the interview guide to ensure clarity and expand the sampling framework in order to increase understanding of the effects on SWB in men following surgery for AOES. Minor adaptations were made to the main study design (see Appendix F) based on the results of the pilot study (see Appendix E). These included the rewording of some questions used to attain data in the pilot study, and additional questions to ensure greater amounts of data was attained to support necessary matters of discussion.

Main Study

The main study included five participants who chose neurosurgery to reduce seizure activity. All participants were men who had experienced AOES pre-surgery. Although the participants were not positioned in the same social environments, each of them was required to address how they deal with similar social reactions post-surgery.

Design

The main study interview guide was found to be suitable and dependable through the assessment and assurance of its trustworthiness by the participants in the pilot study. The main study interview guide (see Table 4.6) that was used for data collection about the participant’s SWB, comprised the following sections; demographics and severity of
disability, family environment, medical environment, general social networks, and self-reflection.
Table 4.6 Main Study Participant Demographic Summary

<table>
<thead>
<tr>
<th>Main Case Studies</th>
<th>Present Age and Status</th>
<th>Age at Seizure Onset</th>
<th>Age and status at surgery</th>
<th>Focal point</th>
<th>Living Arrangements</th>
<th>Sexual Drive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>34 Single</td>
<td>24</td>
<td>30 De facto</td>
<td>Left Temporal Lobe</td>
<td>Alone Rented Accommodation</td>
<td>Strong Desire Small Practice</td>
</tr>
<tr>
<td>Brian</td>
<td>54 Divorced</td>
<td>32</td>
<td>46 Married</td>
<td>Left Temporal Lobe</td>
<td>Alone Rented Accommodation</td>
<td>Strong Desire Small Practice</td>
</tr>
<tr>
<td>Chris</td>
<td>46 Married</td>
<td>31</td>
<td>36 Married</td>
<td>Right Temporal Lobe</td>
<td>Lived with IFE Owned Accommodation</td>
<td>Small Desire Small Practice</td>
</tr>
<tr>
<td>David</td>
<td>55 Married</td>
<td>32</td>
<td>38 Married</td>
<td>Right Temporal Lobe</td>
<td>Lived with IFE Owned Accommodation</td>
<td>Small Desire Small Practice</td>
</tr>
<tr>
<td>Eden</td>
<td>59 Married</td>
<td>45</td>
<td>52 Married</td>
<td>Right Temporal Lobe</td>
<td>Lived with IFE Owned Accommodation</td>
<td>Small Desire Small Practice</td>
</tr>
</tbody>
</table>
Table 4.7 Main Study Participant Social Network Summary

<table>
<thead>
<tr>
<th>Participant Pseudonyms</th>
<th>Family Structure</th>
<th>Medical Consultations Post-Surgery</th>
<th>Post-Surgery Rehabilitation</th>
<th>Social Network Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>No Children</td>
<td>Clinical Neurologist</td>
<td>No immediate post-surgery rehabilitation</td>
<td>Small communication Small support or understanding</td>
</tr>
<tr>
<td></td>
<td>Small communication with the External Family Environment (EFE)</td>
<td>Psychologist &gt;5 times each year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brian</td>
<td>Three Children</td>
<td>Clinical Neurologist</td>
<td>Small post-surgery rehabilitation</td>
<td>Small communication Small support Small understanding Reclusive</td>
</tr>
<tr>
<td></td>
<td>Small communication with Immediate Family Environment (IFE) of EFE</td>
<td>Psychologist &lt;5 times each year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>No children</td>
<td>Clinical Neurologist</td>
<td>No immediate post-surgery rehabilitation</td>
<td>Moderate communication Small support Small understanding</td>
</tr>
<tr>
<td></td>
<td>Small communication with EFE</td>
<td>Psychologist &gt;5 times each year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>David</td>
<td>Two Children</td>
<td>Clinical Neurologist</td>
<td>Small post-surgery rehabilitation</td>
<td>Small communication Small support Small understanding</td>
</tr>
<tr>
<td></td>
<td>Small communication with EFE</td>
<td>Psychologist &lt;5 times each year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eden</td>
<td>Three Children</td>
<td>Clinical Neurologist</td>
<td>No immediate post-surgery rehabilitation</td>
<td>Small communication Small support Small understanding Reclusive</td>
</tr>
<tr>
<td></td>
<td>Small communication with EFE</td>
<td>Psychologist &gt;5 times each year</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Participants and Settings

Three participants were recruited with the help of two epilepsy support group organisations; Epilepsy Australia, and Epilepsy action, Australia. One participant was recruited with the assistance of advertising placed in a community magazine. One participant was recruited through the process of snowballing. Table 4.7 presents a summary of the participants who took part in this study.

Age

The age of the five male participants varied from 34-years to 59-years. Each of the participants developed the chronic illness at different stages in their life, mostly within the past 10 years. On average, participants experienced surgery within nine years following their diagnosis.

Type of Epilepsy

Each of the participants had experienced complex partial seizures that commenced in a single epileptogenic zone prior to experiencing neurosurgery. The focal point of seizures for two participants, Adam and Brian was located in the left temporal lobe (LTL). The focal point of seizures for the other three participants, Chris, David and Eden was located in the right temporal lobe (RTL).

Living arrangements

Two of the participants lived in sole apartment accommodation. Three participants lived in a family residence. When the surgical procedure was performed, all five participants were involved in a personal relationship. Following surgery, the personal relationship of two of the participants, Adam and Brian dissolved, whilst those of Chris, David and Eden have remained intact. Due to these arrangements, the amount of contact with members of the family environment and the part each member played in the participant’s life varied.

Healthcare relationships

Three of the five participants, Adam, Chris, and David experienced limited consultations with health professionals. Each participant consulted their neurologist on a yearly base and their clinician every six months when a new prescription for relevant medication is required. Brian
and Eden were consulting their neurologist every four months. Additionally, Brian was consulted by a psychologist on a monthly basis.

**Main Study Data Analysis**

Similar to the pilot study, following each interview, the recordings were accurately transcribed, with the interviews being reassessed a number of times and analysed using a line-by-line analysis (Luborsky, 1994). Based on the results of the pilot study, these methods were felt to be an adequate method for attaining responses. Noted observations of participant body movements when answering questions were assessed in relation to the interview responses.

**Conclusion**

The use of a qualitative methodology of analysis within this study also entailed the use of a hermeneutics approach to identify how men with AOES perceive the psychosocial effects they experience post-surgery. Additionally, the analytical approach assisted the researcher to identify how the adverse judgements of persons in relevant environments, which are often the result of a lack of education, affect the SWB of these men post-neurosurgery. This effect on SWB was initially indicated from the results of the pilot study. The results attained from the pilot study confirmed the conceptual framework, procedures and data collection methods were appropriate to be applied whilst conducting the main study and to ensure that the standard expectations of credibility, transferability, dependability and conformability were met. Based on the findings of the pilot study, the main study protocol was adapted to include adjustments to the interview guide to attain greater clarity and a more elaborate understanding of the effects on the SWB of men following neurosurgery for AOES.

The main study was comprised of five cases. Each participant had commenced the experiencing of the seizure activity in adult years, which led to the option of neurosurgery. Each participant was questioned about their family, medical professional and social network relationships to determine what elements of these relationships affect SWB. Additionally, each participant was questioned about self-perception and the effects on SWB. The following chapter will examine the findings that resulted from the interview process.
Chapter 5

Results

Introduction

This study applied an interpretive phenomenological analysis approach to understand the subjective well-being (SWB) of men following neurosurgery for adult onset epileptic seizures (AOES), and to understand how living with AOES influence their well-being in family, health care environment, social networks and also coping strategies men with AOES used. Overall, participants reported happiness, self-perception, fulfilment and life-satisfaction these relationships post-surgery. However, they perceived role positioning changes across participation settings and in which they tended to experience exclusion.

Changes in family relationships post-surgery

Changes in various aspects of family relationships influenced the SWB of participants following elective neurosurgery for AOES: role positioning, marginalization, escalating expectations for dependency, perceived reduced capacity for decision-making and enmeshment or loss of social boundaries. Each of these changes influenced specific aspects of participants’ SWB including happiness, peacefulness, fulfilment and self-perception. Table 5.1 shows the impact of role positioning and responsibility in the family environments of participants.

In some cases, all participants experienced a positive or negative effect. At other times, there was a mixture of effects experienced, with some participants being positive and others negative.
Table 5.1 Impact of role positioning and responsibility in the family Environment

<table>
<thead>
<tr>
<th>Role Positioning</th>
<th>Marginalization</th>
<th>Subjective-Well Being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Parent</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sibling</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dependency</td>
<td>Self-care</td>
<td>+/−</td>
</tr>
<tr>
<td>Transportation</td>
<td>+/−</td>
<td>-</td>
</tr>
<tr>
<td>Financial</td>
<td>+/−</td>
<td>-</td>
</tr>
<tr>
<td>Enmeshment</td>
<td>Spouse-Child</td>
<td>+/−</td>
</tr>
<tr>
<td>Parent-Child</td>
<td>-</td>
<td>+/−</td>
</tr>
<tr>
<td>Adult-Child</td>
<td>-</td>
<td>+/−</td>
</tr>
<tr>
<td>Responsibility</td>
<td>Accountability</td>
<td>+/−</td>
</tr>
<tr>
<td>Duty to care</td>
<td>+/−</td>
<td>-</td>
</tr>
<tr>
<td>Decision making</td>
<td>+/−</td>
<td>+/−</td>
</tr>
</tbody>
</table>

Note. Family relationships had both positive and negative effects on SWB. Some role positioning effects on SWB are mixed or unidentified. Positive effects on SWB are positive (+) and negative (-) and mixed (+/-).
Role positioning

Marginalization

All participants reported significant role marginalization. Table 5.2 presents illustrative data on aspects of role marginalization within the family of the participants.

Table 5.2 Illustrative Statements on role marginalization

<table>
<thead>
<tr>
<th>Person</th>
<th>Marginalized role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spouse</td>
</tr>
<tr>
<td>Adam</td>
<td>Because my partner was embarrassed that I was still on a pension after the surgery, she didn't want her friends to see us together.</td>
</tr>
<tr>
<td>Brian</td>
<td>I am now afraid of starting a new relationship because of the financial stress and pressure that will accompany the inability to maintain full-time employment.</td>
</tr>
<tr>
<td>Chris</td>
<td></td>
</tr>
<tr>
<td>David</td>
<td></td>
</tr>
<tr>
<td>Eden</td>
<td></td>
</tr>
</tbody>
</table>
Distancing of companionship

All five participants reported that being recipients of a disability support pension post-surgery caused marginalization to occur in their personal relationships. Only two participants, Adam and Brian, reported marginalization has occurred in their personal relationship.

Adam said that prior to the surgery he had a close relationship with both his partner’s family and her friends. He addressed how the need to remain a recipient of the pension post-surgery can cause isolation in their companionship with her family and friends by saying:

“It was something that was never discussed in front of her family or her friends because being with someone who is on a pension is embarrassing.

Adam reported that his partner chose to isolate him from contact with her family and friends due to the stigma of receiving the disability support pension. He said that she was ashamed of social judgement towards her because Adam was still receiving a pension, and that this strongly influenced their subsequent separation.

Adam said that during last year he has not been able to sleep the full night through because he missed his spouse. He addressed how he could not go out alone to perform daily activities, such as paying the bills or buying the weekend newspaper by saying, “I still don’t want to see anyone who knew both of us because they will ask about her, which hurts.”

Brian reported his wife might have perceived him as a less than adequate husband, emotionally deserted him. He addressed his surprise about the speed at which the relationship ended by saying,

I was living with my wife and my three children. She seemed happy about this, but before I realised it, she was gone. We both knew that I needed the operation, but I was unaware of what would result after surgery.

Brian labelled the reactions of those closest to him towards the AOES and the surgery as being the result of selfishness. He addressed the neurological damage causing AOES and surgery resulted in his inability to act in a selfish manner by saying, “so by not being selfish I actually do myself harm in psychological ways.” Brian said this left him vulnerable to the manipulation of others, resulting in distancing of companionship.
Chapter 5: Results

**Relationship finder and nurturer**

Adam and Brian reported they found it difficult to establish and nurture new relationships after surgery. Based on the post-surgery effects they experienced, both participants spoke of reduced confidence when wishing to approach women they found sexually attractive. Adam said,

> I still want to have sex like everyone else, that hasn’t changed. But you can’t exactly talk to a woman for two hours and then say, ‘What is your name again?’ It’s a lost opportunity.

Brian said his wife’s choice to leave him post-surgery affected his role as “a constructor of close personal relationships” with members of the opposite sex. He said it had taken over five years before he had the confidence to date another woman, yet it was not his own actions that changed this. Brian said, “...this lady approached me at a gig I was doing. She very warmly introduced herself.” He reported difficulties nurturing the relationship beyond two years, after she received an offer to take up employment interstate. Brian said they had separate residencies when they both lived in Sydney. Although they were prepared to share the same residency in Canberra, the negative responses by her children caused the relationship to end. He said:

> They seemed to be a bit negative when they were around. I’m sure they would have preferred her to be dating a man who could look after her financially. So you've always got those questions. Do you agree? They are always in my mind all the time.

Brian considered the failure of the second relationship caused him to experience a lower self-perception and unhappiness, with marginalization affecting the fostering of a newly found personal relationship by stating,

> I am now afraid of starting a new relationship because of the financial stress and pressure that will accompany the inability to maintain full-time employment. It would never last.

Participants appear to report challenges from role expectation as income earners and providers with a condition that may require frequent temporary work withdraw.

**Exclusion by family of origin**

Participants perceived that members of their family of origin, including parents and siblings may lack in understanding towards them; questioning the participants’ energy levels and lack
of motivation. Adam reported being excluded by his family. He said his two brothers failed to recognise the difficulties he was experiencing with recovery; accusing him of choosing not to return to the daily activities they were involved in together pre-surgery. Adam said,

My two brothers said: ‘Tell me why you are still so sick and have no energy? You need to get more exercise.’ They were thinking it would all get better straight away, like going and playing a game of tennis. They were embarrassed because I couldn’t do these things with them anymore and so they just stop wanting me around.

Brian reported experiencing marginalization on the part of his parents. He reported certain loneliness had resulted by commenting:

I’m never asked how I’m going. I’m never asked, whether I have or haven't had a seizure (post-surgery). It’s like been and gone. It's not like I can go to even ring my parents (to talk about the) grief and tension epilepsy still causes me. It's my problem.

Brian said his siblings were aware of the surgery, but showed no understanding or support. He said, “...one of my siblings for instance has never wanted to know. He has acted as if I had just had a cold, or I was a wuss if it was to be any more.”

Brian reported his two sisters chose to remain isolated from him post-surgery by saying, “to varying degrees, they really do not understand, and I don't think they’ve ever tried much to understand it.” He perceived it might have been of benefit to his self-perception just to know his siblings did care about him post-surgery. Brian said that due to a lack of their support, he experienced emotional difficulty when in their presence.

Chris reported that his siblings chose to isolate him from regular contact with their own immediate families. He said that he was aware of this occurring when he regularly experienced AOES prior to the surgery, and was accepting of this at that time. However, Chris said this to be offensive to him post-surgery. He said, “...my second sister was the only one who wanted to know about it.”

Chris judged himself as being responsible for the distancing that occurred in his family of origin. This is because he was the one who developed AOES and was required to undertake a surgical operation, necessary to control his chronic illness. However, Chris reported their behaviour was no longer justified. He said the distancing now caused him to feel nervous when in their presence, resulting in unhappiness and poor self-perception. He said:

This now affects my confidence when I go to family events, like a barbeque at my sister’s place if they [other siblings] are there. I’m not motivated to do so. If I do, I
don’t offer my help to cook when they are there. This has negatively impacted my happiness and motivation.

Eden said the marginalization he had experienced in his family of origin became greater following his neurosurgery for AOES. He reported the support of his twin brother and two sisters was quite strong following an earlier operation to remove a brain tumour, but they did not maintain support following surgery to control his AOES. Eden said:

My brother has kept a big distance from me. In fact, all three presently still don’t discuss epilepsy or the operation with me. They seem uncomfortable when I’m around their children and they just won’t talk about it.

Eden reported this lack of overt support to have affected his fulfilment and self-perception when spending time with his siblings and their families.

David said he originally excluded his family of origin from knowing about his experience with AOES prior to surgery, as their relationships were already weak at that time. He reported informing his family of origin of the need for surgery and they provided some emotional support leading up to the procedure. This support however deteriorated post-surgery.

David addressed his sister’s response to him post-surgery, by stating, “at first my sister did want to understand it [epilepsy and the need for surgery]…, (but in the end) it was too much hard work (for her to continue doing so). She was happy with her own (immediate) family, so she didn’t need any other family activities in her life.” He said he understood her circumstances, as he also has a family.

Analysis of themes raised by participants in the interviews showed that the family environments have a strong influence on SWB post-surgery. The actions of each participant’s family members resulted in each participant experiencing periods of unhappiness and low fulfilment, with a poor self-perception resulting from this.

**Dependency**

Table 5.3 presents illustrative example statements on the role of dependency in the family environment as self-reported by the participants.
Table 5.3 Illustrative Statements on role dependency

<table>
<thead>
<tr>
<th>Person</th>
<th>Role dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self-care</td>
</tr>
<tr>
<td>Adam</td>
<td>After my partner left me I moved in with my mum but she just over protected me. She wanted to make my decisions for me... I eventually moved out and cared for myself in a flat by myself.</td>
</tr>
<tr>
<td>Brian</td>
<td>As I couldn't drive anymore, I had to rely on my wife; that made me feel useless.</td>
</tr>
<tr>
<td>Chris</td>
<td>I was happy to ask my wife for her opinion on everything before I made a decision. She was really supportive then.</td>
</tr>
<tr>
<td>David</td>
<td>Because of the frequency of seizures before the operation, my wife had begun to make all the important decisions and I just allowed for that.... We just understood our roles.</td>
</tr>
<tr>
<td>Eden</td>
<td>I was angry that I could not drive after the surgery. But now when I go without my wife I drive myself.</td>
</tr>
</tbody>
</table>

**Overprotection and indebtedness**

Adam experienced intimidation by his mother’s actions following the decision to share her residence after the separation from his spouse post-surgery. He said “my mother didn’t understand the condition and the need for surgery. All she ended up doing was trying to over protect me (following surgery).” This affected his SWB by reducing his self-perception and quality of life.

Living on the pension and the separation from his partner caused Brian to experience unhappiness and poor life satisfaction. He said although he was embarrassed because of his
dependency on the Government for financial support, he reported he had no other choices. For this reason, he did not want to meet with others who knew him before the operation.

Chris reported emotional dependence upon his wife prior to the operation and immediately post-surgery. He said, “I would be calling her several times a day just to say hello and ask her for her opinion on the decisions I should make. You know, whether they were the right ones.” However, Chris said he enjoyed this dependency, as it encouraged happiness and fulfilment.

Both Chris and David were happy for their wives to be supporting them. The three participants reported that their comfort depended on their partner’s financial and emotional support post-surgery. They said the changes of role positioning did not affect their SWB, including their happiness and self-perception. Typically, people are happy to make their own decisions, however under these conditions, Chris and David found it easier to follow their wives’ suggestions.

**Transportation**

All five participants experienced a problem with transportation. Each participant was dependent on his spouse to take care of his transportation needs because he could not legally hold a driver’s licence. It was an uncomfortable situation for the participants who once drove themselves everywhere. All five participants consistently reported this loss of independence lowered their SWB, with Eden saying “I felt quite intimidated when I had to rely on her (my wife) to do things like drive me around. Following the surgery for epilepsy, I didn’t drive three years.” David and Eden did not wish to maintain this dependency forever. Chris said that as he was experiencing seizures prior to meeting his wife, she accepted the consequences of him not having a driver’s licence. Chris reported happiness for her to be the one who drove the car by saying, “after the surgery I wanted to start driving her wherever she needed to go and not the other way around. You know, it takes three years to get a licence after it [surgery].”

**Financial**

Chris stated that he accepted his wife as the sole income earner at the time of the operation by saying, “I was happy for her to be doing that and we were not in any debt at all.” Eden also reported his wife’s income mostly supported their relationship financially. He said,
I now believe, with me losing my job and income, and the need to rely strongly on my wife, you know both physically and financially following the surgery for epilepsy, I was lucky to have her.

Chris and Eden reported their partners were accepting of this at the time of the surgery. Adam, Brian and David reported difficulties relying solely on their partners for financial support post-surgery. Although the participants were receiving a disability pension at that time, the money was insufficient to support them. This caused emotional instability to arise.

Adam considered his need to be dependent on his partner after the surgery by saying:

I think she was expecting everything to be ok straight away after [surgery]. I know she had got to the point where she was responsible for me. I think that she only thought that was ‘til we could get back to the life we were living before it all started.

Adam said his relationship weakened because it took too long for him to return to the work place. He reported his inability to maintain a successful business because of AOES had also influenced the ending of his personal relationship.

Adam said that he planned to strengthen the small industrial business he developed with a past friend many years earlier. However, he said it was due to post-surgery effects, including tiredness, and a lack of patience on the part of the co-owner that caused his business to experience bankruptcy. Adam reported he once financially supported his partner; he said he is now uncomfortable living on her income and the need for her to solve his financial problems.

Brian said the need for him to rely upon his wife for financial support post-surgery caused great difficulties to arise in their personal relationship. He reported the difficulty that both partners experienced led to the loss of his home and also his family by stating:

Because I couldn’t get work the mortgage wasn’t paid. We needed to move somewhere else and live on my pension. This is when my wife left me and moved in with her boss who gave her more money than I could ever do then. I did not blame her, I blamed myself.

All five participants reported the effects of financial stability on SWB. Participants acknowledged financial support of their spouse and / or the Australian Government to assist their well-being. Adam, Brian, and Eden expected to gain employment immediately post-surgery and create financial stability within the Immediate Family Environment (IFE). The inability to do so caused these three participants to experience reduced self-perception and life-satisfaction.
Role Enmeshment

Table 5.4 presents sample statements on role enmeshment in the context of family environment.

Table 5.4 Illustrative Statements on role enmeshment

<table>
<thead>
<tr>
<th>Person</th>
<th>Role enmeshment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spouse – Child</td>
</tr>
<tr>
<td>Adam</td>
<td>I felt like I was her child. I could not make any money; all I could do is rely on her for money.</td>
</tr>
<tr>
<td>Brian</td>
<td>For some time following the surgery I still couldn’t take full responsibility for my children, leaving them to make our decisions.</td>
</tr>
<tr>
<td>Chris</td>
<td>I depended on my wife. She was happy to look after me. I was able to get a job, but she still takes care of me like I was a child.</td>
</tr>
<tr>
<td>David</td>
<td>I needed my wife to take care of me during the depression period. She was happy to take that role and I was happy to follow her decisions.</td>
</tr>
<tr>
<td>Eden</td>
<td>Before the surgery my children needed to care for me as much as I did for them. After the surgery, with the seizures stopping it was no-longer necessary.</td>
</tr>
</tbody>
</table>

**Spouse - Child**

All five participants experienced role enmeshment in their families, in that role reversals and overlaps occurred. For instance, Adam described his role in his personal relationship as being both a spouse and parent to his spouse prior to the surgery as follows:

I was a father figure to her, both financial and knowledge. I was working 7 days and nights, getting $60,000 a year. I had (bought) us two good cars. I was getting six hours sleep if I was lucky. The changes affected our lives.
Adam reported these roles reversed post-surgery. He said following the surgery to be both her spouse and child, and he needed to listen to everything she said. He said it was confusing to him and lowered his self-perception and life satisfaction.

David addressed the need to rely on his spouse to care for him during his long period of depression post-surgery by saying, “I needed my wife to take care of me during the depression period. That is hard for me because she use to rely on me.”

**Parent – Child**

Brian reported being unable to take full responsibility for making decisions for his children, and at times needing them to make decisions that they were less well prepare. For instance, Brian’s children at times had to supervise him whilst he experienced a seizure.

Similarly, Eden said he needed to rely on his children to care for his safety post-seizure. He noted that one of his children would stay with him whilst the other sought help with an imminent convulsion. Eden said that this has changed post-surgery, with him now being able to take full care of his symptoms without the need for the children to do the same.

**Adult – Child**

Chris perceived infantilization by addressed how his sister by stating, “She mostly blamed my wife for me having so many (seizures). She reckoned that the way she treated me was causing them to happen.” He reported while his sister’s views were well intentioned, these overt expressions of sentiments caused his personal relationship with his wife to deteriorate.

Both Chris and Brian reported that the experiencing of adult-child relationship post-surgery influenced their respective SWB, including reduced happiness, self-perception, fulfilment, and life-satisfaction.
Responsibility

Table 5.5 shows the impact of Responsibility in the family environment.

Table 5.5 Illustrative Statements on Responsibility

<table>
<thead>
<tr>
<th>Person</th>
<th>Accountability</th>
<th>Duty to care</th>
<th>Decision making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>I was a ‘Father figure’ to her, both financial and knowledge before the surgery. Because my business went Bankrupt, this meant it was not possible after.</td>
<td>After a while I needed to start caring for myself. I moved out of my mum’s place and got my own flat. It felt good to be looking after myself again.</td>
<td>I wanted to be the one who made all the decisions again in my personal relationship, but I couldn’t do that because my partner didn’t trust me.</td>
</tr>
<tr>
<td>Brian</td>
<td>Before all this started, I would drive my kids without a problem. I was then unable to manage their needs. I was a weaker man physically and emotionally because I lost their respect.</td>
<td>---------------</td>
<td>I was happy that my wife helped me to make decisions but I did not realise that she hated doing that until she left.</td>
</tr>
<tr>
<td>Chris</td>
<td>It was my responsibility to be able to have children after the surgery. However, erectile difficulties meant that it wasn’t possible. It was hard.</td>
<td>---------------</td>
<td>I was lucky that my wife was making the decision for me. It made my life easier and she never has any problems with that.</td>
</tr>
<tr>
<td>David</td>
<td>They couldn’t prove I had epilepsy and it was my responsibility to look after my family by working. I think that men, or most men want to be head of the family.</td>
<td>With depression it was difficult to feel confident to care for the family’s needs. It’s something a lot of men might find difficult after surgery.</td>
<td>My wife helped me to make decisions. Because I was depressed for over a year and I needed her to do this for me.</td>
</tr>
<tr>
<td>Eden</td>
<td></td>
<td>Prior to the first operation I was working for the council and earning good income for the both of us. I still feel that I have failed.</td>
<td>I felt happy to rely on my wife to make all the decisions. She had been doing it since the first operation.</td>
</tr>
</tbody>
</table>

Accountability

Adam said he thought about trying to establish a new business, but was questioning his capability to do so successfully, or that he might not be able to make the same income as he used to get before the operation. Brian reported post-surgery limitations to social life with his children by saying,
That made me feel useless. I couldn’t drive to the footy or go camping on our own. Even if my wife did come, they were too worried about what could go wrong. I couldn’t swim any more with them, that kind of killed things.

Brian addressed the inability to regain this role post-surgery resulted in him questioning his ability to be responsible for the care of his children by saying, “…what kind of a father am I if I can’t do this. I was a weaker man physically and emotionally.” He reported losing the respect of his children for many years following this.

Chris reported being compromised by erectile difficulties resulting from the surgery by saying, “I think this might be something that many couples would experience after surgery. It is hard not to feel that you are responsible for making this happen now the surgery’s been done.” He addressed the increase in life satisfaction that may occur in the family by saying, “through talking and understanding of each other’s attitudes and views, I think that a family can make all the difference for your life satisfaction. We are responsible to make sure that you can have children and make it safe.”

David reported trouble with financial accountability post-surgery due to the time it took for him to gain new employment. He said that prior to surgery he recognised these difficulties to be the result of AOES. However post-surgery it was unclear to him why difficulty was still experienced gaining employment, reporting as a result experiencing depression. David reported symptoms of depression remained unrecognised for over a year. He experienced challenges gaining employment to maintain financial stability for family. He said “I think that men, or most men want to be the head of their families. You know, make the right decisions. That is hard to be that leader when you have depression.”

All five participants reported accountability to develop further stability within the IFE post-surgery. Each participant said the instability experienced at that time was the result of poor post-surgery rehabilitation.

**Duty to care**

Following Adam separated from his spouse post-surgery and resided with his mother, who offered him duty of care. This appeared to suit him well. He observed: “…although it was hard at first, it felt good to be looking after myself again.” Adam said adjusting to self-care was at first difficult, but with the assistance of a community support group he was able to do so.
Chapter 5: Results

Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures

Brian addressed the original emotions experienced after his wife’s choice for both her and their children to leave his residence by saying,

“It was difficult to do it all again by myself. You know, like buy food and pay bills. Although it was something, I did for a long time before the seizures got bad and I had the operation, after it I felt like I had to start all over again, like a boy out of school.”

David reported difficulties maintaining his duty of care to his family from the effect of depression following surgery. He observed, “With depression it was difficult to feel confident to care for the family’s needs. It’s something a lot of men might find difficult after surgery.”

All five participants consistently recognised Duty to Care as being a facet that influenced SWB post-surgery. Although the causes and results were different for each participant, they all reported to have experienced reduced happiness, self-perception, fulfilment and life-satisfaction.

Decision-making

Adam, Brian, David, and Eden spoke about being the main decision maker in their families when they started to experience seizures. Chris’ spouse was the decision maker from the start of their relationship. Following the surgery Chris, like all of the other study participants had lost his role as the decision maker and this continued initially post-surgery.

All five participants were consistently happy to transfer decision-making role to their partners when they were not ready to make them. However, when they physically recovered from the surgery, the participants wanted to take charge of their own decision making to prove they were able to stand on their own feet again.

Adam reported rescoping responsibility roles in family post-surgery. He believed he would be the same person as before the surgery. But, when everything did not turn out as he had expected, he felt very depressed and felt lower self belief.

Brian reported his wife to not want to make decisions for him anymore. He reported to experience challenges with the responsibility for the decision-making process. This was also a reason for her leaving.

Chris, David and Eden reported a role of decision making shift to their partners post-surgery. However, the role shift varied depending on the trust and confidence their partner felt.
towards them. David reported a joint decision making process being agreed upon between he and his spouse with its practice positively influenced David’s SWB, including fulfilment and happiness.

**Changes in Health Professional / Consultant relationships post-surgery**

Changes in health professional/consultant relationships influenced the SWB of the participants following elective neurosurgery for AOES. Two major themes emerged from the data analysis: perceived changes in duty to care especially mismatch in time/availability of health professionals/consultants. All five participants reported experiencing poor post-surgery communication difficulties with relevant health care providers, which resulted in unhappiness, poor fulfilment, low self-perception and quality of life.

Duty to care was compromised when professionals did not adapt their communication style to the changed needs of the client. Table 5.6 shows illustrative statements of the impact of role positioning and the responsibility of health professional/consultant relationships on happiness/peacefulness, fulfilment, life-satisfaction and quality of life post-surgery.
### Table 5.6 The impact of role positioning and responsibility in health relationships on SWB

<table>
<thead>
<tr>
<th>Role</th>
<th>Professional / Consultant Relationship</th>
<th>Subjective-Well Being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in relationships</td>
<td>Mismatch in time needed / available to address the participant’s post-surgery medical issues.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Specialist</td>
<td>Happiness/peacefulness</td>
</tr>
<tr>
<td></td>
<td>+/−</td>
<td>−</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>−</td>
</tr>
<tr>
<td></td>
<td>Consultant</td>
<td>−</td>
</tr>
<tr>
<td>Support for the participant</td>
<td>Time</td>
<td>+/−</td>
</tr>
<tr>
<td></td>
<td>Understanding</td>
<td>+/−</td>
</tr>
<tr>
<td></td>
<td>Empathy</td>
<td>+/−</td>
</tr>
<tr>
<td>Expertness in epilepsy and post-surgery effects</td>
<td>Clinicians</td>
<td>−</td>
</tr>
<tr>
<td>Responsibility</td>
<td>Adapting the communication style</td>
<td>−</td>
</tr>
<tr>
<td>Self – care</td>
<td>+/−</td>
<td>+/−</td>
</tr>
<tr>
<td>Decision making process</td>
<td>−</td>
<td>−</td>
</tr>
</tbody>
</table>

Note. Heath Professional / Consultant relationship changes had both positive and negative effects on SWB and some situations can have mixed or unidentified effects. Positive effects on SWB are positive (+) and negative (−) and mixed (+/−)
Perceived Change in the context of Professional / Consultant relationships

The data suggest two aspects of the doctor-patient relationship influenced the SWB of study participants post-surgery. These aspects were mismatch and support.

**Neglect**

Participants reported health professionals to neglect to provide supportive education post-surgery, resulting in lower SWB. Participants perceived experiencing routine exclusion in the consultation process, including a denial of the right to know about their surgery outcome, and were treated in an impersonal manner. Chris said, “They don’t involve you when discussing your condition. I think that they don’t think you have the intelligence to understand and therefore you don’t have the right to know.”

Participants’ perceived not to be asked for opinion in relation to medical procedures, and/or whether they received the level of explanation required about their epilepsy. Participants said this occurred purely as the result of disinterest on the part of the health professional/consultant.

Table 5.7 illustrates statements of professionals neglectful to provide all necessary knowledge.
Table 5.7 Illustrative Statements on neglect

<table>
<thead>
<tr>
<th>Person</th>
<th>Specialist</th>
<th>Clinician</th>
<th>Consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>Their attitude after the surgery is they don't have time to address anything.</td>
<td>You don't get any direction from the doctors.</td>
<td>------------</td>
</tr>
<tr>
<td>Brian</td>
<td>My neurologist gives me the time to answer my questions, which means I feel comfortable after it.</td>
<td>It occur 'cause doctors change states, cities, surgeries and you are left out.</td>
<td>I spoke with a psychologist who helped me get my pension but I wasn't told anything that helped me understand.</td>
</tr>
<tr>
<td>Chris</td>
<td>They cause you to feel isolated because they don't tell you about your own condition.</td>
<td>He gets the information from my neurologist but refuses to share it with me.</td>
<td>------------</td>
</tr>
<tr>
<td>David</td>
<td>They can talk about the surgery, a bit about that, but I don't think they can help you on how are you going to live past it.</td>
<td>I even spoke to the epilepsy co-ordinator at the hospital and she wouldn't tell me.</td>
<td></td>
</tr>
<tr>
<td>Eden</td>
<td>I am not motivated to do things that I would if I understood.</td>
<td>I think there was a far lower understanding and respect shown by doctors after the second one that made it difficult to see them.</td>
<td>Access to rehabilitation after the surgery (for epilepsy) it would have made it a lot easier, but they don't have the same time or interest following it.</td>
</tr>
</tbody>
</table>

**Expertness**

Adam, Brian, Chris and Eden reported observing the undervaluing of the treatment of epilepsy as a chronic illness. They said many clinicians saw epilepsy as a part-time condition that medication alone can control. Therefore, the only reason they would need to see a clinician post-surgery was when needing a new script for an anti-convulsive medication. Chris said:

I call up a new GP when I need a script written for my [anti-convulsive] drugs... I don’t know how much of a part the GP plays in the whole thing [post-surgery care], as they never really knew anything about epilepsy when I would see them. Maybe they need to learn more about how it can always affect you.

Similarly, David said: “I guess we expect doctors to know it all and I'm starting to recognise that as they are not specialists, it is ok that most doctors don't know it all about epilepsy.”
Chris addressed the inattentiveness of health professional/consultants toward duty to care for information and empathy, leaving the former to question their own future care and treatment by saying,

> They cause you to feel isolated because they don’t tell you about your own condition. It makes you ask yourself just how important will it be to them to care for me in the future if it [AOES] starts again.

He further stated: “it is hard to feel comfortable with a doctor when you feel his attitude is that he doesn’t have the time or need to address it with you.” Adam addressed the omission now makes him feel uncomfortable when he meets with these professionals by saying,

> I’m always nervous. Even though it has stopped [the seizures], you are still worried of what you could be told. Then after, I feel angry because you are told nothing about what to do.

Chris perceived purposeful omission in duty to care by health care providers by saying: “I imagine the doctor is sent a letter from my neurologist after seeing me to let him know what he thinks, but that is never passed on to me.” He addressed the miscommunication between professionals, such as the neurologist and clinician resulted in the latter also failing to provide a necessary explanation stating, “It is like my doctor’s attitude is that if your neurologist didn’t tell you then I’m not going to either”.

All five participants reported omission often caused them to feel nervousness when meeting with health care professionals, resulting in not asking relevant questions. Eden considered his chronic illness was no longer important to health care professionals by saying:

> They [hospital clinic staff] really have no idea who I am and so I feel like I am not motivated to do things that I would (such as ask questions) if I understood. I think respect should be something that they should have given by including me in understanding what’s happening.

Participants reported often experienced low SWB when a clinician was no longer accessible due to relocation, experiencing disruption when one medical centre failed to transfer information about their chronic illness to another when required. Three participants reported the wrong medical centre receiving their relevant medical documentation, causing health data to be lost in the process. Participants felt this lack of communication was disruptive of appointments, some of which were made up to one year in advance.
Eden addressed the need for a new computerised system to be developed in the health-care environment so relevant professionals have full access to a patient’s medical history when needed by saying, “this would save so much time and confusion, and feel like they [health care professionals] understand and care”.

**Support**

Table 5.8 illustrates statements of role support in the health care professional environment on time availability, understanding and empathy.

Table 5.8 Illustrative statements on role support.

<table>
<thead>
<tr>
<th>Person</th>
<th>Time availability</th>
<th>Support</th>
<th>Empathy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>Their attitude is that we’ve done all we can.</td>
<td>Doctors need to continue to learn so they gain more new understanding about epilepsy</td>
<td>I felt like I was old wood. It makes you feel like you are unimportant to them.</td>
</tr>
<tr>
<td>Brian</td>
<td>The first GP had good time for me, but after him there was no one who cared.</td>
<td>Most of the doctors have little understanding at all, so they can’t help understand.</td>
<td>My neurologist is a very gentle soft-spoken man and is supportive</td>
</tr>
<tr>
<td>Chris</td>
<td>They didn’t make the time to explain what’s happening after it [surgery].</td>
<td>You have no idea what’s happening and no-one bothers to explain it.</td>
<td>I saw a psychologist after, but he didn’t help anyone understand how to deal with it.</td>
</tr>
<tr>
<td>David</td>
<td>They choose not to get involved. They start medicine too quickly after high school and don’t have enough life experience.</td>
<td>Many doctors don’t understand. They don’t know how to help besides drugs.</td>
<td>I got to see a social-worker after it. That one on one counselling helped.</td>
</tr>
<tr>
<td>Eden</td>
<td>They needed to be prepared to put in the same time to discuss epilepsy after surgery.</td>
<td>Doctors were not interested to know as much about it as compared to the tumour.</td>
<td>You feel like they just can’t help you then why bother.</td>
</tr>
</tbody>
</table>

David reported there being two aspects in the process of recovery following neurosurgery for AOES: medical intervention and counselling support. He noted; “there is a big gap (in communication) between medical people and support groups” in that counsellors were more empathic and understanding. He perceived medical care to be more technical.

**Time availability**

Participants reported experiencing a mismatch between the consultation times needed and those made available by health care professionals/consultants to address the physical and
emotional effects of the surgery. All five participants reported a lack of consultation time with their specialists to cause important issues to remain unaddressed. Especially the absence of clear routines in post-surgery rehabilitation often caused them to feel confused, insecure, and worried about their future care. According to Adam:

I think his attitude (physician) was that, that he did what he could, and that’s it. So during the time I saw him, because there was no clear routine, I didn’t feel confident to ask him questions and that left me with a lot of unanswered questions.

Chris speaking to the same issues said:

…when I went in there (to the hospital), I think I was so confused because I knew nothing about it [the result of surgery], so I didn’t really say or ask anything. I know afterwards I used to think I got nothing really out of it, and so I would be angry with myself.

Eden reported being marginalized by saying:

You’re never given enough time to ask questions, so you end up leaving without information. It is hard to feel comfortable when you feel like you are taking up his time and he’s got better things to do.

In addition, he said, “they push you through and don’t have time to care.” Participants reported a sufficient period must be allocated to the appointment, as it takes time for them to understand all circumstances. Adam addressed the result of the health care professional neglecting to address his needs by saying, “I feel like I’m not important enough to them.” Participants reported when professionals stated they had many patients and could not take time to provide more information that this was a way for the latter to avoid his or her responsibility.

Participants reported experiencing insecurity in their role and interaction with medical professionals. This negatively affected their SWB. Chris addressed this lack of available time and routine of care by health professionals post-surgery resulting in a lack of happiness, self-perception and quality of life by saying:

Little had been done to help cope with the effects of surgery. But you would expect that time would be taken to help with the emotional side of it; to see you on a regular basis and take care of you. I guess I was waiting for that part to be set up by my doctors, but it wasn’t. It made me feel unimportant.
Adam reported the hospital failure to provide adequate time post-surgery to answer questions and set an adequate recovery routine both physically and emotionally by saying:

You don’t get any direction from the doctors. There isn’t a directory that you can look up to find these things. Because I was not given any real instructions, I was just left to sit around, waiting for the next appointment. I seemed to just disappear out of their care.

David believed the important to understand their treatment routines in order to care actively for their needs post-surgery and for their family to be involved by saying, “We [as family] were worried and they [health professionals] did nothing to address our concerns and questions.” Chris also said:

It does take a long time to get stable again [following surgery], and I just don't mean physically. I think it might be harder even mentally to do it, because you've gone through so much difficulty that includes belief in yourself. The lack of help (from health professionals) made it probably one of the hardest things for us [the family] to build up again.

David considered the lack of knowledge and understanding held by clinicians about the patients’ specific needs and concerns occurred due to the lack of time made available by the specialist to discuss their patient’s chronic illness by saying, “I think there needs to be people, medical people who take time to know what the other one is doing. It’s like they [health professionals] are expecting someone else to explain it and no-one does. They’re just as confused as you are.” Participants said they would be happier if regular communication occurred between relevant health care professionals.

Understanding and Empathy

From the participant’s perspective, the level of attention, empathy, respect and understanding the professional showed them influenced the length of the appointment time, leading to either positive or negative feelings following their meeting. Chris speaking to empathy by health providers post-surgery said:

This psychologist reckoned that because I was not seizuring anymore, and I wished I was, it meant that I didn’t want to get on with my life. She felt that I wanted to hang on to this image of needing other’s sympathy.

Adam perceived the lack of empathy to be explained thus: “Because of their lack of understanding, I felt like I was old wood when I met with them [health professionals]. It makes you feel like you are unimportant to them.” David said, “Doctors don’t like to have
their level of knowledge gained through many years of study be questioned or answer questions by another one who’s had surgery. Doctors fail to ask how a person will cope post-surgery, they do.”

He also said,

[Clinicians] say; ‘you’ve had the surgery, you can now get on with your life. You’ve been fixed, so get on with it’. … Doctors need further catch-up training so they know how to properly treat people with epilepsy.

Participants reported a need for clinicians to also develop their counselling skills and gain an understanding of patients with epilepsy.

Chris perceived general clinician to focus on basic actions of care only: “The only useful reason you can see them was for a script. They have no knowledge (about seizures) or even time to get some”.

Brian was the one participant who was happy with the quality of care a clinician provided at the time of his surgery. He said, “I stayed with him because he was a counsellor. For instance, he told me, ‘remember what you [are] mostly needing here is my compassion’, which was very special.” However, after his clinician moved inter-state Brian stated he was unable to find another one who offered similar understanding and empathy.

Adam perceived the imbalance of emotions and self-perception they experienced as the result of AOES and surgery influenced their confidence to seek this care by saying,

You think about it sometimes but it’s hard to do it. I don’t know why, but it’s hard to call someone, like a counsellor and say you need help. That’s what the hospital’s part should be after the surgery.

Brian was the only participant to report his neurologist showing empathy. He said “my neurologist is now a very gentle soft-spoken man and is supportive. I think, through the support and encouragement that I have got from him, I have become stabler.”

All five participants reported the hospital is responsible for the co-ordination of post-surgery care with relevant health professionals. David was the only participant to attain psychiatric assistance post-surgery. He said, “My neurologist also mentioned I’ve got to see a psychiatrist to help deal with that.” A neurologist who consulted David asked a psychiatrist located at the same hospital to assess David’s condition. David reported the importance of
additional specialised care gave him further understanding about his condition, creating stronger self-perception and fulfilment by saying, “It’s something that everyone needs after surgery, especially this type.”

How the participants categorised the responses of health-care professionals and their effects on SWB are further set out in Table 5.9.

**Responsibility of Health Professional / Consultant**

<table>
<thead>
<tr>
<th>Person</th>
<th>Responsibility of Healthcare Professional / Consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>They are responsible to provide education but you don’t get any direction from the doctors. That affected my trust. I was able to care for my needs, but it was difficult when I later recognised the effect of the surgery. That made it hard emotionally. I am always nervous when making decisions about my health. I am still worried of what could go wrong. It would help if they did offer support.</td>
</tr>
<tr>
<td>Brian</td>
<td>It is the doctor’s responsibility to ensure you understand what is happening in words you understand. It is the duty of the hospital to provide care that will help you cope after surgery. You are required to impractically care for yourself. When I decided I needed to get back on the pension, my neurologist spoke to a psychologist who wrote a letter saying he needed it because I will never work again.</td>
</tr>
<tr>
<td>Chris</td>
<td>I wanted to take more positive actions post-surgery; however a lack of education and involvement in post-surgery care resulted in poor respect. Caring for oneself after surgery is hard, but I’m sure it would have been harder if I didn’t have my wife. Specialists don’t teach what the right decisions to make are. Like if you took the wrong tablets, or even what is the best thing to eat and drink.</td>
</tr>
<tr>
<td>David</td>
<td>Because they don’t offer you any knowledge about your condition, it means you must sit back and let them make all the decisions. The hospital is responsible for providing counselling after surgery. It makes it worse if you experience depression. Doctors question your ability to make decisions, so they don’t tell you what you needed to do.</td>
</tr>
<tr>
<td>Eden</td>
<td>Sure, they’ve read it in a book, but it harder for them to deal with the reality of explaining it to you in a way you understand. After the operation for epilepsy I was not given any real help about how to care for myself so I needed to follow the same instructions as for the tumour. Maybe they didn’t want to help with counselling because it would have been a waste of time. So it was hard to set your own model.</td>
</tr>
</tbody>
</table>

*Adapt communication style*

Participants perceived to be treated to a passive role in the treatment of their chronic illness. David said that he did not receive adequate knowledge about AOES and surgery from his
medical professionals. He said, “You must sit back and let them make all the decisions. This means you have no input on how to treat your condition.”

Adam believed it was the responsibility of the professional to educate them on their present findings relating to their chronic illness by saying:

…they [health professional/consultant] are responsible to provide education but you don’t get any direction from the doctors. Because they cannot explain what is happening in a way that you can understand. That affected my trust.

Eden reported not receiving adequate orientation on his impending repeat surgery by saying:

If you are talking about motivation to do new things, then I would say not at all. Following the (second) operation, they really didn’t care who I was and so feeling like they motivated me to do things is pretty absurd…. By no means did their actions make me feel more confident about myself.

David perceived this lack of adapted communication to be a source of discontent in respect to their fulfilment and life satisfaction by saying, “The problem in many doctors being that one person’s experiences or knowledge is going to affect another person’s one.”

Eden said that his hospital post-surgery introduced him to a member of a support group at an epilepsy foundation. He reported that although they offered him support at that time, it was early following the surgery and he was not ready to address these issues as a member of a support group. Eden said, “I did not pursue this any further, as I felt my epilepsy wasn’t severe enough to require this support. I did not think that I could access this support (when seizures commenced) after the surgery to try to control the epilepsy.” He reported there being a necessity for knowledge about epilepsy to be provided as basic education to society more generally.

**Self-care**

Following the surgery the all five participants stated that health professionals did not provide this same level of assistance to be aware of possible challenges they may face.

For instance, health professionals did not educate participants on what were the appropriate actions they should take in regard to their self-care. Brian stated that professional guidance was needed post-surgery to understand further what was the right and wrong decisions regarding self-care, and the consequences of doing so. He commented:
Some people (with epilepsy) say that you shouldn’t do things like drink tea… I don’t know why… It’s hard (to understand) without training or even guidance (from appropriate health professionals).

Adam reported experiencing difficulties with self-care following his surgery by saying, “…it was six months before I started to realise the physical effects, like the loss of so much vision on one side (of my body). It’s like being (emotionally) smacked by a truck.” He reported although being able to continue caring for his own needs, these difficulties caused him to experience lower happiness, self-perception, and life-satisfaction.

David addressed low self-perception resulting from limited education about self-care often saw them needing to contact their partner to support basic decisions, including which groceries to buy and the appropriate amount to withdraw from an ATM by saying, Because I didn’t have the confidence to make decisions that were relevant to my own care and my family, even deciding what to eat or how much money to carry around was difficult for me to make at first.

Brian, who has mostly lived a single life since the surgery, reported having learnt to make decisions best suited to self-care. He addressed the required confident to continue to care for his self-needs by saying, “I stick to a basic routine of what I feel is best to eat and when I should leave the comfort of my home to buy food and other basic items.”

**Decision-making support**

Chris pointed to the diminished decisional support post-surgery by saying, “The problem is that they don’t teach you what the right decisions to make are. Like if you took the wrong tablets, or even what is the best thing to eat and drink.” All five participants consistently reported difficulties setting and reaching new goals due to a lack of understanding of their circumstances, which lowered self-perception and life-satisfaction.

David considered health care professionals to play a small role in post-surgery care, which limited their effectiveness. He reported:

I even said to the epilepsy coordinator ‘I wish I had known more about surgery’. But the answer was ‘people deal with it very, very differently’ and so they [medical specialist] tend not to give too much information.

Eden considered the lack of communication at times caused them to feel the operation was not successful and therefore the decision to undergo the partial temporal lobectomy was the
wrong one to make by saying, “Following the second operation they didn’t want to help with counselling because it would have been a waste of time. Like my ability to make decisions were gone.” He reported the best means to maintain inner-peace was by reducing his contact with health professionals to a level of absolute necessity.

**Changes in Social Network Relationships Post-surgery**

Change in aspects of social networks influence SWB following elective neurosurgery for AOES. Two major themes emerged from the interpretive phenomenological analysis: perceived changes in affiliation and responsibility affecting lived SWB. Changing in responsibility affected mostly perceived exclusion, and social reaction. Each of these changes influenced specific aspects of SWB: happiness, self-perception, fulfilment and life-satisfaction.

**Social Affiliation**

All five participants consistently reported experiencing a range of impacts on their SWB when affiliated with social groups they felt was of relevant importance. Table 5.10 illustrates how the effects of these social groups influenced the participants’ SWB.
Table 5.10 Illustration of how the effects of relevant social networks influenced the participants’ SWB.

<table>
<thead>
<tr>
<th>Relevant Social Networks</th>
<th>Subjective-Well Being</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Happiness/peacefulness</td>
</tr>
<tr>
<td>Affiliation</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>Social Exclusion/Inclusion</td>
</tr>
<tr>
<td>Neighbourhoods</td>
<td>Labelling</td>
</tr>
<tr>
<td></td>
<td>Rejection</td>
</tr>
<tr>
<td></td>
<td>Support</td>
</tr>
<tr>
<td>Work-place</td>
<td>Social Responsibility</td>
</tr>
<tr>
<td></td>
<td>Epilepsy supporting group (Volunteer)</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
</tbody>
</table>

Note. Family relationships changes had both positive and negative effects on SWB and some situations can have mixed or unidentified effects.

Positive effects on SWB are positive (+) and negative (-) and mixed (+/-)
### Social Exclusion / Inclusion

Table 5.11 presents illustrative data from the five participants’ statements of exclusion / inclusion in collapsed social network, neighbourhood collaboration and work-place engagement.

Table 5.11 Illustrative Statements of exclusion / inclusion in a social affiliation

<table>
<thead>
<tr>
<th>Person</th>
<th>Social Affiliations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Collapsed Social Network</td>
</tr>
<tr>
<td>Adam</td>
<td>Before the operation I had three groups of friends, but after it I had three friends. The rest didn't trust me.</td>
</tr>
<tr>
<td>Brian</td>
<td>I've never had so few friends in my life as I do now. They stopped caring, leaving me feeling unimportant.</td>
</tr>
<tr>
<td>Chris</td>
<td>My friends back then were so critical. The relationships deteriorated because they feared what could happen next. I have no friends now.</td>
</tr>
<tr>
<td>David</td>
<td>After the operation friends showed a lot more respect for my wife, than me. I was cut out because they felt they couldn't help me now.</td>
</tr>
<tr>
<td>Eden</td>
<td>------------------</td>
</tr>
</tbody>
</table>

**Collapsed social network**

The interviews showed that all five participants experienced social exclusion. Adam reported, “I had three groups of friends; those from school, my work, and others, but after the operation
I had three (friends).” He said friends deserted him due to what he referred to as their “selfishness” or their ignorance. Adam said,

So many of them [friends] thought they could catch it [epilepsy] before the operation, and afterwards whether it would be safe to do things with me. You know who your true friends are.

Adam reported experiencing poor self-perception, believing it to be his fault that he had lost most of his friends. He said “I was just too tired to go out and going out was not possible. I was sleeping for up to 16 hours at time…. I lost the respect of a lot of people in this area [work-place]. No-one believed I could ever do it again [successfully run a business] following the surgery.”

Brian reported to experience rejection by past friends which made it difficult for him to relate to them. He self-blamed by saying, “...it’s due to my unusual behaviours, poor memory, and then in turn I think unbelievable misunderstanding about some of my nature, um, friends have just been gradually dropping off, leaving me feeling unimportant.” Brian reported this being the reason many of his friends now reject him from taking part in activities, such as barbeques (BBQ). He addressed these actions now encouraged him to live a low quality of life, with him failing to care for his basic hygiene in the way he once did prior to surgery by saying:

My sort of hurts or concerns about what other people think of me has actually overcome me to the point where I don't look after myself. Because no matter what you do, it's not good enough. I know that is a very negative feeling, but its reality.

Brian reported to restricted access to friendships and recreational group activities by saying, “I'm very much a homebody. I can have periods of time, say of up to three days, four days where I have no contact with anybody whatsoever.” He said he was lonely, but he did not want to meet with anyone either because he feared their judgement.

Chris reported the negative judgement by friends post-surgery by saying, “my closest two friends felt that I needed to have surgery… but these relationships deteriorated because they feared me afterwards.” In a similar way to the experiences of Brian and Eden, Chris reported choosing now to let few people into his life. He said “with people complaining about what you don’t or can’t do following surgery [for AOES]… It’s better to close them out (of your life) and have only a few friends.”
David reported social exclusion by friends who interacted with family members more than with him: “friends ... were supportive to my wife and kids in kind of taking the kids to school and sharing of that kind of stuff... they were showing a lot of respect for my wife, but no respect to me (after surgery).”

Eden reported that apparent failures of the surgery to cure symptoms to result in social isolation by friends. “I guess friends didn’t support me because of the surgery, but rather by the fact that I was continuing to have absence seizures, and that’s why they supported me.” He said his new friends found it easier to except a new form of seizure activities and to adjust their actions to encompass the new symptoms associated with his chronic illness.

**Neighbourhood collaboration**

Eden reported neighbourhood communities to neglect education on epilepsy. He said, “Campaigns are often run to educate the community about saving electricity; not driving when drinking alcohol; the effects of obesity…; there is nothing offered about understanding epilepsy and not to fear it.”

All five participants reported experiencing increased insecurity when present in social network realms, such as the workplace, due to the poor respect they received because of epilepsy.

**Work-place engagement**

Adam reported experiencing rejection by work-place colleagues as the post-surgery. He commented that this did not change when he was amongst this group of people post-surgery. This influenced his choice to seek employment in a new work environment. Adam addressed his choice to accept an employment position that a family friend offered him a place in his business, which involved mailroom activity by saying, “Although it was a position I previously would have rejected, I guess the thing is, they [work colleagues] don't know about the operation. I try not to tell them [new people] now (about AOES), because they don't look at me as someone who has fits.”

Eden and David reported experiencing workplace difficulties post-surgery relating to poor energy levels caused by long commutes between the home and the work place. Eden addressed the difficulty to maintain energy at work following his second operation by saying, “I was travelling a long distance to work. I was required to leave home by 6 AM, because I’d
have to travel 15 km to the closest train station and spend 90 minutes travelling on a country train.” He addressed the normality his work colleagues expected after his second surgery for AOES by saying, “My colleagues put up with the seizures because they believed the second surgery would stop their occurrence.”

Eden perceived many of his colleagues to be less accepting of the effects of the second operation by saying, “Fellow employees (were not accepting) after the second operation… they expected me to recover much quicker and so I was labelled as being lazy and also no longer capable to do my work.” He said this was the reason he no longer held his employment.

David reported on workplace rejection by colleagues said. “Some of them … not keen for it at all. They had seen the seizures and had put up with them, but I think they were worried about the effects of the surgery.” He reported when returning to this work place, at times being anxious because of the lack of understanding shown by these individuals.

To summarise, the five participants reported limited community education or acceptance of epilepsy and the need for associated surgery led to both negative and positive experiences including social labelling.

**Education Responsibility**

All five participants reported a need for community education programmes to improve the understanding and support offered by community members to the participants post-surgery. Table 5.12 shows illustrative statements on the educational responsibility of support groups and other relevant social network assemblages.
Table 5.12 Illustrative Statements on education responsibility

<table>
<thead>
<tr>
<th>Person</th>
<th>Epilepsy Support Groups</th>
<th>Communities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>I think epilepsy groups are the ones who need to teach people about it. People need to learn more about epilepsy and how it can affect people.</td>
<td>It would be a good idea to start educating people. What would be difficult is; who do you decide to tell when you want mostly for people to not know about it?</td>
</tr>
<tr>
<td>Brian</td>
<td>I know the idea of educating people would cost a lot of money and time, but it is something they need to do.</td>
<td>People have no understanding and empathy. Even if they try to understand it, at some point in time they think you’re using it as an excuse.</td>
</tr>
<tr>
<td>Chris</td>
<td>If the government financially support these groups to get out and educate people, then doing things like going back to work would be so much easier.</td>
<td>Further education for everyone out there would make it easier for people like us to be comfortable around others. People everywhere need to know much more.</td>
</tr>
<tr>
<td>David</td>
<td>I now offer my time to talk to people about the operation. It would be good if epilepsy groups were able to educate all societies about it.</td>
<td>There was very little knowledge about epilepsy in communities like neighbourhoods. This would help the whole family.</td>
</tr>
<tr>
<td>Eden</td>
<td>Epilepsy groups should also be good for educating places like where they work. That would also help other people just understand and accept it.</td>
<td>I think there is too little known on epilepsy in all socials. That would also help other people in places like work just understand and accept it.</td>
</tr>
</tbody>
</table>

**Epilepsy Support Groups and Communities**

The following section looks at examples of neighbourhood communities’ participation needs as perceived by study participants; separated into five sections:

(a) For support education in the community to understand epilepsy and how to live with people, especially men, who have AOES
(b) To show respect for people’s rights, which includes the right of men who have AOES
(c) To ensure the community understands
(d) To reduce the risk of discrimination for people with a disability, including men with AOES
(e) Increase the community quality of life.
**Support education**

Adam said “Assistance to help educating people, such as your friends to understand what you were experiencing before the surgery and afterwards could help strengthen your relationships”. He reported many people fear he will die while having a seizure and therefore they do not wish to be the ones who are with him when this happens.

Brian reported a lack of information on post-surgery effects by saying, “They had information about mothers with epilepsy and children with epilepsy, but there was nothing about fathers with epilepsy.” He reported a lack of basic education negatively affected his SWB, including reduced self-perception and fulfilment. Brian said it had not been important to others to understand the effect of AOES on men, which exacerbated lower life satisfaction post-surgery. He addressed the reason he felt motivated to take part in this study by saying:

> I am a very big supporter of what you are doing. I am very, very strong because you're speaking of the person who has it, and you understand others who have it in a way more than anyone else will ever know.

Brian reported further support and education about men and epilepsy important for their social networks. He said this lack of effort to understand has caused him to experience emotional instability when participating in general social activities.

Chris addressed the importance of contacting epilepsy associations for support following the surgery by saying, “I contacted one of them and spoke to someone who had the operation before I had it. It wasn’t a lot, but it was good to just hear someone else.” He found it difficult to find information on epilepsy written in lay-person’s terms. Chris said he presently receives magazines from two epilepsy associations throughout the year “that lets me know what’s happening around the place. But it's nothing really.”

**Show respect for people’s rights**

Brian perceived others in the community not to accept his chronic illness, which adversely affected his daily activities. He said:

> It's not like when you have an injury to your arm or leg. Everyone can see it, so people have understanding and empathy. Yeah, so as they can't detect a scar on you at the moment, most people go, ‘what's this bull shit’? Another thing with memory, even if they try to understand it, at some point in time they think you're using it as an excuse.
Reduce the risk of discrimination

Chris reported due to disruptive community social judgement post-surgery, he chose to relocate his family. He said:

I needed to get away from those people I knew before the operation. Now that I live up here, over 500 km from where I lived when I had the operation, I have a completely new life. I have a new group of friends [in my new neighbourhood]… I no-longer need to discuss the condition or operation to these new people.

Chris reported their relocation allowed him to live a happier and satisfying life away from the judgement shown by individuals who were aware of the skills he lost due to neurosurgery.

Increase the community quality of life

Participants reported epilepsy support group to enhance their quality of life post-surgery. For instance, David said, “I was positively affected by the attention the epilepsy support group gave me… They offered some good understanding and empathy when I spoke to them. I don’t know if it was because they told me a lot or because they just listened, but it was helpful.” He reported confidence building from the epilepsy association inviting him to attend basic group learning classes to improve learning skills. David addressed the confidence he gained from this assistance, which now has influenced him to participate as a volunteer in this inclusion programme by saying, “I think when you talk to someone who’s had the operation, like they do with me now; it makes it a lot more understanding that you’re normal.” Adam and Eden reported gaining assistance from other community support associations.

Social Labelling

Table 5.13 presents illustrative statements on social labelling of five participants with AOES post-surgery. The judgement of neighbourhood communities appeared most likely to influence the participants SWB.
Table 5.13 Social Labelling

<table>
<thead>
<tr>
<th>Person</th>
<th>Social Labelling</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Stigma</td>
</tr>
<tr>
<td>Adam</td>
<td>I was labelled by it, even though they [AOES] had stopped. There was now this shame or humiliation.</td>
</tr>
<tr>
<td>Brian</td>
<td>Many of them labelled me as being too much hard work. They said ‘People don’t have time to your problems.’ How can you contest that? So it is a reality.</td>
</tr>
<tr>
<td>Chris</td>
<td>I think it is like I was labelled as someone they can no-longer depend on, so they don’t want to know me.</td>
</tr>
<tr>
<td>David</td>
<td>-------------------</td>
</tr>
<tr>
<td>Eden</td>
<td>My fellow employees expected me to recover much quicker and so I was labelled as being lazy and no longer reliable to do my work.</td>
</tr>
</tbody>
</table>

**Stigma**

Adam addressed the stigma experienced post-surgery, including by sporting groups and clubs, which were reluctant to allow him to participate in the activities by saying:

I was going to take part in these groups after I was back on my feet, but I was disappointed by the reactions of them all. Suddenly I was labelled by it [AOES], even though they [seizures] had stopped. There was now this shame or humiliation. They didn’t want me back.

Brian reported many of his friends to label him as being “too much hard work”. He added “they lacked empathy of my forgetfulness. One literally said, ‘Listen you know it’s a very busy world, everyone is flat out. People don't have time to listen to your problems’.”
Brian reported being unable to contest these stigmatizing attitudes “because if they were having difficulty just managing their own lives, then they would have had no time for my own.” He stated that this was a reality of community groups post-surgery and he must accept that it is unlikely to change.

Eden stated labelling “had a negative effect on my confidence, as I felt inadequate. They [communities] had no acceptance of the epilepsy… causing absence seizures post-surgery.” He reported the negativity that came from labelling was the cause of him being unable to regain his accounting employment position with the local council post-surgery.

**Positive Labelling and Community Support**

Brian reported having benefited from speaking with others at epilepsy support group meeting by saying, “I visited it and heard what others had to say and that did help me feel more normal, at least while I was there [two hours].” However, he said that following the need to find alternative affordable accommodation, the location of the support group made it difficult for him to continue to attend while needing to commute via public transport.

David also reported gained support from an epilepsy support association post-surgery. He stated that the positivity this support gave him was the reason he chose to later offer his time to counsel individuals who had experienced a similar surgical procedure. David said:

> I wish I had been able to talk to someone who had had surgery before I went through it. That's in fact why I contacted the Epilepsy Foundation as a volunteer because I felt that if somebody could talk to me, at least I could give them some sort of indication that they might know what it's like to go through the process.

David reported his actions as a counsellor made him feel important. He said the recognition as someone with epilepsy was now a positive label to him. Adam and Eden reported gaining confidence by following the encouragement offered by further community support groups not directly associated with epilepsy post-surgery, The Brain and Mind Institute (BMI) and the Commonwealth Rehabilitation Service (CRS).

Adam reported that the support he gained from The Brain and Mind Institute (BMI) was of great importance post-surgery. He reported a result of the encouragement attending the BMI was to give him, was the confidence to move outside of the security his mother’s home had provided post-surgery. Adam said:
Results: Chapter 5

After a couple of years I felt I needed to start caring for myself. I moved out of my mum’s place and got my own flat with the help of BMI. Although it was hard at first, it felt good to be looking after myself again. They still at times call or have someone come over to help me with stuff.

Eden reported gaining assistance from the Commonwealth Rehabilitation Service (CRS) due to the large region of peripheral vision he lost as the result of the surgery. He addressed how the programme that the CRS developed was to assist him to return to regular activities, including employment by saying,

...part of the CRS programme was to give work placements, which included cleaning jobs where I wasn’t paid... due to a lack of confidence (post-surgery) I kept thinking I wasn’t capable of doing these jobs, so the programme (was) ceased (by me).

Eden said that he decided to end the CRS programme because he had only lost his peripheral vision. He said that others who had experienced full vision impairment should take his place in the programme.

The data from the interviews with the five participants showed all of them encountered difficulties within social networks. Those difficulties have affected their SWB. The two aspects of social networks, in terms of role positioning and responsibility have caused a negative impact on the happiness, peacefulness, fulfillment and self-perception of the participants. It is important for the SWB of each participant that hospitals and other health-based societies provide education to all social networks to develop support and understanding about epilepsy and the effects of seizures and relevant surgical procedures.

**Coping Strategies to Enhance the Participants’ SWB**

Table 5.14 shows types of coping strategies from the thematic analysis of the data and summative ratings on the specific types of SWB.
Table 5.14 The coping strategies of Personal Environment on Subjective Well-Being

<table>
<thead>
<tr>
<th>Personal Environment</th>
<th>Subjective Well-Being</th>
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<tbody>
<tr>
<td></td>
<td>Self-perception</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>Cognitive reconstruction</td>
</tr>
<tr>
<td></td>
<td>Threat minimisation</td>
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<tr>
<td></td>
<td>Emotional expression</td>
</tr>
<tr>
<td></td>
<td>Wish-fulfilling fantasy</td>
</tr>
<tr>
<td>Behavioural</td>
<td>Information-seeking</td>
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</tbody>
</table>

Coping strategies have both positive and negative effects on SWB and some situations can have mixed or unidentified effects. Effects on SWB are positive (+) and negative (-) and mixed (+/-). Note: Negative effect SWB often occurred when participants were unable to attain relevant information/material post-surgery.
### Table 5.15 Cognitive coping strategies of participants

<table>
<thead>
<tr>
<th>Person</th>
<th>Cognitive Reconstruction</th>
<th>Threat Minimisation</th>
<th>Emotional Expression</th>
<th>Wish-fulfilling Fantasy</th>
<th>Self-blame</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>After having surgery...</td>
<td>By changing the field that I now work in, people don't know anything about my past experiences (with epilepsy).</td>
<td>I got angry with people I knew after the surgery... [which] caused problems with my girlfriend.</td>
<td>I perceived myself to be brave and stronger, even while emotional.</td>
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<tr>
<td></td>
<td>[I perceived]... to improve my memory so I could remember like everyone else.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brian</td>
<td>When it comes to strategies are used to cope with my condition and social attitudes... it is easier to stay at home and be lonely than need to discuss it (epilepsy) and be judged by society.</td>
<td>I was happier [post-surgery] and could go back to playing gigs and earning an income.... In the end, maybe the whole experience... made me more satisfied.</td>
<td>I wanted it [surgery] to take away all the distractions that epilepsy caused.... to change how people saw me.</td>
<td>My isolation is probably due more to my own feelings of hurt, but then also depression. It [depression] could be the long-term effect of (my) isolation</td>
<td></td>
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<tr>
<td></td>
<td>[I perceived myself] confident... it made me feel stronger.... I could now get a job and support my family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>When the seizures stopped I [perceived myself] confident... it made me feel stronger.... I could now get a job and support my family.</td>
<td>Where I now live people see me being no different to them... None of them knew me before surgery. I go on as if nothing happened.... I don't let it get to me.</td>
<td>My co-ordination skills... didn't get any better.... When I tripped, I just made a joke of it so I wasn't judged for it.</td>
<td>Straight after the surgery I wanted to get a licence and start driving again.... It takes 3-years before you can get one again.</td>
<td>Although I want to [find new friends], the truth is... I'm not in my 20's anymore. It's not their fault I don't remember names.</td>
</tr>
<tr>
<td></td>
<td>[I perceived myself] confident... it made me feel stronger.... I could now get a job and support my family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>David</td>
<td>I was happy [post-surgery] by helping others who were to have the same operation I had.</td>
<td>When I... lost my balance and tripped, I'd make a joke of it... It made people feel more comfortable.</td>
<td>I wanted the surgery to add to my dependability when at home... and it didn't.</td>
<td>I blamed myself that depression stopped me from doing things. I didn't see it... but that doesn't mean it was anyone else's fault.</td>
<td></td>
</tr>
<tr>
<td>Eden</td>
<td>[From reading about] Emma Miall who had the same surgery for epilepsy... I felt like I wasn't alone. I still have it... I can think past surgery</td>
<td>To make sure I remembered my experiences, it was important to write down the things that happened (in a diary) on a daily basis, and have written evidence of things I did on that day.</td>
<td>Although the seizures [abated]... I got angry with my family and they would forgive me.... And they would forgive me.... Expressing my emotions made me feel better.</td>
<td></td>
<td>After a three month camping trip around Australia with my wife, I was unaware of any memories... It was my fault that I didn't remember it.</td>
</tr>
</tbody>
</table>
Cognitive Coping Strategies

The study found participants used four cognitive coping strategies while living with AOES post-surgery: cognitive reconstruction, threat-minimisation, and emotional expression, wish fulfilling fantasy, and self-blame. Cognitive reconstruction and emotional expression strategies tended to have largely positive effects on SWB whereas wish-fulfilling fantasy and self-blame seemed to have mostly negative effect. Table 5.15 presents examples of specific coping strategies used by the participants, with the evidence of them to follow.

**Cognitive Reconstruction**

As an example of cognitive reconstruction, David spoke of his post-surgery experience as an opportunity to understand his health experiences with AOES as resources to helping others. David said, “I was happy [post-surgery] to help others who were to have the same operation I had.” He reported the importance of his new identity as ‘a man with epilepsy’ by saying, “I feel happy to talk to people who have epilepsy and their families about it and surgery… It makes me now feel proud now that I am seen as a man with epilepsy who can help others.”

Post-surgery, Adams reported the importance of developing improved memory recall by saying, “I often questioned my memory and whether it was ever going to get better…, that’s why it was important for me to study again. To improve my memory so I could remember like everyone else was so important.”

Brian addressed the surgery as assisting his career participation by saying “I’ve done some work; I’ve done some good gigs since the surgery because I can still play (the guitar) and not worry about seizures. Post-operation I [was happier and] could go back to playing gigs and earning an income doing what is important to me. It is important to have goals like these to focus on after surgery…. In the end maybe the whole experience… made me more satisfied”.

**Threat minimization**

Chris said, “I go on (behaving) as if nothing has happened…. I don’t let it [consequences of surgery] get to me.” Some participants thought of withdrawal from social interaction as a method to practise threat minimisation.
Adam addressed threat minimisation resulted following changing his work-place environment by saying, “By changing the field that I now work in, people don’t know anything about my past experiences (with epilepsy)... I still eat alone, but epilepsy’s no-longer the reason.”

Brian addressed a certain sense of inner sadness resulted from his choice to isolate regular contact with members from the social network by saying,

I am on my own and feel that I need time on my own.... I do appreciate the lack of attention too.... I go within myself and don't correspond, but I also don't get correspondence.... I guess that’s the long term consequences of living an isolated existence.

Eden addressed the threat management he considered he had attained by recording his daily experiences in writing by saying, “to make sure I always remembered experiences, it was important to write down the things that happened (in a diary) on a daily basis.... I have written evidence of things I have done. This, he believed, would help him to attain greater self-protection.

**Emotional Expression**

All five participants spoke of a variety of emotional expressions: blunting, acceptance, recognition and depression. As an example of blunting, Eden said, “although I wanted to ignore the effects of [surgery].... I got angry with my family... and they would forgive me.... Of the end, it made our marriage stronger”. David addressed his emotional acceptance by saying,

Even when I was going through the period of depression, I always had their [family] respect.... When I recognised the symptoms (of depression) I experienced and accepted them..., this helped me feel stronger not only at home but with others.

Chris addressed the recognised and accepted the emotions around the disco-ordination that resulted from the neurological procedure by saying,

My co-ordination skills were pretty bad after the surgery, which often saw me losing my balance. Whenever I tripped, I just tried to make a joke out of it so that I wasn’t (psychologically) affected by how others judged me for my lack of (physiological) co-ordination that came after surgery.
David reported experiencing disco-ordination post-surgery by saying, “When I did something like lost my balance and tripped, I’d make a joke of it... It made people (in all societies) feel more comfortable.”

Emotional expressions helped social relationships for some of the participants. For instance, Eden reported the positive SWB he experienced from his emotional communication with others, which he could facilitate his recovery by saying, “Expressing my emotions made me feel better”. David said as he has been able to speak with similar individuals about how epilepsy emotionally affected him post-surgery, “other people were able to connect with me because they could understand my pain”.

**Wish-fulfilling Fantasy**

An example of a reconciliation fantasy, Brian said, “I wanted it [surgery] to take away all the distractions that epilepsy caused. I wished for people to accept that it [surgery] stopped them [AOES] and I would be able to return to the music industry. It needed to be like I was starting a new career, which I felt I could do, but it [surgery] didn’t change how people saw me.”

An example of the characteristics of a compensatory fantasy, Chris said, “As I didn’t have a driver’s licence before we [Chris and his spouse] met, I didn’t have a car. So she was the one who drove us around. Straight after the surgery, I wanted to start driving her wherever she needed to go and not the other way around. You know, it takes three years to get a licence after it. It was important for me to set goals like this.”

**Self-blame**

Chris reported poor short-term memory following surgery to cause social isolation from friends post-surgery by saying, “I understand now that it wasn’t their fault that I didn’t remember their names... it’s mine” An example of perceived helplessness, David said,

I want to be able to make my own decisions and be confident doing so. I blamed myself for [AOES related] depression stopping me for doing things for some time, like making decisions.

Eden self-blamed for experience of social isolation by saying,

I decided to do this [self-blame] after a three month camping trip around Australia with my wife. I was aware of the fact I visited certain places, like Uluru, but am unaware of any
memory of the memories. I forget the places we visited on holidays…. When it comes to it, it was my fault that I didn’t remember it.

**Behavioural Coping Strategies**

Thematic analysis of the data suggested the participants used one major behavioural coping strategy to attain positive SWB post-surgery: information-seeking (see Table 5.16 for examples).

<table>
<thead>
<tr>
<th>Person</th>
<th>Behavioural Coping Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information-seeking</strong></td>
<td></td>
</tr>
<tr>
<td>Adam</td>
<td>I found some information [surgery] on the internet, but that wasn't that helpful... I didn't think there'd be anything more I could get if I called them [epilepsy support groups].</td>
</tr>
<tr>
<td>Brian</td>
<td>I asked doctors and [epilepsy] support groups about info on men with epilepsy, but there was nothing... that made it harder.</td>
</tr>
<tr>
<td>Chris</td>
<td>I wasn't able to find any real information about this epilepsy [AOES] and the effect on men. That made it difficult to cope.</td>
</tr>
<tr>
<td>David</td>
<td>I am always looking for new information. That's why I go to classes [epilepsy groups] that help improve your memory.</td>
</tr>
<tr>
<td>Eden</td>
<td>Through the year magazines [epilepsy] are sent to me in the mail... Now you can go to the internet and find more (information), but that wasn't there when I had it [surgery].</td>
</tr>
</tbody>
</table>

**Information-seeking**

As an example of information seeking, Eden said, “[I receive] magazines… from different epilepsy groups…. It is good to sometimes read about other peoples’ success…. Now you can go to the internet and find more (information), but that wasn’t there when I had it [surgery].” Brian sought additional information about anti-convulsive medications in relation to the quantity that must now be taken, and new side-effects that could result from this. He said, “I wanted to learn more about medication and side-effects so I could learn how to live with my condition”.

*Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures* 129
Brian sought information on the effect of surgery and medication on adults with epilepsy. He reported experiencing reduced life satisfaction when he was unable to find information on the issues of being a father with epilepsy. He said; “I asked doctors and [epilepsy] support groups about info on men with epilepsy, but there was nothing... that made it harder.”

In contrast, David reported to have information certainty through regular contact with an epilepsy foundation, and attaining a variety of newly published literature. He said; “I am always looking for new information. That’s why I go to meetings like (epilepsy) conferences.”

David assumed that it was this regular contact and attainment of updated material that made him feel satisfied with the result of the surgery, allowing him now to discuss this with other individuals in a comfortable manner.

Participants said some support groups also provided information support. Chris said, “I went to a few (support group) meetings before I moved interstate… it wasn’t a lot (of information), but at least it was good to just hear someone else (who had experienced surgery for epilepsy).” Brian said; “I spoke with others [Adults] with epilepsy… This gave me some understanding on how others live (with) it [epilepsy] after surgery.”

From the social groups they learnt how to live positively with AOES. This positively influenced their threat minimisation skills.

Cognitive reconstruction includes rethinking about how one belongs to a community of similar others. Eden said,

   The Melbourne Age had a magazine supplement, which had an article written by someone called Emma Miall, who had undergone surgery for epilepsy similar to mine. I kept this article in my bedside draw and often pulled it out and read it between seizures to prove that someone else out there had experienced a similar thing and therefore I was not going mad. This article greatly assisted me during these dark days.

The article allowed him to understand himself living with epilepsy as a person who is a member of the community of people with epilepsy.
Conclusion

Through the use of the interpretive phenomenological analysis approach, data gained from the participants offered better understanding on what factors influence the SWB in men following surgery for AOES. This study helped answer questions linked to the importance of Family, Health Professional/Consultant, and Social Network relationships. Additionally, it described how the level of rehabilitation the participants received influenced their SWB post-surgery. The data also indicated how the internal perception of men with AOES post-surgery influenced their comfort using self-regulation and coping skills adopted to enhance SWB following the operation.

The results indicate that men with AOES perceive relationships within the family environment as having the strongest impact on happiness, fulfilment, self-perception and life-satisfaction post-surgery. Health Professional/Consultant relationships were the second most influential factor on SWB. Social Network relationships also influenced these men with AOES post-surgery; however, a reduced level of social contact indicates social relationships have the least influence on SWB.

The data from the interviews showed that all of the participants have practised a variety of cognitive and behavioural coping strategies to encourage positive SWB. These two different types of coping strategies caused positive and negative impacts on the happiness, fulfillment, self-perception and life-satisfaction of the participants.

Participants found their ability to practise cognitive reconstruction activities post-surgery was to influence the degree of positive effect on their self-perception and fulfilment. Positive effects were evident in the life-satisfaction of participants who were able to voice their difficulties through emotional expression. Other participants attained emotional comfort when choosing to joke about their post-surgery symptoms after experiencing these whilst present in their social network.

Inability for most participants to attain wish-fulfilling fantasies resulted in a negative effect on their quality of life. Most participants experienced negativity in life satisfaction as the result of a lack of success when information-seeking, and practicing self-taught acts of threat minimisation, including social avoidance. This often resulted in negative self-blame.
Happiness, fulfilment, self-perception and life-satisfaction were most strongly influenced by education and understanding. Further, participants defined social acceptance as liberating, which allowed them to experience positive SWB. Participants’ individual circumstances emphasize the importance of demographics in considering and understanding external perception and the effects on SWB. Additionally, how rehabilitation or lack thereof influences SWB post-surgery is important. As such, education and understanding seem to be of primary importance to the SWB in men with AOES following surgery. The following chapter will consider the findings, discussing the perceived quality of Immediate and Extended Family Relationships, Health Specialist/Consultants, Social Network Relationships, and Coping Strategies when living with AOES.
Chapter 6

Discussion and Conclusion

Introduction

The present study investigated the SWB in men following neurosurgery for AOES. This is the first in-depth study on SWB among people with AOES post-surgery. The discussion of the findings considers the perceived qualities of relationships family, health consultation, community/neighborhood and social networks. These relationship qualities are to the extent possibly considered in reference to the preliminary conceptual model proposed in the first chapter of this thesis, and also the literature on social identity, social stigma, cultural norms about the male role and social network theory. The discussion also considers limitations of the study and avenues for future research.

Quality of immediate and extended relationships

The participants perceived changes occurring post-surgery in both immediate and extended family relationships, particularly in role positioning and responsibility. Specifically, participants reported experiencing marginalization, dependency and enmeshment in their role positioning post-surgery. They also reported reduced accountability, duty of care, and decision making from the changes in role positioning and responsibility. On the surface, these findings are counterintuitive in view of the fact that the surgery should have increased functioning and participation as a result of curative relief from symptoms.

Role Positioning

The changes in role positioning that were found to have occurred in this study may explain why individuals perceive their families think the individual is not capable to perform their previous or expected post-surgery roles following the procedure. This explanation is likely given the reported initial increased post-surgery reliance on family by participants for important activities of daily living. Previous studies by Wilson, Wrench, McIntosh, Bladin, and Berkovic, (2010), observed a similar role positioning.
change for people with epilepsy post-surgery, reporting less confidence by family members in their decision making capability post-surgery. For instance, the individuals with epilepsy were restricted in budgeting decisions. In some cases, role denial by family contributed to their lack of trust to support the person with AOES to act responsibly when making financial decisions. The participants who experienced role denial post-surgery felt this lack of family trust at times resulted in their own self-questioning.

Similarly, Maschio (2012) reported role marginalization by family towards individuals with hemiparesis and speech problems; some people with AOES may experience speech impairment adding to existing communication difficulties. Participants with communication difficulties may experience lower SWB arising from frustration by their spouse within their personal relationship. Role positioning and responsibility management difficulties can arise when a person with chronic illness has to experience heightened help-seeking behaviours (McPherson, Wilson, Chyurlia, & Leclerc, 2010). Communicating a need for personal help from the family can be particularly challenging, especially for some males who perceive they are the dominant or lead partner in the relationship.

Role repositioning and responsibility discounting may have arisen from perceptions by the family that the participants had high emotional dependency on them. A study by Feddersen, et al. (2005) found that adults with temporal lobe epilepsy (TLE) experienced emotional fluctuations post-surgery, demonstrating an increase in emotional dependency on family or significant others. Without adequate understanding by the family on why dependency occurs, poorer quality in personal relationships and SWB can be experienced by an individual with AOES. It is likely role enmeshment could occur when others assume certain activities on behalf of the participant that had been previously solely conducted by the individual. Wilson, Bladin, and Saling (2001) proposed actions of enmeshment would result in lower quality of family life for participants with epilepsy.

Some of the study participants with greater seizure control post-surgery perceived that they experienced higher role expectations by their family or greater than they believed themselves capable of, including their duty of care to family members. Such a situation
as being seizure free after surgery may have had the counter intuitive effect of reducing their SWB. For instance, Gilbert (2012) claimed that following neurosurgery for epilepsy, the responsibility that accompanies a seizure free life might be what many patients are not prepared to address. Thus, responsibility discounting might not be only from family role denial. It might also be from fear by the person with epilepsy post-surgery of the “burden of normality” (Wilson, et al., 2007, p.651).

The findings on role positioning and responsibility accountability are limited in their reliability by the fact that it was data obtained from the participant only that was used for the analysis. Further research involving interviewing of the partners of the participants or family could assist in gaining greater understanding of role positioning and responsibility discounting AOES post-surgery. The secondary information sources could also clarify perceived effects of changes in role positioning and responsibility on SWB. Research in which participants kept diaries on their role functioning responsibility changes could clarify or confirm reports by participant informants from this study.

**Changes in Health Professional/Consultant Relationships Post-surgery**

Participants experienced perceived changes in post-surgery care, and limited time availability with health providers, which led to perceptions of reduced professional support and expertness. The effects of perceived reduced health professional support appeared to be a source of distress for many of the participants. This may be from perceived reduced treatment alliance with the primary health-care provider. Greater SWB is more likely post-surgery when health providers and the patient work as a team to manage post-surgery symptoms (Fearon, 2005). Better condition management solutions are likely, with strong teamwork with the provider. For instance, Lee, and Emanuel (2013) reported on the importance of health providers to help participants design solutions to their health management when living with chronic illness or disability. Decision-making support can assist the person to attain satisfying solutions. A lack of support may result in self-perceptions of incompetence and related SWB. According to Caligtan, Carroll, Hurley, Gersh-Zaremski, and Dykes (2012) the participants’ ownership of decisions from the health management partnership is important for long-term health sustenance.
A previous study by Nystrup, Larsen, and Risør (2010) observed limited availability of clinicians to discuss treatment options post-surgery, including issues of self-care (Wilson, Arshad, Nnamoko, Whiteman, Ring, et al. 2012). Bodenheimer, Lorig, Holman, and Grumbach, (2002) claimed that without a strong health management alliance with the treating clinician the patient would likely experience reduced fulfilment and satisfaction with life. According to Lelorain, Brédart, Dolbeault, and Sultan (2012), disvaluing by a health professional/consultant of the need of a patient for understanding and empathy can result in feelings of insecurity or lower health-related quality of life. Low health-related quality of life may compromise self-care values.

Self-care is easier for participants to manage with education by health professionals. According to Cassin, Sockalingam, Wnuk, and Parikh (2013), a lack of self-care education can increase the risk of emotional instability from uncertainty or not knowing how to cope. Adaptation of self-care habits, such as exercising regularly, practising healthy sleep hygiene, and avoiding caffeine substances could result in greater SWB with post-surgery epilepsy. Comfort in professional consultative relationships on self-care behaviours would also likely increase SWB.

Arora (2003) also reported that time-mismatch or limited time-availability by the health professionals deprived the patient of an opportunity for learning or education about the management of his or her chronic illness. Perceptions of a weak treatment alliance with the health professional by people with AOES can result in experiences of confusion and uncertainty. Greater time availability by the health professional/consultant may translate to perceptions of greater respect toward the patient (Pennbrant, 2013), leading to a stronger treatment alliance. According to Richardson, et al. (2012), if a health professional/consultant provides adequate time-availability to address the patients’ needs, the person is more likely to be successful with health management.

However, a number of caveats should temper appreciation of the study findings concerning the impact of the professional consultant relationship on the participants’ SWB. First, patients may interpret the consultation relationship to be primarily about power. Considering the consultation relationships in healthcare as power relationships often occurs when the health professional is the expert and the patient’s lived experience is devalued. Second, patients may have a unique view and experience of
medical consultations and this could be different from health professionals. Further research could examine perceived influences of power on health outcomes with epilepsy post-surgery. Research on the perspectives of health professionals regarding the influences of any power imbalance when consulting with patients with AOES could clarify the veracity of this perception of power imbalance by the participant.

Changes in Social Network Relationships Post-Surgery

Participants reported changes in their social network relationships post-surgery. The social network changes included diminished social cycle, less opportunity for disability education and lower quality of work-place participation.

Social Affiliation

Social Affiliation change reported by the participants included exclusion from preferred network activities. For instance, participants perceived that social network members excluded them from recreational social activities of choice or those they had participated in before surgery. According to Hayes, Gray, and Edwards (2008) and Fay and Maner, (2012), social groups can place restrictions on people with chronic illness and disease (CID), as when people with epilepsy are excluded from group programmes accessed by others. The length of time that has passed since both parties communicated might be what influenced social distancing. If during this period of absence, the focus of group interests had changed, the social network may no longer observe the individual as holding their same aspirations. Patients with AOES who experience periods of absence from typical social networks due to nursing or post-surgery care may result in an exclusion from future social participation.

Lindemann (2007) noted that a change in a social network might have both positive and negative effects on SWB. Positive effects may include happiness with a more compatible social network or one that is more accessible. Positive self-perceptions could be from acceptance by others as a person of worth. When a desired social network excludes the individual, negative effects may include reduced self-confidence and self-perception (Sciulli & Bebko, 2012).

Study participants reported isolation largely due to exclusion from disability/epilepsy education social networks in the community. This might result from a lack of
recognition by these networks of how valuable the participants’ knowledge and unique understanding about AOES would be to them. If community support networks adequately recognised the participants’ knowledge about AOES, it might have resulted in a positive effect of SWB. According to Link, et al. (2001), if community support groups partner with those with epilepsy to address social inclusion issues, this will encourage community acceptance of the chronic condition. Wilson (2013) reported involvement in disability education to result in positive SWB for individuals with epilepsy.

Some of the study participants reported heightened work-place expectations post-surgery. This was due to a misunderstanding between treatment and cure, with many believing the surgery would cure the chronic illness rather than control/reduce seizure activity. The lack of co-worker education about epilepsy would leave many participants feeling negatively socially labelled at the workplace (Royal, Reynolds, & Houlden, 2009). Participants felt that with greater understanding within the community, the participant is likely to develop higher confidence and self-belief when present in those societies.

A limitation of the finding on social participation effects is that the study only examined the participants’ perception of their social networks. Future studies should examine the structure and functions of the actual social network of people with AOES and its effects on their SWB. Furthermore, future studies could examine in persons with AOES their sense of personal agency to engage in mutually beneficial social networks with others in the community. Questioning people within the network on how they perceive the participants role could also be beneficial, – maybe the participants are incorrect in their subjective perceptions. Other secondary information sources (e.g. significant others) could also help clarify the perceived social affiliations that influence SWB with AOES.

**Coping Strategies Effects on SWB**

Participants reported attempting a variety of coping strategies, including strategies associated with cognitive reconstruction and information seeking. Cognitive reconstruction actions to cope with living with AOES included adopting positive
thought patterns and beliefs for improved SWB. Information seeking actions included reaching out to others or to the media resources regarding living with AOES.

**Information Seeking Actions**

Information seeking seemed to enhance the participants’ overall understanding of what were necessary actions to improve well-being. Participants reported seeking information from the support groups in epilepsy communities following surgery, such as subscribing to receive published magazines or newsletters that provided basic education about their chronic illness and discussed others’ experiences with the condition. Washington, Meadows, Elliott, & Koopman (2011) observed that most people seek information because they strive for certainty. The same was true for the participants in this study.

In contrast, Sweeny, Melnyk, Miller and Shepperd (2010) reported information avoidance actions practised by some individuals to prevent effectively coping with chronic illness or disability. They claimed that although acquiring information can provide many benefits, some people might choose not to seek relevant information, resulting in less certainty and lower SWB. Some participants questioned whether they initially delayed gaining full knowledge of the circumstances of the operation, as they feared a lack of success. Information avoidance behaviour may be from wanting to delay the full knowledge of the implications of a health condition.

**Cognitive restructuring**

According to Gandya, Sharpea, and Perry (2012) people living with a chronic illness or disability who have less cognitive reconstruction of their personal ability to live with health management may experience negative SWB. Summerville (2011) stated that individuals may experience more life satisfaction when choosing not to attain significant information about their chronic illness. Braikir (2006) reported some people engage in self-blame as a result experiencing hopelessness and despair from not seeking information on living with chronic illness or disability.

Participants in this study experienced cognitive reconstruction difficulties when they were unable to identify dysfunctional automatic thoughts, social environments and future goals. Participants felt the lack of information attained from health professionals
or support groups resulted in difficulties establishing relevant coping strategies and behavioural plans. Most participants believed this lack of understanding led to thought avoidance, or avoiding acknowledgement of difficulties they had experienced.

Most participants experienced difficulty understanding the thought patterns of others when in their presence because of the impact of surgery, leading to low SWB. As a result, they often chose avoidance strategies to deal with the social insecurities they experienced. David, who showed greater determination to gain self-understanding by approaching a counsellor and relevant support groups, developed more stable coping strategies. His later choice to offer time to talk to others experiencing similar difficulties led to stronger SWB.

**Modified Conceptual Model**

Figure 6.1 is a modified conceptual model illustrating the effects of post-surgery relationships on SWB based on these findings. One of the modifications to the model is that an indirect effect on SWB can result from tension, anger and rejection expressed between the immediate and extended family environments. The external perception in all three main relationship environments, -Family, Health Professional/Consultant and Social Networks, -includes attributing participants with low respectability and unaccountability.
Figure 6.1 Modified Conceptual Model

Modified Conceptual Model

**Context**

**Family Relationship**
- Wife/Partner
- Child/Children
- His family
- Partner’s family

**Personal Individual Framing**
- Immediate family

**Direct Effects on SWB**
- Role enmeshment
- Responsibility disconnection
- Distrust
- Diminished life-satisfaction

**External perception**
- Low Respectability
- Unaccountability
- Understanding
  - Diminished treatment alliance
  - Patronization
  - Indifference
  - Depress
  - Learned helplessness

**Health**
- Professional / Consultant Relationship
  - Specialist
  - Consultants
  - Healthcare
  - Rehabilitation
  - Psycho-education

**Social Networks**
- Friends
- Neighbour
- Group Societies
- Workplace

**Coping Strategies**
- Cognitive reconstruction
- Information seeking

**Internal perception**
- Self-regulation
- Coping skills
  - Confidence
  - Independence

**Indirect Effect on SWB**
- Exclusion
- Marginalization
- Labeling
- Anxiety
- Depression

- Happiness
- Fulfillment
- Satisfaction
- Self-Respect
- Recognition

Modified Conceptual Model on the Direct Effects on SWB following elective surgery for AOES. Note: Needed rehabilitation and psycho-education for the Immediate Family has been noted; additional green arrows connect the Healthcare providers to Immediate Family and to both the External and Internal Perception.
In family relationships, the direct effect of role enmeshment, responsibility disconnection and distrust may lead to diminished life-satisfaction of the participant. In health professional/consultant relationships, diminished treatment alliance may result from the disrespect of health-care providers. Participants often experienced patronization and indifference on the part of health providers, leading to disempowerment and learned helplessness. The perceptions of members of social networks toward the participant were often similar, resulting in the exclusion, marginalization, and labelling of the individual. The effect on SWB post-surgery often results in participants experiencing anxiety and depression.

Coping strategies, including cognitive reconstruction and information seeking influence internal perception. For those patients who experience optimal rehabilitation and psycho-education from their health-care providers, confidence and independence can develop (Wedlund, Nilsson, Tomson, & Erdner, 2013). The direct effect of increased happiness, fulfilment and satisfaction in participants can result in their perceived higher self-respect and recognition. Further psycho-education for immediate family members may also develop further understanding and positively influence SWB.

Overall, self-reported data on coping strategies rather than actual actions in regards to lived situations was analysed. Such data are limited in their trustworthiness. For instance, informants may under or over-report on coping strategies they presumably used. Further observational studies or scenario lead analysis by participants could corroborate findings from this study.

**Cultural Norms and Gender Role Identity**

Although there have been significant cultural shifts in Western society regarding gender equity, this still remains aspirational and social attitudes to privilege males in most social contexts persist (Loscocco, & Walzer, 2013). These attitudes translate to males believing to be with control over social outcomes and particularly over their close relationships (Copenhaver, Lash, & Eisler, 2000). As previously discussed, AOES has the effect to compromise sense of control from the unpredictability of seizure and associated need to depend on social others. This challenges traditional self-perception of males as in control. Even with surgery, symptoms typically persist, requiring role re-positioning which impacts cultural norms in a masculine social setting.
Findings from this study suggested changes to the social role identity of participants towards non-dominant, even dependent roles. In a previous study, Wilson, et al, (2001) explained that people who are living with men with AOES have already believed that they do not have the capability to think and make decision on the important issues. The family may not want to take any risks or give an opportunity for men with AOES to try to prove his ability (Maschio, 2012); further impacting cultural norms in which males believe to determine social outcomes for others. The role positioning changes which go against typical cultural norms may be reducing the subjective well-being in men with AOES, preventing them from creating a new egalitarian role positions for them and significant others.

### Social Identity and Social Stigma

Epilepsy carries significant social stigma (Buelow, et al., 2003), and mostly from its paralysing effects on both the person experiencing it and onlookers. There are many studies show that whether men with AOES no longer have seizures because of surgical or pharmacological treatments, their social stigma remains, not only influencing a reduction in their quality of life but also an increase in depressive symptoms (Poochikian-Sarkissian, et al., 2008). Moreover, men with AOES have been attached to stereotypes that includes notions of contamination, danger, sin, divine punishment, supernatural forces and madness, which lowers their opportunity for employment or participating in educational institutions (Espinola-Nadurille, Crail-Melenda, & Sanchez-Guzman, 2014). The expectations of the surgery is that AOES can be cured, with the patient no longer experiencing seizures sets up people with AOES to experience enhanced stigmatization as they may be perceived to be irredeemable.

However, the greatest social stigma for men with AOES is experiencing seizures in front of another. Participants of this study reported to experience embarrassment from experiencing seizures they cannot control. They considered both them and their social others to be stigmatized by others in the community. At a personal level, the individuals with AOES perceived their social identities to be wrapped around their persistent neurological health; crowding out other possible social identities, which they are entitled to as humans. A social identity around a challenging health can cause self-isolation, lower self-esteem and reduced opportunity to reconstruct an enabling social
self (Espinola-Nadurille, Crail-Melenda, & Sanchez-Guzman, 2014). This sense of social compromise also is from social discrimination and negative attitudes towards men with AOES and their families (Hasan, et al, 2010). The experience of social stigma comprises a sense of positive social identity, which also feeds back into being socially stigmatized.

**Social Network Effects**

The three social networks that include friendly, neighbourhood and workplace are critical roles to the subjective well-being of men with AOES. This study’s findings suggest that after they have been isolated from the social networks, because of experiencing seizures or other medical care issues post-surgery, most men with AOES avoid participating in or returning to original social networks. This in part because the individuals with AOES with symptoms post-surgery are unsure how they may be perceived by others expecting them to be “normal” or “cured” or who might believe them to be “playing sick” when in fact “cured”. According to Hayes, Gray, and Edwards (2008) and Fay and Maner, (2012), misaligned social networks or those with negative attitudes towards the individual can cause uncomfortable feelings or emotional instability and socially awkward situations for individuals with chronic illness and disease (CID), like men with AOES. Participating in support groups for men with AOES is a proven approach to enable the creation and maintenance of positive social networks (Link, et al., 2001) or those with least risk for social rejection. Community (self) advocacy as a person with AOES likely will create social roles in which men with AOES are perceived by others to be more than and different from their health condition.

**Limitations of the Study**

To the exploration of psychosocial effects on SWB was focused on the perspective of individuals affects, the research did not explore the direct reaction of members of relevant social environments, including the family and health professionals. Additionally, it did not examine how the participants interacted with others in relevant societies within the social network. The study examined social reactions solely through the eyes of the participants in this study. This limited the information to that of a third-person’s perspective of first-person experiences. The process did not include initial interviews prior to surgery, nor how they experienced the subsequent events at the time.
Further research could address this limitation, employing a case study approach combined with a narrative inquiry using members of the IFE who initially are, and secondarily were, part of these men’s lives during the period of investigation. By incorporating this recommendation into further studies, including a longitudinal study, researchers may have the opportunity to observe the participants’ individual reactions and symptoms starting immediately post-surgery. Observing how these men interact, how the relevant social environments fit within the overall context, and the levels of stress created may provide a stronger understanding of the best means to educate the community about AOES and neurosurgery to control these symptoms. By comparing capacities and levels of SWB, before and after surgery a more meaningful narrative might emerge in relation to the differences between them. Research participation was limited to a small number of men solely located in Australia. Further research that involves men from other settings will add to understanding SWB among men with AOES and elective surgery.

**Recommendations**

Following the findings of this study, the benefit of addressing the causes of the relevant social behaviour and individual experience of men with AOES post-surgery in order to heighten their SWB is evident. This may help to alleviate emotional scarring, caused by psychosocial effects and give the men an increased chance of successfully participating in all social atmospheres, including the home, workplace, and other environments.

Health professionals must perform an extensive investigation into each man’s personal and medical history (which may include the experiencing of physical or medical injury), and ongoing post-surgery counselling assessments should be completed and evaluated. In-depth interviews with relevant members of the IFE in the individual’s life, such as partners, children, and siblings, along with observations of the individual during formal assessment and/or therapy should be included to assist with post-surgery rehabilitation.

Men and women with uncontrolled AOES spend most of their weekly life in the home environment. The home has a strong influence on how these adults maintain stability and self-identity. When members of the IFE have little knowledge of the condition of
AOES, the SWB is too often poorly affected. I strongly recommend the providing of community learning about epilepsy for individuals within the family environments.

Community Support Groups, such as Epilepsy Australia, and Epilepsy Action, Australia are presently voluntarily entering the home environment of some individuals with epilepsy, offering basic education for members of the IFE. However, limited finances and the high levels of social embarrassment about the condition are restricting these initiatives. I recommend government funding be allocated to social support groups, such as the Victorian Epilepsy Foundation, Australia to ensure this necessary education continues.

Men experiencing AOES mostly fail to receive adequate education about their condition. Unless the medical consultants are knowledgeable about all forms of epilepsy, problems that may occur for a man with AOES may not be appropriately addressed. A higher level of education, which I wrote about earlier needing to be provided to the IFE about AOES, should also be provided to pre-service health professionals. Giving an adequate level of education to students at a tertiary level about epilepsy would also help address problems often experienced by health professionals when counselling individuals with AOES. Further communication is required between all relevant healthcare providers to ensure the patient gains full advantage of the consultation. Fundamentally, further knowledge about AOES and relevant neurosurgical procedures require attainment by health professionals to ensure they provide adequate psychological care.

Additional knowledge is necessary for members of relevant social network environments, such as the workplace and social community groups. When speaking with typical people such as my neighbours, I found that they have little knowledge about forms of epilepsy. Especially, when questioned about the condition, most members are unaware of how to act when observing a seizure, with many believing that a hard object requires placing in the individual’s mouth to stop him/her from swallowing their tongue. I recommend further information be made available to those who spend some time in locations such as medical practices, or even bars and hotels so these individuals can easily gain important information and ensure dangerous actions are not practised.
All people with epilepsy and those who are closest to them require education on the chronic illness. Following the diagnosis of epilepsy, a high number of men neither receive relevant information about the condition, such as the publication *Men with Epilepsy*, nor are they supported through counselling. I recommend the creating of support groups for these people to offer this necessary education. Without receiving adequate information, people can experience difficulties understanding and accepting the chronic illness.

The findings from this study have created a foundation for further research relating to all forms of epilepsy as well as for others who experience neurosurgery to control symptoms associated with their chronic illness including both genders. Further studies, including exploring psychosocial effects on all age groups experiencing different forms of epilepsy, the effects on all family members, and people experiencing other neurological chronic illnesses is required. Further investigation on the assistance that support groups offer in terms of educating the workplace on epilepsy is necessary to improve efficiency. Moreover, research through a case study approach combined with a narrative inquiry could focus on how addressing these issues could help in the overall social education on epilepsy. As Australia is extremely culturally diverse, there is also the need to understand how a range of cultural settings interprets epilepsy, seizures and relevant surgery procedures.

It is necessary that non-judgmental support from members of the family, health, and social network environments be provided for men with neurosurgery for AOES. Individuals with other forms of epilepsy and other neurological chronic illnesses who experience surgery found within these and other relevant social settings may benefit from the findings of this research.

There are cycles of successful change when actions reflect positive outcomes, and cycles of failure when negativity is what results. All members of relevant social environments must accept the possible deterioration in stability and its effects in order for new stability to occur. The longer the individual or fellow members resist change, the more difficult it is for the individual to create inner stability and progress. Adequate post-surgery rehabilitation would greatly assist this process of transition.
To ensure all facets of change are understood and accepted, rehabilitation, which must include psycho-education for all members of the IFE is necessary post-surgery. It is with this understanding that SWB will stabilise and may become positive over time. It is necessary for the individual to except the actions they may experience for higher SWB to remain stable.

Too often individuals with a chronic illness such as epilepsy will recognise seizures as being a major influence that determines their identity. When this is so, it becomes difficult to attain and maintain strong SWB when the condition is no longer present. It is only when this dependency no-longer exists that the fear of social judgement will wither and greater happiness, self-perception, fulfilment and life-satisfaction can be attained and maintained. Although the individual may not necessarily be happy with the result, adequate post-surgery rehabilitation will assist the development of positive SWB. This will allow more stability to take place.

Rehabilitation Implications

The focus of the current research was on the Subjective Well-Being (SWB) of five men who experienced neurosurgery to control Adult Onset Epileptic Seizures (AOES). I explored the nature of the social reactions experienced throughout the post-surgery recovery period as associated with four environment groups: Family, Health Professional/Consultant, Social Network, and Personal. The conclusion reflects upon the explanatory model for relationships in these environments. How post elective surgery relationships influence SWB.

Several clinical implications for rehabilitation post-neurosurgery for AOES, including potential limitations of surgery long term on SWB. Special emphasis is placed on the important role of psychoeducation with individuals with AOES, and significant others involved. Stresses may increase in one’s personal relationship due to misunderstanding about the post-surgery recovery process. Poor education may lead to the weakening or termination of personal and social relationships.
Family participation

Individuals with uncontrolled AOES often spend most of their weekly life in the home environment. The family has a strong influence on how these individuals maintain stability and self-identity post-surgery. When members of the family hold little knowledge on AOES and post-surgery effects, the SWB is often poorly affected. Appropriate and supportive role participation is important for SWB.

Psycho-education is critical post-surgery. Changes associated with psycho-education include improved self-esteem and self-care. According to Janda, Steginga, Dunn, Langbecker, Walker et al. (2008), post-surgery psycho-education is necessary for patients and significant other(s). Koorenhof, et al., (2012) considered psycho-education important to the person with AOES and family. Social ignorance about AOES and clinical implications post-surgery saw participants experience problems in social affiliation with clubs or teams. Further social network education on the difficulties often experienced by participants may lead to greater social acceptance. Whilst present in this domain, network support is necessary to reduce the implications of negative SWB. For instance, appropriate psychoeducation could considerably strengthen relationships and SWB in the participant and others (Livneh, 2013).

As instance of psychoeducation, role re-positioning education may be necessary where participation in family decisions are perceived to be with need for support; - which could be by other family members taking on decision functions for which the person with AOES elects assistants. Education through a rehabilitation programme may benefit decision making on how to restructure and develop new daily activities. Communication with a support group may ensure comfortability and less-likely negative SWB as the result of change.

Health Professions with Patient Oriented Care

Health professionals’ consultative relationships need patient oriented care practices. Health providers also may benefit from psycho-education to assist effective communication with the person with AOES post-surgery. According to Sherman (2009), most health institutions fail to provide adequate programmes that address the psychosocial, educational, vocational, and emotional needs of the patient and their...
families. For instance, health professionals may vary their methods of explanation to ensure the individual understands all aspects of his health condition. For instance, direct communication between both the psychiatrist and neuro-psychologist is also necessary for a comprehensive psycho-education programme to develop. The sharing of findings is necessary to ensure realistic scoping of participation in own health management by the person with AOES post-surgery. Communication between rehabilitation team members, including a clinician, psychologist and social worker may also assist when later focusing on the attainment of practical goals, including employment (Wilson, et al., 2001). SWB will arise from gaining normality through employment and greater social positioning.

Psychoeducation support may assist the participant to identify and alleviate non-medical concerns. The development of stronger problem-solving skills and the encouragement of the participant to ask necessary questions may enhance positive SWB. Providing education in the social network will encourage increased levels of support and understanding.

Social Support is Important

The social network is an environment where men with AOES and most adults with other chronic illnesses experience low SWB. This is often the result of discriminative and poor general social knowledge about the chronic illness. It is evident within some environments that men with AOES may be more vulnerable to stigma and isolation, resulting from a lack of adequate education about their chronic illness.

Social support is important for the development of higher SWB post elective surgery. Greater understanding and acceptance of post-surgery effects, including fear often experienced when entering social environments will positively influence SWB. A low level of social support poorly influences aspects of SWB, including self-confidence and self-respect.

Coping strategies

Strategies associated with cognitive reconstruction and information seeking are important for individuals post-surgery to attain higher SWB. Practicing actions of
cognitive reconstruction, including adopting positive thought patterns and beliefs also improves SWB. Additionally, information seeking actions, including communication with others with similar medical experiences and through the accessing of media resources regarding living with AOES will increase quality of life.

**Conclusion**

In summary, the desire of this study was to gain greater understanding of how the Subjective Well-Being (SWB) of men who experienced neurosurgery as a means to control Adult Onset Epileptic Seizures (AOES) is affected post-surgery. The findings identified that SWB was influenced by the nature of social reaction in the family, health care, and social network environments. The study found that the quality of communication about AOES post-surgical procedure influence SWB in family, consultative, and community participation. Individuals with AOES following elective neurosurgery can attain a preferred quality of life.
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*Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures* 157


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Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures 173


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Subjective Well-Being in Men Following Neurosurgery for Adult Onset Epileptic Seizures 192


Definition of terms used in the thesis

Communication style
How the participant understood the information received from the health professional depended on the participant’s familiarity (e.g., education, hospitalization, hospital visits, work) with the health and hospital care environment. When the health professional fails to adjust the style and vocabulary of the institutional meeting to the patient’s abilities and knowledge, it becomes difficult for the participant to understand the information (Pennbrant, 2013).

Coping Skills
Coping skills are those mechanisms the participants use to enable them to deal with such things as others passing judgment on them, or when they find they cannot achieve the goals they aspire to.

Several coping strategies have been proposed to deal with SWB following a medical impairment: Cognitive and Behavioural coping strategies have been recommended (Cassin, Sockalingam, Wnuk, & Parikh, 2013). Cognitive coping strategies include cognitive reconstruction, emotional expression, wish-fulfilling fantasy, and self-blame. Behavioural coping strategies include information-seeking and treatment minimisation (Folkman, 2010).

The various strategies of coping often function in tandem or in complementary ways. For instance, the review of underlying values and goals (wish-fulfilling fantasy) as coping can be regulated through behavioural actions, such as information-seeking (Mahalik, Johnstone, Glass, & Yoon, 2007). Influences of adapted coping strategies on SWB are variable and may be positive or negative.

Cognitive Reconstruction
Cognitive reconstruction reflects efforts on the part of the individual to uncover the positive aspects of living with a health condition and to view the experience as an opportunity for further growth (Livneh, et al., 2001). Cognitive reconstruction may occur through rational disputation of negative thoughts or the development of positive rational life choices. Cognitive reconstruction may positively impact SWB by altering stress-inducing thought patterns and beliefs or by stopping trusting one’s automatic tendency to accept the contents of one’s thoughts as being an accurate assessment of reality.
**Emotional Expression**

Emotional expression as a coping strategy refers to verbal and nonverbal behaviours that communicate internal feelings or affective state (Shariff, & Tracy, 2011). It operates through several pathways to influence well-being, including recognition and acceptance and strengthening of social relationships (Zangi, Hauge, Steen, Finset, & Hagen, 2011).

**Information-seeking**

Information-seeking describes an activity aimed at reducing uncertainty by attaining relevant information to minimise, including mitigating, emotional stress (Shiloh, Ben-Sinai, & Keinan, 1999). Uncertainty can lead to reduced SWB.

**Decision making support**

In the context of health care relationships, decision-making support is necessary to ensure appropriate present and future counselling is made available to the participant (Snowden, & Boone, 2007). The counsellor must help the participant to look at issues, service and solutions in new ways, finding alternative solutions and choosing one to test in the home environment (Lee, & Emanuel, 2013).

**Dependency**

In the context of family, dependency refers to “a state in which assistance from others is intuitively expected or actively sought for emotional or financial support, protection, security, or daily care” (VandenBos, 2006. p.269). Examples of dependency include wanting and receiving help to perform typical activities of daily living, transportation, cleaning the house, assistance with personal grooming and medication adherence (Keikelame & Swartz, 2013).

**Health Professional / Consultant relationships**

The role of health professional / consultants in doctor-patient relationships can include, a) eliciting the patient’s main problems and perception of their condition, b) tailoring information to what suits the patient’s level of understanding, c) discussing treatment options, and d) maximising the possibility of the patient following agreed decisions about treatment and recommended changes in lifestyle (Larsen, Risor, & Putnam, 1997). Changes can occur in a patient’s perception and confidence to follow agreed treatment options based on the approach the health care professional has in the relationship.

A positive and respectful approach by the health care professional/consultant has a positive impact on the health partnership. Several variables are identified in this context.
Responsibility
Responsibility refers to “the diffusion of one’s sense of responsibility to act in a particular situation owing to the presence of many other people, all of whom may be viewed as potentially responsible for acting” (Reber & Reber, 2001. p.629). Responsibility can be separated into three factors; accountability, duty of care and decision making.

Accountability
In the context of family, accountability is “the extent to which a person is answerable to another member for his or her behaviours, decisions, or judgements (VandenBos, 2006, p.8)”.

Decision making
Decision making is “the cognitive process of choosing between two or more alternatives, ranging from the relatively clear cut to the complex” (VandenBos, 2006. p. 259). Decision making is one of the most important responsibilities in family life (O’Conner & Leonard, 2013).

Duty to care
In the context of family, “the spouses are considered to have a duty of care towards each other (Yamakawa, et al., 2005, p.180).”

Role Enmeshment
Enmeshment describes a dysfunctional relationship between people in which emotional boundaries are so unclear that they experience difficulty functioning or developing independently. In the family environment “the members are involved in each other’s lives to an excessive degree, thus limiting or precluding healthy functioning of the unit, or system, and compromising individual autonomy” (VandenBos, 2006. p.332).

Role positioning
In the context of family, role positioning refers to “where the participants position themselves or are positioned in different circumstances according to changes in storylines” (Yamakawa, Forman, & Ansell, 2005). Role positioning changes may have both positive and negative effects on SWB. Role positioning has been separated into three factors: marginalization, dependency, and enmeshment.

Marginalization
Marginalization refers to “a reciprocal process through which an individual or group with relatively distinctive qualities become identified as one that is not accepted fully into the group (VandenBos, 2006. p. 554).” A person is marginalized in a role when they are in the family environment and do not feel equal to other members.
Self-care

In the context of health professional/consultant relationships, self-care is any activity of an individual, family or community, with the intention of improving or restoring health, or treating or preventing disease (Bodenheimer, et al., 2002). There has been a recent increase in medical research about whether supported self-care is improving the confidence and self-perception of patients with chronic illnesses (Ludman, et. al, 2013; Riegel, Jaarsma, & Strömberg, 2012). Long term self-care or the administration of one’s own health treatment is mostly practiced following the participant’s discharge from hospital post-surgery.

Self-Environment

Self-environment refers to the participant’s perception of oneself. It includes the individual’s attitude to self-regulation (VandenBos, 2007).

Social Affiliation

‘Social affiliation’ refers to a social relationship with one or more other individuals, usually based on liking or a personal attachment rather than on perceived material benefits (Foster, 2012). The sense of loneliness stemming from the absence of such relationships often leads to feelings of an individual being worthless, hopeless, and powerless (Fay, & Maner, 2012).

In the context of social networks, the affiliation an individual may hold falls into the categories of, for example, secondary relationships (friends), work-place (business owner, employee), neighbourhoods (member of associations and organisations), hobbies (member of various clubs and organisations), among others (Lindemann, 2007). An individual is likely to be nested in a hierarchy of such positions, where one will be a central position while the rest are peripheral positions. Due to centrality, changes may have both positive and negative effects on SWB (Sciulli & Bebko, 2012).

Social Exclusion / Inclusion

Social exclusion is defined as the restriction of access to opportunities and limitation of the capabilities required to utilize these opportunities (Hayes, Gray & Edwards, 2008). It is fundamentally about a lack of connectedness and participation (Saunders, Naidoo & Griffiths, 2008). By contrast, social inclusion is about enhancing participation and connectedness (Friendly & Lero, 2002).

Neighbourhood Participants

The term ‘neighbourhood’ is often defined on an environmental scale where residents share proximity and circumstance (Bernard, et. al, 2007). The importance of neighbourhood participation and judgement is often influenced by social acceptance and more heavily influences the quality of life and SWB of older people and those with a chronic illness (WHO, 2007). The responsibility of social networks (in this case,
hospital, support groups and community) is to provide continuing ethical commitment that contributes to the SWB of men who have AOES. The intention of this process is to improve the quality of life that both the participant and their families experience post-surgery.

**Social Network Relationships**

Social network relationships consist of the friends, neighbours, workplace colleagues, bosses, members of associations, people with similar hobbies etc. with whom the participant is in contact.

**Social Labelling**

Social labelling is often influenced by social attitudes towards an individual’s personal or group behavioural characteristics (Wilson, 2013). Once an individual has been successfully labelled, the title often becomes the dominant label or 'master status' recognised as more important than all the other aspects of the person (Link, & Phelan, 2013). For example, an individual who develops AOES is often labelled as one who has a mental illness rather than as a father, mother or friend.

**Negative Labelling**

Link, et al. (2001) claimed negative labelling, often based on social discrimination and bias, frequently causes victims to become negatively self-centred and withdrawn. Due to these community conceptions, an individual with AOES may be labelled as mentally ill with concomitant negative social conceptions for the individual (Molden & Maner, 2013). The five participants experienced stigma, leading to negative effects on self-perception, working ability, social functioning, and further network ties.

**Positive Labelling and Community Support**

Positive labelling is when social recognition is based on one’s positive achievements and is often influenced by community support. Link and Phelan (2001) claimed in neighbourhood community conceptions the image of a person with a mental illness is rarely positive. However, the individual may experience happiness and higher self-perception when community support groups offer social education, encouraging greater SWB (Link, & Phelan, 2013).

The aims of most social support groups are to develop inclusion programmes that address social exclusion, and encourage positive labelling and community support. This can often improve group education and training, health care and housing (VandenBros, 2007). In relation to this study, this includes both epilepsy and non-epilepsy support groups.
**Self-blame**

Self-blame is an attribute of one’s negative social outcomes. It is a form of self-victimization. Self-victimization includes a pervasive sense of helplessness, passivity, loss of control, pessimism, and negative thinking (Taylor, Sullivan, & Kliewer, 2013). Strong feelings of self-blame can lead to hopelessness and despair. Individuals who experience behavioural self-blame feel that they should have done something differently and therefore feel at fault (Braiker, 2006).

**Threat minimization**

Threat minimization is a cognitive strategy that can occur by discounting distressing thoughts (Braiker, 2006).

**Wish-fulfilling Fantasy**

Wish-fulfilling fantasy describes an indulgence in pining and longing for the illness to go away or be over with (Feinberg, 2013). This strategy presumably allows people to alleviate the emotional distress of being ill by providing an escape in fantasy (Upton and Thompson, 1992). According to Clancy, Vince, and Gabriel (2011) wish-fulfilling fantasy is not, by definition, untrue, and some fantasies do indeed become realities. Types of wishful fantasies include Compensatory, Reconciliation, and Life-Fulfilment.

**Support**

In general terms, support is the providing of that which needs or lacking, providing for higher well-being or improvement (Reber & Reber, 2001). In the role of health professional/consultant relationships, support refers to time availability, understanding and empathy.
PARTICIPANT CONSENT FORM

I, ...............................................……. give consent for my participation in the research project.

Name (please print)

TITLE: Subjective Well-Being in Men with Epilepsy having required Neurosurgery for Adult Onset Seizures.

In giving my consent I acknowledge that:
1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that if further time is required to gather the full information, a second interview will take place, and I consent to audio-taping.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

Signed: ...............................................................................................................................

Name: ..............................................................................................................................

Date: ..............................................................................................................................

Mr. Martin Raffaele
Telephone: +61 2 9351 6371
E-mail: martin.raffaele@sydney.edu.au
Participant Information Statement

Title: Subjective Well-Being in Men with Epilepsy having required Neurosurgery for Adult Onset Seizures.

This study will investigate the subjective well-being (SWB) in men who have undergone neurosurgery for adult onset epileptic seizures (AOES). The findings are potentially important for researchers and practitioners in medicine, psychology, education, and counselling.

The study is being conducted by Mr Martin Raffaele, and will form the basis for the degree of Doctorate of Philosophy in Health Sciences at The University of Sydney under the supervision of Associate Professor Elias Mpofu, Programme Director of Health Systems.

The study will involve five candidates of 20 years or older, whose began to experience seizure activity in their adult years. Each of the candidates will have previously experience neurosurgery to assist to condition seizure frequency. A secondary participant from each case study will be interviewed to attain further relevant data that the candidate may have not recalled at the time of the interview. Interviews will be conducted to collect data. Interviews will be aurally-recorded with the candidate’s consent and will be of approximately 1 hour in duration. The interview will be conducted in a private room on the University of Sydney Camperdown campus or at a location that both the participant and I feel is appropriate. A second interview will be made available to the candidates if further time is needed to discuss the experiences and answer further questions once the initial 30 minute interview has come to an end. An interview with secondary participants will be approximately 30 minutes in duration.

Participating in this study is completely voluntary and you are not under any obligation to consent. You are free to withdraw your consent in this study at any time without prejudice. You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study. All aspects of the study, including results, will be strictly confidential and only the researcher will have access to information on participants. The results of this study will be submitted to the University of Sydney for a Doctorate of Philosophy thesis being written in the Faculty of Health Sciences.

When you have read this information, Mr. Martin Raffaele will be available to further discuss it with you and answer any questions you may have. If you would like to know more information at any stage, please feel free to contact Mr. Martin Raffaele martin.raffaele@sydney.edu.au, +61 2 9351 6371.

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep
Adult Onset Epilepsy Research

Research questions

*There are 4 interview topics to be covered*

1. What aspects of family relationships influence SWB in individuals with elective neurosurgery for AOES?

2. How do professional/consultant relationships influence SWB in men with elective neurosurgery for AOES?

3. How do participants’ nominated social networks influence SWB in men with AOES following elective neurosurgery?

4. What coping strategies do people with elective neurosurgery for AOES use to enhance their SWB?
Primary Participant Semi-Structured Interview

“Good morning (primary participant), my name is Martin Raffaele. How are you today?
I am conducting this interview to gain knowledge on about your personal experiences of
living with AOES following brain surgery to control your adult onset epileptic seizures. I am
also interested in learning about your social participation with epilepsy, including access and
use of medical consultants. If at any time you wish to rest or stop your participation in this
interview please let me know and we can do so.

I'm now going to ask you some questions that I would like you to answer to the best of your
ability. If you do not understand a question, please say so.

If it is okay with you, I will start recording our conversation with this audio recorder. The
reason for doing this is to gain all the details and at the same time allow me to stay focused on
my conversation with you. I assure you that all your comments will remain confidential. I will
write a research report that will contain some of your comments, but it will not include the
names of any individual that we discussed.

1. I'd like to start by asking you questions about your social experiences with epilepsy within
your family environment, sometime referred to as the Primary environment. (Note: I may
need to probe- "At what age did you begin to experience seizures? At what age did you
receive elective neurosurgery for your condition? What were the initial reactions of people
within your immediate and extended family? Were you living with other people at this time?
(If so) what were the reactions of those you were living with?"
2. How was the quality of your everyday life with others influenced the way you judged yourself as a member of this group of people? (Note: I may need to probe- How did that make you feel? What did others feel you should be capable of doing following the operation? Why do you think they felt this way?)

3. Following the operation, how often were you seen by your specialist and other medical teams? How did you feel about the quality of the medical consultation? (Note: I may need to probe- What help did you receive from the specialists and following the operation? How did that make you feel? How do you fell this affects your relationship with those closest to you? How do you think this affected your relationship with people in the medical environment?)

4. How did others, such as friends or work colleagues perceive you following the surgery? (Note: I may need to probe- What changed for you following the surgery? (If so) What were the differences? How did that make you feel?)

5. What may have influenced the reactions of others to you? (Note: I may need to probe- Describe examples of instances involving how others reacted to you from having Adult-Onset Epilepsy after neurosurgery? How did these social situations influence how you judged yourself?)

6. What strategies do now use to understand and cope with the reaction of the people in these social environments? (Note: I may need to probe- How did you try to maintain your friendship with the people in this social environment? What were their reactions towards you when you did this? How has this changed since the operation? How has that made you feel since the operation?)

7. How do you perceive yourself since surgery? (Note: I may need to probe- Speak to any aspect important to you over the period since surgery? How is it different now?)

8. What do you perceive to be other’s knowledge about epilepsy and adult onset seizures from their interaction with you?
I wish to thank you for your time, your knowledge and suggestions in relation to these questions. Do you have any questions at all that you would like to ask me? Please take my card and if you have any further information you feel would be appropriate to this study, feel free to contact me at any time. If you would like another opportunity to be interviewed I am happy to arrange this with you.
Appendix E

Pilot Study Interview Guide

In designing the pilot study interview guide, three possible constructs of social relationships were included: family, medical and participational. The intention here was to derive a multi-layered data set from each participant. In doing so this study tried to incorporate conceptualizations of social judgement that influence the construction of subjective well-being. The use of these three social environments aimed to provide a richer, multi-dimensional and more credible data set about SWB and the effects of relevant social environments post-surgery rather than simply discussing overall social judgement of epilepsy. As such, the pilot study interview guide comprised of the following sections; demographics and severity of disability, private sexual scripts, interactional sexual scripts, public sexual scripts and conclusion.

1. Demographics and severity of disability
   a. What is your age?
   b. When did you first experience an epileptic seizure?
   c. What is your form of epilepsy?
   d. When did you have brain surgery?
   e. Do you presently experience epileptic seizures?
   f. Are you living with the same people as you were prior to having the operation?

2. Family relationships
   a. How would you explain your feelings when with your immediate family?
   b. How would you explain your feelings of inner peace when with your family?
   c. How fulfilled do you feel when you are with your family?
   d. How has the result of the surgery influenced this role you play when with your family?

3. Professional/Consultant relationships
   a. How much time was dedicated rehabilitation and education following the surgery?
b. How do you feel that this has influenced the relationship you have with your neurologist and GP?

c. How happy do you feel following meeting with medical professional?

d. How peaceful do you feel before and after meeting with medical professionals?

e. How satisfied are you with the support and the relationship that you now receive when with medical professionals?

4. General Social relationships

a. How do you feel your health influenced you life and participation in general social groups since the operation?

b. Are you in employment at the moment?

c. How peaceful do you feel when you are with many people?

d. How satisfied do you feel when you are with people from general social groups?

5. Self perception

a. Do you have difficulties reasoning and solving problems (such as making plans, making decisions, and learning new things)? If yes, how so?

b. How do you feel when you spend time alone?

c. How do you feel by the way other people judge you?

d. How does this influence the way you judge yourself?

e. How has the surgery influenced the goals you wish to achieve?

f. How has your self-perception and quality of life changed since the operation?

g. What level of education do you feel needs to be offered to the people in a man’s life following neurosurgery?

6. Conclusion

a. Is there anything else about your life experiences since the brain surgery you think I should know?
Appendix F

Main Study Interview Guide

1. Demographics and severity of disability
   a. What is your present age?
   b. At what age did you first experience an epileptic seizure?
   c. What is your form of epilepsy?
   d. When did you have brain surgery?
   e. Do you presently experience epileptic seizures? If so, how often?
   f. Are you forms of seizures as you were prior to the surgery?
   g. Are you presently living with the same people as you were prior to having the operation?
   h. Are you in employment at the moment?

2. Family relationships
   a. How would you explain your feelings when with your immediate family?
   b. How would you explain your feelings of inner peace when with your family?
   c. How fulfilled do you feel when you are with your family?
   d. How has the result of the surgery influenced the role you play when with your family?

3. Professional/Consultant relationships
   a. How much time was dedicated to rehabilitation and your education following the surgery?
   b. How do you feel that this has influenced the relationship you have with your neurologist and clinician?
   c. How happy do you feel following meeting with medical professional?
   d. How peaceful do you feel before and after meeting with medical professionals?
   e. How satisfied are you with the support and the relationship that you now receive when with medical professionals?
   f. Was adequate rehabilitation provided post-surgery?

4. General Social relationships
a. How do you feel your health influenced your life and participation in general social groups since the operation?
b. How happy do you feel around people from general social groups?
c. How peaceful do you feel when you are with many people?
d. How satisfied do you feel when you are with people from general social groups?

5. Self perception
   a. Do you have difficulties reasoning and solving problems (such as making plans, making decisions, and learning new things)? If yes, how so?
b. How do you feel when you spend time alone?
c. How do you feel by the way other people judge you?
d. How does this influence the way you judge yourself?
   e. How has the surgery influenced the goals you wish to achieve?
f. How has your self-awareness changed since the operation?
g. How has this affected your quality of life?
h. What level of education do you feel needs to be offered to the people in a man’s life following neurosurgery?

6. Conclusion
   a. Is there anything else about your life experiences since the brain surgery you think I should know?
Adult Onset Epilepsy Research

Research questions

There are 4 interview topics to be covered

1. What aspects of family relationships influence SWB in individuals with elective neurosurgery for AOES?

2. How do professional/consultant relationships influence SWB in men with elective neurosurgery for AOES?

3. How do participants’ nominated social networks influence SWB in men with AOES following elective neurosurgery?

4. What coping strategies do people with elective neurosurgery for AOES use to enhance their SWB?
Name of Interviewer________________________
Date____________________________________
Name of Interviewee_______________________

Primary Participant Semi-Structured Interview

“Good morning (primary participant), my name is Martin Raffaele. How are you today?
I am conducting this interview to gain knowledge on about your personal experiences of living with AOES following brain surgery to control your adult onset epileptic seizures. I am also interested in learning about your social participation with epilepsy, including access and use of medical consultants. If at any time you wish to rest or stop your participation in this interview please let me know and we can do so.

I'm now going to ask you some questions that I would like you to answer to the best of your ability. If you do not understand a question, please say so.

If it is okay with you, I will start recording our conversation with this audio recorder. The reason for doing this is to gain all the details and at the same time allow me to stay focused on my conversation with you. I assure you that all your comments will remain confidential. I will write a research report that will contain some of your comments, but it will not include the names of any individual that we discussed.

1. I'd like to start by asking you questions about your social experiences with epilepsy within your family environment, sometime referred to as the Primary environment. (Note: I may need to probe- "At what age did you begin to experience seizures? At what age did you receive elective neurosurgery for your condition? What were the initial reactions of people within your immediate and extended family? Were you living with other people at this time? (If so) what were the reactions of those you were living with?

2. How was the quality of your everyday life with others influenced the way you judged yourself as a member of this group of people? (Note: I may need to probe- How did that make you feel? What did others feel you should be capable of doing following the operation? Why do you think they felt this way?

3. Following the operation, how often were you seen by your specialist and other medical teams? How did you feel about the quality of the medical consultation? (Note: I may need to probe- What help did you receive from the specialists and following the operation? How did that make you feel? How do you feel this affects your relationship with those closest to you? How do you think this affected your relationship with people in the medical environment?
4. How did others, such as friends or work colleagues perceive you following the surgery? 
(Note: I may need to probe- What changed for you following the surgery? (If so) What were the differences? How did that make you feel?)

5. What may have influenced the reactions of others to you? (Note: I may need to probe- Describe examples of instances involving how others reacted to you from having Adult-Onset Epilepsy after neurosurgery? How did these social situations influence how you judged yourself?)

6. What strategies do now use to understand and cope with the reaction of the people in these social environments? (Note: I may need to probe- How did you try to maintain your friendship with the people in this social environment? What were their reactions towards you when you did this? How has this changed since the operation? How has that made you feel since the operation?)

7. How do you perceive yourself since surgery? (Note: I may need to probe- Speak to any aspect important to you over the period since surgery? How is it different now?)

8. What do you perceive to be other’s knowledge about epilepsy and adult onset seizures from their interaction with you?

I wish to thank you for your time, your knowledge and suggestions in relation to these questions. Do you have any questions at all that you would like to ask me? Please take my card and if you have any further information you feel would be appropriate to this study, feel free to contact me at any time. If you would like another opportunity to be interviewed I am happy to arrange this with you.

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).
Safety Protocol

Adult Onset Epileptic Seizure Research

The following guidelines have been prepared to ensure ethical and safe outcomes when working with participants in the family home. At all times the welfare of the participants, their family and yourself must best be considered.

Prior to attending the home:
- Phone the participant to set up a time for the appointment, at least 7 days in advance of the proposed appointed. Outline the details of what will be addressed during the visit, who is to be there during the visit, and how long it will take.
- Provide the office phone number of the Chief Investigator in case participant needs to cancel the appointment.
- Following this through by sending via mail a written outline of the details discussed by phone.

Attending the home:
- Arrive on time, with mobile phone. (If you do not have one, collect one from the Chief Investigator.)
- Introduce yourself, showing a picture identification of yourself (e.g., University library card; not drivers license)

When interviewing a participant:
- Ask if the participant wishes for another person to stay in the room during the assessment.
- Settle the participant, and make them comfortable
- Undertake only the interview that was outlined prior to the meeting
- Be aware of any difficulties the participant, or tiredness that may be evident.

When tasks have been completed, thank the participant and leave.
- Phone the Chief investigator to notify him that you have left the premises (e.g., leave a message on voice mail noting time and date).
- Follow the visit up with a thank you letter, and notice that the participants can access a copy of the study findings at the end of the study.

At all times, a record must be kept on the accompanying sheet of the time you contact the family, when you visit and follow-up communication you have with the family.
# Adult Onset Epilepsy Research

Off-campus Information and Record Form

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Chief Investigator’s Office phone: +61 2 9036 7370
'Subjective well-being in Australian Men after Neurosurgery for Adult On-set Epileptic Seizures' Study

CALLING ALL MEN WHO HAVE UNDERGONE EPILEPSY SURGERY

If you:
- are a male over 21 years
- developed epilepsy after you turned 18 years
- have undergone epilepsy surgery
- understand and speak English

You are just who we are looking for!

This research study aims to develop stronger knowledge of the circumstances that men often encounter in all social environments following surgery to reduce adult onset epileptic seizures related to the period of emotional recovery following surgery.

The findings will contribute to understand the difficulties that men, who have undergone neurosurgery for adult on-set epileptic seizures, may experience when re-establishing themselves in all relevant social environments. It will also verify the need for providing necessary rehabilitation to all patients, and those closest to them, post surgery.

If you would like to participate in this study or would like more information please contact:

Martin Raffaele
Email: mrafa4695@uni.sydney.edu.au (mailto:mrafa4695@uni.sydney.edu.au)
Mobile: 0422 582 902

OR

Professor Elias Mpofu
Head of Discipline of Rehabilitation Counselling Sydney University
Email: elias.mpofu@sydney.edu.au (mailto:elias.mpofu@sydney.edu.au)

HREC Ethics Approval No: 14329
Investigate the life of men following surgery for adult onset epileptic seizures

Researchers: Professor Elias MPofu, Dr. Martin Mackey, Mr. Martin Raffaele

We would like to invite you to take part in a research study, which aims to develop stronger knowledge of the circumstances that men often encounter in all social environments following their surgery to reduce adult onset epileptic seizures. Our research involves interviewing men who began to experience seizures in their adult life, which led to brain surgery. The questions that will be asked of the participant relate to the period of emotional recovery following surgery.

A participants will be asked to take part in an interview at a location that is convenient for him, e.g. in a quiet room at The University of Sydney, Camperdown campus, or at the participant’s home.

You may consider participating if:
• you are a male aged 21 years or above
• you developed seizure activity in your adult years
• you are able to understand and speak English.

The present research study is NOT suitable for the following people:
• A male who began experiencing partial seizures before 18 years of age
• A male who has not experienced elective surgery to reduce his seizure activity
• A male younger than 21 years of age

If you are interested in taking part please contact:

Martin Raffaele
Work hours: (02) 9351 6371
Mobile: 0422 582 902
Email: mraf4695@uni.sydney.edu.au

Version 2, 13 December, 2011 - Humanities
Hello everyone,

Welcome to the first newsletter for our research participants for 2012.

Report on Wave 2 of the Longitudinal Study

The report of the Wave 2 of the Longitudinal Study has been released: (http://www.epinet.org.au/articles/social_research_projects).

This report has produced some interesting data. The Executive Summary contains the following:

The Wave 2 survey of 2010 had 343 from 621 research register participants (response rate 55%);

- Wave 2 results demonstrate lower education levels amongst older people and higher school retention amongst the younger; however lower than average employment and possibly underemployment across all ages. Education has not led to employment amongst these respondents with only 16% of the total number having full-time jobs even though the majority of them were of working age;

- Income is also generally very low with 49% living below the current Henderson poverty line;

- Wave 2 also explored seizure activity and levels of seizure control. This group has less seizure control than reported in the literature with only 33% reporting no seizures over twelve months. There are no data to analyse severity of seizures, however. Injuries and hospitalisations are high amongst this group. This is an important finding which deserves further exploration in the next Wave;

- People with epilepsy reported experiencing varying levels of stigmatising behaviour. While many felt they had been fairly treated and had not suffered any discrimination the numbers who reported unfair treatment were still high at 45%. For some people this led to social isolation;

- A substantial proportion (32%) of people with epilepsy reported that they had experienced a lack of understanding from Government bodies that they had turned to for assistance;

Seizure triggers in people with epilepsy and intellectual disabilities

Jo Illingworth is a PhD student from Cambridge Intellectual and Developmental Disabilities Research Group University of Cambridge, UK. She writes:

I am a PhD student at the University of Cambridge, UK. I am funded by Epilepsy Action UK, and my research concerns seizure triggers in people with epilepsy and intellectual disabilities.

We are currently carrying out a carer survey on this subject, which we are publicising via charities both in the UK and internationally. We are trying to understand more about when seizures occur in people with epilepsy and intellectual disabilities. We hope that this will lead to improved seizure management for people with epilepsy and intellectual disabilities.

I am writing to ask if you may be able to assist with publicising the survey in Australia, via your research participant register (or via alternative routes that you think may be appropriate). I have attached our letter of ethical approval and also our recruitment email to potential participants and website/newsletter advert.

If carers of a person with epilepsy and an intellectual disability would like to contribute to this research they can complete the survey below. If you would like to see the ethics approval beforehand then please feel free to email cwalker@chronicillness.org.au or call 03 9882 4654 to request a copy.

The survey can be found here (the password is "cambridge"):

http://cambridge.qualtrics.com/SE/?SID=SV_6iX1WXS4E0PR76
Driving remains a highly desirable and necessary component in the quality of a person’s life; being a driver or being driven by someone else remains the preferred mode of transport;

The future of the Australian Epilepsy Research Register (AERR): More recruitment from states other than Victoria is required in order to make this a more representative sample of people living with epilepsy in the community. This is proceeding via members of Epilepsy Australia and Epilepsy Action but the AERR requires more entry points for recruitment.

The issues members of the Australian Epilepsy Research Register (AERR) would like researched

At the end of 2011 many of you completed a little questionnaire where we asked you to tell us which of three areas you thought most important for us to research.

Of the 80 people who answered more than half thought the most important area to research related to accepting the diagnosis and learning how to manage it; the next priority was researching the barriers and exclusions to daily activities while least important was the issue of falling through the gaps and not being eligible for funding and services. As funding opportunities become available these areas will all be explored and incorporated into service improvements.

The Reducing Epilepsy Deaths Project Update

The Reducing Epilepsy Deaths (RED) project was established to investigate a range of issues associated with epilepsy-related death in Australia. This project is continuing. One key area of activity is to examine the experiences of those who have been bereaved by epilepsy. A pilot study has now been completed and Dr Michelle Bellon of Flinders University has joined with Dr Rosey Panelli to take this important work to the next stage. An online questionnaire will be used to gather data from families and friends who have suffered bereavement due to epilepsy. The study is currently under consideration by the ethics committee and once approval is obtained, details about how to participate in the survey will be made available on the Epilepsy Australia Website.

Other aspects of the study including the National Coroner’s Information Service (NCIS) continue to move forward, but progress has been restricted by lack of funding. Several applications have been put forward to government and philanthropic institutions seeking support for this important activity and we look forward to being able to report success in funding in the near future.

Best wishes to all the members of the AERR. Your contribution to our work is gratefully acknowledged.

Christine Walker, Research Manager

Martin Raffaele from Australia was one of eight people who received an award as an Outstanding Person with Epilepsy at the Asian and Oceanian Epilepsy Congress in Manila this year. Martin is conducting research into the experience of men who have had neurosurgery for his PhD. Some people may be interested and eligible to contribute to his research:

Subjective Well Being (SWB) in men following neurosurgery for Adult Onset Epileptic Seizures (AOES).

Researchers: Professor Elias MPofu, Dr. Martin Mackey, Mr. Martin Raffaele

Our national research study aims to develop stronger knowledge on the circumstances that men often encounter in relevant social environments following neurosurgery to reduce AOES. The data collection process involves the interviewing of men who began to experience seizures in their adult life, which led to neurosurgery. The questions that are asked of a participant relate to the period of emotional recovery following surgery. Participants are men who developed partial seizure activity in their adult years, with at least two years having past since the resection. A participant is asked to take part in a semi-structured interview at a location that is convenient for him, e.g. in a quiet room at The University of Sydney, Camperdown campus, or at the participant’s home.

If you are aware of suitable participants who may be interested in taking part in this research study, please contact:

Martin Raffaele
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Mobile: 0422 582 902
Email: mraf4695@uni.sydney.edu.au