Empowering People With ABI To Acquire Better Insight Into Brain Injury: An Application Of Educational Principles

Christine Yvonne Durham
GradDip Ed (Curriculum), BEdSt (Post Graduate), MEd Melb

A thesis submitted in the fulfilment of the requirements for the degree of Doctor of Philosophy
RMIT University
College of Science, Engineering and Health
School of Health Sciences

May 2012
DISCLOSURE OF POTENTIAL BIAS

This qualitative, interpretative inquiry places me, a person with acquired brain injury (ABI), as a ‘visible’ researcher, the primary instrument of analysis and interpreter of data (Denzin, 1994; Wolcott, 1990; Van Maanen, 1995), as a more realistic situated speaker, subjectively engaged with the data (Richardson, 1994). Some chapters of this thesis are written in the first person, as reflective text, to provide an honest disclosure of the bracketing of my opinion, as someone with acquired brain injury rather than hiding my undeniable connection to the subject of ABI by a ‘studied neutrality’ or apparent absence of the author in-text (Van Maanen, 1988).
DECLARATION

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and, ethics procedures and guidelines have been followed.

Christine Yvonne Durham

May 2012
ACKNOWLEDGEMENTS

I am greatly indebted to my senior supervisor Dr Paul Ramcharan for his insight, wisdom, support and elegant guidance. This thesis has benefited from his belief in the subject under investigation, and my capabilities in spite of my brain injury. I am grateful for his encouragement, assistance and good humour. My thanks also go to my supervisor Dr Josephine Lang for her expert guidance on educational matters. Finally, I express my gratitude to Ms. Tina Thornton for her skilful and knowledgeable editing of this thesis.

This thesis would not have been possible without the blood, sweat and support from my husband Ted, who drove me to each interview, set up the computer and sound recording equipment, assisted in carrying and setting up the large bird cage to interviews, and other presentations. It was cumbersome and awkward. I will always remember completing an ABC television interview that showed Keys to the ABI Cage – knowing Ted had split stitches from back surgery manhandling it from the car, unbeknown to him, his shirt was soaked with blood. Fortunately, the surgeon could restitch the wound immediately after the interview. Ted also encouraged and supported me each step of the long journey, and spent many days as husband/research assistant.

My son Rob assisted me in so many various ways including providing a listening ear and adviser, and with his computer skills. My son Ken has helped with formatting PowerPoint® presentations and notes on hundreds of occasions. My daughters Helen and An have given me unconditional encouragement and support, and my grandchildren Lucinda, Leroy, Alexander, Hannah, Spencer, Sebastian and Ruben have showered me with love and support.

This study would not have been possible without the participants who most generously allowed me into their world, to see and feel their experiences.

This study would not have been undertaken but for the insight and kindness of the late Dr Maureen Malloy who, 18 years ago, in a hour-long evaluation of my condition for the lawyers, allowed me to see myself not as a broken crushed person, finished for life, but by teaching me a little about brain injury, she gave me back some of my ‘old’ self. Dr Malloy was most interested and encouraging about the intent and focus of this study. I honour her, and thank her on behalf of all the people with brain injury whose lives she has touched.
And lastly I thank my father, the late Marcus Rupert Liege Tarrant, whose words, wisdom and encouragement about the power of the mind is deeply imbedded in my mind. Dad would always say to me ‘Nil desperandum’ – and I never have.
Dedicated to my husband Ted
PREFACE

This phenomenological thesis is a record of a journey that examines the narratives of people with brain injury as they explore negative and positive elements of living with brain injury. It demonstrates that brain damage damages more than the brain. Primarily it sets out to capture the voice and opinions of thirty six people with brain injury whose voice may not have been heard. It also considers the views of ten people who care for and support people with brain injury.

The contribution of the participants has been recognized in the acknowledgements and the reader of this thesis might wish to read pen portraits of these people who freely shared their stories, thoughts and experiences. Each ABI case is unique and in part that unique-ness is both important to the story but also troublesome in terms of anonymity. Many and varied direct quotes of participants will be found in Chapters 7 and 8, however the wellbeing of the participants was of prime importance, and their wellbeing could be affected if they were recognized by other people with brain injury or by those providing professional or family care. Many people with brain injury ‘know of’ others with brain injury, and even a pen portrait of composite ‘characters’ could make identification of specific people possible because their particular stories, the special way they acquired their brain injury and the ramifications of brain injury on their life. This could influence what are already very fragile social networks and relationships.

Additionally many participants were frank in their criticism of medical professionals and the rehabilitation experience. If a health professionals recognized the input from someone who had been a client, it could lead to difficulties for the participant. For these reasons I thought it was imperative that the participants could not be identified in case they might be adversely affected.

This thesis directs the reader away from the deficit based model that is widely used by medical and health professionals working in the ABI field, to the ‘insider’s’ view and to educational principles that are not the perspectives normally adopted by studies into brain injury. Instead, as I have brain injury, the content and themes put forward the insider’s view of brain injury, and brain injury is investigated from their perspective, as they are led to reflect upon and acquire better insight into their brain injury experience. Since I am an educator by training and profession, educational principles direct and scaffold this thesis.
The participant’s difficulties and needs are embedded in each step of this journey through the employment of van Maanen’s concept of ‘Headwork’. ‘Headwork’ (shown in Figures placed in boxes) in chapters 1, 3, 4 and 5, allows the reader to understand the concepts that inform the method, and the development of the new and novel interview and learning tool including the talk-about cards. At the same time, ‘Headwork’ allows in-depth consideration of those ethical dilemmas that needed to be addressed so as to accomplish this as a thesis that ‘did no harm’. This explains the unusual structure and content of this thesis, which has been developed specifically to allow the reader to view brain injury through a new lens.

Because of the unusual structure and nature of this thesis it was purposefully ‘anchored’ with chapter introductions to review concepts covered in previous chapters, set out the information to be covered in the chapter, and to make a brief mention of information examined in the following chapter in order to anchor the chapter in the thesis and make connections to support the flow of the thesis arguments.

Chapter 1 allows the reader to enter the private lifeworld of a person struggling with brain injury. I share my own personal challenges of a life changed by brain injury in order to provide an example of the challenges that may be experienced by participants in this study. This background information explains the reason why the method employed by this study carefully considered ways to take these difficulties into account in order to do no harm to the participants: to preserve their rights, privacy, dignity and wellbeing. The raison d’être and the focus of this research is discussed and examples of the ‘narrative’ that can be told using symbols and images is explained.

This chapter purposely visits and discusses ‘grey’ literature, including information from brain injury support organizations for several reasons: to allow the reader to enter the lifeworld and rehearse the learning journey or information gathering most likely to be carried out by the person with brain injury and their family; to prepare the reader for the focus of this thesis where the researcher is a collaborator, an ‘insider’ with the participants, rather than being a thesis ‘about’ or ‘on’ brain injury; to acknowledge the voice of people with brain injury to demonstrate that weight will be given to their words, rather than only looking at input from professionals.
Many studies show people with brain injuries lack self awareness, and information written by people with brain injury is discussed to demonstrate that some people do have awareness and understanding of the phenomena of brain injury, and to highlight issues they consider important. ‘Grey’ literature is examined to allow the reader to compare and contrast the person’s experience of brain injury with concepts of people who care for and support people with brain injury, with information about different models or paradigms of brain injury, and the areas focused upon in quantitative body-object studies in Chapter 3, and qualitative body-subject studies in Chapter 4.

Another example of how this thesis is structured in a non-traditional way is the placement of information in Chapter 2. This brief introduction to the method developed specifically for this study, ‘Keys to the ABI Cage’, has been deliberately placed in Chapter 2, and not later in the document, in order to provide an explanation and overview of the research method employed in this thesis which was developed to address some of the problems associated with brain injury as outlined in Chapter 1. ‘Keys to the ABI Cage’ employs a visual and symbolic methodology to increase the participatory and emancipatory nature of this study.

As the following chapters show, the cage is populated piece by piece, and yet it seemed necessary for the reader to have the cage set out in its entirety so that they could see how it would all fit together. In that way the significance of each part to the whole would be apparent, and avoid the reader struggling to understand the meaning and intention of each disembodied part. The early presentation of the cage therefore aimed to help the reader to conceptualize the order and the place each part played in the development of ‘Keys to the ABI Cage’.

The intent of dividing the literature review of brain injury studies into two chapters was to examine studies from the perspective of how the data was obtained from the participant. For this reason studies have been sorted and pigeonholed into two different paradigms: Chapter 3 considers models and paradigms of ABI and reviews some body-object quantitative studies; Chapter 4 considers ABI from the perspective of the body-subject model of some qualitative studies.

An argument for employing educational learning principles is put forward in Chapter 5. This chapter provides an overview of important theories of learning including the vital nature of motivation and engagement in the learning process, the theory of association, cognition and
thinking, and the concepts of the learner having multiple ‘intelligences’ and different preferred learning styles.

Chapter 6 explains the research methods employed including the interview and the ‘Reflection kit’, the sample, ethical considerations, and triangulation. The second part of this chapter discusses analysis of the 150 000 words of data obtained from the interviews, and includes a worked example of Interpretative Phenomenological Analysis that was employed.

Chapter 7 carefully considers the findings of the study in regards to factors that negatively affected the lifeword of the participants with brain injury. The triangulation of data identified the similarities and differences of people with brain injury and mothers and wives of people with brain injury and professionals working in the field of brain injury. The voice of the participants is presented with numerous direct quotations. The moral and the social model of disability outlined in Chapter 3 can be seen to influence the four negative overarching themes, however these themes did not populate the talk-about cards.

Chapter 8 powerfully demonstrates that for the individual with brain injury, brain injury may not be all bad. This chapter provides valuable information about factors that have had a positive effect on the lives of the participants. Once again direct quotes are used to both typify and explain categories induced from the analysed transcripts. These positive themes did not directly populate the talk-about cards, and were not represented in body-object studies reviewed in Chapter 3. These themes however link to the social model of disability, body-subject studies reviewed in Chapter 4 and information about education in Chapter 5.

Chapter 9 discusses and reconnects the findings from chapters 7 and 8 with the literature introduced in the first five chapters. Firstly the chapter discusses factors that had a negative impact on the participants’ including their fear, loss of status, the difficulties associated with learning, rehabilitation and medical terminology. Secondly the chapter discusses factors that had a positive impact on the participants including the many things that can help people with ABI to feel and fare better, and that improved knowledge and understanding can assist people them to understand. Thirdly the research tool ‘Keys to the ABI Cage’ and the method employed is critically discussed and comments from the participants show the reaction to being involved with this interview and learning tool.
Chapter 10 provides some recommendations for people with brain injury and their family members, and recommendations for policy and practice that are drawn from the findings of this study. This thesis concludes by expressing the multifaceted challenges before the person with brain injury as they learn to live with the overpowering complexity and fragile balance that typifies life with brain injury.
TABLE OF CONTENTS

DISCLOSURE OF POTENTIAL BIAS ........................................................................................................ ii
DECLARATION ........................................................................................................................................ iii
ACKNOWLEDGEMENTS ....................................................................................................................... iv
PREFACE ................................................................................................................................................ vii
TABLE OF CONTENTS .......................................................................................................................... xx
LIST OF TABLES ....................................................................................................................................... xx
LIST OF FIGURES AND PHOTOGRAPHS ............................................................................................. xxii

CHAPTER 1 ............................................................................................................................................... 1
AN INTRODUCTION TO BRAIN INJURY AND THIS STUDY ......................................................... 1
  Part A: Introduction and Raison D’être for This Study ................................................................. 1
  1.1 My World Was Turned Upside Down by Brain Injury ............................................................ 1
  Part B: A Briefing on Brain Injury and the Purpose of this Study .............................................. 9
  1.2 The Problem and the Reasons for This Study ....................................................................... 9
  1.2.1 Finding a Way to Make Progress ...................................................................................... 10
  1.3 An Introduction to Brain Injury ............................................................................................. 11
  1.3.1 The Problem of Brain Injury ............................................................................................ 12
  1.3.2 Finding Out About ABI ................................................................................................... 14
  1.3.3 Information from the World Wide Web ............................................................................ 14
  1.4 Web Information Indicates Participants in This Study may be Challenged by .......... 20
  1.5 How narratives provide another way to view ABI .............................................................. 21
    1.5.1 Books ................................................................................................................................. 21
    1.5.2 Books Written by People with ABI: Narratives from the ‘Emic’ (Merleau-Ponty, 1962) ‘Insider’s’ Perspective ......................................................................................... 21
    1.5.3 Dr Mark Sherry’s book ........................................................................................................ 24
    1.5.4 Books Written by People with ABI with Their Family Members .................................. 25
    1.5.5 Narratives Written by Family Members: ....................................................................... 26
  1.6 Narratives Presented on the World Wide Web ...................................................................... 26
  1.7 Self-help books ......................................................................................................................... 27
  1.8 Developing a focus for the current research ............................................................................ 28
    1.8.1 Application of van Maanen’s Fieldwork, Textwork and Headwork ............................... 28
  1.9 The Aims of This Study ............................................................................................................. 30
  1.10 Thesis structure ......................................................................................................................... 32
CHAPTER 2
INTRODUCING KEYS TO THE ABI CAGE: A TOOL TO FACILITATE COMMUNICATION AND LEARNING — THE MAIN RESEARCH TOOL USED IN THIS STUDY.............................................................................................................. 34

2.1 An Introduction to Keys to the ABI Cage.............................................................................. 34

2.2 Description of Keys to the ABI Cage Interview/Learning Tool Concept.................. 38

2.2.1 Theme 1. ‘Our Differences and Difficulties Can Put Us in the ABI Cage’.................. 38

2.2.2 Theme 2. ‘How We Feel About Our Differences and Difficulties Can Lock Us in the ABI Cage’ ................................................................................................................................. 39

2.2.3 Theme 3. ‘Keys Can Release Us from the ABI Cage’. ............................................ 39

2.3 Summary .......................................................................................................................... 40

CHAPTER 3
MODELS AND PARADIGMS OF BRAIN INJURY AND THE ‘BODY-OBJECT’ PERSPECTIVE OF ABI — LITERATURE REVIEW: QUANTITATIVE STUDIES ................................................................. 41

3.1 Introduction ......................................................................................................................... 41

3.2 Differences in Perspectives of Disability ........................................................................ 41

3.2.1 The Body-Object Model ............................................................................................. 42

3.2.2 The Moral Model ........................................................................................................ 44

3.2.3 The Medical Model ..................................................................................................... 46

3.2.4 The Social Model ....................................................................................................... 48

3.3 ABI is a Unique Disability .............................................................................................. 50

3.4 ABI and the Medical Model Assumptions .................................................................... 51

3.5 Some Categories of Body-Object Research .................................................................... 52

3.5.1 IQ Loss After ABI ..................................................................................................... 52

3.5.2 Memory Loss After ABI .......................................................................................... 53

3.5.3 Depression/Suicide After ABI ................................................................................. 54

3.5.4 Fatigue After ABI ...................................................................................................... 55

3.5.5 Coping Strategies of People with ABI ....................................................................... 56

3.5.6 Pain Following ABI .................................................................................................. 57

3.5.7 Cognitive Rehabilitation Therapy ............................................................................. 57

3.5.8 Self-Awareness After ABI ....................................................................................... 58

3.5.9 Posttraumatic Stress Disorder After ABI ................................................................. 59

3.5.10 Learning Difficulties After ABI ........................................................................... 59

3.5.11 Other Areas of Focus in Studies ............................................................................... 60
### 3.6 Some Reflections on Quantitative Body-Object Research .............................................. 61
### 3.7 Summary .................................................................................................................. 63

## CHAPTER 4

### THE ‘INSIDER’S’ PERSPECTIVE – THE BODY-SUBJECT PERSPECTIVE OF ABI. LITERATURE REVIEW: QUALITATIVE STUDIES .......................................................... 66

#### 4.1 Introduction ......................................................................................................... 66

#### 4.2 Intentionality: Another Way to Consider ABI ...................................................... 67

#### 4.3 ABI from the Qualitative Body-Subject, Emic, Insider’s Perspective ................. 70

#### 4.4 Qualitative Academic Research: The Insider’s Experience from the Outsiders’ Perspective .................................................................................................................. 72

#### 4.5 Narrative as the Insider’s Perspective of ABI ..................................................... 75

##### 4.5.1 Narrative to Reveal the Insider’s Perspective: Books Written by Professionals ......................................................... 76

##### 4.5.2 Narrative to Explain ABI to Children .................................................................. 79

#### 4.6 Setting the Groundwork for the Study Methodology ........................................... 79

#### 4.7 Research Involving Vulnerable People: The Feminist Perspective ..................... 82

#### 4.8 Phenomenology as a Philosophy .......................................................................... 85

#### 4.9 Summary .............................................................................................................. 87

## CHAPTER 5

### REFLECTION, UNDERSTANDING AND INSIGHT FROM THE EDUCATIONAL/LEARNING PERSPECTIVE: EDUCATION LITERATURE REVIEW .................................................. 89

#### 5.1 Introduction ......................................................................................................... 89

#### 5.2 Educational Theories About Motivation and Learning ......................................... 92

##### 5.2.1 Motivation and Engagement Are Crucial Elements in the Learning Process ................................................................................................................................. 94

##### 5.2.2 Engagement is influenced by expectations and self-perceptions: ..................... 95

##### 5.2.3 Perceptions of attributing success or failure .................................................... 97

##### 5.2.4 People Are Strongly Motivated to Preserve Their Self-Worth ......................... 98

##### 5.2.5 ‘Flow’ .............................................................................................................. 99

##### 5.2.6 Evasion Can Be a Coping Strategy ..................................................................... 100

##### 5.2.7 Active or Experiential Learning ........................................................................ 101

##### 5.2.8 The Theory of Association ............................................................................... 102

##### 5.2.9 Learning in a ‘Community’ ................................................................................ 103

#### 5.3 Educational Theories About Cognition and Learning .............................................. 104
Cognition ......................................................................................... 104
Cognitive Rehabilitation ........................................................................ 104
Cognition/Thinking Involves Steps and Skills ........................................ 105
Learning Styles .................................................................................. 107
Multiple Intelligences. ........................................................................ 107

Summary ........................................................................................... 110

CHAPTER 6 ......................................................................................... 112
RESEARCH METHODS ......................................................................... 112

Introduction .......................................................................................... 112
Introduction to the ‘Introductory Digital Storage Disk’ ................................ 114
Methods Part A: Data Collection ............................................................ 117

The Sample .......................................................................................... 117
Sample Sizes ......................................................................................... 117
Type of Sample (Inclusion Criteria) of Participants withABI .................. 118
Authenticity of Sampling — Triangulation ............................................. 118

The Interview ....................................................................................... 119
Reasons Why an Interview was used to Gather Data .............................. 119

The Reflection Kit ................................................................................ 121
Procedure re the ‘Reflection Kit’ Group .................................................. 122

Data from Interviews and the Reflection Kit ........................................... 122

Procedure ............................................................................................ 123
Recruitment Procedure .......................................................................... 123
Interview Procedure ............................................................................... 125

On a personal note ................................................................................ 127

Ethics .................................................................................................... 128

Methods Part B: Analysis ..................................................................... 131

Background .......................................................................................... 131
The Phenomenological Approach to Data Analysis/Understanding ......... 131
Struggles with Different Approaches ....................................................... 132

Adopting Smith ..................................................................................... 133
Applying Smith and Osborne (2008): A Practical Example ..................... 135

A Worked Example: Factors That Negatively Affect the Lifeworld of
Participants with ABI ........................................................................... 136
Loss of Identity: The ‘New’ And ‘Old’ Me: Comparisons ......................... 138

Summary ............................................................................................... 140
CHAPTER 7

FINDINGS OF THE STUDY: FACTORS THAT NEGATIVELY AFFECT THE LIFE OF PEOPLE WITH ABI

7.1 Introduction

7.2 Participants with ABI: Factors That Negatively Affect the Life of Participants with ABI

7.2.1 Overview of Factors

7.2.2 First Overarching Theme: Loss, Lost and Trapped

7.2.3 Second Overarching Theme: Not Like a ‘Normal’ Person Any More...

7.2.4 Third Overarching Theme: Grappling with Emotional Fallout

Many participants said that

7.2.5 Fourth Overarching Theme: The Rehab Experience Didn’t Suit Me

7.2.6 The Superordinate Themes of Factors That Had a Negative Impact on the Life of Participants with ABI

7.3 Mothers and Wives’ Views of Factors That Have a Negative Impact on the Life of Their Loved Ones

7.3.1 Overview of Factors That Negatively Affect the Life of People with ABI from the Perspective of Mothers and Wives

7.3.2 First Overarching Theme: Lack of Understanding and Guilt

7.3.3 Second Overarching Theme: Being Judged by Others — The Stigma of ABI

7.3.4 Third Overarching Theme: Sadness for the Future

7.3.5 Superordinate Themes: It’s very hard being a person with ABI and very hard caring for and supporting a person with ABI

7.4 Professionals’ Views of Factors That Have a Negative Impact on the Life of Their Clients

7.4.1 Overview of Factors That Negatively Affect the Life of Participants with ABI

7.4.2 First Overarching Theme: the Losses of ABI

7.4.3 Second Overarching Theme: People Don’t Understand ABI

7.4.4 Third Overarching Theme: Emotional Challenges

7.4.5 Superordinate Theme: Brain Injury Is a Bugger

7.5 Summary

CHAPTER 8

FACTORS THAT POSITIVELY AFFECT THE LIFEWORLD OF THE PERSON WITH ABI: ‘KEYS’ FOR CHANGE

8.1 Introduction
8.2 Participants with ABI: Factors That Positively Affect the Lifeworld of People with ABI

8.2.1 ‘Keys’ to the ‘ABI Cage’ — An Amalgamation of Perceptions, Opinions, Emotions, and Factors That Positively Affect the Lifeworld of People with ABI

8.2.2 Overview of Factors That Positively Affect the Lifeworld of People with ABI

8.2.3 First Overarching Theme: Hope

8.2.4 Second Overarching Theme: Love

8.2.5 Third Overarching Theme: Learning to Understanding ABI and Working Things Out

8.2.6 Fourth Overarching Theme: Learning to Face the Facts (Acceptance)

8.2.7 Fifth Overarching Theme: Making Progress — Brain Injury Is Not All Bad

8.2.9 Superordinate Themes: ‘Many Keys’ and ‘Constructivist Circumnambulation’

8.2.10 Triggers and Turning Points

8.3 Wives and Mothers: Factors That Positively Affect the Lifeworld of People with ABI

8.3.1 Factors That Positively Affect the Lifeworld of Sons and Husbands with ABI

8.3.3 Second Overarching Theme: Understanding — Getting the ‘Right’ Information

8.3.4 Third Overarching Theme: Developing Some Quality of Life

8.3.5 Superordinate Theme: With Love, Hard Work and the ‘Right’ Attitude Life His Life Can Improve

8.4 Professionals: Factors That Positively Affect the Lifeworld of Clients with ABI

8.4.1 Overview of the Professionals’ Perspectives of Things That Positively Affect the Lifeworld of Clients with ABI

8.4.2 First Overarching Theme (Group X): The Professional Fills the Gap After the Person Leaves Rehabilitation

8.4.3 Second Overarching Theme (Group Y): The Person’s Acceptance and Attitude Is Important

8.4.4 Technology and Specific Social Groups

8.4.4 Professionals: Superordinate Themes (1) ‘Fill the Gap’ and (2) Needs to Understand, Accept and Have Hope

8.5 Summary
CHAPTER 9 .............................................................................................................................. 201

DISCUSSION .......................................................................................................................... 201

9.1 Introduction .......................................................................................................................... 201

Part A: ‘Golden Threads’ and ‘Blind Spots’ ............................................................................. 202

9.2 Discussion of Factors That Have a Negative Effect on the Lifeworld of People
with ABI .................................................................................................................................. 202

9.2.1 Golden Thread/Blind Spot 1: ABI Damages More Than the Brain ......................... 202

9.2.1.1 Different perceptions of fear ................................................................................... 203

9.2.1.2 Different perceptions or delusions ........................................................................ 204

9.2.1.3 Different perceptions of courage ........................................................................... 204

9.2.1.4 Shame and loss of status ..................................................................................... 205

9.2.1.5 Time passing may not mean the person’s life gets better .................................. 206

9.2.1.6 Relevance and implications of these findings ...................................................... 206

9.2.2 Golden Thread/Blind Spot 2: Learning Is Hard Labour ........................................... 207

9.2.3 Golden Thread/Blind Spot 3: Negative Effects of the Rehabilitation
Experience and Medical Terminology ................................................................................... 209

9.2.3.1 Mistrust ................................................................................................................ 210

9.2.3.2 Terminology ......................................................................................................... 210

9.2.3.3 The Two-Year Rule ............................................................................................. 211

9.2.3.4 ‘You Will Never...’ .............................................................................................. 211

9.2.3.5 Relevance and Implications ............................................................................... 211

9.3 Discussion of Factors That Have a Positive Effect on the Lifeworld of People
with ABI .................................................................................................................................. 213

9.3.1 Golden Thread/Blind Spot 4: The Positive Effect of ‘Humanity’ .............................. 213

9.3.2 Golden Thread/Blind Spot 5. Many ‘Keys’ to Open the ‘ABI Cage’ ....................... 215

9.3.2.1 A satisfying life .................................................................................................... 215

9.3.2.2 Quality of life ...................................................................................................... 217

9.3.3 Golden Thread/Blind Spot 6: ‘Keys’ Can Assist the Person with ABI to
Learn Coping Skills ........................................................................................................... 218

9.3.3.1 Coping ................................................................................................................ 218

9.3.4 Golden Thread/Blind Spot 5: Some ‘Keys’ Involve Optimism .................................. 221

9.3.5 Relevance and Implications: Research Is Needed ............................................... 222

Part B: The Research Tool and method .............................................................................. 223

9.4 Keys to the ABI Cage ........................................................................................................ 223

9.4.1 Strengths of Keys to the ABI Cage ........................................................................... 224

9.4.2 Weaknesses of Keys to the ABI Cage ...................................................................... 227

9.4.3 Possible Uses for Keys to the ABI Cage ................................................................. 227

9.4.4 Keys to the ABI Cage Reflection Kit Digital Storage Disk and Fill in
Sheets .................................................................................................................................. 227

9.4.5 Some Comments from Participants with ABI About Keys to the ABI
Cage ..................................................................................................................................... 228
LIST OF TABLES

Table 5.1: Anderson and Krathwohl’s Learning Taxonomy (2001) ........................................ 105
Table 5.2: Employment of Gardner’s Multiple Intelligences in Keys to the ABI Cage ........ 109
Table 6.1: Methods of Data Collection .............................................................................. 123
Table 6.2: Recruitment Procedure .................................................................................. 124
Table 6.3: Smith and Osborne’s Stages and Approach Used ......................................... 136
Table 6.4: Themes in the first case, emergent and overarching themes ....................... 137
Table 6.5: Emergent Themes from Several Participants, Including Sally’s ‘Anger’ ....... 138
Table 6.6: Superordinate, Overarching and Emergent Themes ..................................... 139
Table 7.1: Participants with ABI Overview of Findings ................................................. 143
Table 7.2: First Overarching Theme: Loss of ‘Self’ the ‘Old’ Me................................. 144
Table 7.3: Comparisons to the ‘Old’ and ‘New’ Me Taken from the Data ..................... 145
Table 7.4: Second Overarching Theme: Not Like a ‘Normal’ Person Any More .......... 148
Table 7.5: Third Overarching Theme: Grappling with Emotional Fallout ................. 151
Table 7.6: Fourth Overarching Theme: the Rehab Experience Didn’t Suit Me ............ 154
Table 7.7: Superordinate Theme: Learning with ABI Is Hard labour. ABI Damages
  Not Only the Person’s Brain but Also Their Hope, Honour, Trust and Safety
  and Security ................................................................................................................. 156
Table 7.8: Mothers and Wives: Overview of Findings .................................................. 157
Table 7.9: First Overarching Theme: Lack of Understanding. Guilt ................................ 158
Table 7.10: Second Overarching Theme: Being Judged by Others — The Stigma of
  ABI, the Distress of Loving a Person with ABI .............................................................. 160
Table 7.11: Third Overarching theme: Sadness for the future .................................... 161
Table 7.12: Professionals Overview of Findings: Factors That Negatively Affect the
  Lifeworld of Clients with ABI ...................................................................................... 164
Table 7.13: First Overarching theme: The losses of ABI .............................................. 165
Table 7.14: Second Overarching theme: People don’t understand ABI ...................... 166
Table 7.15: Third Overarching Theme: Emotional Challenges .................................... 168
Table 8.1: People with ABI Overview of Findings ......................................................... 174
Table 8.2: Overarching Theme: Hope .......................................................................... 175
Table 8.3: Second Overarching Theme: Love ............................................................... 178
Table 8.4: Third Overarching Theme: Learning to Understand ABI and Working
  Things Out ..................................................................................................................... 180
Table 8.5: Fourth Overarching Theme: Learning to Face the Facts (Acceptance) ....... 183
Table 8.6: Fifth Overarching Theme: Making Progress: Brain Injury Is Not All Bad........ 185
Table 8.7: Superordinate Themes.................................................................................. 187
Table 8.8: Mothers and Wives’ Overview of Findings: Factors That Positively Affect
  the Lifeworld of Sons and Husbands with ABI....................................................... 189
Table 8.9: First Overarching Theme: Love .................................................................. 189
Table 8.10: Second Overarching Theme: Understanding — Getting the ‘Right’
  Information.................................................................................................................. 190
Table 8.11: Third Overarching Theme: Developing Some Quality of Life .............. 192
Table 8.12: Professionals: Overview of Findings ......................................................... 194
Table 8.13: First Overarching Theme (Group X): the Professional Fills the Gap After
  the Person Leaves Rehabilitation .............................................................................. 195
Table 8.14: Second Overarching Theme (Group Y): the Person’s Acceptance and
  Attitude Is Important .................................................................................................. 196
Table 8.15: Overarching Theme 3: Technology and Specific Social Groups............. 198
<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Websites reviewed in 2009.</td>
<td>16</td>
</tr>
<tr>
<td>1.2</td>
<td>Observations of 20 websites reviewed in 2012.</td>
<td>18</td>
</tr>
<tr>
<td>1.3</td>
<td>Web-based information revealed problems that people with ABI experience i.e. participants in this study might have these problems.</td>
<td>20</td>
</tr>
<tr>
<td>1.4</td>
<td>Headwork 1: The data collection must address these issues about ABI.</td>
<td>29</td>
</tr>
<tr>
<td>1.5</td>
<td>Headwork 2: Talk-about cards ‘My differences and Difficulties’.</td>
<td>29</td>
</tr>
<tr>
<td>1.6</td>
<td>Headwork 3: Talk-about cards ‘How I feel’.</td>
<td>29</td>
</tr>
<tr>
<td>1.7</td>
<td>Headwork 4: Talk-about cards ‘Keys that can release me from the ABI Cage’.</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Photograph 1. Keys to the ABI Cage</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>Photograph 2. ‘How we feel can lock us in the ABI Cage’</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>Photograph 3. ‘Keys can release us from the ABI Cage’</td>
<td>40</td>
</tr>
<tr>
<td>3.1</td>
<td>Headwork 1: Talk-about cards’ relevant to the literature on IQ loss.</td>
<td>53</td>
</tr>
<tr>
<td>3.2</td>
<td>Headwork 2: The memory difficulties of the participant should be considered in the method of data collection.</td>
<td>54</td>
</tr>
<tr>
<td>3.3</td>
<td>Headwork 3: Talk-about cards relevant to the literature on memory loss.</td>
<td>54</td>
</tr>
<tr>
<td>3.4</td>
<td>Headwork 4: The depression and emotional fragility of the participant should be considered in the method of data collection.</td>
<td>55</td>
</tr>
<tr>
<td>3.5</td>
<td>Headwork 5: Talk-about cards relevant to the literature on depression.</td>
<td>55</td>
</tr>
<tr>
<td>3.6</td>
<td>Headwork 6: The fatigue of the participant should be considered in the method of data collection.</td>
<td>56</td>
</tr>
<tr>
<td>3.7</td>
<td>Headwork 7: Talk-about cards relevant to the literature on fatigue.</td>
<td>56</td>
</tr>
<tr>
<td>3.8</td>
<td>Headwork 8: Talk-about cards relevant to the literature on coping.</td>
<td>57</td>
</tr>
<tr>
<td>3.9</td>
<td>Headwork 9: Talk-about cards relevant to the literature on the consequences of pain.</td>
<td>57</td>
</tr>
<tr>
<td>3.10</td>
<td>Headwork 10: Reflecting on body-objects tests and this study.</td>
<td>62</td>
</tr>
<tr>
<td>3.11</td>
<td>Headwork 11: Participants should feel comfortable.</td>
<td>63</td>
</tr>
<tr>
<td>4.1</td>
<td>Headwork 12: Strategies in the method employed to help them feel better/cope better.</td>
<td>74</td>
</tr>
<tr>
<td>4.2</td>
<td>Headwork 13: Talk-about cards allow participants to reflect on issues.</td>
<td>75</td>
</tr>
<tr>
<td>5.1</td>
<td>Headwork 14: How Keys to the ABI Cage addresses the issue of motivation.</td>
<td>75</td>
</tr>
<tr>
<td>5.2</td>
<td>Headwork 15: Keys to the ABI Cage addresses the issue of engagement and motivation.</td>
<td>95</td>
</tr>
<tr>
<td>5.3</td>
<td>Headwork 16: Keys to the ABI Cage addresses the issue of attribution of success.</td>
<td>97</td>
</tr>
<tr>
<td>5.4</td>
<td>Headwork 17: Keys to the ABI Cage addresses the issue of self worth.</td>
<td>98</td>
</tr>
<tr>
<td>5.5</td>
<td>Headwork 18: Keys to the ABI Cage addresses the issue of ‘flow’.</td>
<td>100</td>
</tr>
</tbody>
</table>
Figure 5.6. Headwork 19: Keys to the ABI Cage addresses the issue of evasion. .......... 101
Figure 5.7. Headwork 20: Keys to the ABI Cage addresses the issue of active learning. ........................................................................................................................................................................ 102
Figure 5.8. Headwork 21: Keys to the ABI Cage addresses the issue of theories of association. ......................................................................................................................................................... 103
Figure 5.9. Headwork 22: Keys to the ABI Cage addresses the issue of participants feeling they are part of a community of people with ABI. .... 103
Figure 5.10. Headwork 23: Keys to the ABI Cage addresses issues from cognitive rehabilitation. ........................................................................................................................................................................ 105
Figure 5.11. Headwork 24: Keys to the ABI Cage provides steps for participants to engage in higher order thinking. ........................................................................................................................................................................ 107
Figure 5.12. Headwork 25: Keys to the ABI Cage provides an experience for participants to review. ........................................................................................................................................................................ 107
Figure 6.1. Introductory Digital Storage Disk and Reflection Kit. ........................... 129
Figure 6.2. Clause inserted in Plain Language Statement ................................. 129
CHAPTER 1
AN INTRODUCTION TO BRAIN INJURY AND THIS STUDY

Part A: Introduction and Raison D'etre for This Study

The psychiatrist insisted she be committed, Institutionalised there and then.
She felt she was mad — so who was she to disagree?
But summoning all her courage
She insisted on first going home to pack a bag.
(She’d spent too many months in hospital, unprepared.)
Once home, her daughter, a lawyer
Explained
Once committed
It would be difficult to obtain her release.
She did not return to the hospital and incarceration
Instead
She committed her life to learning all she could about brain injury.
(C. Durham)

1.1 My World Was Turned Upside Down by Brain Injury

I was involved in a horrific motor vehicle accident in 1991. After a day teaching I was driving to Melbourne University, where I was studying for my Masters of Education, when my car was hit by a car running a stop sign. Spun round by the force of the other vehicle, my flight was stopped by a power pole in the driver’s door. Leaving me choking on my seat belt and having an epileptic fit, the other driver went to get a quote to have his car repaired.
Fortunately, a passerby witnessed the accident, ran to my aid, smashed the driver’s window and removed the seat belt that was choking me.

Eventually I regained consciousness. I was told (but immediately forgot) that I was in intensive care in hospital. I was in agony from injuries that included multiple breaks to more than half of my ribs that took my breath away a well as a collapsed lung and double pneumonia that nearly took my breath away permanently. After some days, when I briefly opened my eyes, I was horrified to see that in this terrible hell I now inhabited, people had two heads. They emerged from the fog to torture me and then retreated back into the white mist. To my bewilderment I had no words to express my terror.

That was a long time ago but ever since that horrific experience I’ve had a daily struggle to cope with my brain injury, pain, double vision, memory and cognition problems as well as the difficulty with limbs that do not function properly. Life is an exhausting and daunting challenge when you have difficulty understanding, accessing and comprehending information;
when you have lost the ‘old me’ yet you do not know the ‘new me’; when you feel like a ‘bumbling idiot’, a ‘lesser person’, like a child again — frustrated, bored and ashamed as you relearn how to dress/eat/walk/talk.

You lose autonomy and have to be told what to do all the time. There is no place for privacy or modesty because strangers, medical professionals and lawyers demand to ‘know your business’ and ‘test’ and ‘judge’ you constantly. This left me feeling even more disempowered and I contemplated doing something drastic to end my misery. As the day for leaving hospital grew closer doctors and nurses spoke of my need to go to another hospital, a rehabilitation hospital. I didn’t want to go to another hospital — I just wanted to go home to find ‘myself’. I also thought all the doctors and nurses were mixed up and thought I was a soldier. I knew soldiers had rehabilitation and one thing I knew was I wasn’t a soldier!

*I was lost*

After several months in hospital I returned home where I thought I would find ‘me’ — but ‘I’ was not there. The ‘new’ me didn’t even know where the light switches were or where the tap was and how to turn it on. Fortunately, I have a devoted supportive family, a dedicated husband, a daughter who stayed home from work to be my carer and three other children who all helped me in different ways.

After some weeks I attended a rehabilitation hospital for ‘rehab’ two half days a week. A taxi would pick me up at noon. Having no concept of time I would eat my lunch at 9 a.m. and stand in the drive waiting for the taxi. I did balance classes, occupational training and completed many tests. I felt so ashamed that I could not do simple arithmetic (the sort I’d do with my class at school). I didn’t understand and I could not ‘get better’, no matter how hard I tried. I was like a lost soul.

As my children cooked the evening meal I would weep and wish I was dead. Dread of the nightmare of the long night ahead, when I would be overwhelmed by pain, petrified me. I struggled to hold on to ideas so I could try to make sense of my predicament so I recorded thoughts with very bad handwriting and even worse spelling on the backs of envelopes or scraps of paper — anything that was handy. Six months after my accident I returned to school, helping in the library for two half days a week.

I thought I would find the ‘old’ me at school, but of course she was not there either. The trip home in the taxi was frightening. I would then stand under a boiling shower to try to get warm
and then collapse in bed, totally exhausted. The following years were spent in a similar way: school, resting, visiting doctors, completing tests for the lawyers.

Finding myself through writing

Some early mornings when my brain and eye (one was patched) were ‘fresh’ I tried to record my experience and what I’d learnt about brain injury. My sons set up a new computer with bold size 18 point font and I tapped away with one finger (I still type this way). I was determined that no one else with brain injury should ever be as lost and frightened as I was. I also wanted to show the man who caused my accident what he had done to another human being. I thought about giving him a copy of my subsequently published book Doing Up Buttons (Durham, 1995), but did not contact him. ‘Buttons’ as it became ubiquitously known is autoethnographical text, a personal narrative exploring my experience of brain injury and my subjective experience of a changed life. It also gives readers insights into their own problems of brain injury.

I discovered that reading can help people find themselves

I gave my manuscript to a literary agent and within a week had signed a contract with Penguin Books. Doing Up Buttons was published in 1997 and it immediately struck a chord with many people whose lives had been changed by brain injury or who worked with people with brain injury, because it translates brain injury into something people can understand. Weekly letters over 15 years continue to arrive with a variety of positive messages:

…Your ability to take us so intimately on this horrendous journey with you is truly amazing...not only did I enjoy what I was reading, but reading my first book after eyesight damage from a stroke was an important one…

…yesterday, I bought it and last night I read it. I couldn’t put it down. I laughed, I cried, I became angry and I read large chunks of it out loud to my husband. At the end I was emotionally exhausted but also astounded...I started reading it during dinner and did not move until I had finished it. I literally could not put it down…For me your book is about a whole lot of things — tragedy, enormous struggle, courage, support, love, loyalty, triumph and a journey that never ends…but most of all it is about guts…

…As I can no longer rely on my memory to recall, I ‘dog eared’ the pages of your book as I came across relevant information. Would you believe when I came to the end I had ‘dog eared’ nearly every page!…For me it is so confirming of my head injuries and changes…

…I am sure it will prove a most helpful story/account for many people…I am sure clinicians, therapists, lawyers and so on would be informed better were they to read it; let us hope some do…
Speaking presentations using analogies were effective

Invitations flowed to speak at conferences, meetings and workshops for people with brain injury, brain injury organisations and rehabilitation professionals both in Victoria and other states. Often this would involve my husband driving me for some hours to a country location where people had travelled great distances to attend. It was humbling to think that the book had made such a difference to their lives. I formed a speaking business Talk About Change and spoke to a wide variety of groups (see Appendix 1.1) — at first assisted by my sons or daughters, given I was still experiencing pain and had difficulty expressing my thoughts. In presenting, I drew on my experience as a teacher and used pictures, analogies, stories and Alice from ‘Alice in Wonderland’ to express my experience of brain injury.

At the conclusion to my talk, in order to capture the curiosity of the audience (and give them a take-home message to remember), I’d asked my 20-year-old son to walk down the aisle from the back of the auditorium carrying a mixing bowl and ingredients to make a cake while I donned an apron. As he placed these objects onto a table on the platform I encouraged the audience to reflect on their previous knowledge of brain injury and what they had been reminded of with pictures, objects and analogies of my presentation.

I used making a cake to sum up the brain injury experience. Calling it ‘The Coping Cake’ I showed the ingredients to the audience asking them what flour (the greatest quantity of ingredient in the cake) could represent. What did they think the most important ‘ingredient of recovery’ was? Using metaphor I identified flour as hope — the most important ingredient to help people cope with their brain injury, sugar represented the sweet/good things of life, milk represented the milk of human kindness and eggs thinking and talking to bind together information and ideas. Once these ingredients were assembled in the bowl I asked the audience of rehabilitation specialists if this was a cake. Of course, the answer was ‘No’. From the show of hands someone said, ‘First you have to beat the mixture, then cook it’.

I produced a giant golden spoon and explained that the job of these professionals was to encourage their patients to put in the effort and pick up the spoon to put an effort into their own recovery (they the specialist couldn’t ‘give’ them ‘recovery’). I gave the participants golden spoons with the label ‘Changes in life to understand? Remember Alice in Wonderland’ as a take home message.

I used a number of devices like this in the scores of presentations I continued delivering over the years, to brain injury, business and educational audiences. At my first rehabilitation
conference presentation at the Hilton in Melbourne, I was amazed to experience my first standing ovation. I discovered from this and other presentations that by using learning principles in producing a symbol of a concept, then making connections between the objects/symbols to practical everyday issues, the interest and understanding of the audience could be enhanced. In addition, this use of humour, the unexpected and a twist to make an association proved to be a powerful vehicle whether I was speaking to professionals or people with brain injury. This was very different to just giving them information — *they* had to put in the effort and make connections and understand.

Alice from *Alice in Wonderland*, an analogy I used firstly as ‘blurb’ on the back cover of ‘Buttons’, was later used to explain to professionals what it feels like to experience brain injury. This analogy also resonated with people with brain injury. I spoke to one woman who became blind because of her brain injury — she obtained a ‘talking book’ copy of *Doing Up Buttons*. She told me she had had to listen to the reading of the back cover several times because she was crying with relief that, at last, *here was someone who understood brain injury*. Such recognition committed me to listening to people’s stories.

*Listening to the voices of others*

I spent a decade speaking to groups about brain injury. *Doing Up Buttons* had been out of print for several years when a young man contacted me to get a copy of the book for his friends ‘so they would understand’. He said the book should be available for people and he made phone calls and obtained some funding and I put in sufficient money for Penguin Books to reprint 1,000 copies of the book. Together, Harry Troedel, and I gave away the books from the Transport Accident Commission’s stall at the 5th Congress on Brain Injury in Melbourne, 2005. I purchased another 100 copies to give to organisations that had supported the publication and to give to Headway.

With the book we gave out what I called ‘Hope Stones’ — beautiful, black polished river pebbles purchased from a garden supply outlet. I attached small gold stars (like I used as a teacher to reward good work) to the stones. The message of this object was that people with brain injury *can* tackle the hard things (like the hard stone) and reach for the stars. Although these ‘take home messages’ (like the golden spoons) had been enthusiastically received by audiences after presentations, I was unsure of how they would be received by the delegates of this international Brain Injury conference.
But I did not need to fear. The keynote speaker from United States (US) requested thirty stones to take back to her students and we gave away forty kilograms of these stones. Attendees would come up to me on subsequent days of the conference and pat their pockets saying ‘I’ve still got it with me’ — and over the years when I’ve encountered some of these people they still speak about the influence of their stone.

The experience of this conference was remarkable. I met nurses who told me how they had purchased copies of the book to give to people with brain injury and I learnt that the book was a recommended text at universities from Darwin to Perth to Sydney. It affirmed to me that the book was useful to people with brain injury, their families and professionals. I would not have embarked on this PhD if I had not experienced the face-to-face reactions I had with the rehabilitation professionals at this conference. Today, the book has been out of print for many years but I still have strangers with brain injury contacting me.

Significantly, I realised I had discovered a different way to communicate aspects of brain injury and the need for a ‘translation’ of the consequences of brain injury. A combination of experience teaching, writing and my personal story of brain injury could be a useful vehicle. I now faced a quandary, I had put such a tremendous effort into regaining my life and I still experienced so many brain injury and accident-related difficulties that some days I thought to myself, ‘at last now I can put my brain injury experience behind me’. Yet on other days, I felt compelled to speak on behalf of all those people who could not speak for themselves.

At the time of my accident I was partway through a Masters in Education at Melbourne University, which I completed. I returned to part-time teaching. I progressed from weeping into my eye patch as I tried to help in the library, to taking more than 4,000 philosophy/thinking workshops for children in the 10 years following my accident. As double vision and memory loss meant that reading was difficult, I used objects similar to the ‘coping cake’ to engage and focus the students’ (and my) attention. I made notes (or the children took the pen from my hand saying ‘I’ll do it, you know you can’t spell Mrs D’), and from these notes I wrote Chasing Ideas (Durham, 2001) a book about helping children to think. Many teachers write books, however this book was endorsed by Dr Edward de Bono and published for Australian audiences by Finch Publishing, and for United Kingdom (UK), US, Europe and African audiences by Jessica Kingsley Publishers and it was also translated into Taiwanese, Chinese and Arabic. This book led to invitations to speak about ‘thinking’ and conducting workshops for Melbourne University, Nan Yang University, Singapore and speaking to
principals, teachers and parents. This study employs concepts first explained in *Chasing Ideas*.

I continued to teach for two days a week for 10 years and also spoke to brain injury groups; however, the pain, double vision and fatigue forced me to leave teaching, as the effort required to teach two days a week consumed most of my available energy. But I kept asking myself ‘What more can I do to help people with brain injury?’ My new approach to teaching, through metaphor, had done something else. My students had taught me how to talk and how to think again.

It was now 16 years after the accident and each day I felt fortunate to be alive — that I did not die in the accident, or by my own hand. I wanted to find something ‘worthwhile’ to do but I was at a loss about what to do next. Each time I spoke to a group I heard many ideas from conversations I had with people after the presentation. One presentation was to a group of University Disability Liaison Officers at a conference. Over coffee, several members of the audience suggested I should use my experience and knowledge to do further study and use the information to help people understand and gain better insight into brain injury. About this time I also heard about completing a PhD by exegesis and the philosophy of phenomenology. These two new concepts fired my imagination.

Writing, thinking, speaking and hearing led to the challenge of further study. This was how I embarked on PhD studies at the age of 63 in spite of double vision, limited memory, constant pain, and fatigue (I still need an afternoon nap). I was driven by the hope that I could learn more about Acquired Brain Injury (ABI) to pass on to people with ABI. My position as a person with brain injury and decades of experience helping students learn (which had helped me to find a way to write and speak about brain injury in a way that helped others make sense of their experience), could all come together to produce something useful and encouraging for others with brain injury. As will be discussed in Chapter 4, I would approach brain injury from the ‘body-subject’ perspective of my experience, to support and encourage participants so they would not feel diminished by reflecting and learning about factors that influenced their lifeworld.

Thus, this study is a journey of learning. It explores and connects my reflections and insight about brain injury with the reflections and insights of other people with brain injury, family members of people with brain injury and professionals engaged with people with brain injury. The enthusiasm of people with brain injury and their gratitude expressed in relation to my books and public appearances demonstrated that although every brain injury is biologically
different, the way people *feel* about their injury contains many similar themes or ‘golden threads’. The purpose of this study is to identify and tease out these golden threads to weave them together to form a safety net to catch, support and encourage people, whose life hangs by a thread, because of brain injury.

Thus I started on a learning journey that was to consume four years of my life.
Part B: A briefing on brain injury and the purpose of this study

If I have lost confidence in myself,  
I have the universe against me.  
(Ralph Waldo Emerson)

1.2 The Problem and the Reasons for This Study

Brain injury is the single greatest cause of permanent acquired disability in our society (Rees, 2005, p. xi). It affects body, brain, life, status and future of one in 45 persons. (Australian Institute of Health and Welfare [AIHW], 2007). These people do not ‘get better’, ‘recover’ or ‘return to a normal state of health, mind, or strength’ (Oxford Dictionaries, 2010) they cannot be cured or restored to health by operations, medication, or ‘treatment’, although millions of dollars have been invested in studies that strive to discover ways to help people with brain injury make ‘progress’.

‘Recovery for people with brain injury is relative, and in this context means learning again and developing skills and behaviours that enable the person to enjoy and achieve irrespective of brain injury’ (Rees, 2005, p. 8). The person’s knowledge and beliefs about their impaired abilities (their self-awareness) are important components of their recovery and adjustment (Cicerone, 1991; Medley & Powell, 2010; Medley, Powell, Worthington, & Chohan, 2010; Stuart, Thomas, & Yudofsky, 2011). But their motivation to participate in rehabilitation, or to adopt compensatory strategies, may be affected by impaired self-awareness (Bogod & Mateer, 2003; Fleming & Strong, 1999).

To obtain self-awareness, the person needs to have both the will and the way — the will to concede they do have difficulties (this requires courage, confidence and hope that they can do something about their difficulties). The person also needs to find a way to learn about their difficulties, to understand how they have been affected by brain injury and what they can do to deal with, compensate for, or cope with their deficits (Durham, 1997).

This study has endeavoured to find an approach to help people with brain injury discover ‘their will’ and ‘their way’ because poor self-awareness after brain injury can cause low motivation, noncompliance, minimal engagement, and lack of progress in therapy (Desbois, Fleming, Grant, Ownsworth, & Strong, 2006; Fleming, Strong, & Ashton, 1996; Fleming, Winnington, McGillivray, Tatarevic, & Ownsworth, 2006). When a person’s life is shattered by brain injury they need to be motivated and actively engaged to make progress. But studies have demonstrated that increased self-awareness can result in increased emotional distress
and higher levels of depression (Fleming, Lucas, & Lightbody, 2006; Fleming et al., 1998). Here is the problem, how can people acquire better insight into brain injury in a positive and beneficial way?

The journey to self-awareness is complex. The person may be aware of physical difficulties (e.g., they can’t move their limb) one moment, but ‘forget’ the next; a result of impaired memory might be that many times a day they have to ‘re-acknowledge’ this fact and additionally, the ‘intense effort’ required to form a word or to move a limb may be expressed as ‘anger, depression, anxiety, or fear’, (Yudofsky & Hales, 2008, p. 630). Cognitive and emotional difficulties may only become apparent when the person discovers an inability to understand a question or ‘find the words’ to answer it, when they can’t tell the time or work out what to do, or uncharacteristically lose their temper, or feel defeated when they labour to complete a ‘test’ in rehabilitation.

The rehabilitation practitioner generally obtains information about the person’s self-awareness by comparing the patient’s self-report of their function, with reports from family members and the rehabilitation staff’s more objective measures (Silver, McAllister, & Yudofsky, 2011), from methods such as structured interview questions, scored according to a rating scale, which rely on the patient’s verbal ability (Silver et al., 2011). These methods may not be the most helpful way for the individual to learn about their difficulties, differences and deficits (Durham, 1997). It will be argued in later chapters that assessment testing (and data collection) has the potential to negatively affect the self-confidence and self-esteem of people with brain injury.

1.2.1 Finding a Way to Make Progress

I have faced the daily struggle to find the will and the way to make ‘progress’ since my brain injury 20 years ago. Additionally, as an educator, I have been striving to answer the question: can educational and learning principles be employed to empower people with brain injury to reflect upon, and better understand themselves — obtain greater self-awareness — so they can learn to feel and fare better? This research is an attempt to answer this question.

This study aimed to find a method to ask ‘new questions to illuminate “blind spots”, areas in which existing theories, methods and perceptions (might) actually keep us from seeing phenomena as clearly as we might’ (Wagner, 1993, p. 16) to find answers to questions we do not know to ask of people with memory and communication difficulties. ‘What we don’t know well enough to even ask about or care about are our “blind spots”’ (Wagner, 1993, p.
This approach contrasts to the assessment tests, scales and questionnaires used to find answers to what Wagner terms ‘blank spots’, where enough is known about an issue to pose questions, to gather data to fill in the ‘blank spot’, as is used by quantitative research.

Nietzsche (1887), when writing about pain, stated that pain can ‘deepen’ us. If we can be ‘deepened’ by suffering, do some people gain something by their brain injury experience? If this is so, could this information be helpful to people struggling with brain injury? Recently, the concepts of Positive Psychology (PP) (Evans, 2011) and the potential of posttraumatic growth (PTG) to enhance psychological adjustment of the person with ABI and their family and friends (McGrath, 2011; Ownsworth & Fleming, 2011) have been considered, where ‘introspective processes and coping behaviours in efforts to make sense of the loss…in time, can restore one’s sense of meaning in life and lead to fundamental changes and values and directions in life, self-identity, relationships and a deepened spirituality’ (Ownsworth & Fleming, 2011, p. 79).

This study aimed to help people explore their lifeworld (Leberswelt), the world of their lived experience (described by Husserl, 1859–1938, the founder of phenomenology). A tool would be developed to empower the participant, who may be fragile and vulnerable, to reflect and talk about their lifeworld in a constructive way. This tool would employ principles of education and learning and it would be trialled to observe if it encouraged participants to explore their lifeworld and, in so doing, develop greater constructive self-awareness.

Models and metaphors were employed to assist the participant reflect their lifeworld in a positive way. Nietzsche wrote that ‘One must employ models and metaphors drawn from whatever resources are available’ (Nietzsche, 1995, p. 622). Collected data in this research was analysed using interpretative phenomenological analysis. Factors that negatively and positively affected the lifeworld of the person with brain injury were identified. Later, this data was used to compile an ABI learning resource. This resource encourages the person to explore their own the brain injury experience (acquire insight and self-awareness), and discover for themselves things they can do to help themselves.

1.3 An Introduction to Brain Injury

Injury to the brain is a complicated phenomenon that can be recognised medically through brain scans and assessment instruments. The results of injury to the brain involve complex phenomena, a plethora of deficits and difficulties that affect and influence each other and influence the lifeworld of the person. Damaged brains produce damaged bodies, damaged
cognition, damaged emotions, damaged behaviour, damaged interactions, damaged people and damaged lives.

The person with brain damage needs to learn ways to exist with these multiplicities of problems as they try to ‘reconstruct’ themselves. Chapter 3 will examine literature from some of the innumerable body-object quantitative studies that examine specific issues to do with brain injury. The medical model focuses on pathology and ‘mending bodies’ but, as this research inquiry posits, this is not the only possible approach to assist people with brain injury. Social model of disability theorists speculate that the reliance on the medical model leads to a model of pathology and obscures how society can be disabling in its approach to individuals, (Barnes, 1990; Barnes & Mercer, 2004; Barnes, Oliver, & Barton, 2002; Finkelstein, 1980, 1993; Oliver, 1983, 1990, 1996). Chapter 4 will examine literature from the body-subject qualitative studies that examine issues such as quality of life and coping, but it is surprising how little research has been undertaken to examine how the individual, as a whole person, attempts to ‘reconstruct’ themselves and their lives.

This chapter will now provide an introduction to brain injury from information that a person with brain injury (or their family or friends) might obtain. The purpose of this review is to illustrate the characteristics of brain injury, to supply an example of information available about brain injury and its ability to meet their needs and to present a catalogue of the types of problems participants in this study might be contending with. The chapter will explore some of the information from support organisations in official web-based material. Included will be books and blogs written by people with brain injury, which attempt to explain how the whole person goes about reconstructing themselves. By the end of this chapter the reader will be aware of some of the effects of injury to the brain and the complexity of this phenomenon we call brain injury. At the conclusion of this chapter the aims, purpose and structure of this study will be explained.

1.3.1 The Problem of Brain Injury

Brain injury is a big problem worldwide.

Traumatic brain injury (TBI), according to the World Health Organization, will surpass many diseases as the major cause of death and disability by the year 2020. With an estimated 10 million people affected annually by TBI, the burden of mortality and morbidity that this condition imposes on society, makes TBI a pressing public health and medical problem. (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007)
It is difficult to gain a picture of numbers of people affected by brain injury as some sources only report the number of people admitted to hospital. Many people who suffer a traumatic brain injury (TBI) are not admitted to hospital and the numbers might not include people with acquired brain injury (ABI), where brain injury is acquired through stroke or other medical conditions. In 2003, the Australian Bureau of Statistics (ABS) reported that the annual incidence rate in Australia, the UK and the US totals some 2.7 million traumatic brain injuries. Often referred to as the ‘hidden disability’, one in every 45 Australians had a brain injury with ‘activity limitations’ or ‘participation restrictions’ due to their disability (AIHW, 2007, p. 1).

In the US there are 1.7 million new cases of brain injury each year — 4,000 a day or three per minute — and each year there are 52,000 deaths due to brain injury (Faul, Xu, Wald, & Coronado, 2010). To put this number in context it is more than all the American troops killed in the Vietnam War and today up to 20% of U.S. soldiers returning from duty in war-torn areas have mild traumatic brain injury (Bigler & Kelly, 2010).

Societies carry considerable financial cost for the lifetime care of people with brain injury. The Access Economics report for the Victorian Neurotrauma Initiative (June 2009 p. xiii) identified for the year 2008 in Australia there were an estimated 1,493 new cases of moderate TBI and 1,000 new cases of severe TBI. In this 2009 report the total cost of TBI in Australia was estimated to be A$8.6 billion:

The greatest portion [is] born by individuals (64.9%), the State Government (19.1%) and Federal Government (11.2%). The lifetime costs per incident case of TBI were estimated to be $2.5 million and $4.8 million for moderate TBI and severe TBI respectively, across Australia. (p. xvi)

These figures do not take into account the cost of care for people with ‘mild’ traumatic brain injury.

There are also significant personal costs associated with ABI. An Australian Institute of Health and Welfare Bulletin (AIHW, 2007) stated that:

People with ABI tended to have complex disabilities, they reported more health conditions than the average person with disability, more than one in three people with ABI needed cognitive and/or emotional support, 82% of people with ABI also had physical disabilities, 42% had psychiatric disabilities, 39% had sensory or speech disabilities, 29% had intellectual disabilities, people with ABI report problems including depression and mood affective disorders, 32% of people with ABI received some assistance with cognitive or emotional tasks, but stated that they required more help. (p. 1)
Solving everyday problems that are highly relevant to a person’s welfare can be also be affected by brain injury. This can mean the person has fewer ways to buffer or deal with external stressors (Lazarus & Folkman, 1984). In a study conducted in the US there was a mean loss of 14 points of Full Scale IQ from pre-injury baseline IQ for people with brain injury (Parker & Rosenblum, 1996).

In the future, with an ageing population, it is estimated that more people will suffer from ABI as a result of falls and other accidents. In an article about ABI among people aged 65 years or over in 2003, it was claimed that 4.7% of this population had ABI (AIHW, 2007), which caused diverse disability affecting physical, sensory, speech, cognitive and emotional problems.

The following review of publicly available information has been approached from a person with ABI’s perspective who has recently left hospital.

1.3.2 Finding Out About ABI

How does the individual with brain injury, or their family or friends find out about brain injury? Initially, information is provided by hospitals, medical practitioners and health professionals but the person with ABI may not be in a fit state to understand any more information than ‘You’ve been in a car accident’, ‘You’ve had a stroke’. Their family members ask the medical practitioners questions as they have many ‘blank’ spots about ABI to fill in, and, as time goes by, ‘blind’ spots become apparent. They search intently for information, but as they move from the sender–receiver model, which characterises the period under health and medical care, to the seeker–finder model, their approach can be a hit and miss exercise.

When the person leaves hospital and they seek to re-engage with everyday life, they may be in a state of trauma contending with pain from physical damage, or they may appear to be undamaged, but be experiencing difficulty understanding and talking so that information can be overwhelming, difficult to translate and understand and deeply disturbing. They may try to digest information from pamphlets given to them at the hospital and then they may search for more information on the World Wide Web.

1.3.3 Information from the World Wide Web

The person with brain injury, and their family, may search the World Wide Web for information provided by brain injury support organisations to try to find out about brain
injury. In this search they may locate information published in academic journals, but this information is not in a form that they can readily interpret and understand.

There is a plethora of brain injury support organisations’ web sites and readers will be informed that the impairments, deficits and psychological and emotional effects of brain injury vary according to the cause and severity of the injury. It is difficult to identify effects of brain injury because many problems are initially not obvious, or it requires a certain circumstance to highlight a specific difficulty. Thus it is not easy to search for relevant information, and organisations cannot possibly impart information that is relevant to every situation and every circumstance. The reader becomes aware that there are many ‘unknowns’ and ‘variations’ in brain injury, so that the information may initially accentuate the sense of confusion and bewilderment.

Over the past four years, since I commenced this study, the use of the World Wide Web has expanded both in information it contains and the number of people who use the web. I searched the ‘grey literature’, from the World Wide Web for clear information about brain injury and I learnt:


Traumatic brain injury (TBI) is an injury to the brain caused by external trauma such as in car accidents, sporting injuries including concussions and assaults. TBI (ABI) can cause long-term physical disability and complex neuro-behavioural effects which disrupt quality of life, including neurological impairment (e.g., motor function impairment and sensory loss), medical complications (e.g., spasticity and post traumatic epilepsy), cognitive impairment (e.g. memory impairment and problems with planning, language and safety awareness) personality and behavioural changes (e.g., impaired social and coping skills) and lifetime consequences (e.g. unemployment, difficulty maintaining interpersonal relationships and loss of independence.)

Mild traumatic brain injury (MTBI) is the term used when the person experiences a blow to the head resulting in a brief loss of consciousness, and with minor brain injury (MBI) the person may experience complaints such as headaches, and some cognitive issues can persist up to a year after a mild head injury, the long-term prognosis is good. (Access Economics The economic cost of spinal cord injury and traumatic brain injury in Australia, June 2009, p. xii)

This lengthy quote has been included because it provides an example of information available for people with ABI. It demonstrates the use of language and vocabulary that might be
unfamiliar to the individual (motor function, cognitive impairment and so forth). It also presents ABI terminology and definitions that are ‘problem-based’ and biological. There is very little, if any, information about ‘getting better’, ‘faring better’ or re-engagement with everyday life. Both the information, and the ‘voice’ or tone by which the information is presented, can play a role in the expectations of people with ABI and their families.

In this study I will refer to brain injury as ABI — this term encompasses both TBI where the injury was caused by an external traumatic event and ABI where the injury to the brain was caused by a stroke, tumour or other medical condition (an internal traumatic event).

In order to get a more detailed view of the information available in the public domain a review of web sites was undertaken in 2009 in order to examine what information was being provided for the person with ABI and their family. The websites reviewed are shown in Figure 1.1.

1. Headway Victoria (Australia) Changed Lives Modules, (reviewed)
2. The Children’s Hospital at Westmead, NSW, Australia.(reviewed)
4. CBIT (UK) Factsheets, (reviewed)
5. Brain Injury Association of Queensland (Australia) Facts Sheets, (reviewed)
6. Monash-Epworth Rehabilitation Centre, Victoria (Australia) : Information about Mild Head Injury or Concussion, (reviewed)
9. Bethesda Hospital, Melbourne website, Steps Project: Skills to Enable People
10. Communities Health Queensland Government

**Figure 1.1.  Websites reviewed in 2009.**

The first six websites were chosen for a more detailed review that involved assessment of whether the information was suitable for a person with physical, cognitive and emotional difficulties associated with ABI. Appendix 1.2 contains a matrix of this analysis. The review looked for potential difficulties a person with ABI might experience (Appendix 1.3) and included identification of the intended audience (the person with ABI and/or a family members) and the relevance of the information included, the writing style and language used (formal medical language, or everyday language including jargon), print size, the manual dexterity required to negotiate round the site, presence of any distracting amount of information on the webpage (if there were distracting flashing advertisements to join the organisation or make a donation).
The scope of information on the web sites was also examined. Issues covered by the six web sites were information about the brain, causes of brain injury, minor brain injury, rehabilitation, the law/guardianship, balance, sensory problems, headaches, hearing, speech and swallowing, sexual problems, poor concentration, poor problem-solving, lack of initiative, inflexibility, impulsivity, visual disorders, memory and anger, socially inappropriate behaviour and emotional irritation. Detailed strategies to cope with these difficulties were not available in all web sites. Panic attacks, posttraumatic stress, and pain were not covered in any of the web sites; information about depression, epilepsy, self-centredness and hospital were only to be found in three of the web sites.

The web sites were also evaluated to ascertain if educational learning theories were used. They were not. Web sites were ‘seeker’ models of information. They contained factual information and educational learning theories (discussed in Chapter 5) did not appear to be employed.

Three years following the above search of web sites in 2009, a further review of the World Wide Web elicited from Google (the most obvious search engine a lay-person or person with ABI would use) using the search terms ‘Information about brain injury’, I visited the first 20 web sites listed. These were prepared by health services, brain injury support organisations, doctors, lawyers, rehabilitation hospitals and national institutes and are shown in Figure 1.2.
Some web sites had increased the size of the print from size 11 to size 14.

Several web sites had a ‘font resize button’ (if the searcher could locate it) but this information would still be inaccessible for many people with vision impairment.

The general format of the web sites was still complicated and ‘busy’ — two or three or four ‘columns’, the centre column would contain information, the left column a menu to select from — about membership of the organization, donations and so forth.

The sites contained advertisements, colourful/moving pictures of advertising material, moving images and other distracting non-related material.

Some sites had several bold headings — hierarchy of material from most important to least important was difficult to determine. This can cause confusion for the reader as it is difficult to determine where to commence reading.

Some sites had movement of images as the page established itself, some sites clicked straight into a video.

As the layout of web pages varies for each website, each web site required figuring out how to ‘unlock’ a way to access information. The menu to select a specific topic (e.g., physical, cognitive or emotional outcomes of brain injury) for the person to click upon, to access a ‘page’ on the topic, could be found at the top of the page, or on the left or right column of various web sites.

If the person with ABI wished to revisit the material they needed to remember not only which web site contained the relevant material, but where on the web site the information could be found.

<table>
<thead>
<tr>
<th>Figure 1.2 Observations of 20 websites reviewed in 2012.</th>
</tr>
</thead>
<tbody>
<tr>
<td>This review revealed that it can be still be tricky for a person with memory, sight and other difficulties to access web-based information. This information can also be problematic to revisit, compared to reviewing material in a book, where important information can be highlighted for future reference and pages marked with paper or post-it labels.</td>
</tr>
<tr>
<td>Over the past three years on numerous occasions I have embarked on a search for helpful material about ABI. Each search has left me nauseated (due to my double vision — moving images, memory difficulties) and frustrated at the complexity of searching through this material. Seeking meaningful information can be messy, complicated and difficult, and leave the seeker with ABI frustrated and overwhelmed; it can be assumed that many other people with ABI would have similar experiences.</td>
</tr>
<tr>
<td>Reading and understanding about ABI is not a straightforward and linear process. But learning and understanding about ABI can prompt reflection and acceptance, which in turn can prompt a search for more information. In order to learn, people with ABI require information when they are ready to hear and understand it. Relevant information must be presented in a form they can understand, at a time when they are ready to absorb and act upon it. The way the person with ABI is motivated to engage with learning can be affected by a</td>
</tr>
</tbody>
</table>

18
plethora of problems — cognition, processing information, applying knowledge, making choices and making informed decisions.

In spite of numerous searches for helpful material on the internet, I only recently ‘happened upon’ Johnson’s (2010) online book *Traumatic Brain Injury Survival Guide*. Johnson states that he wrote the online book because

> Nearly all of the survivors of traumatic head injury and their families with whom I have worked have had one complaint: There is nothing written that explains head injury in clear, easy to understand language. Most say the available material is too medical or too difficult to read. (Johnson, 2010, p. 1)

The format of this web site was easy to follow; you simply clicked ‘next’ at the bottom of each page, the information was presented in clear everyday language, in large print, with obvious headings, and had no distracting other material on the page. It contained explanations, examples and advice presented in a friendly, positive and empathetic tone.
1.4 Web Information Indicates that Participants in This Study may be Challenged by the following

The World Wide Web search revealed that web pages generally isolate problems and classify them accordingly as physical, cognitive, behavioural and emotional, with smaller areas on social consequences and improvement, even though the effects of these problems overlap and influence each other (see Figure 1.3). **Physical problems:** headaches, nausea, limb weakness or paralysis, reduced strength and coordination of body arms and legs, aphasia — difficulty articulating words, blurred vision, decreased smell or taste and hearing loss.

**Cognitive problems:** short-term memory, concentration, confusion, slow thinking, slow processing of information, difficulty understanding, planning, organising, problem-solving, rigid concrete thinking and mental fatigue.

**Frustration and anger:** anger about injuries or problems that are caused by their ABI, at being disabled, at losing their job, at the loss of friends, money and control of their life. Impulse anger is a direct effect of the damage to the brain. Areas of the brain that normally inhibit angry feelings and behaviour are damaged so the person’s anger threshold is lowered so they become angry more easily and more intensely. (Brain Injury Association of Washington, 1992)

**Emotional problems:** and personality and behavioural changes such as disinhibition, reduced self-control, emotional fragility, difficulty self-monitoring, reduced social skills, inertia and restlessness, (Brain Injury Association of NSW, 1999) all feature as potential side effects of brain injury.

**Severe depression:** and/or panic and anxiety attacks, low self-esteem, mood swings, uncontrollable emotional outbursts, irritability, agitation and unexplained anger, improper social communications, anti social behaviour, sexual dysfunction, denial of changes, delusional paranoia, excessive compulsive disorders and posttraumatic stress disorders are all reported. (Brain Injury Centre, 2008)

**Mental illness:** people with ABI have an 80% likelihood of developing a diagnosable mental illness, and are 3-4 times greater risk of death by suicide. (Brain Injury Australia: Policy Paper – Falls related Traumatic Brain Injury April 2009).

**Grief:** the vast majority of people experience grief and find it much harder to deal with stress after a brain injury resulting in very little ability to cope with the normal stresses of everyday life. (Brain Injury Association of Queensland, Inc., 2007)

**Behavioural problems:** provide challenges for persons engaged in rehabilitation or attempting to successfully re-enter their communities, these problems affect not only a person’s success in rehabilitation, but also his/her social relationships, educational or vocational pursuits, safety and the ability to live happily and independently. (Brain Injury Association of America, 2007)

**Social consequences** of brain injury indirectly contribute to the rising divorce, suicide, violent crimes, illicit drug and alcohol dependency and unemployment in society. People with brain injury are overrepresented in jails 25% to 87% of prisoners suffer from TBI depending on measurement compared to 8.7% in the general public having brain injury (United States Department of Health and Human Sciences)

**Improvement.** Many medical opinions state that people with ABI make the greatest improvement in the first six months following injury, this is followed by slow progress for two and up to five years. Then improvement levels out with some experts stating that people with brain injury don’t get better beyond a certain point.(Kay & Lezak, 1990)

---

**Figure 1.3.** Web-based information revealed problems that people with ABI experience i.e. participants in this study might have these problems.

This overview has provided a background to the problems participants in this study might be experiencing, but failed to identify how the person might progress to learn to fare better, and the negative issues described could seem overly pessimistic to people with ABI.

An additional search for relevant literature resources was conducted on the basis of what other areas a person with ABI, recently out of hospital, would seek out. An established library,
which houses valuable resources covering ABI, was approached but this specialist library did not appear to be widely used by people with ABI or their families.

This study was undertaken as I believe that there is an urgent need to balance the challenges people face with a more hopeful, positive approach. A more recent trend on some brain injury support sites include first-person narratives, stories of hope and courage, which talk about the trauma of ABI, but also provide a positive perspective on living with ABI as a ‘whole’ human being. These will be explored in the following section.

1.5  How narratives provide another way to view ABI

1.5.1  Books

There is a broad array of books and blogs that use narrative (see Chapter 4) to provide valuable insight into the lifeworld of people with ABI. These narratives explain what it’s like to have ABI and contrasts with the medical ‘facts’ about ABI. Narratives facilitate understanding of the emotional and psychological needs of people with ABI by highlighting the way people endure and cope with ABI. Narratives provide information and personal insight for people with ABI and their families. In searching for books and blogs about ABI, terms used included: Brain injury autobiographies, personal narratives, memoirs, brain injury books, brain injury blogs, recovering after brain injury, brain injury - children’s books.

Because the information is in story form, narrative may not be as confronting as reading aggregated information. Additionally, these narratives illuminate blind spots (Wagner, 1993) that are not the focus of medical studies. Reading narrative accounts of other peoples’ ABI experiences can allow the person to reflect and make connections to their own experiences.

Appendix 1.4 lists over one hundred books that can help people understand and deal with ABI, including self-help books. The books and narratives in the following review include those written by people with ABI, books co-authored by people with ABI and their family carers, and books written by family carers, professional writers and rehabilitation professionals. Some of these books are published by mainstream publishers, others by self-publishing organisations.

1.5.2  Books Written by People with ABI: Narratives from the ‘Emic’ (Merleau-Ponty, 1962) ‘Insider’s’ Perspective

Personal narratives are important in all societies (Linde, 1993; Peterson & McCabe, 1991; Widdershoven, 1993). People with ABI portray themselves as fully rounded complex human
beings, with distinct personal histories, a wealth of experiences to talk about and with similarities and differences to other people in their books. The following section includes examples of narratives to put the experience of brain injury in terms of the individual, to contrast with the ‘medical model’ of isolating deficits.

Many books written by people with ABI echo the belief that telling their story is important. Garrison (1996) wrote about how she woke up in hospital after a substantial stroke and thought that she had survived for a reason or a purpose. Recording the experience of ABI is a powerful step in healing. Bruner (1990) hypothesises that people make sense of their experience as they impart it to others. Books written by people with ABI contain an explanation that ‘I am not who you see’, ‘I am really a combination of who “I was” and who “I am”’; they tell the story of how this calamity happened — black ice, fall, car accident, stroke — the story is important (if this happened to me it could happen to you too). They are written in a readable conversational style using easy-to-read words and they speak with authority, genuine understanding and knowledge. They express the struggle, the complexities, the difficulties of ABI; they reiterate again and again that understanding and knowledge is power to the brain damaged person. They seek to motivate people with ABI and their families to never give up, they comfort and guide by passing on their discoveries and they bring hope.

Like mountain climbers, or solo sailors who have circumnavigated the globe, many authors are now motivational speakers. They have had an epiphany, an insight to life. They are examples of Niezsche’s statement:

> If we manage to achieve some measure of understanding of the kind of world in which our human reality has emerged... but if we cannot do much more than comprehend ourselves and things human, this will at least be something — and something quite significant and well worth achieving at that. (cited in Honderich 1995, p. 623)

Explaining the lived experience of ABI is the focus of the narratives that deal with many issues about ABI that I wrote about in ‘Buttons’. They focus on the day-to-day frustrations of living with brain injury. For example, Osborn’s (1997) narrative leads the reader to contrast her pre brain-injury life as a medical doctor, to her post brain-injury life where she has difficulty showering and dressing. Nine years post injury Osborne believes that she is still improving due to learnt strategies. Not only does she tell about what it is like to have ABI, she gives hope as we read of her progress from confusion, grief, loss, dysfunction and alienation to a happy life.
Some narratives focus on the loss of identity. Becker (2004), author of a *New York Times* bestseller, grapples with the question of identity as she provides insight into creativity, identity, love, relationships and the elusive something that makes us us. These could be classed as blind spots of medical research.

A thread that runs through some stories is the importance of acceptance. Skloot, an author of seventeen books, a novelist, poet and essayist wrote his book to tell how he came to accept his injury.

> I used to be able to think. My brain circuits were all connected...I had a memory and an intuition I could trust.... now [14 years later] I can say that I’ve become adept at being brain damaged. It is not that my symptoms have gone away: I still try to dice a stalk of celery with a carrot instead of a knife...Along the way, though, I’ve learned to manage my encounters with the world. (Skloot, 2003, p. 196)

Some books focus on how the person is treated by other people. Calderwood’s (2003) book tells of her struggle to discover her identity and come to terms with her disability and her sense of loss, grief and rage as she’d been labelled a ‘hypochondriac, a liar and a junkie’ (p. 32) and was bullied in the nine months it took to be diagnosed. Calderwood points out blind spots of how undiagnosed people can be treated very poorly by medical professionals and the public. Mason’s (2009) book narrates her struggle to independent living from a vegetative state after being hit by a drunk driver while cycling. This is another ‘blind’ spot — how people with ABI can struggle to live independently.

Another issue written about by people with ABI is their rehabilitation experience. Strand (2004) wrote how the controlled and structured environment of rehabilitation reminded him of elementary school. Because he was not informed of the reason for doing certain tasks, he believed he was expected to agree to complete the task and he resumed the outlook and behaviour he’d had when he was at school. He didn’t realise he was completing tasks to benefit himself, rather he thought it was his duty to please the rehabilitation professional, which resulted in learning very little. He realises that if he’d understood the reason for completing tasks he would have been more engaged in his learning experience.

Strand used metaphors to reflect on the importance of being engaged in the learning process. He uses the analogy of feeling as if he is trapped under ice of a frozen lake, that no one can see or hear him, he can’t get a message through to the outsiders: it is ‘cold, dark and lonely’. He chronicles his achievements so that others can use his experiences to ‘forge their own tools to chip through the ice’.
Meili’s (2003) book, written fourteen years after she was assaulted and raped as she jogged in Central Park, New York, identifies many of the reasons why people with ABI write books: She was looking for a way to turn what was truly horrible into something positive; the attack, meant to take her life, gave her a deeper life, one richer and more meaningful than it might have been (Meili, p. 7). She writes about the capacity of the human body and the human spirit to heal and the power of touch, of the mind. She believes that the heart is as important as medicine in healing, and even though she still suffers from her injuries her experience has let her find her own humanity, kindness and love.

Other first-person narratives take slightly different lines. For example, in his book Winslade (1998), a professor of philosophy and medicine, argues for increasing the amount of rehabilitation available for people with brain injury. Kelly (2010) queries whether he will ever heal from the terrible injury and whether his family will ever enjoy quality of life. Mason (2009), Fairclough (2002), Long (2005) and Carey’s (2006) books tell of the importance of love, faith, acceptance, gratitude, humility, compassion, hope and beauty.

The most immediate, but easily missed, point is that these writers have achieved a great deal simply through the process of writing a book that is published. Their work is an accomplishment in itself, and points to a significant degree of resilience and a commitment and motivation to connect with other people with ABI and society at large, often under very difficult conditions. It indicates that the person has also re-engaged with life and, significantly, many talk about their struggle to relearn both who they are (the new me) as well as the simple practical tasks required to be a writer. This theme of relearning is vitally important as will be seen.

Moreover, in comparison to the formal information content of many web sites, the stories convey hope, determination and a positive view that life can be good, despite their changed identity and circumstances.

1.5.3 Dr Mark Sherry’s Book

Perhaps the most significant book encompassing both an academic view and a true insider’s perspective of ABI is Sherry’s doctoral thesis, published as a book If Only I Had a Brain: Deconstructing Brain Injury (2006). Sherry’s research is ‘insider research’, which is well established in anthropological, feminist and disability research (Barnes, 1990; Bolak, 1995; Morris, 1991). He used a cross-disciplinary theoretical approach that includes social and medical models of disability, lessons from feminism, queer theory, postcolonial and
postmodern literature in his thesis, which examines ABI in terms of impairment, identity and embodiment, and his research draws on his own circumstances as well as that of others.

Sherry states that ‘many disabled people find traditional research methods oppressive’ (Sherry, 2006, p. 15) and concludes that ‘there is a need for important, practical revisions in the way we understand and respond to the experience of brain injury (p. 212). He writes of domestic violence and brain injury, young people in nursing homes and the charity approach of the service delivery system, which came under a great deal of criticism from his participants (p. 212). He also writes about the alarming misdiagnosis of the ‘vegetative state’ and that inability to assess any culturally appropriate information or services is particularly alarming. He states that ‘What has kept me going is knowing that there are many brain injury survivors and allies who are prepared to fight for an alternative vision, where we have rights, choices and respect’ (p. 212).

This brief overview has provided the insiders’ views of issues considered of importance to people with ABI and these issues have informed this study. The following section briefly identifies books written by the person with ABI in conjunction with their family members to detect topics they consider important.

1.5.4 Books Written by People with ABI with Their Family Members

Narrative themes from books written by people with ABI are related to themes written by family members. They have been included here to allow the reader to observe issues considered to be important by people with ABI and their family. Bob and Lee Woodruff’s (2008) book tells of Bob Woodruff’s experience since he was injured by a roadside bomb while an anchor of ABC News in Iraq. Bob and Lee Woodruff have established the Bob Woodruff Foundation to raise money to provide resources to the estimated 320,000 service members who have sustained TBI and estimated 300,000 service members who have probable psychological wounds.

Some books aim to help the person with ABI to obtain power, by helping them to understand ABI. Jameson and Jameson’s (2007) book contains advice to others with brain injury and they assert that for the brain injured person that knowledge is power. Kelleys (2010) describes the effects of brain injury, his denial and the deficits that will not go away, techniques that help him manage and his legal battle for compensation. This book identifies that legal battles could be termed another blind spot. Brennan, (2002), a professor of English with special interest in memory, ‘jump-started’ the memory of her daughter who had ABI by constantly retelling her
story and fostering creativity and humour (traits she had before her brain injury). She states that the book is ‘a collaborative effort bound by love, recovery and reinvention’ and that ‘we’ve showed these doctors how much of you remains, my darling’ (Brennan, 2002, p. 162).

1.5.5 Narratives Written by Family Members

A number of books have been written by family members of people with ABI (Biagioni, 2004; Brennan, 2002; Camp, 2005; Coenig, 2008; Cohen, 2003; Crimmins, 2000; Cromer, 2006 [self-published]; Johansen, 2002; Johns, 2005 [self-published]; Lash, 1993; Morningstar, 1998; Rocchio, 2004). These people have written accounts to tell of the experience of a family adapting to life with a brain injured person, to give hope and motivation to others with ABI and raise awareness of ABI. Themes include grief, loss, love, hope, acceptance and adaptation.

The books introduced in this section are available to be read by people whose life has been affected by ABI as well as the general public. They raise awareness and understanding about the consequences of ABI.

For example writer Thomas’s (2006) book about her husband who sustained ABI was selected as one of the best books of 2006 by the L.A. Times and the Washington Post. The book demonstrates how tragedy can bend, but not break some relationships. Thomas writes of grief and guilt as she shows that a new life can be built upon tragedy. Visiting her husband in the nursing home, where he now lives, he cheerfully said to her ‘if I wasn’t with you and we weren’t getting food, the dark would envelop my soul’ (Thomas, 2006, p. 6). This statement exquisitely expresses what was in Thomas’s husband’s mind at that split second — his appreciation of his wife (and also his need for food) — a good example of what Medved and Brockmeir (2012) would term a story presented in a ‘weird fashion’.

1.6 Narratives Presented on the World Wide Web

ABI support organisations now publish the stories of people with ABI. Brain Injury Australia has a website ‘Your Stories’ (http://www.bia.net.Au/index.php?option=com_content&view=category&layout=blog&id=14&Itemid=32) from which the following are drawn. Some narratives simply tell a story. Lersher tells of how he had a brain abscess and he is still reclaiming the life that he nearly lost, ‘it’s a long road back, and I’m not there yet’. Jess’s story tells about how a fungal chest infection spread to her brain and she was given a 5% chance of survival — she states that she now has ‘a second chance of survival’. Ross Cottee’s story about his fall-induced ABI uses the word ‘fall’ in an
imaginative way. ‘Brain injury is a tragedy? Or a new beginning? Like any piece of art, it is what you make of it how will you view “fall”? The onus falls on you’.

The purpose of some stories is to pass on words of warning: Gladys’s story about her daughter Quita encourages all horse riders to wear a hard hat.

(http://www.abc.net.au/rural/qld/content/2006/s1816663.htm) Brad Schmitz wanted to pass on advice to others with ABI — ‘It’s going to be hard, get organized, take photos (to help memory) set goals and have dreams’.

(http://www.bia.net.au/index.php?option=com_content&view=article&id=269:bbrad-schmitzs-story&catid=14:your-stories&Itemid=32 ) Kimberly Carnevale’s blog (http://www.canineandabledgorving.blogspot.com.au/) is a campaign to prevent ABI and promote awareness. She makes a very significant statement: ‘I do expect compassion and acknowledgement that something life-altering has happened to me’. Ralph Perrin’s story is ‘dedicated to all the people who were about to give up but never did’.

Blogs by people with ABI appear to have a common theme of never giving up, the importance of hope and trying to express what it is like to live a changed life. Indeed, there is an inherent recognition that self-help can be an important part of the process of adaptation and coping, as discussed below.

1.7 Self-help books

There are an increasing number of self-help books being published and these can provide valuable information and strategies — many involve workbooks. These kits and books are most helpful and worthwhile for the person who acknowledges their difficulties and understands the consequences and ramifications of their ABI. The person who actively pursues knowledge to help them deal with grief, memory, organisation and other challenges, and can read and understand words, can benefit from these publications.

But some individuals with ABI may not understand or acknowledge their ABI, they may be stuck in a ‘dark place’ where they pretend they are alright and they ignore or dismiss their difficulties. Their reading, writing and spelling difficulties might make engaging with written material a daunting experience, and memory difficulties might mean they do not retain a lot of what they have written. Additionally, if they do not have a positive memory of school, they may not engage with a workbook-type format as it might seem too much like their memories of school, too much hard work. All products are not suitable to all people with ABI.
This section about narrative commenced with Bruner’s (1990) hypotheses that taking experience can help people make sense of it. A hypothesis is posed that if people with ABI can become involved in a meaningful conversation about their experiences, they can, with dignity, be led to understand and acknowledge their challenges. Then they can become more involved in the rehabilitation process; they will choose to complete a workbook, or write a journal (as suggested in some self-help books) and in so doing discover for themselves things that affect their lifeworld, their life, their wellbeing or quality of life — positively and negatively. They can then choose a way forward.

1.8 Developing a focus for the current research

1.8.1 Application of van Maanen’s Fieldwork, Textwork and Headwork

Characteristics that simultaneously informed my research methods, principles that guided my research methodology, my choice of methods and the ‘talk-about cards’ (see later) employed in the interviews in this study, have been informed by the public information about ABI, and books written by people with ABI reviewed in this chapter. This review also established difficulties/differences/deficits that participants in this study might have.

I have discussed how I have been listening to and observing people with ABI, and I have produced stories and narratives about ABI. This could be viewed as John van Maanen’s (1995) conceptual framework of ‘Fieldwork’ and ‘Textwork’. I have also established that my engagement in education over the past half century has influenced this study.

In order to synthesise the literature reviewed, van Maanen’s ‘Headwork’ will be identified in the figures that follow. Headwork verifies how knowledge gained from literature was analysed, evaluated and applied to inform the method used, and ‘translated’ into everyday language on ‘talk-about cards’. These are a carefully developed group of cards, in easy English, used in this study to support people to choose areas of relevance to speak about their experiences.

It will be appreciated that many issues recorded on the talk-about cards fit several themes, they overlap and do not only fit one topic alone, and the Headwork recorded below identifies how information from this chapter informed the method. In later chapters quantitative and qualitative studies also identify these and other issues.
1. The participant may be fragile and be contending with many challenges. The method of data collection must be user friendly. The way participants engage with this study may be influenced by a plethora of issues: physical problems (headaches, nausea, dizziness, visual, hearing, paralysis, epilepsy, sleeping problems, swallowing, sensory, speech), cognitive problems (intellectual, memory, concentration, inflexibility, lack of initiative, impulsivity, day-to-day difficulties, problems with time, money, problem-solving, confusion, an ‘old me’ and a ‘new me’) and posttraumatic stress and emotional problems (depression, suicidal thoughts).

2. In reviewed books and blogs people with ABI have revealed many important elements that helped them: understanding, knowledge, hope, love, courage, acceptance, faith, beauty, nature, and determination. This information must be made available to participants.

**Figure 1.4.** Headwork 1: The data collection must address these issues about ABI.

<table>
<thead>
<tr>
<th>1. Consequences of physical problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have terrible pain; I can’t walk properly; I dribble and choke when I eat; I fall over and walk into walls; I look like I’m drunk; I can’t talk properly; I can’t do things I used to do; I have to see lots of doctors; I’ve lost my job; I can’t do up my buttons; I go to rehab; I can’t eat properly; I feel sick and dizzy; I can’t see properly; My hands don’t work properly</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Consequences of cognitive/memory problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can’t think properly; I’ve lost my memory; I forget my name; I forget where I live; I forget what things look like; I can’t talk properly; I’ve lost my freedom — I can’t drive; I can’t do things I used to do; I’ve lost my job; I’m dependent and get lost; I forget what you’re saying or I’m saying; I look different; I have to do lots of tests; I’ve lost my family; I’ve lost my friends</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Consequences of emotional problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>I laugh and cry at the wrong time; I can’t do things I used to do; I have to see lots of doctors; I’ve lost my family; I’ve lost my friends</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Other consequences of ABI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement with police, lawyers, isolated</td>
</tr>
</tbody>
</table>

**Figure 1.5.** Headwork 2: Talk-about cards ‘My differences and Difficulties’.

These are populated from the literature, from consequences of deficits/difficulties ‘translated’ into everyday language (statements on the talk-about cards can be easily identified by the shaded boxes).

I feel sad; I feel depressed; I feel distressed; I feel disappointed; I feel bad because I say and do the wrong thing; I feel mad; I feel frustrated; I feel angry; I feel nuts or crazy; I feel scared; I hate myself; I feel unlucky; I feel hopeless (the experts can’t fix me).

**Figure 1.6.** Headwork 3: Talk-about cards ‘How I feel’.

These are populated from the publicly available information about ABI from consequences of emotional problems. And, in stark contrast to the public information available about ABI, a group of positive cards with themes once again drawn from the narratives written by people with ABI or their family.
<table>
<thead>
<tr>
<th>1. People who love me</th>
<th>Love - My family; My friends; Animals; Encouragement;</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Faith and hope</td>
<td>Having hope; Religion</td>
</tr>
<tr>
<td>3. Things that make me feel better</td>
<td>Sunshine; The sea; The country; A cup of tea/coffee; Going out; Staying home; Talking books; Flowers; Sport; Talking; My sense of humour</td>
</tr>
<tr>
<td>4. Things I can do to feel better</td>
<td>Being useful; My garden; Exercise; Doing things I couldn’t do before; Doing hard things; Achieving hard things; Stretching my comfort zone; Making things; Saying ‘I can try to do it’; Books</td>
</tr>
<tr>
<td>5. People who help me</td>
<td>My health professionals; My OT; my counsellor; my doctor; What other people with ABI have done;</td>
</tr>
<tr>
<td>6. Time to heal</td>
<td>Time passing</td>
</tr>
</tbody>
</table>

**Figure 1.7.**  **Headwork 4: Talk-about cards ‘Keys that can release me from the ABI Cage’**.

These are populated from the narratives.

This chapter will conclude by setting out the aims of this study and provide the structure of this thesis.

### 1.9 The Aims of This Study

Gaining self-awareness is imperative for people to make progress. To gain self-awareness takes time. My personal experience and the experience of a significant number of people with ABI indicates that there is a very big gap when people leave the focused body-mending, therapeutically orientated practical task learning they are likely to receive in hospital or rehabilitation hospital. Mending broken bodies can only go part way to mending broken lives.

The complexities of re-engaging with everyday life, becoming self-aware, often poses problems so complex as to further undermine the person’s confidence, and there are seldom sufficient support services available at this time to bridge this gap. Moreover, much of the information that could help the person become aware of their differences, difficulties and deficits provided in web sites is factual, describing problems the person faces without telling them how to address them. This information may lack positivity and hopefulness.

A first theme taken from the initially reviewed publicly accessible literature for people with ABI is that this study must be a *positive experience* for the people involved, both in the process of being engaged with it and also in terms of what they can take away with them. While the negatives, challenges and struggles with life are identified, they must at all times be counter-balanced by positive encouragement and an approach that leads participants to focus on the positive. Participants will not only reflect on their challenges but also on things they
find helpful in their day-to-day lives. The methodology chapter will deal with this issue in greater depth.

A second theme taken from the above initial review of information is the importance of the learning process as a precursor to obtaining self-awareness to re-engage successfully with everyday life. This thesis is therefore also interested in the extent to which this relearning can support adaptation, resilience and ultimately, a satisfying life after acquiring ABI. In the words of Freeman:

"Long term recovery from brain injury is not a medical problem... Medicine has very little to offer in this direction. The way forward lies in education... in fact the medical model... is also often counterproductive to follow. The medical model sees the patient as subservient to the professional. It sees the power of recovery lying in the hands of the physician, whereas the power for recovery lies within the injured person as they relearn their daily living skills. Education is the key. (1998, p. 14)"

A third theme for this study examines the hypothesis that people with ABI can be empowered in a positive way to reflect upon their lifeworld, to identify and consider things that negatively and positively affect their life experience. They can then acquire better insight into their own ABI experience and things they can do to feel and learn to fare better.

Through this enquiry, it is strongly argued that people with ABI benefit from drawing on their own inner resources and their personal support networks, rather than relying solely on external-or expert-driven interventions and treatments. This underpinning assumption has been formed through my personal experience, feedback from my writing and speaking about the lived experience of ABI and books written by people with ABI and their family members. Acceptance, understanding and hope are of vital importance for the person to make progress.

The study aims to test these ideas to see if they hold true for participants of this study and, if so, what particular things help people with ABI. While testing and validating the hypothesis, participants’ experiences will be drawn upon to inform the development of an educational learning tool to use with people who have ABI. The ABI learning resource will support them to identify and harness their own inner strengths and network resources.

The research question is:

- What issues need to be considered to design and trial a method that employs educational/learning principles in order to empower the person with ABI to constructively reflect upon their ABI experience, to better understand themselves (gain greater self-awareness), so they can feel and learn to fare better?
The complexity of the research question can be unpacked through the following subquestions:

- What factors positively affect the lifeworld of the person with ABI?
- Can an individual gain something, ‘be deepened’, by the experience of ABI? If so, can this be used to help others experiencing similar life challenges?
- What factors negatively affect the lifeworld of the person with ABI?

Because of the significant weight of data from the outsider’s perspective in the research area, this study attempts to address the imbalance by employing the binary insider/outsider approach through purposefully examining the issues predominantly from the insider’s perspective. Some outsiders, people who care for and support people with ABI and health professionals, will be interviewed and their data will be used for the purpose of data triangulation.

From an ethical stance, it was important to me that the method used in the study also aim to:

- Do no harm to participants, to give them ‘rights, choices and respect’ (Sherry, 2006, p. 213).
- Build on a foundation, view, model or belief that the wellbeing of the individual with ABI is the most important element to consider. Indeed, building from that strength is more important than any pre-theorised model of disability, the medical or, indeed the social models.
- Assist understanding about ABI, the personal construction of knowledge and identification of things that could assist them to tackle the challenges of ABI.
- Engage participants in a positive, empowering manner by developing and using an ABI learning resource that supports people to learn about the ramifications of ABI, express their frustrations and difficulties and also allow them to reflect upon things that help them, and things that they could apply to help themselves live with ABI.

The following chapter will set out in detail the method employed to address these issues. Subsequent chapters provide literature to support this method and considerations given to the design and implementation, theoretical background and method used to analyse data.

1.10 Thesis structure

Chapter 1 has introduced the raison d’être for this study and brain injury through publically available literature. Chapter 2 will introduce ‘Keys to the ABI Cage’, the tool developed for this study to encourage and facilitate the sharing and learning experience of participants. This
will allow the reader to understand how information from the following three chapters informed this method.

Chapter 3 views ABI from the ‘body-object’ perspective through a literature review of quantitative studies with Chapter 4 viewing ABI from the ‘body-subject’ perspective through a literature review of qualitative studies.

Chapter 5 examines reflection, understanding and insight from the educational perspective. Literature review in this chapter will be focused upon education and learning. The foundation has now been established regarding factors of brain injury and how people learn and Chapter 6 brings together and applies this information in the Methodology chapter.

The following two chapters examine the findings of this study. Chapter 7 is bleak as it examines the factors that negatively affected the lifeworld of the participants with ABI. For the purpose of triangulation, mothers and wives of boys and men with ABI and professionals who work with people with ABI discuss factors that negatively affected their sons, husbands and clients. Chapter 8, in contrast, examines the factors that positively affect the lifeworld of people with ABI and demonstrates that there are a plethora of things that can positively affect the person’s lifeworld.

In Chapter 9 Discussion I consider and review the method *Keys to the ABI Cage* used in this study. The chapter then discusses ‘five golden threads’ that could be considered blind spots of research, once again looking at factors that negatively and positively affected life satisfaction or quality of life or coping of the participants with ABI and mothers, wives, sons and husbands, and professionals’ clients with ABI.

Chapter 10 Conclusions: Finding a balance. This chapter makes six recommendations under the headings of ‘Information so that people can learn about ABI’ and ‘To address some of the factors that negatively affect the lifeworld of the person with ABI’.
CHAPTER 2
INTRODUCING KEYS TO THE ABI CAGE: A TOOL TO FACILITATE COMMUNICATION AND LEARNING — THE MAIN RESEARCH TOOL USED IN THE STUDY

2.1 An Introduction to Keys to the ABI Cage

Chapter 1 introduced ABI from the perspectives of my experience, publicly available information, the perception of people with ABI recorded in books and blogs, and also identified difficulties participants in this study might experience. Chapter 1 also introduced the research question: ‘What issues need to be considered to design and test a method that employs educational/learning principles, to empower the participant with ABI to constructively reflect upon their ABI experience to better understand themselves, (gain greater self-awareness), so they can feel and fare better?’

An examination of the formal academic literature will follow in Chapters 3 and 4. As detailed in the Preface, this chapter provides a very short introduction is made to the main research tool that was developed to encourage the participants to gain greater self-awareness by identifying and talking about issues that positively and negatively affect their everyday life. The reasons for this unorthodox placement of the tool within this thesis are:

- Firstly, the initial idea for the tool comes, in part, from my own experience of ABI, from my ‘fieldwork’, ‘textwork’ and ‘headwork’ (refer to Chapter 1), and provides a link between my past experiences and the present formal study.
- Secondly, Keys to the ABI Cage, a visual and interactive tool to support learning and engagement, is placed at this juncture to allow the reader to obtain a clear image of the research tool.
- Thirdly, as the literature is reviewed (in Chapters 3, 4 and 5), this placement will allow better understanding of the ways in which the formal literature informed the development of the tool.
- Finally, by placing the research tool in this chapter, further reference to and explanation of Keys to the ABI Cage will not be required, making this a more efficient approach.
In the previous chapter I explained how the ‘Coping Cake’ and the ‘Hope Stone’ were used to gain the attention and curiosity of audiences and how these metaphors were employed on scores of occasions for a wide variety of audiences. I used similar analogies, symbols, metaphors and imagery over time, which gained audience interest and led people to reflect and understand important issues about ABI.

In the search for an engaging, original, nonmedical, nonthreatening way to connect and communicate with people with ABI, I was drawn to the metaphor of how brain injury ‘imprisons the individual’. I thought about symbols that could be used to help participants with memory, cognitive and physical difficulties focus on their experience in a completely different way.

I have an ornamental bird cage that has significant meaning for me. For several years following my accident I wore a black eye patch, like a pirate. Friends gave me brooches and china parrots as a joke, but I longed for a dove, a symbol of peace and freedom. When I was working on the manuscript of my book Doing Up Buttons my son Ken located two baby fantail doves, which he presented to me. These tame white doves kept me company. I’d wrap them in a towel and they rested on my lap while I worked on the manuscript, or they would perch on my shoulder. I would take them outside to let them walk about and I tried to give them flying lessons. Fantail doves are not like ‘proper’ birds, as they can neither fly nor walk properly. I felt I wasn’t a proper person as I could neither walk nor talk ‘properly’. These doves appear to have lost their head as they frequently position it behind their shoulders along their back. I felt as if I’d completely lost my head — we had a lot in common and we developed a great bond.

Once Penguin Australia published the book I had numerous media interviews and the doves were often included in the photographs taken to accompany the story. When I went on television, or spoke to groups, I’d take the birds in the fancy travelling cage to remind me to explain how these birds are bred to be like this, so when they are released, they cause a commotion, and flutter in the air, providing a guide to help the homing pigeons find their way home. This provided me with a prompt to say I hoped my book could cause a flutter to help people with brain injury find peace and hope.

Over the years I’ve often looked at the cage and thought brain injury is just like being locked in a cage and the key is thrown away. This was how I decided to use the cage, my old walking stick and a wooden pole topped by a wooden flying pig with fly-wire wings, as an interesting structure to hold cards on which were written words that had been spoken by people with ABI
in my fieldwork prior to this study. Thus, symbols and words were combined to assist people reflect on their experience of ABI. The participant-guided interview was a conversation with a purpose — to help participants review things that helped them in a positive way.

The cage was labelled ‘The ABI Cage’ and once the interview/learning tool was fully developed I called this metaphor-model *Keys to the ABI Cage* to give the process a positive focus. The cage, walking stick and pole held what I initially called ‘talking-cards’ (after Cameron & Murphy’s Talking-mats, 2002) but later changed the name to ‘talk-about cards’ because the cards did not ‘talk’, but they did contain information people had talked to me about and the statements were used to invite participants to talk about their experiences.

The *Keys to the ABI Cage* is presented below and is fully labelled for the reader’s convenience. The cage itself is around 80 cm high and 160 cm high when the pole of the flying pig is added. It is 100 cm wide with the walking stick inserted. This actual physical object, the cage itself, was physically transported to many interviews (see procedure, Chapter 6.2). It immediately captured the interest of the involved parties.
1. Our difficulties and differences can put us in the ABI cage.

2. How we feel about our differences and difficulties can lock us in the ABI cage.

3. Keys that can release us from the ABI cage.
2.2 Description of *Keys to the ABI Cage Interview/Learning Tool*

**Concept**

Knowledge emerges only through invention and reinvention, through the restless, impatient, continuing, hopeful inquiry men/women pursue in the world, with the world, and with each other. (Freire, 1974, p. 58)

Visual images are not only an aid to memory, they form part of how we piece together the relevancy of the past in relation to our present concerns. This is a complex and multi-layered activity, and goes far beyond treating the visual images as simple ‘reminders’ or ‘evidence’ of past events or experiences. (Reavey, 2011, p.25)

Participants with ABI would not expect to be confronted with *Keys to the ABI Cage* — an unusual metaphor-model of ABI, a visually attention-grabbing ‘tool’ to facilitate reflection, communication and learning. The tool divides the complicated issues and consequences of ABI into three main themes. This simplification allows the participant to reflect and more easily understand how ABI affects their lifeworld.

### 2.2.1 Theme 1. ‘Our Differences and Difficulties Can Put Us in ‘the ABI Cage’

This sign can be seen hanging on my old walking stick horizontally inserted into the left side of the cage, along with black-backed talk-about cards held in plastic pockets. Like the two other themes described below, the choice of talk-about cards for this theme were drawn from the literature reviewed in Chapters 3 and 4 (and summarised in Headwork in Chapters 1, 3 and 4), from public information and from personal and wider experiences of people with ABI.

The interview took the form of a participant guided conversation with a purpose. The talk-about cards and other objects in the cage were employed to provide interactive prompts for participants to think about and talk about their own chosen concepts and ideas in the three themed interview focus areas.

The details of how these talk-about cards were populated will be related as the academic literature is reviewed in Chapters 3 and 4. A further point to note is that the tool is ‘organic’. If people wanted to add categories that did not already exist they were able to write on a blank talk-about card and add to the cards available for subsequent interviewees to use. Chapter 5 will further explain how the talk-about cards allowed participants to ‘wander’ through the concepts as they chose, make connections and change their mind after further reflection.
2.2.2 **Theme 2. ‘How We Feel About Our Differences and Difficulties Can Lock Us in ‘the ABI Cage’**

This sign can be seen near the padlock on the cage door. Hanging inside the cage were red-backed talk-about cards, hung on hooks held by bird-shaped mirrors — to remind people to look and reflect. Words on the talk-about cards were drawn from literature (see Headwork, Chapters 1, 3 and 4). Additionally, there were also objects that were metaphors or symbols — a crushed Solo® drink can (to symbolise a crushed life), a snuffed out candle (a finished life) and a toy snake (people see me as scary).

**Photograph 2. ‘How we feel can lock us in the ABI Cage’**

2.2.3 **Theme 3. ‘Keys Can Release Us from the ABI Cage’**

This sign can be seen on the right side of the cage at the top of the long wooden pole with golden keys attached to it. The pole was crowned with a wooden pig with flywire wings — a flying pig — symbolising achieving the impossible. Hanging on the pole were white-backed talk-about cards fixed to a rigid Perspex sheet. These cards had mini objects attached to them (e.g., sun for sunshine, mushroom for nature, tiny cup for coffee) to capture the interest and hold the attention of participants, as by the time they reached this most important stage of the
interview, participant’s attention might be flagging and they might be experiencing fatigue. These particular cards focused on those factors that help to ‘release’ people from the cage. Words on these talk-about cards were drawn from literature (see Headwork Chapters 1, 3 and 4).

Photograph 3. ‘Keys can release us from the ABI Cage’

2.3 Summary

This chapter has introduced Keys to the ABI Cage metaphor/tool and has pointed to the three themes focused upon in the interviews and a number of talk-about cards that variously populate both the physical cage and the Reflection Kit. Thus, clear knowledge bases have been provided to readers by explaining the image of Keys to the ABI Cage. This will allow readers to make connections with the tool’s impact and applications as well as its ongoing development in the following chapters. Appendix 2.1 provides a history of the development of Keys to the ABI Cage.

Chapters 3 and 4 will examine academic literature and, as this review proceeds, further reference will be made to characteristics of participants and how the tool (including themes and talk-about cards) came to be devised.
CHAPTER 3
MODELS AND PARADIGMS OF BRAIN INJURY AND
THE ‘BODY-OBJECT’ PERSPECTIVE OF ABI — LITERATURE REVIEW:
QUANTITATIVE STUDIES

3.1 Introduction

Chapter 1 introduced ABI through my personal experience, a review of books and blogs written by people with ABI, supplemented by a consideration of the information and resources most readily available to people with ABI. In the following chapters the term the ‘golden period’ will be used to refer to the two-year period after acquiring an ABI. This time frame is golden insofar as it attracts the greatest professional input designed to mend bodies and to re-establish basic skills. After the golden period, which can vary in length, people with ABI go home to their communities where they have to mend their ‘fractured lives’. Examples of information and resources that are typically available have been examined, but from what source does this information come? Upon what assumptions is it based?

This chapter, and the one to follow, review the academic literature to explore the model or assumptions upon which data about ABI is sought, and the source of the information. Additionally, this review seeks to provide theoretically sound alternative assumptions, and to inform and populate the methodological tool *Keys to the ABI Cage* that is used in this study.

In the first section of this chapter some of the theoretical frameworks around disability are discussed and two broad categories are identified, the body-object view of ABI and the body-subject view of ABI. The remainder of this chapter will then examine features and assumptions of the body-object view, including research into ABI, leaving a focus on the body-subject view for the chapter to follow.

3.2 Differences in Perspectives of Disability

As already mentioned, it is all too easy to slip into a view that damaged brains produced damaged emotions, damaged behaviour, damaged interaction...damaged people...disabled people. The following introduces philosophies and ways a person with ABI can be viewed.
3.2.1 The Body-Object Model

According to the French phenomenological philosopher Merleau-Ponty (1962), the view we have of the body plays a foundational role in the way we understand and engage with the world. He wrote of difference between the ‘body-object’, as determined and predicted by medical science, as the outsider’s perspective, and the ‘body-subject’, as the body as we experience it, the body that gives meaning to the world around us, as the insider’s perspective. An outsider or etic (Pike, 1954) description of an observed behaviour or belief often holds a different perspective or philosophy to that of an ‘insider’ (emic) (Pike, 1954). Just as body-object proponents rely upon Cartesian dualism and the separation of the body as an external object from its observation, so the body-subject proponents see object and subject as one-and-the-same.

However, even within the bifurcated category, body-object or body-subject, which is used to structure this and the following chapter, there are many different philosophies, ‘models’, or belief systems that have evolved, define and fundamentally affect the way in which the individual with ABI is viewed and treated. Perception of ABI is dictated by the dominant belief, model or ‘lens’ through which the individual, the medical or rehabilitation professional, family member, friend or the general public view, consider, assess, or judge the person with ABI. These different beliefs can affect the way outsiders regard and behave towards the person with ABI.

Disablement models that developed in the 20th century ‘defined the meaning of terms we use every day, and that do not always exert a positive effect upon the people to whom such terms refer’ (Masala & Petretto, 2008, p. 1242). So before reviewing the ABI literature, it is essential to discuss the place of theoretical systems in research. As a researcher, do such frameworks dictate the scientific approach and limit what I want to observe or measure? Should a theory be used as an apparatus to interpret a person’s world? Or should we be looking in our data for the ways in which people themselves construct their own realities and mould something out of these accounts? These questions are not inconsequential because consideration of these questions had a bearing on the method employed in this study.

The individual with ABI may also experience a dichotomy of views, seeing themselves both as a ‘body-object’ (as viewed by medical professionals) and a ‘body-subject’ — the body as they experience it. Zetlin and Turner’s typology (1984) suggest responses to mild intellectual disabilities include ‘acceptors’, ‘tactical dependents’, ‘blame attributors’ and ‘deniers’. These responses also affect the way the person views themselves. For example, if they feel
dependent they may expect the medical profession to rescue and cure them. With their
cognitive difficulties caused by ABI the person may be perplexed because different people
treat them in different ways — from the extreme positions of overpowering sympathy to scorn
and rejection. Confusion, unease and bewilderment can result from this baffling puzzle.
Durham (2007) asserts that disability is at least partly defined by the model through which the
outsider views the insider and this has a powerful influence on the way the insider views
themselves, a point made by Smart (2009) in terms of the relationship between self and other.
Thus, as this study is approached from the insider’s perspective, it will approach ABI from an
interactionist standpoint.

Drawing on the interactionist model it can also be posited that the way the insider is treated
also depends on the model or view of the outsider. Indeed, this often dictates how a person
with a disability acts as a result. The ‘cloak of competence’ described in the seminal work by
Edgerton, Zetlin and Turner (Edgerton, 1993) for example, demonstrates how men with mild
intellectual disabilities seek to ‘pass off’ their disabilities and to ‘get by’ through the veneer of
constructed capability. The stigma of being classified as having ABI (being mentally inferior)
can also lead people to devote their lives to appearing normal and denying to themselves that
they have ABI.

French (1994, p. 3) posits that disabled people are subjected to many disabling expectations,
for example to be independent, normal, to adjust and accept their situation. Added to their
impairments and their comparisons between their current and previous life, these expectations
from others can add to their unhappiness. People with ABI may experience stigma,
discrimination and attitudinal and environmental barriers as they struggle to live as
independently and productively as possible. Legislation, policies and practices have deemed
people who have a disability as unfit for society, sick, functionally limited and unable to work
(Brooks, 1991; Hahn, 1983; Hiranandani, 2005; Mackelprag, 1986; Mackelprang & Salsgiver,
1999).

Indeed Dagnan and Sandhu (1999) argue that the social comparison theory, where an
individual’s self-concept is largely formed by the manner in which they are treated by others
who hold a place of significance in their lives, has impacted upon intellectual disability
theories. From Edgerton’s (1993) perspective, people with intellectual disabilities are
members of a stigmatised category of society. This is why some seek to pass themselves off
as normal. However, the literature based on such labelling theory does not consider people
with ABI. Being labelled disabled/brain injured can impact on a person’s self-concept; it may affect how they cope in social situations and affect their own defined self-image.

The issue of changes in self-image are therefore fundamentally important from the very first point at which the person acquires an ABI and is thrown into close interaction with the medical and therapeutic professions. Practitioners are people of significance in the life of the person with ABI. Therefore, the way the individual is labelled and treated by the professional plays a crucial role in their self-concept.

ABI involves:

Identity, disability, difference, the public and private, human variation...the complex interaction of biological and social focus... power and oppression, and how people are situated in a complex web of interlocking social positions which rarely makes them “pure” victim or a “pure oppressor. (Sherry, 2006, p. 1)

Most practitioners function according to the way in which they have been educated and trained (Smart, 2009, p. 3). They may not focus on other models, or on the fact that their clients hold a different view. This difference in perspectives can affect the establishment of the professional/client relationship as the insider defines their disability differently to the outsider (Gill, Kewman, & Brannon, 2003). Here the professional must rely on their authority, trust by the person or forms of pressure to seek compliance with their regime. Yet the details of such interactional disagreement is often ignored, seldom acknowledged, questioned or challenged (Gill et al., 2003; Pledger, 2003; Smart, 2009). Indeed, it has been argued that ‘much mainstream sociology itself has reinforced the physician’s view that disability is a sickness’ (Barnes, Oliver, & Barton, 2002, p. 11). This view is intricately tied to the history of government policy and practice, which recognises the leadership of some professions over others.

3.2.2 The Moral Model

The first and oldest model of disability is the moral model. In this view disability is a defect caused by a moral lapse or sin….it brings shame to the person with the disability. (Olkin, 1999, p. 25)

Terms such as lame, dumb, mad, feeble and imbecile were used to describe disability. (Cornish et al., 2010, p. 59)

Quinn (1998) posits that up to and during the mid-1900s many people who had disabilities either died when they were young or lived their lives hidden away in institutions or their homes. In the first half of the twentieth century, both the moral and medical models were firmly entrenched in western culture and people with disabilities were segregated from society
Segregation was considered a caring policy in a society which did not care about disabled people.... but World War 1 produced hundreds of thousands of people with disability — who took on the role of the worthy poor’ (British Broadcasting Corporation, 1999, cited in Mackelprang & Salsgiver, 2009, p. 7).

Stereotypes of people with disabilities have developed over the ages and include ‘perpetual children’ (Mackelprang & Salsgiver, 1999); ‘an object to be pitied’ (Wolfensberger, 1973, 1980); ‘brave but pitiable’, ‘objects to raise money for’; ‘a menace or threat to society’ or ‘people to be feared’ (Wolfensberger, 1973). People with disabilities are often portrayed as deviant in literature, films and television. Bogden and Biklen, (1993), suggest that most monsters are in fact persons with disabilities. People with disabilities have been perceived as: ‘sick’, ‘needing special treatment for they should be thankful’, a ‘burden to society — they never quite fit in’, ‘ugly and sexless’, ‘incompetent’, ‘freaks’ ‘cursed by God’, or that the disability was a ‘gift or test from God’ (Gill, 1993, pp. 12–15).

It is easy to see that the fundamental view held by persons within society will lead to actions that reflect such views. People act rationally, but do so in a way that reflects the premise upon which that rationality is based. The perception of the person with a disability being a menace or threat would lead to the persons so labelled being distanced from society. The view that the disabled person’s body and biology are broken and need to be mended, would lead to the primacy of the medical professions in their lives. For the person on the receiving end of such views, the effect of such labels cannot but affect the own self-concept and their reaction to it.

The moral model of labelling views the person with a disability as being responsible for it. It is a result of their bad actions or those of their parents. The religious model has, in the past, been an extreme model where disability is viewed as punishment by God, or a supernatural force and was common in the Middle Ages and particularly during the Inquisition. Although the moral model of viewing ABI can be seen as ignorant, some insiders privately still hold onto this perception (Durham, 1997). This influences their wellbeing and self-efficacy. Some outsiders behave towards insiders, people with ABI, as if they are being punished by God, or because they asked for it by engaging in reckless behaviour, driving dangerously or taking drugs, for example (Durham, 1997).

From a social policy perspective, the person with ABI is seen as a victim of circumstances, deserving pity and the recipient of charity due to the tragedy of their disability. The emergence of the Poor Laws in the UK, for example, demonstrate how a tragedy/charity
model of the 1800s involved the transfer of the responsibility of giving alms from the Church to the government. The personal/charitable model views the disabled as having a tragic, negative, miserable existence but through raising money and resources somehow the suffering and sadness of the disabled person’s lives will be reduced (Oliver, 1990, p. 1; Swain & French, 2004).

Related to this model was the ‘economic model’ in which the state distinguished between the ‘employed, unemployed and unemployable’ (Scull, 1989, p. 219). In this model the person’s inability to work and the consequences of this for the individual, employer and state are established as a basis for social policy. This model is used primarily by policymakers to assess distribution of benefits and to counter fraudulent claims, but this model can lead to confusion and lack of coordination in disablement policy. Another important dimension of this model is that by declaring themselves disabled, the person effectively declares themselves unemployable, the result of which means they are more likely to be confined to the financially disadvantaged sectors of society or, later, institutions.

3.2.3 The Medical Model

The Medical Model places the source of the problem with the person with the disability and stresses the importance of finding a cure or helping the person be more normal (Mackelprang & Salsgiver, 1999; Olkin, 1999). In the mid-1800s the medical model gained momentum as more enlightened and humanistic medicine was introduced and disability was seen as a medical problem, as a defect or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible and rehabilitation...persons with disability are expected to avail themselves of services offered to them and to spend time in the role of patient or learner being helped by trained professionals. (Olkin, 1999, p. 26)

The links between the emergence of medicine and the Great War 1914–1918, cannot be underestimated as the crowds of injured returned from the fronts in Europe, ‘the earliest disability policies of the 20th century around ABI were entrenched in a medical model primarily focused on the physical restoration of individuals who had suffered some sort of physical trauma or impairment as a result of war’ (Blessing, Golden, & Bruy’ere, 2009, p. 2).

Prior to the 20th century there was a high mortality rate of people suffering from ABI but improvement in care made during World War 1 reduced the death rate (Boake & Diller, 2005). Since the Iraq and Afghanistan conflicts, blast injuries caused by war have led to
significant new research into brain function (Belanger, Kretzmer, Yoash-Gantz, Pickett, & Tupler, 2009; Jones, Fear, & Wesseley, 2007).

The medical or biomedical model of disability has had dominance in the public’s perception of disability. The medical model has regarded disability as a defect or sickness that must be cured through medical intervention. It focuses on, for example, training the body to walk and limbs to work again, in order for the person to be able to accomplish everyday tasks; therapy to assist speech; and training to be safe inside and outside the safety of home or a rehabilitation hospital.

Although ABI does not feature in the early literature it was perhaps seen in those times as manifested in physical impairment and mental impairment. It was not until the mid-20th century that it began to have an identity of its own. Looking at the history of professions and their legitimacy it may be that the capacity of medicine to work on the brain and the injured body together gave the category of ABI a life of its own. In this thesis, as will be seen, that life now needs to be similarly transcended to engage with the latter end of a ‘recovery model’, that is, with re-engaging in everyday life.

While the recognition of ABI as a medical issue first and foremost came at the turn of the 20th century it was not until much later that it was formally incorporated within a disability model. In 1980 the World Health Organization described:

> Impairments as any loss or abnormality of psychological or anatomical structure or function; disability as any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being; and a handicap as any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual. (WHO, 1980, p. 14)

People with ABI may fit under this disability or handicap classification, but it was not until 1993, at a meeting on ABI held in Oxford (UK), that the International Brain Injury Association was formed to encourage global exchange of information, to support research, provide training and to advocate for brain injury (International Brain Injury Association).

The body-object approach — the biomedical model — imposes power differences between professional and client (Sherry, 2006; Smart, 2009).

There may be important weaknesses and limitations of the Biomedical Model which are less visible and rarely acknowledged, but have far greater implications...prejudices and discrimination towards people with disabilities has developed not in spite of but because of it. (Smart, 2009, p. 4)
3.2.4 The Social Model

Some models have sought to provide grand or all-encompassing theories around disability. In recent years, the social model of disability has posed a significant challenge to the medical model as a global theoretical framework for understanding disability (Barnes, Oliver, & Barton, 2002). The social model thesis separates the impairment from disability.

Impairment — lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability — the disadvantage or restriction of activity caused by contemporary social organization which takes no account of people who have physical impairments and thus excludes them from mainstream social activities. (UPIAS, 1976, quoted by Oliver, 1990, p. 11.)

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS 1976 p. 4.)

In this model the impairment is seen as a characteristic, feature or attribute that affects an individual’s mind or body function as a result of an injury, genetic make-up or disease. In contrast, disability is seen as socially constructed. Society is built for the able-bodied and so it discriminates against people with impairments. It creates disadvantage through attitudes and culture (e.g., negative images in the media) that reinforces stereotypical views of incapacity, inaccessible environments (e.g., homes, businesses, transport, workplaces, education) and organisations that do not question discrimination nor provide accessible environments. All of these are socially produced barriers to which there can be socially produced solutions.

But there are some limitations to the social model. For example, Shakespeare and Watson (2001) argue that the social model has not so much as replaced the medical model but has simply placed a higher emphasis on addressing disability as a social issue. They go on to explore the background to British academic and political debates over the social model and argue that the time has come to move beyond this position. Three central criticisms of the British social model are presented and focus on the issue of impairment, the impairment/disability dualism and the issue of identity. It is suggested that an embodied ontology offers the best starting point for disability studies and some signposts on the way to a more adequate social theory of disability are provided.

Indeed, the impairment/disability distinction remains unresolved and fails to establish an embodied ontology (i.e., the disability identity itself). Looking at the history of labelling by others, as discussed above, the embodied ontology or body-subject view is potentially hugely
important. Shakespeare (2006) suggests that the way forward lies in a combination of the medical and the social model and new ways of thinking. The issue of impairment, the impairment/disability dualism and the issue of identity are included in the criticisms of the British social model and echo the breakdown of Shakespeare’s relationship with the UK disabled people’s movement as disability studies became too reliant on political rhetoric and ideology (Shakespeare & Watson 2001). Shakespeare states that ‘there is no qualitative difference between disabled and non-disabled people because we are all impaired in some form, some more than others’ (2002, p. 27).

However, the very act of saying the word disability may not be helpful. If there is no qualitative difference, as Shakespeare suggests, then why is it we still recognise a group of people with disabilities versus the rest of society? The issue is borne out in the tone and focus of disability studies literature. Longmore (2003), Garland-Thomas (1997a) and Sherry (2006) argue that the social model of disability focuses upon physical disabilities, while cognitive impairments such as brain injury are overlooked. Chappell posits that ABI is marginalised within the social model and states ‘some of the arguments emanating from within the social model are assumed to refer to all disabled people, when in reality they do not’ (1998, p. 212).

Oliver (2004) acknowledges five common criticisms of the social model (of which he was the key architect): it ignores or is unable to deal adequately with the realities of impairment, it ignores the ‘pains’ (Oliver, 2004, p. 8) of both impairment and disablement, it is unable to incorporate other social divisions, disabled people are viewed as ‘other’ (Oliver, 2004, p. 9) and it is inadequate as a social theory.

More recently, the social model has generated a number of radical critiques posing various alternative terminologies around people with a disability. Abberly asserts ‘a liberative theory of disability requires the posing of values counter to the classical sociological and revolutionary consensus, the assertion of the rights of the human ‘being’ against the universalisation of human ‘doing’ (1999, p. 14). While Finkelstein (1980, 1993) argues that ‘the predominant factor contributing to the disablement of different groups is the way in which people can participate in the creation of social wealth’ (Finkelstein, 1993, p. 12).

Oliver (1990) posits that the comprehensive materialistic account of the creation of disability places ideology at the centre of arguments about disability. In the above models, the assumptions underlying the role of the state/society and the body-object, even though not a medical model, are no less likely to have huge ramifications on the persons so-defined. It is
not without concern that even today, ‘compared to other countries, Australia has a lower level of spending as a share of GDP on long term care...’ (Price Waterhouse Coopers, 2011).

3.3 ABI Is A Unique Disability

The limited consideration of ABI in social science engagement around disability theory is surprising, given the statistics related in Chapter 1 about prevalence and cost of ABI to the community. Perhaps one of the key issues here has been the primacy of the medical model in relation to ABI, as well as the recognition that mending bodies is a legitimate role for medicine and its allied professions. Power is held by the professional who holds the knowledge about ABI. Abberley (1996) states that knowledge is itself an aspect of power:

The standpoint of disabled people, whose interests are not necessarily served by the standpoints of other social groups, dominant or themselves oppressed, of which disabled people are also members. Such society involves the empowerment of disabled people because knowledge is itself an aspect of power (Abberley, 1996, p. 93).

If knowledge is itself an aspect of power how do people with ABI acquire knowledge so they feel they have some ‘power’?

This brief overview has illustrated some of the many ways the person with ABI might be viewed. The person with ABI has many people in their life: family, friends, professionals and people they meet in daily contact who may hold any one, or a mixture, of these models/beliefs. The models have power to influence not only the way the person is treated by others, but how they in turn feel about themselves and also how they believe they should be treated. Models and approaches are not inconsequential, therefore the complexities of invisible but powerful different models and the invisible complex cognitive and memory difficulties the person with ABI may have to manage are an important factor in the reality of ABI as the person themselves experiences it.

As will be seen below, the particular significance of a medical model definition is the concomitant expenditure of resources on research and then therapeutic approaches based on that evidence base. It is argued that this has the potential to diminish the value of other approaches.

The content population of web sites are equally dependent upon these assumptions, so when we see their focus on negative issues around ABI we begin to see that their effect can be significant and challenging. Many of the categories of information reviewed from such web sites in Chapter 1 come from the medical model and the assumption that people with ABI
have broken bodies and that they are broken people. Seeking to maximise people’s capacity to function through medical means is essential, but there are other issues that need to be considered for the person to learn to feel and fare better in the community. These issues are the focus of this thesis.

A cursory review of medical model research, its focus, nature, character and its effects is undertaken below. This literature will focus upon the physical and emotional issues that the medical model seeks to address. The issues can be compared by the reader with issues identified as important by people with ABI in Chapter 1, which link the effects of the physical injury of ABI to the effect it has on them as a social being.

### 3.4 ABI and the Medical Model Assumptions

Millions of dollars are spent on research into ABI, and millions of dollars are spent on rehabilitation programs. The professional has a potentially vast array of data at their fingertips as there are a plethora of tests they can administer to people with ABI, as will be demonstrated in the following section.

Truism though it be, it needs stating that most practitioners function in the way in which they have been educated and trained, (Smart, 2009, p. 3). A search of major medical, rehabilitation and nursing journals demonstrates that the majority of ABI studies follow quantitative approaches. The results of these studies are reported in the plethora of journals, examples of which are shown in Appendix 3.1. In undertaking this review of the literature a number of web engines were used that included: Informa Healthcare; PubMed; ProQuest; Wiley Online Library; Taylor & Francis online; ScienceDirect; Medical Collective; Google Scholar; Web of Science; Ovid Health; Ingentaconnect; Sage Journals online. The search strategy entailed using the following key words: Quantitative studies, brain injury, ABI, traumatic brain injury, TBI, and these in combination with each other and with IQ loss, memory loss, depression, fatigue, coping, pain, cognitive rehabilitation therapy, self awareness, posttraumatic stress disorder, learning disorders, tests, scales, measures, and questionnaires.

A review of the above journals was undertaken by looking at ABI-specific studies in the past twenty years (1991–2011). It is 20 years since I suffered ABI and I hold keen interest in developments made over this period of time. The 20-year time period was chosen in order to establish when the issue was identified to be of interest and to observe new knowledge that was developed over the significant length of time. The review also examined articles in the *Journal of Sociology and Social Welfare, Journal of Poverty, Journal of Social Work* and the
International Journal of Intercultural Relations, which were more social science orientated journals but when searched were found to carry ABI relevant studies.

Quantitative journal articles were reviewed to establish an objective perspective of difficulties/differences and deficits of ABI to (a) provide a background to problems participants may experience, in order to inform the method employed and the tone of this study; (b) examine issues identified by professional studies, which could inform the talk-about cards; (c) identify issues that could be addressed in the ABI learning resource and (d) to look for similarities and differences to issues identified in qualitative studies and books and blogs written by people with ABI. As I am not a rehabilitation professional I did not review studies involving specific rehabilitation programs.

The assessment of ABI and its associated co-morbidities were found to occupy a significant number of studies. However, the co-morbidities themselves were a significant proportion of the literature and they fell into a number of categories. Ten of these categories, the main ones identified, are used as subsections in the review that follows. Where relevant, some of the methods of assessment are also mentioned because they are part and parcel of the approach that turns the ABI into an object, the body-object, to be more precise. Needless to say, some of the more established assessment approaches have a longer history than the 20-year search dates.

3.5 Some Categories of Body-Object Research

3.5.1 IQ Loss After ABI

Intelligent Quotient (IQ) loss represents one of the primary tools through which the medical and associated professions have estimated the effect of ABI. Not surprisingly, a significant number of assessment methods were found in the article review, as highlighted in Appendix 3.2.

Findings in studies reviewed include: people with ABI have a mean loss of 14 points of Full Scale IQ from estimated pre-injury baseline and they show no evidence of recovery 20 months later (Parker & Rosenblum, 1996); performance IQ score on the Wechsler Adult Intelligence Scale-Revised emerged as the most significant predictor of return to work/school following brain injury (Ip, Doran, & Schentag, 1995). Kay and Lezak (1990) posit that traditional intelligence tests, devised using artificial tasks that emphasise old learning, are not an indication to how the person will function with everyday tasks. An average IQ score can mask severe differences — the person can be performing in a superior range on some tasks,
but be severely impaired on others and have trouble with memory, planning and self-monitoring.

I can’t understand; I can’t do things I used to; I can’t think properly; I’ve lost my job;

Figure 3.1. Headwork 1: Talk-about cards’ relevant to the literature on IQ loss

3.5.2 Memory Loss After ABI

Assessment of memory is also important in the objectification of the person with ABI and, as for IQ, a significant number of agendas were identified from the article review. Memory tests used in the studies reviewed can be seen in Appendix 3.3.

There were numerous studies around memory and ABI in the literature reviewed — working memory, prospective memory, deficits in attention and memory, bilateral damage to key structures of the brain, ways to improve prospective memory (Fleming, Shum, Strong, & Lightbody, 2005; Gil, Caspi, Ben-Ari, Koren, & Klein, 2005; Raskin & Sohlberg, 2009; Roche, Fleming, & Shum, 2002; Roche, Moody, Szabo, Fleming, & Shum, 2007; Sunderland, Harris & Baddeley, 1983). Memory impairments are among the greatest impediments to people returning to work, but may be one area of cognition that can respond to restorative intervention (Raskin & Sohlberg, 2009).

Findings from these studies highlight difficulties people with ABI experience with encoding, performance and executing phases of prospective memory, which is the foundation of an intention and remembering to perform the intention. Evaluation of the effectiveness of rehabilitation methods, the frequency of memory lapses and working memory difficulties were identified in the studies.

Schacter, Chiao and Mitchell (2003) posit that ‘...not only is our sense of self based on memories of past experience...but our retrieval, recollection, and reconstruction of the past is, reciprocally, influenced by the self’ (p. 227). Added to the memory difficulties of people with ABI, Schacter and Slotnick (2004), state that memory can be ‘distorted’. Schacter, Chiao and Mitchell (2003) conceptualise this with a metaphor of ‘The Seven Sins of Memory’. These ‘flawed memory experiences’ (Schacter et al., 2003, p. 227) include transience (refers to forgetting over time), absent-mindedness (refers to lapses of attention), blocking (temporary inaccessibility of stored information), misattribution (attribution of memories to incorrect sources or believing you have seen/heard something you haven’t — distorted
misinformation), suggestibility (distorted or invented including bias) and persistence of memories (unwanted recollections for example with posttraumatic stress disorder).

If memory cannot be relied upon (Schacter et al., 2003) how reliable are the test results of people with brain injury? Could their assessment results differ on another day, or another hour of the day? For purpose of this study all these factors must be considered.

Data collection must assist participants to access memories by:

- Having an inbuilt way to help them focus on remembering.
- Developing a new strategy to assist them to discuss their memories or their experience in a positive way.
- Engaging sensory, short-term, long-term and prospective memory.
- Ensuring participants do not feel foolish: they will need prompts to help them to remember issues and also some way to prompt them so that they will remember what they are talking about.

Figure: 3.2. Headwork 2: The memory difficulties of the participant should be considered in the method of data collection.

I forget my name; I forget where I live; I’ve lost my memory; I’ve lost my friends; I’ve lost my job; I can’t talk properly; I forget what things look like; I’m dependent; I get lost; I have to do lots of tests;

Figure 3.3. Headwork 3: Talk-about cards relevant to the literature on memory loss.

3.5.3 Depression/Suicide After ABI

Depression and suicide were also well represented among the articles reviewed. Clinical studies have reported high levels of suicide attempts (18%) and clinically significant suicidal thoughts (20–21%) (Simpson & Tate, 2002). The prevalence, symptoms, significance of cognitive impairment and depression and suicide have been widely reported (Fann, Uomoto, & Katon, 2001; Hoofien, Gilboa, Vakil, & Donovick, 2001; Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 1993; Jorge et al., 2004; Kreutzer, Steel & Gourley, 2001; Rapoport, McCullagh, Streiner, & Feinstein, 2003). These studies employ another series of formalised objective assessment measures as shown in Appendix 3.4.
Data collection must help participants feel comfortable by:

- Taking place at a location where the participant feels comfortable — a local library, coffee shop etc.
- Helping them feel ‘safe’ by explaining several times what they will be asked to do
- Allowing them to take their time
- Letting them lead the discussion
- Allowing them privacy — they must not be ‘pushed’ to divulge private things
- Having ways to redirect negative thinking by reviewing positive things they have achieved
- Demonstrating understanding about their challenges
- Making it a positive process by not ‘threatening’ their self confidence by pointing out their deficits
- Giving them positive ideas to think about as they remember their difficulties

**Figure 3.4.** Headwork 4: The depression and emotional fragility of the participant should be considered in the method of data collection.

Sad; Depressed; Distressed; Frustrated; Angry; Have to do lots of tests

**Figure 3.5.** Headwork 5: Talk-about cards relevant to the literature on depression.

### 3.5.4 Fatigue After ABI

A large number of scales have been developed that attempt to measure the nature, severity and impact of fatigue. Dittner, Wessely and Brown (2004, p. 157) report details of 30 scales and recommend that scales are selected to suit the clinician’s needs and that existing and new scales are developed and validated.

Fatigue greatly influences the post-ABI life of the person and there have been innumerable studies employing different ways to measure and compare fatigue between people with and without ABI. There were many surveys, interviews, questionnaires and scales for the researcher to employ (see Appendix 3.5). Findings of these studies, which include those conducted with people who have ABI, report significantly greater levels of fatigue than the general population, increased daytime sleepiness, lack of energy and exhaustion (Borgaro, Baker, Wethe, Prigatano, & Kwasnica, 2005; Borgaro, Gierok, Caples, & Kwasnica, 2004; La Chapelle & Finlayson, 1998; Olver & Ponsford, 1996; Olver, Ponsford, & Curran, 1996; Ziino & Ponsford, 2006a, 2006b). It has been well established that people with ABI experience fatigue.
Interview/data collection must be of a suitable length of time so participants are not distressed by fatigue.

- Opportunity for participants to take a break – a coffee break.
- Interview broken into segments – each segment discussed so they can see progress.
- By using objects/cards/pictures and words they obtain input not just in words.

**Figure 3.6.** Headwork 6: The fatigue of the participant should be considered in the method of data collection.

I can’t do the things I used to do; I’ve lost my job; I’ve lost my friends; I have to do lots of tests

**Figure 3.7.** Headwork 7: Talk-about cards relevant to the literature on fatigue.

### 3.5.5 Coping Strategies of People with ABI

Studies around emotions and coping (Bornhofen & McDonald, 2008; Pagulayan, Hoffman, Temkin, Machamer, & Dikmen, 2008), emotional and executive functioning (Douglas, 2010; Garcia-Molina, Bernabeu Guitart, & Roig-Rovira, 2010) have examined ways people cope with ABI. During rehabilitation, and post rehabilitation, studies have been conducted into community programs (Vander Laan, Brandys, Sullivan, & Lemsy 2001; Ylvisaker, Feeney, 1998), intimacy (Aloni, Keren, Cohen, Rosentul, Romm, & Groswasser, 1999; Gill, Sander, Robins, Mazzei, & Struchen, 2011), assessing care and support needs (Ladanyi & Elliot, 2008; Turner-Stokes, Williams, & Johnson, 2009). Studies into peer support suggest that peer support can enhance coping, and can also help offset loneliness and the disruption of social support that can be associated with brain injury (Hibbard et al., 2002; Struchen, Davis, Bogaards, Hudler-Hull, Clark, & Mazzei, 2011).

There have also been studies of people with ABI that have investigated coping strategies and relationships between coping, apathy, depression, denial and avoidance and emotional adjustment (Anson and Ponsford, 2006; Curran, Ponsford, & Crowe, 2000; Ownsworth, Desbois, Grant, Fleming, & Strong, 2006; Ownsworth, Fleming, Strong, Radel, Chan, & Clare, 2007).

High levels of emotional distress have been shown to affect coping; higher levels of depression were associated with coping strategies characterised by worry, wishful thinking and self-blame; strategies that focus on problem-solving and having a positive outlook were related to lower anxiety levels. Major coping types identified include emotion-focused, problem-focused, perception-focused and avoidance coping. Examples of inventories used in coping research are again shown in Appendix 3.6.
### Coping strategy identified in literature

<table>
<thead>
<tr>
<th></th>
<th>Examples of talk-about cards</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidance coping</td>
<td>Going out, staying home</td>
</tr>
<tr>
<td>Problem focused</td>
<td>Doing hard things, achieving hard things, Seeing some progress, Doing things I couldn’t do before</td>
</tr>
<tr>
<td>Emotion focused</td>
<td>Talking</td>
</tr>
<tr>
<td>Peer support</td>
<td>My family, my friends, what others with ABI have done</td>
</tr>
<tr>
<td>Health Professionals</td>
<td>Doctor; Occupational Therapist; Counsellor; Health Professionals</td>
</tr>
</tbody>
</table>

**Figure 3.8.** Headwork 8: Talk-about cards relevant to the literature on coping

Chapter 4 will review qualitative studies around coping, resilience and quality of life.

#### 3.5.6 **Pain Following ABI**

The incidence of pain following brain injury shows that chronic pain is a significant problem in mild, moderate and severe TBI (Lahz & Bryant, 1996); that shoulder pain after TBI is a clinical issue that has not been well researched or recognised (Leung, 2006) and that pain is quite common because the nature of many ABIs being the result of accident (Sherman, Goldberg, & Bell, 2006). Scales and tests are again listed in Appendix 3.7.

| I have terrible pain; I have to see lots of doctors; I attend rehab; I have to do lots of tests (medical); I can’t do the things I used to do; I’ve lost my job; |

**Figure 3.9.** Headwork 9: Talk-about cards relevant to the literature on the consequences of pain.

#### 3.5.7 **Cognitive Rehabilitation Therapy**

Perhaps one of the closest links between therapeutic intervention and re-engagement in everyday life was in the area of cognitive rehabilitation therapy. Several articles were found in the review of this area. Giles (2010) conducted one of the largest randomised controlled trials of rehabilitation after traumatic brain injury to examine the theoretical relationships between cognitive and functional rehabilitation. The study added to the evidence base supporting neurofunctional intervention in addition to standard care in improving independent living skills in people with moderate or severe TBI.

Cognitive rehabilitation therapy is a process of relearning cognitive skills that have been changed or lost because of damage to the brain cells or chemistry. It involves education about cognitive weakness and strengths, process training — practicing cognitive skills, strategy training and functional activities training. Harley et al. describe it as ‘reinforcing, strengthening, or re-establishing previously learned patterns of behaviour, or establishing new..."
patterns of cognitive activity or compensatory mechanisms for impaired neurological systems’ (1992, p. 63).

Schoenberg et al. (2011) compared outcomes of patients who received computer-based cognitive therapy with participants who received face-to-face speech–language rehabilitation and established that similar outcomes at a similar cost were the result. Carney et al. (1999) ascertained that specific forms of cognitive rehabilitation reduce memory failures and anxiety, and improve self-concept and interpersonal relationships. Cernich, Kurtz, Mordecai, and Ryan (2010) explain current treatment options and Grealy, Johnson and Rushton (1999) used exercise and virtual reality to improve cognitive function. They concluded that exercising in a virtual environment offers the potential for significant gains in cognitive function. Yet Kay and Lezak (1990) warn against ‘The Rehab Wizard’ — where people with brain injury and their families feel let down by the belief that cognitive retraining would be the answer to behavioural and cognitive difficulties.

The links between cognitive function and re-engagement with everyday life are obvious. The objective measurement, based upon pre-established understanding of cognition, establishes an important framework through which to maximise cognitive functioning. However, the objectification of the person’s cognitive skills can miss the connections between cognition and other aspects of the person’s life, and the person’s view is an important feature as a focus for re-engagement in everyday life. Cognitive rehabilitation therapy involves professional intervention and there are computer-based programs that can be used by the person once they have returned home. In Chapter 5 more will be said of the links between cognition, learning and ABI.

3.5.8 Self-Awareness After ABI

Self-awareness is another important area that has been the focus of studies examined in the review. Fleming, Lucas and Lightbody (2005) posit that self-awareness is a complex phenomenon that impedes rehabilitation process and outcome. Their study provided an individualised program to improve self-awareness. These programs were successful but, in all four cases, were accompanied by anxiety. Ownsworth et al., (2007) studied awareness and long-term adjustment and different awareness typologies were identified. Individuals with good self-awareness and high defensiveness demonstrated the most favourable outcomes. Ownsworth, Desbois, Grant, Fleming and Strong’s (2006) study of the associations between self-awareness and emotional wellbeing empirically supported the theoretical view that an increase in self-awareness is associated with improved employment status. Fleming and
Ownsworth’s 2006 review of awareness interventions in brain injury rehabilitation was conducted because ‘...unawareness related to brain injury has implications in rehabilitation, functional outcomes, and the emotional well-being of clients’ (Fleming & Ownsworth, 2006. p. 74).


Research has shown that clients with better self-awareness of their impairments have better participation or involvement and compliance in rehabilitation (Fleming et al., 2005; Fleming et al., 1998). Thus, there is a complex interaction between self-awareness and compliance. Self awareness and compliance will be issues to address in this study for participants with ABI.

### 3.5.9 Posttraumatic Stress Disorder After ABI

Studies also evaluate the relationship between acute stress and posttraumatic stress, memory and amnesia (Bryant & Harvey, 1998; Bryant & Harvey, 1999; Harvey & Bryant, 2000; Gil, Caspi, Ben-Ari, Koren, and Klein, 2005). There are other studies about persistent postconcussive symptoms and posttraumatic stress disorder (PTSD) as a consequence of war by Schneiderman, Braver, and Kang (2008); Hoge, McGurk, Thomas, Cox, Engel, and Castro (2008) and Ohry, Rattok, and Solomon (1996). Bryant, Marosszeky, Crooks, Baguley and Gurka (2000) investigated the effect of PTSD on rehabilitation after severe ABI. Many scales are used in these studies (see Appendix 3.8.)

### 3.5.10 Learning Difficulties After ABI

Studies suggest learning difficulties can result from ABI through the combination of cognitive, memory, sight, hearing, understanding impairments that result from damage to the brain. There are many studies in regards to such learning disabilities: Siegal (1989, 1999), Sternberg and Spear-Swerling (1999), Stanovich (1991), Swanson (1993a, 1993b), U.S. Department of Education (2000), Wagner and Garon (1999) and Wong (1996). This topic will be examined at length in Chapter 5, which focuses upon education and learning.
This brief examination of quantitative academic literature identifies the focus on selected issues. Other areas of interest are represented in the section below.

3.5.11 Other Areas of Focus in Studies

Studies of the ‘effect of ABI on the family’ of people with ABI examine the needs of the family members of patients with severe TBI. Bond, Draeger and Manleco (2003) concluded that ‘the need to know, the need for consistent information and the need to make sense of the experience was vital’ (Verhaeghe, Defloor, & Grypdonck, 2005).

There are also studies that touch upon social identity and social support, which have been viewed from different perspectives with various discoveries. These include: cognitive deficits have been found to bring the person closer to family (Haslam, Jetten, Postmes, & Haslam, 2009); there is an identity crisis and disruption associated with ABI (Teasdale & Engberg, 2001) and the social isolation and relaxed way of living in rural areas has been found to accommodate the fatigue of the person with ABI (Jones & Curtin, 2010). Community integration involving relationships with others, independence in one’s living situation and activities to fill one’s time have been recommended in McColl et al.’s 1998 study.

Chapter 4 will review further studies about coping and brain injury, occupational adaption, experience of recovery, the meaning of feeling well and quality of life by examining qualitative studies. Chapter 5 will review literature around learning, learning and brain injury, learning disabilities, experiential learning, learning theory. However, prior to moving to these reviews, more needs to be said about the body-object literature and its relevance to this study.

The studies above show particular foci, most of which are based around deficits. Another indicator of the breadth and depth of interest was the range of topics investigated in research articles in the *Journal of the Australian Society for the Study of Brain Impairment* over the past two years on these areas: memory (23 articles), communication (10), cognition/motivation (9), community rehabilitation support (8), rehabilitation outcomes (5), residential care (4), executive function (4), anxiety (4), social behaviour (3) and family (3). Two or less articles were found on: neural cells/genes, physical fitness/leisure activities, behavioural change, goal setting, depression, dementia, emotional adjustment, emotional impact hospital to home, occupational issues, early recovery rates, reasoning, and positive psychology.

As demonstrated by information under the ‘Headwork’ headings, the development of *Keys to the ABI Cage* drew upon this literature. The literature review was used to inform the process
through which to engage people with ABI so as to do no harm. It was anticipated that they would be suffering from IQ loss, memory impairment, depression (even suicidal thoughts), fatigue, lack of self-awareness, posttraumatic stress disorder, difficulty coping and pain. Thus I was approaching and engaging fragile, vulnerable people in reflecting upon their ABI experience.

The talk-about cards, which were a central part of the process, ‘translated’ difficulties participants may be experiencing, and the differences of their pre- and post-ABI life into everyday, colloquial comments upon which they could choose to reflect if they wished.

### 3.6 Some Reflections on Quantitative Body-Object Research

The approach of the medical model is that ‘defects or failure of a bodily system are detected and ... goals of intervention are cure, amelioration of the physical condition to the greatest extent possible’ (Olkin, 1999, p. 26). The literature reviewed has demonstrated how specific difficulties/differences/deficits have been separated for specific examination by experts in various fields. But it is the combination of the total of the overlapping difficulties/differences/deficits that affect the lived experience or lifeworld of people with ABI. Moreover, these must be set against the positive aspects of their lives, which are seldom if ever mentioned.

The importance of the difficulties/differences/deficits (IQ and memory loss, depression, cognitive rehabilitation therapy, fatigue, lack of self-awareness, posttraumatic stress, coping and pain) cannot be ignored. These topics focus upon and consider answers to blank spots, areas that have been identified as some of the things that are more likely to be found among people with ABI. However, these studies are second-order accounts, which may fail to establish the self-reported impact and meaning from a person-first perspective.

Tests for IQ or memory loss are not the same as the initial medical tests conducted in the acute hospital stage to determine the damage to the person’s brain (for example, magnetic resonance imaging; computed tomography or computerised axial tomography; electroencephalogram; position emission). These medical tests are used to ‘prove’ the physical brain has been damaged.

It is more difficult to prove ABI through IQ and other tests, and tests may not identify how the person feels because of their ABI. Some people feel uncomfortable about others judging and knowing about their difficulties, and there are many reasons why a person may perform a
test badly or well. These include motivation, whether or not they are having a good or bad day, time of day the test is given and so forth, but test results are taken to be of great importance when used in legal proceedings. The body-object perspective investigated by these studies ‘filters down’ to be reported in web based material, as the basis for information in many brain injury support web sites. For the person with ABI, reading about possible difficulties/differences/deficits can be valuable because they provide information so they realise they are not imagining things and that they are not alone, but there may be little information to aid or help the person adapt, cope and re-engage in life, and the reporting may reinforce the view that they are ‘more damaged’ and ‘less normal’ than the rest of society.

Viewed from the ‘body-object’ perspective, ABI leads to the assumption that a formulaic piece-by-piece response by medical and rehabilitation practitioners is all that can be done. But, as will be shown, this perspective is problematic as the approach is one based on defining problems and not about examining the positive aspects of the person’s life.

The nature of data collection, where the person with ABI may be treated as ‘the object’ of professional and professionally shared expertise, may further disempower the individual. Most importantly, this medical model of research is transposed into the rehabilitation setting, where the issues of the inequality of power between the professional and the client is taken as a given. The professional (the expert with all the knowledge) administers a test or questionnaire (that may have been trialled and developed in studies) and the client, the person with ABI, is required to comply and answer the predetermined test questions (See Appendix 3.9).

- Because of the number of ‘tests’ given to people with ABI, the method employed in this research should not be like a test.
- The method should give the interviewee the power to choose issues to discuss and whether or not to disclose information.
- The participant should hold the power, be in control.
- The method should focus upon things the interviewee does to help themselves.
- Engagement with the method should have a positive outcome.
- The method should acknowledge that the interviewee has many challenges, and acknowledge that having ABI is difficult.
- The method should foster hope and empower people to share with others the ways they tackle their difficulties.
- The method must be user friendly, easy, use non medical language and be nonthreatening.
- Participants must not feel they ‘have’ to participate in this study, they must not be bullied or coerced to participate.
- Participants will be the ‘expert’.
- The possible emotional fragility and fear of new situations will need to be addressed.

Figure 3.10. Headwork 10: Reflecting on body-objects tests and this study.
Participants must be comfortable being engaged in this study by:

- Helping them to understand what is required of them.
- Helping them to understand why they are participating – the purpose.
- Ensuring they don’t feel foolish: they will need prompts to help them to remember issues and also some way to prompt them so that they will remember what they are talking about.
- Ensuring that they can reflect upon their experiences (including their deficits) in a way that does not upset them.

Figure 3.11. Headwork 11: Participants should feel comfortable.

‘Headwork’ Figures 3.10 and 3.11 demonstrate considerations of the participants that were made from the body-subject perspective. Chapter 1 demonstrated other important issues (love, hope, courage, determination etc.) that affect the lifeworld of people with ABI, both in hospital and once they leave the rehabilitation setting. These could be regarded as blind spots. These factors are not generally the focus of quantitative research (nor rehabilitation); indeed, they may not be issues that can be addressed by medical professionals, but that does not mean that these other issues are not vital to the individual as they re-engage with life. This study intends to identify things that help people with ABI to learn to feel and fare better and to share these collective concepts.

Appendix 3.1, Box 3.1 demonstrates there are a great number of academic medical, rehabilitative and nursing journals. The focus of literature reviewed in these journals predominantly covers the ‘golden period’ when the person with ABI has most contact with professionals who can ‘make a difference’, the period over which the body can be ‘salvaged’ and ‘repaired’. Previously, the topics that appeared in the literature in the Journal of the Australian Society for the Study of Brain Impairment over a two-year period were employed as an example to illustrate the connection between the research funding and professional and academic interest, and the focus upon the ‘golden period’.

But the consequences of ABI remain with the person for many years, or a lifetime, not just the golden period. In spite of the tremendous advancement in knowledge gained about ABI there is little information available about the way people with ABI understand their new situation, or how they feel about rehabilitation, or being involved with research studies or how they regain their sense of identity, or things they can do to help themselves.

3.7 Summary

Quantitative body-object literature provides empirical data about particular difficulties/differences/deficits that are examined. These studies have led to the development
of questionnaires, standardised measures, scales, tests, collateral reports from relatives to
determine deficits in order to identify the impairment of the person with ABI, and to assess
improvement. But ‘learning to improve’ or ‘learning to live again’ does not cease for the
person with ABI once their engagement with the professions has diminished or ended. Indeed,
it might be argued that the importance of relearning in situ, where they re-engage with their
everyday lives is as important as the initial professionally dominated period.

From the literature reviewed in this chapter it has been found that people with ABI are known
to lack self-awareness, they can experience memory difficulties and can become distressed
when they become aware of their difficulties and limitations. These issues were considered in
the development of Keys to the ABI Cage method, which aims to provide a positive
experience for participants as ‘Headwork’ in this chapter has demonstrated. Examples of talk-
about cards informed from the quantitative, body-object literature will allow the participant to
reflect upon their own experience, by exploring both the positive as well as negative aspects
of their lifeworld. Being involved in this research should not pose a challenge, as participants
will be reflecting upon and speaking of their experience.

This study is designed to access the first-person experiences of people with ABI. Participants
should not be obliged to understand and answer questions. As it presently stands, the
quantitative, outsiders’, body-object, medical model may not fit the needs of the fragile
participant experiencing multiple challenges.

The period of relearning for people who acquire an ABI lasts a lifetime, yet few studies
examine the period post professional input. This study will focus on the period when people
are learning to re-engage with the complexities of their relationships and home lives after the
professional period. This implies that the methodology for this thesis should seek to adopt an
approach in which there is a learning element. Chapter 5 will examine literature about
learning.

Finally, the approach adopted should not accept that body-object based information exhausts
the information that should be publicly available. Indeed, such information may be
counterproductive to personal identity and the views other have of relatives with an ABI. In
his study Sherry (2006) suggests:

... a need for the theoretical revision of both the medical and social models of
disability. Issues of rights, inclusion, respect, and diversity are often
marginalized within the medical model, where the focus is on labelling the
‘deficits’ of an impaired body. Likewise, issues of identity, embodiment and
human agency are often sidelined in the social model, where the focus is on
identifying disabling barriers, often from a structuralist or materialistic perspective. (Sherry, 2006, p. 203)

Taking into account Sherry’s recommendation, the following chapter will examine the body-subject, qualitative literature. The debate in Chapter 4 will compare and contrast the phenomenon of ABI from the perspective of qualitative studies with the body-subject or the insider’s’ perspective, as a counterpoint to the view so far developed in this chapter.
CHAPTER 4

THE BODY-SUBJECT PERSPECTIVE OF ABI. LITERATURE REVIEW:

QUALITATIVE STUDIES

People create reality and their lived experience as they reflect on, interact with and respond to others; thus reality is fundamentally inter-subjective. Only theories that take into account this inter-subjective nature of human experience can understand, explain, and illuminate how people create their social and personal realities. (Prus, 1996, p. xii)

4.1 Introduction

Brain injury was introduced in Chapter 1 by reviewing publicly available information and narratives from people with ABI, including my personal experience. Keys to the ABI Cage, the research tool used in this study, was presented in Chapter 2. Different philosophies or models through which ABI has been viewed were discussed in Chapter 3, along with a brief review of ‘body-object’ quantitative studies to demonstrate the breadth and depth of ABI research. van Maanen’s Headwork was used to inform both the method and the talk-about cards, which comprised the collection used with the research tool. The models of disability outlined in Chapter 3 established pre-theorised versions of reality which, it has been argued, would impose a prior framework for interpretation if adopted. The phenomenological stance allows the data from people with ABI to ‘speak for itself’, to establish their meaning and, from this, to ground our understanding in those areas that have meaning and relevance to those with ABI. Collectively, much of the research reviewed in Chapter 3 was undertaken to quantify deficits and assist treatment to help people with ABI make progress within the golden period. The findings of these studies were reported to professionals in academic journals using medical language and quantitative data. However, this process can be blind to anything outside of the syllogism that starts with mending broken bodies as a premise. Wagner (1993) would classify a focus on mending deficits as blank spots.

This is not the only way to perceive ABI, nor treat people with ABI, and as will be demonstrated in this chapter, the body-object study misses a large portion of the phenomenon that is of importance to the insiders, to people with ABI who question ‘Will I ever feel better? Will life always be this awful? I’m lost, how can I find myself?’ (Durham, 1997).

As this study is approached from the insider’s perspective and I place myself as a ‘visible researcher’ (Denzin, 1994), this chapter returns to the perspective of the insider’s, body-subject, emic view introduced in Chapter 1. To do this I will commence by considering the
person with ABI as being *more* than the sum of their parts. Then I will revisit the concept of ‘intentionality’ to establish that the insiders’ view *is* important. Next, I will review the insiders’ perspective as it exists in the qualitative academic literature, which places an emphasis on personal narratives and insider views. This will be followed by a discussion of the feminist perspective of research involving vulnerable people and phenomenology as a philosophy and from which ideas were drawn for an ethical approach to data collection.

This chapter will establish the place of this study within the body of work of qualitative body-subject research: research that focuses on ways people experience ABI. The review of qualitative studies, together with the perspectives discussed in this chapter, informed the methodology employed in this thesis. Chapter 5 will continue to provide a background to the methodology by reviewing relevant learning theories and concepts from educational literature.

### 4.2 Intentionality: Another Way to Consider ABI

Since the second century, when problems of brain injury were first recorded, people have been searching for a way to make ‘broken heads’ ‘better’. The old nursery rhyme ‘Jack and Jill’ (1795) tells the story of two children who went up and fell down a hill — Jack fell down, and broke his crown, and went to bed to mend his head with vinegar and brown paper. Jack and Jill, if taken literally, suggests that binding the head with vinegar and brown paper was a way of treating ‘broken heads’. This study aimed to find a new way to help ‘mend’ broken heads.

A sinister origin of this rhyme suggests another theory about the head, and offers another way to view brain injury. ‘Jack and Jill’ is claimed to tell the story of King Louis XVI’s (Jack’s) beheading (lost his crown) followed by Queen Marie Antoinette (Jill) who came tumbling after. Louis XVI’s severed head was held aloft, by the hair, by the executioner, to allow the head to gaze on its body as consciousness was believed to remain for at least eight seconds after beheading until lack of oxygen caused unconsciousness and eventual death.

For many people ABI is akin to ‘losing their head’. Like King Louis’s eyes gazing at its own body, they can observe their own body and life, but they are quite disconnected from it. In a split second mind, memory, movement and hope can vanish leaving the individual with ABI profoundly damaged, unable to understand, unable to call on prior knowledge, unable to find a way forward. It is as if they have ‘lost’ their head, ‘lost’ themselves, and ‘lost’ their life as they knew it. As weeks and months pass they can spiral down feeling discouraged, desperate, humiliated, worthless and disorientated (Durham, 1997) because to improve cognitively and
physically is a long, slow process. This study poses the question: Can we find a new or different way to reconnect head, body, life and dreams for people who suffer from ABI?

Until fairly recently there has been a focus on the body-object and the limitations of impairment, and rehabilitation has been the dominant intervention for people with ABI. Now, from within educational and disability studies, ideas are being examined about diversity (Barnes, Oliver, & Marton, 2002; Mercer, 2002; Vernon & Swain, 2002; Walmsley & Downer, 1997), inclusion (Hall, 2002; Stroman, 2003), and ‘invisible disabilities’ (Stone, 2005). Stone’s (2005) study demonstrated that there is an unspoken belief that disabilities worth taking seriously are readily visible. However, there are many mental conditions such as depression, anxiety, schizophrenia, cognitive impairments related to stroke, and brain injury and chronic pain conditions that The National Rehabilitation Information Centre classify as invisible disabilities.

The body-object perspective, the medical model, focuses on mending deficits and does so by isolating different aspects of the person affected by ABI. Saxe, in the nineteenth century poem ‘The Blind Men And The Elephant’ (Appendix 4.1), points out that the beast was more than the sum of its parts; that people think they can ‘see’ when in fact they are ‘blind’ or unaware and they speak knowledgeable about that which they do not know. This poem articulates how the person with ABI may view the way they are treated as just isolated ‘bits’ of themselves, rather than taking them as a whole person. This poem could be viewed as a metaphor for the body-object view — it does not see the person as a whole person.

Rees (2011), in his book Out of Calamity, depicts people with ABI as whole people with many facets. In his narratives about people with ABI, Rees tells the story of Phillip, a young man with ABI. Phillip’s parents are delighted when they come across notes that he has scribbled: in their eyes this is an indication of improvement. But ‘his mother’s claims about his improvement has raised a few eyebrows among the more prescriptive and sceptical professionals…(who said) anyway his mother is not objective and doesn’t know what she is talking about’ (Rees, 2011, p. 60).

From the perspective of the insider, ‘those professional gainsayers, and there are many of them...’ (Rees, p. 64) can impact upon the individual. In considering Joe, another person with ABI, ‘few (professionals) if any gave Joe any hope’ (Rees, p. 79); fortunately Joe received kindness and understanding from the hospital cleaners. ‘Joe’s serious injury, isolation, lack of hope, let alone activity had drained his strength’. These quotes provide an example of how some people with ABI and their family perceive their treatment by professionals; their need to
be listened to, their point of view taken into account, even small positive issues to be considered and their need for encouragement and hope.

Encouragement and hope are most important elements for the person struggling with ABI. As I explained in Chapter 1, one reason for undertaking this study was conversations I have had with hundreds of people with ABI who have attended my presentations or workshops, who told me that they felt, and still feel powerless. Simon (all names in this thesis are pseudonyms) stated: ‘They (the professionals) thought I was stupid but I’m not, I’m just slow.’ Mark remarked: ‘The medical viewpoint is that people with ABI don’t have insight. This is not true…we do have insight…we have to re-assess our own lives’. But the body-object perspective can take away hope and further disempower the person with ABI, who, with ‘King Louis XV1’s gaze’ (or the gaze of the decapitated head surveying the person they once were) may see themselves as no longer an individual. They may see themselves as waste material or garbage, someone not taken seriously, stupid, a ‘retard’, an object of ridicule, pity, a victim, a child again, sick or ill because their ‘daily life is medicalized’ and ‘as good as dead’, (Wolfenberger, 1980, p. 71–115).

The body-object language such as ‘physical problems’ does explain the consequences to the person, who may feel unintelligent and dumb: Jo-Anne said: ‘I can’t walk normal and I fall over. I feel stupid’. Jo-Anne, together with the majority of people with ABI would not have used the word ‘cognition’ before their ABI, so terms such as ‘cognitive impairment’ need ‘translation’ so that people like Jo-Anne can understand how having cognitive impairment can impact on their everyday life. Terms like ‘behaviour impairments’ or ‘personality dysfunctions’ may not explain that a person with ABI might feel out of control and do crazy things that they would not have done prior to their ABI.

At writing workshops Peter made the observation: ‘When I get mad I do mad things: I threw my new typewriter in the river because the keys weren’t in alphabetical order!’ demonstrating in a humorous way that later he had insight into what was normal/not normal and the affects of anger and frustration. Max remarked ‘When I was mad I chased an emu’, indicating he also had insight into ‘foolish things’ he could do when he was angry. Phillip said: ‘I need a “cone of protection” like Maxwell Smart, to keep out my anger’, showing he had considered his anger problem and found a ‘socially acceptable’ way to describe it. Martin divulged that ‘I’m not mad. I just pretend to be’ — demonstrating he was aware of ‘what’s what’, and ‘who’s who’ but that he could only accomplish his ends through extreme behaviour. These comments support the findings of Egan, Chenoweth and McAuliffe’s (2006) study, who found that
people with ABI are capable of greater insight, reflection and humour than indicated in previous research.

‘Choice’ and ‘Power’ may not feature in lists of impairments, but people with ABI are acutely aware that ABI brings with it loss of choice, loss of power to have a say in what they want to do. Poignant statements such as from Atticus: ‘The moment my stroke hit me in the back paddock I lost my choice’; Adrian, ‘I felt disempowered in rehab. If you stay disempowered they keep their jobs’. These statements about the predicament of powerlessness of people with ABI have been expressed to me at ABI support meetings.

People with ABI listen to other people with ABI; there is understanding and a bond. Felicity said: ‘It’s helpful to know others have the same experience’; Pip remarked: ‘It’s good to know someone understands’; Ian thought: ‘There’s a lot of wisdom in this room full of people with brain injury, a lot of experiences’; John explained by saying: ‘I can feel what you say mate’; Pru commented: ‘I want to be seen as me, an individual, regardless of any disability’.

These quotes highlight the difference between the body-object and the body-subject, which is private and ‘beyond, or before, language’ (Law & Mol, 2004). The body-subject has been articulated in philosophy, anthropology and sociology as well as in medicine, and the body-subject will be the focus of this research.

### 4.3 ABI from the Qualitative Body-Subject, Emic, Insider’s Perspective

This thesis has looked at quantitative studies and information obtained by professionals about deficits that affect people with ABI. But we have had little explanation of how people understand and make sense of their new lifeworld. The qualitative tool *Keys to the ABI Cage* was developed to provide the person with ABI a way to start to understand their difficulties, differences and attitudes, to make meaning of their ABI experience. This has much in common with the body-subject view, with the seminal ideas of phenomenology.

Qualitative research is a form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live…understand, describe and interpret…explore the behaviour, feeling and experiences of people and what lies at the core of their lives…an interpretative approach to social reality and the description of the lived experience of human beings. (Holloway & Wheeler, 2010, p. 3)

Qualitative research does not have a predetermined theoretical framework, but data has priority; researchers must ‘immerse’ themselves in the setting of participants; it is initially
broadly focused, process orientated, context-bound, and involves getting close to data (Holloway and Wheeler, 2010, p. 10). The focus is on the emic; ‘thick descriptions’ (Geertz, 1973) which are detailed portrayals, interpretations and the uncovering of feeling; the researcher–researched relationship is based on the concept of equality as human beings; the researcher is visible and is the main research ‘tool’.

The use of qualitative research has only recently begun to populate the literature around ABI, but is quickly becoming identifiable, not least through some of the study titles: ‘Women’s Experience of Brain Injury: An Interpretative Phenomenological Analysis’ (Levack, McPherson, & McNaughton, 2004); ‘Success in the Workplace Following Traumatic Brain Injury: Are We Evaluating What Is Most Important?’ (Howes, Benton & Edwards, 2004); ‘Male Body Image Following Acquired Brain Injury’ (Howes, Benton & Edwards, 2005); ‘Perceptions Of Care Access: the Experience of Rural and Urban Women Following Brain Injury’ (Sample & Darragh, 1998); ‘Living With Moderate or Severe Traumatic Brain Injury: The Subjective Experiences’ (Jumisko, Lexell, & Söderberg, 2007); ‘Discovering a New Identity After Brain Injury’ (Lorenz, 2010); ‘Tears in My Eyes ’Cause Somebody Finally Understood’: Client Perceptions of Practitioners Following Brain Injury’ (Darragh, Sample, & Krieger, 2001); ‘Experiences of the Process of Adjustment to a Brain Injury: An Interpretative Phenomenological Analysis’ (Uprichard, 2010); ‘Conducting Qualitative Interview Research with People with Expressive Language Difficulties’ (Lloyd, Gatherer, & Kalsy, 2011); and ‘The Disability Paradox: High Quality of Life Against All Odds’ (Albrecht & Devlieger, 1999).

In undertaking this review of the literature a number of web engines were used, including Informa Healthcare, PubMed, ProQuest, Wiley Online Library, Taylor & Francis online, ScienceDirect, Medical Collective, Google Scholar, Web of Science, Ovid Health, Ingentaconnect, Sage Journals online. Initially, I limited the search to the last five years but broadened the search to include ‘any time period’ to increase the number of studies. The search strategy entailed using key words: qualitative studies, brain injury, ABI, traumatic brain injury, TBI, in combination with each other and with experience, identity, learning, quality of life, coping, resilience, adaptation, brain impairment, narrative, lived experience. Studies that used quantitative methods of tests, scales, measures and questionnaires and studies focusing on the rehabilitation time were excluded. Studies about children with ABI were also excluded. What follows is a structured review of the resultant literature.
4.4 Qualitative Academic Research: The Insider’s Experience from the Outsiders’ Perspective

The literature reviewed included 24 studies and the main elements and findings of these studies have been presented in Appendix 4.2, where more information about these studies can be found. This literature revealed blind spots not covered in conventional quantitative approaches and was relevant and contributed to the method of Keys to the ABI Cage and the talk-about cards as detailed in the Headwork boxes.

This literature, produced largely through open-ended and semistructured interviews and narrative first-person accounts, illuminate the person with ABI’s own perspective and lifeworld. In so doing, they offer a significant contrast to both method and findings to many studies from the ‘body-object’ view. Gelech and Desjardins, (2011, p. 62) posit that although concepts of the personhood of the individual as ‘lost’ or ‘shattered’ have dominated discussions in the literature, they argue that this ‘perspective is a crude representation of the post injury experience of self, and the aspects of stability, recovery, transcendence and moral growth are also involved in this process’.

Nochi (2000) examines how different forms of self-concept and identity combine over time. This involves positive relational concepts of self: comparing the present self with the past self, the self in relation to others or the self as improving over time. Nochi’s categories include the ‘self as better than others’ with ABI; the ‘grown self’ in which the new ABI self is seen as having grown in relation to their past self; the ‘recovering self’ in which progress is being made; the ‘self living in the here and now’, in which people see themselves as normal; and the ‘protesting self’ who find ways to function best given life’s challenges. Nocchi demonstrates how, using these categorisations, the person can come to terms with their new self.

Kendall and Muenchberg (2009) suggest that there is a significant process of grieving for the loss of the old identity and the construction of a new identity. In the examination of 52 biographical accounts by people with ABI they isolated a number of coping strategies: personal discovery (learning about self), goal-directed (practical problem-solving), control and independence, purpose (believing their injury had a purpose, spiritual, social coping (using support networks), focusing on each day and not long term, persistence and hard work and use of emotional coping and seeing the lighter side. The ranges of strategies are not mutually exclusive and focus on an ‘opportunity structure’ for rationalising the new self in a
new environment. In some ways Kendall and Muenchberg’s strategies are generic in that they have relevance to us all. What is different is that acquiring an ABI may change the distance for accomplishment, given that the person needs to find new personal and social resources to make new strategies work, a fact that has led Linge (1990) to suggest a focus on small achievements.

Indeed, the study by Jumisko, Lexell and Söderberg, (2009), in their examination of ‘what it means to feel well’, points to the importance of becoming familiar with the new self, together with showing strength and resolve, re-establishing a sense of control, being close to someone and feeling ‘good enough’. Similarly, Levack, Kayes and Faydl (2010), in their meta-analysis of 23 studies, also emphasise areas of the new self. They point to disconnects between mind–body, pre and post-injury identity, social situations and emotional supports. These factors test the reconstruction of self-identity and reconstruction of both personhood and ‘place in the world’. They also allude to the significant changes that take place in the internal and external resources on which people with ABI can draw, making the discovery of these resources problematic too.

Examining coping themes not present in quantitative coping inventories, Karpmann, Wolfe and Vargo (1986) identify a number of characterising features that are largely about personal qualities and values: hope and optimism, determination, self-evaluation, new attitudes to life, new support networks and religion. But, as pointed out by both McColl et al. (1998) and Turner et al. (2007), people need to find solutions in their own peculiar and individual circumstances. Turner et al. (2007) suggest that this means a need to work with individual experiences as a focus for rehabilitation. But if this focus on the individual is important to the rehabilitation professional, it must be more important to the person as they seek to re-enter life without professional input. Even more importantly, Kendall and Terry (2008) found that while coping produced benefits in short- and long-term functioning, it did not necessarily contribute in the same way to wellbeing and faring well. This significant finding represents a blind spot in the literature, especially for people after the ‘golden period’.

The focus on adaptation and coping styles in the literature reviewed in Chapter 3 focused around professional practice, and how the professional orientates towards delivery of care and support. The collective work around personal accounts speak of the place of love, hope, faith, of the importance of nurturance, social and support networks, of knowledge and personal skills in engaging with the practicalities of everyday life challenges. They speak of relational thinking of the new and old self, the self as changing and of the connection of the self to
others. These and many more feature as the internal and external resources and personal qualities that can be drawn upon from an everyday repertoire, so the person can learn to cope and learn to feel and fare better.

By exploring the subjectively meaningful experience of people with ABI, the qualitative studies establish a multitude of perspectives with a dominant focus of coping, adaptation and recovery. Some of the studies have an interest in further clarification of conceptualisations that might contribute to professional practice in varying ways. Featuring in this way are: the elucidation of coping themes that can be operationalised within coping inventories (Karpmann, Wolfe, & Vargo, 1986); coping styles that allow professionals to orientate towards different responses by people to the acquisition of brain injury (Kendall & Muenchberg, 2009); coping styles that go hand-in-hand with people feeling ‘at ease’ with themselves — successful styles of coping (Nochi, 2000); coping and adaptive responsive in targeted areas such as community inclusion (McColl et al., 1998); employment (Opperman, 2004) and in the transition from hospital to home (Turner et al., 2007).

On the basis of the reviewed studies a number of points informed the development of Keys to the ABI Cage and to the methodological procedure. The boxes are at times repeat concepts previously discussed, these important concepts that apply to ensuring the wellbeing of participants as they (a) engage with this study and (b) return home to continue to struggle with their ABI.

- Taking place at a location where the participant feels comfortable — a local library, coffee shop etc.
- Helping them feel ‘safe’ by explaining several times what they will be asked to do.
- Allowing them to take their time.
- Letting them lead the discussion.
- Allowing them privacy — they must not be ‘pushed’ to divulge private things.
- Having ways to address ‘Faulty Thinking’ to redirect negative thinking by reviewing positive things they have achieved.
- Demonstrating understanding about their challenges.
- Making it a positive process by not ‘threatening’ their self confidence by pointing out their deficits.
- Giving them positive ideas to think about as they remember their difficulties.
- Making interview/data collection must be of a suitable length of time so participants are not distressed by fatigue.
- Giving opportunity for participants to take a break — a coffee break.
- Breaking Interviews into segments — each segment discussed so they can see progress.
- Using objects/cards/pictures and words they obtain input not just in words.

Figure: 4.1. Headwork 12: Strategies in the method employed to help them feel better/cope better
1. Difficulties and differences:
I’ve lost the ‘old’ me; I don’t ‘know’ the ‘new’ me; I forget my name; I forget where I live; I’ve lost my memory; I’ve lost my friends; I’ve lost my job; I can’t talk properly; I forget what things look like; I forget what you’re saying or I’m saying; I’ve lost my freedom; I’m dependent; I get lost; I have to do lots of tests; I can’t understand; I can’t do things I used to; I can’t think properly.

2. How I feel can lock me in the ABI Cage:
Sad - Depressed; Distressed; Disappointed; Mad - Frustrated; Angry; Nuts/crazy; Bad - Guilty, Bad - I say and do the wrong thing; Bad - I don’t understand; I feel crushed; I feel scared; I hate myself; I feel hopeless (the experts can’t fix me).

3. Keys that can release me from the ABI Cage:
Love, Having Hope, My family, my friends, what other people with ABI have done, encouragement, animals, talking, sport, flowers, going out, exercise, sport, staying home, cup of coffee, doing hard things, achieving hard things, stretching my comfort zone, seeing some progress, doing things I couldn’t do before, my doctor, my occupational therapist, my counsellor, health professionals.

Figure 4.2. Headwork 13: Talk-about cards allow participants to reflect on issues.

4.5 Narrative as the Insider’s Perspective of ABI

There is an increasing interest in narrative inquiry among qualitative researchers. This interest is merited because narrative is the linguistic form uniquely suited for displaying human existence as situated action.

(Polkinghorne, 1995, p. 5)

Life stories are important to everyone as they provide an opportunity for the person to express who they are, their sense of self and they also allow others to understand who we are and how we got that way (Linde, 1993; Widdershoven, 1993). Examining problems experienced by people using narrative approaches has shown that problems have been ‘conditioned by empirical rather than narrative or biographical standards of truth by a preoccupation with obtaining information at the expense of understanding expression’ (Sandelowski, 1991, p. 162). Narratives can reveal the personal, situated and practical aspects of coping, and show that coping with ABI is not a single event but ‘coping as inseparable from their existence’ (Marshall, 2009, pp.137–138).

When writing about life stories of people with learning disabilities (sic intellectual disabilities) Atkinson (2010, pp. 2–3) states that stories can help us trace an otherwise hidden history, treat people as ‘expert witnesses’, enable people to represent themselves as fully-rounded human beings, show the beginnings of a resistance movement, encourage historical awareness and reflexivity (Atkinson, p. 5). Atkinson suggests life stories are particularly important ‘because often people have been silent, or silenced, while other people — families, practitioners, historians — have spoken on their behalf’ (2010, p. 2). People with ABI have similar experiences and by telling their stories they have a voice.
The books written by people with brain injury and their families (Chapter 1) demonstrated the need of people to tell of acquiring their injury, to show they have gained wisdom from their experience, help others by passing on advice, encourage them and offer an uplifting story about the importance of love, courage and hope. These three words are the insiders’ perspectives of the important issues that help people endure/cope with brain injury. But these are metaphysical words, not recorded on medical reports, government documents or quantitative research papers. They are also both positive and powerful and are the antithesis to the negativity of the fixing broken bodies approach characterised by much of the body-object writing.

There is a saying ‘beauty is in the eye of the beholder’. I argue that in a similar way a blind spot is in the eye of the beholder. People with ABI and family who write books about their experience do so in order to illuminate issues, thoughts they believe that other people do not see; in other words blind spots. They bring to light things they perceive to be hidden issues of the ABI experience.

Time is needed to make sense of and contextualise key points in the varied books written by people with ABI. To locate, read understand and synthesise this material is a process too complicated for a person to complete early in their recovery, yet this positive, valuable, helpful information could make a difference to someone ‘lost’ in ABI. How could this material be ‘taught’ to a bewildered person? Research into ABI narratives is an example of confusing, messy, frustrating nonlinear study, as further asserted by Tidwell, Heston and Fitzgerald (2009). Making sense of and organising information from narrative is not easy. ‘Quite unlike its pristine and logical presentation in journal articles…real research is often confusing, messy, intensely frustrating and fundamentally nonlinear’, (Marshall & Rossman, 1999, p. 21).

Some of this complexity has been addressed in the professional and academic literature as discussed below.

4.5.1 Narrative to Reveal the Insider’s Perspective: Books Written by Professionals

This section discusses the insider’s perspective produced by or supported by professionals. These accounts have commonalities to the books, web articles and blogs as discussed in Chapter 1.
These commonalities include the importance of the ‘voice’ of the person with ABI, explaining how they perceive and make sense of situations: the person with ABI is treated as ‘expert witness’ with a wealth of valuable experiences to share. These explanatory narratives counterbalance the focus on deficits, as do publications written by people with ABI in Chapter 1. Coping strategies and ways of ‘feeling and faring better’ identified in the qualitative academic literature are also echoed in these narratives. These include: the importance of faith, hope, love, determination, self-evaluation, self-acceptance, religion, searching for meaning, making sense, learning about self, persistence, gathering information, recognising the value of life, sense of purpose, making the most of everything, staying patient, taking pride in accomplishments and humour. These could be termed ‘keys’ to the reconstruction of ‘self’ and ‘life’ for people with ABI.

Additionally they could be considered blind spots according to the medical model. One can see that many of these concepts are the metaphysical categories that prove resistant to scientific objectification and yet, ironically, they are the concepts of most significance as people struggle for the good life — and that is all of us and not only people with ABI.

Brain injury professionals use narrative as a powerful method to confront the reader with the realities of life for the person with ABI. Rees (2011) expresses the bewildering world of the person with brain ABI illuminating the blind spot that positive interactions with others are important.

Negative interactions, or perceived negative interactions, increase the person’s perception of threat and can turn simple frustration into aimless rage. Alternatively, sustained positive exchanges between the environment and brain can help the person develop awareness and socially acceptable behaviour. (Rees, 2011, p. 107)

Rees’s narratives illuminate many issues that could be considered blind spots; although ‘the person is just a shadow stifled by a damaged brain’ (2011, p.55). Rees demonstrates their intelligence, feelings, and awareness of their difficulties, inter alia:

I am well aware that they regard me as intellectually inadequate compared to them. p.17.

My fear of rejection isolates me. p. 17

I want to help people like myself. p. 18

She talks in riddles although there is a consistent theme of her ‘quest for the elusive true self’. p21

Progress is a balancing act. p. 64
The visiting psychologist or social worker who just wants to test Michael and produce a report which is invariably negative. Because they identify his deficiencies as they call them...it’s the lack of positive input which fosters ignorance. Ignorance leads to lack of understanding and being ignored. p. 141

Sometimes we were advised that Ben was ‘plateauing’. That’s another expression that defies accurate definition and is not helpful for someone striving to recover. p. 151

Rees has shone a light upon blind spots that are not the focus of medical model research. The main themes that have come out of his work are:

- people with ABI can be aware of their own perceived deficits and aware of how other people view them
- being brain injured can cause shame and frustration
- people with ABI want to be the same as other people
- people with ABI are isolated and lonely
- recovery may involve good and bad days, one step forward, one step back
- definitions such as ‘plateauing’ are not helpful
- it is not easy to remain positive.

Mason (2008), an ABI case manager, writes of the courage of people with ABI as they ‘put the pieces together’, their perseverance, everyday struggles, search for help and hope for recovery. He writes of the harsh realities endured by the mounting number of ABI survivors whose lives may be unravelling, but telling their story can restore human dignity. Here again we read of the importance of hope, courage and the importance of giving people a voice to tell their story.

Another case manager for physically disabled people, Laskowski (2003) wrote his book after hearing poetry written by a man with a severe ABI. Laskowski was ‘stunned and ashamed’ to find he was surprised by the ‘intelligence and feeling’ expressed in the poetry. His fictionalised journal focuses upon the everyday struggle to communicate and be intimate with others, the person’s efforts to free himself from chains of his caregivers and return to normal life.

Driscoll and Straus’s (2009) stories of American soldiers with TBI and PTSD present us with yet another set of blind spots. Military personnel train so hard they do what they are told and cut off their emotions, which can come back and haunt them. They can feel like they are ‘stained’ by their war experience, that they have ‘blood on their hands’ (Driscoll & Straus,
and this can affect their progress. Several of the issues identified by military personnel could be applied to other people with ABI — low tolerance of things other people did and telling it as they saw it. They write of a man with TBI in a supermarket remarking ‘Lady, if you hit him (small son) again I’ll break your arm and shove it up your ass. You should spend less time on the phone, and more time taking care of your kid’. Driscoll and Straus identified that one of the biggest challenges of ABI is mustering ‘the courage to allow others to help you even when you feel unsafe’ (2009, p. 73).

4.5.2 Narrative to Explain ABI to Children

References to children with ABI have been purposely omitted, but because a story book for children was considered as a component of the final ABI learning resource, a search was conducted to locate books that use narrative to explain ABI to children. Picture story books for children included Snyder’s (1998) ‘Elvin, the Elephant Who Forgets’, Leaf’s (1988) ‘Susan’s Dad: A Child’s Story of Head Injury’ and Moulton’s (1986) ‘My Friend Lucy’, and Parker’s (2005) ‘The Get Well Soon...Balloon!’ The small number of books for children, suggest that a story book for children would be a valuable addition as part of an ABI learning resource.

4.6 Setting the Groundwork for the Study Methodology

Chapter 3 presented a number of features that informed the methodology and procedures adopted in this study in response to the body-object approach. These were displayed in Headwork boxes. The following will continue to discuss the fundamental epistemological distinctions between the body-object and the body-subject approaches.

The body-object approach has been identified largely with the hypothetico-deductive model of science, which seeks to falsify a hypotheses through testing and is predominantly quantitative in orientation. Although this model has been dominant in the latter fifty years of the twentieth century, the present research was a response to my perception that there was a need for a paradigm shift (Kuhn, 1962) in the academic evidence base around ABI. Kuhn states that paradigms come to be questioned and supplanted by new theories, (a ‘paradigm shift’), not because they have been shown to be false but because they no longer speak to the concerns of the practicing scientists, (Terre Blanche & Durrheim, 1999, p. 4). Kuhn suggests that people who achieve fundamental inventions of a new paradigm have either been very young, or very new to the field whose paradigm they change (Kuhn, 1962). I do not fit the former statement but I do fit the latter.
This study did not approach ABI from the body-object quantitative perspective for the following ten reasons:

- This study was from the private body-subject perspective of ABI; from ‘within’ or ‘through’ the eyes of the person with ABI. The participants were the source of expertise, compared to an imposed view based upon the public body-object perspective (Mol & Law, 2004), ‘on’ or ‘about’ people. (Kemmis, 1994; Sikes & Gale, 1998). *Keys to the ABI Cage* was devised so that participants and I could both view ABI from the same perspective, we were ‘on the same page’, we were together trying to understand and make sense of the everyday issues and problems of ABI. This study aimed to produce a body of knowledge from the beliefs and the common sense and opinions of participants. It did not focus on facts, but on perceptions and opinions voiced by participants. ‘Positivists argue that science is able to produce a body of knowledge whose validity is conclusive, which can replace myths and dogma of common sense’ (Hammersley & Atkinson, 1995, p. 5). Each person has their own story; it is the diversity of experience that resists generalisation.

- The previous chapters have provided detail of the diverse communication and learning needs of people with ABI; therefore, I adopted ‘intellectual playfulness’ (Hermanowisz, 2002) and educational learning principles to engage and encourage participants to reveal factors that helped them learn to feel and fare better.

- This study aimed to discover data that would be of value to people with ABI, not to provide data for health professionals.

- This study was based on the premise that a participant’s perceptions and opinions can change as they reflect on an issue: *Keys to the ABI Cage* was devised to allow them to ‘journey round their experience’, revisit ideas from different angles, or change their minds as they reflected and talked about concepts. ‘Some Further Thoughts’ sheets allowed them to express further thoughts after the interview. This was a different experience to ticking a box on a questionnaire.

- This study could not be replicated exactly by another researcher because I was an insider, I understood. Participants’ responses to me might be different to their response to another researcher to whom they could give a socially desirable response to in order to ‘save face’, or please the researcher. In education this is referred to as a ‘teacher-pleaser’.

- Participants focused on issues they considered important, rather than follow strict question wording and sequencing — they were in control of the information they
shared. A positivist, explicit, standardised set of data elicitation procedures, which could be replicated by other researchers, was not seen as a suitable method to use with vulnerable people.

- Rapport and empathy with participants was vital because they had a strong personal stake in the information they divulged (Plummer, 1983). To provide an atmosphere of empathy, flexibility in the data elicitation procedures was crucial. Adaptability was embedded in the method to be able to focus on more positive things if a participant became upset or distressed reflecting on their experiences.

- Self-efficacy was important. Freeman (1998) asserts that in order for people who have suffered impairments to make the most of their capability, they needed to recover some sense of self-efficacy — awareness of their abilities and how they deal with their particular life challenges (Reber, 1985). ‘Power’ is involved with testing, the ‘tester’ holds power as the person who knows, the ‘testee’ is in the position of having to ‘obey’ and answer the questions determined by the tester. Some people with ABI may have found this experience of having to comply as confronting, challenging and demeaning. Thus, participants in this study had control of the interview process and choose whether or not to share concepts, (Bandura, 1995).

- Narrative inquiry. *Keys to the ABI Cage* was developed specifically to obtain data about the meaning participants with ABI attached to their life experience through the stories they told, since knowledge held in stories can be stored, retrieved and relayed (Fry, 2002). Narrative inquiry was incorporated as ‘both phenomena under study and method of study’ (Clandinin & Connelly, 2000), and data sources included ‘stories... fieldnotes... conversations, interviews...and life experience’ (pp. 98–115). Bell (2002) asserts that people make sense of random experiences by imposing story structures on events, by restructuring narratives as they consider new events In allowing the freedom to explore concepts and ideas, this study supported narrative albeit around three key questions. However, memory, word-finding and other difficulties outlined in previous chapters had the potential to affect participants’ retrieval of memories and ability to share stories. In order to use narrative inquiry *Keys to the ABI Cage* was developed to address these difficulties (see Chapter 5). Narrative inquiry has been criticised by Clandin and Connelly (2000) and Richardson (1995) for not being ‘theoretical enough’, and some researchers would consider that it is not a suitable method for formal scholarly research. But I dispute this opinion and argue that narrative inquiry is a most suitable way to engage with vulnerable people who might be uneasy about other data.
collection methods. Narrative inquiry allows them time and space to reflect and change their story as they consider further issues.

- This study modelled or rehearsed narrative as a learning tool to determine if narrative could assist sense-making and memory retrieval for people with ABI. Egan, (1988) states that narrative can be a valuable teaching tool. Narrative allowed the participant to express the impact of living with ABI and, as they told their story and reflected on their experienced “ahah!” moments, emerged from the process. Bell (2002) identified that ‘analysis of people’s stories allowed deeply hidden assumptions to surface’.

- Additionally ‘narrative illuminated the temporal notion of experience, recognizing that one’s understanding of people and events change’ (p. 209). Ethical issues Bell referred to were also identified. The exchange of stories ‘is often understood within a larger story of friendship, so researchers may find disengagement difficult at the end of the research project,’ (p. 210). The atmosphere of ‘friendship’ built up during the interview also provided an atmosphere that led to disclosure.

- Foucault (1975) noted that there is a price to be paid in human subjects speaking ‘the truth’ about themselves. Truths, of course do not materialise out of thin air. I was aware that there was a price to be paid by participants. There was the inconvenience of them attending the interview and the potential that reflecting about their experiences would be upsetting. Strategies and protocols had been put in place to protect the participant (see Chapter 6 on the research ethics of the study). But I had not realised that by hearing the truth I would pay such a high price as the researcher, as will be explained later in this chapter. My involvement in hearing of the experience of fellow people with ABI was upsetting and this study has greatly affected my emotional wellbeing.

4.7 Research Involving Vulnerable People: The Feminist Perspective

When power was seen as an important issue, feminist scholars have used narrative inquiry as a method of data collection and analysis with ideas similar to those rehearsed in the Headwork boxes in the previous two chapters. It has been argued that ‘only qualitative analysis can accurately capture the complex pattern of an individual life without violating the integrity of life or dehumanizing the individual’ (Kotre, 1984, p. 3). Daly (1992, p. 3) states that ‘qualitative methods are especially appropriate to the study of vulnerable people’; Renzetti and Lee (1993, p. 6) assert that ‘extreme sensitivity is needed in the conduct of research that intrudes into the private lives or deeply personal experiences of the research participants’.
Advocates of qualitative methods have argued that ‘individual women’s understandings, emotions, and actions in the world must be explored in those women’s own terms’ (Jayaratine & Stewart 1991, p. 85). This study has attempted to explore the world of brain damaged people in their own terms.

According to Jayaratine and Stewart (1991), quantitative research techniques involve the translation of the individual’s experience into categories predefined by researchers. This results in ‘distorting women’s experience and in a silencing the women’s own voices’ (Jayaratine & Stewart, 1991, p. 87). This statement could also be applied to people with ABI. Jayaratine and Stewart suggest that emphasis should be placed on ‘methods which can best answer particular research questions, but always using them in ways which are consistent with broad feminist goals and ideology’ (p.91) and ‘the ways in which research participants are treated and the care with which researchers attempt to represent the lived experience’(p.90).

Liamputtong (2007), who writes about researching vulnerable groups from the feminist perspective, has suggested that the researcher should ask themselves a series of questions: ‘Who am I researching? How should I conduct research that is sensitive to the needs of the people I am researching? What ethical considerations do I need to observe? What is my role of researcher in relation to the researched?’

The majority of participants in this study — those with ABI and people who care for and support other people with ABI — were ‘vulnerable’, ‘difficult to access’, ‘invisible’ ‘hidden’ and ‘hard to reach’ (Stone, 2005). Their ‘invisibility’ may include their marginality, lack of opportunity to voice their concerns, fear of their identity being disrespected, stigma attached to their social conditions, heavy responsibilities and scepticism about being involved in research (Birman, 2005; Fisher & Ragsdale, 2005; Stone, 2005). I did not have contact with people who had been in the rehabilitation hospital system, but I was able to access these difficult to access people because of my book Doing Up Buttons and subsequent talks to brain injury support organisations who placed information about this study in their newsletters.

From previous chapters it has been demonstrated that this was to be ‘sensitive research’ (Wellings, Branigan, & Mitchell, 2000, p. 256) as ‘it requires disclosure of behaviours or attitudes which would normally be kept private and personal, which might result in offence or lead to social censure or disapproval, and/or which might cause the respondent discomfort to express’. This research aimed to provide a time and place for conversations, described by Robertson and Webber (2000) as ‘deep and meaningful conversations about life experiences, many of which have not previously been voiced’ (p. 531–532).
‘Sensitive research encompasses studies in which there are potential consequences or implications, either directly for the participants...’ (Sieber & Stanley, 1988, p. 49). Previous chapters have explained the careful consideration that was put into ensuring the wellbeing of the participants. But I had not fully understood the warning ‘that there is potential for psychological and/or physical harm to others involved in the research process’ (Dickson-Swift, James, Kippen, & Liamputtong, 2008, p. 134). I was aware that research into fellow ABI sufferers would be painful and upsetting, nevertheless I believed the goal to develop a helpful ABI learning resource for them outweighed the potential harm to myself.

This was one issue in this study that was underestimated. Oakley (1981) suggests the ‘goal of finding out about people through interviewing is best achieved when interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship’ (p. 41). A rapport and understanding of the individual participants was developed over the period of contact, the phone calls and the interview. Specific encounters were particularly upsetting and are etched in my memory. The powerlessness, frustration, perception of being ‘taken advantage of’ or being ‘ripped off’ by ‘the system’ affected some participants profoundly. After an expression of intent this study was halted for some time, and new clauses were inserted into the Ethics Form and the Consent Form to be signed by participants. Personally, this episode has had profound effect on my emotional wellbeing and also affected my husband and family. Separately to that incident, several participants expressed their anger and frustration at the way they had been treated by different organisations.

Mies (1983) argues that because women have had a personal experience with oppression, they ‘are better equipped than their male counterparts to make a comprehensive study of exploited groups’ (Mies, 1983, p. 121). As a woman, and a person with brain injury, I have experienced oppression, loss of power and feelings of having to be ‘obedient’, so I considered myself well equipped to make a study of people who are or who can have the perception they are ‘exploited’.

This concept contrasts with Milgram’s (1974) famous study of ‘obedience’ that relied on the abstract authority of the ‘scientist’, which is an example of research design that depends on maximising the hierarchical distance between researcher and research participant. Keys to the ABI Cage attempted to minimise the distance between researcher and research participant by using methods that can best answer particular research questions, but always using them in ways that are consistent with broad feminist values and goals (Jayaratine & Stewart, 1991, p.
These authors suggest strategies for practical implementation of a feminist methodology that was applied in this study (p. 101). The research topic was selected to have potential to help people with ABI; the study aimed at specifically determining information that would be most useful and have positive impact; the method was designed to be appropriate to ask questions of vulnerable people; the answers and data collected would be to assist people with ABI.

Jayartne and Stewart warn of ‘poor representation’ in studies when only a small number of participants are involved. Forty-six people were involved in this study, the study was as equitable as possible regarding the number of participants — 24 women, 22 men — and my bias as a person with ABI was acknowledged.

Analysis of results looked for different interpretations and how the findings may impact on the lives of people with ABI. Suggestions for rehabilitation policy changes are included in Chapter 9, Discussion. Results have been made available for ABI support groups and groups of professionals at conferences in Australia and overseas. A manuscript for a book to be published by Australian Academic Press is currently under contract.

This study was sensitive research into vulnerable people. Narrative research methods were used involving principles of motivational interviewing, which is a directive, client-centred counselling style for eliciting behaviour change by helping clients explore and resolve ambivalence (Rollnick & Miller, 1995). Using this method the participant was in control to speak about what they considered important, they were led to examine issues, and the relationship between the interviewer and interviewee was more like a partnership rather than expert/non-expert.

This section has demonstrated how I searched for philosophies, theories and methods that were based upon the notion that understanding the true nature of any phenomena would involve perceptions of the many things inside the ‘black box’ of ABI. In Chapter 1, I explained that an interest in the concept of phenomenology was an initial trigger to considering a study into people with ABI.

### 4.8 Phenomenology as a Philosophy

It has been argued so far that ABI can be viewed from the body-object or outsider’s view, or the body-subject or insider’s view (Merleau-Ponty, 1962), and from the perspectives of different models, or belief systems of the person perceiving ABI.
Phenomenology is a philosophy whereby a person reflects and speaks about their interpretational narrative of their experience (Giorgi, 1985a, 1985b). Each person is unique and they can engage in personal understandings and discovery and explore the meaning of their experience. These notions have synergy with Husserl’s phenomenological philosophy and the belief that reality is intentional — as people, we direct our consciousness towards ‘things’. Intentionality is the way in which each person encapsulates the world through their conscious efforts. Previous chapters have demonstrated some of the different ways people might direct their consciousness towards the ‘thing’ or phenomena of ABI. The meaning things hold is actually not located in the thing but in the individual’s perception of it (Giorgi, 1985a). We cannot know what the world is like, we can only know how we perceive it.

Phenomenology, a philosophical movement of the early twentieth century, had immense influence on continental Europe. It was developed as a theory of knowledge by Edmund Husserl (1859–1938) who introduced the term ‘phenomenology’, in his book *Ideas: A General Introduction to Pure Phenomenology* (1913), along with a range of technical vocabulary. Phenomenology is the descriptive analysis of ‘essences’ in general. ‘Essences’ or *eidos* (from the Greek *eidos* ‘form’ – exceptionally vivid visual or auditory images that allow detailed recall of something previously perceived) were not only objects (such as an object of sense-perception) but also acts of consciousness. The phenomenologist must ‘bracket’, suspend judgment, or perform an ‘epoché’, the ‘natural attitude’ to the world. Phenomenology asserts that through ‘eidetic’ ‘intuition’ we have knowledge of the essential features of the life-world, which phenomenologist’s term ‘essences’.

The phenomenological researcher tries to find the essence of a phenomenon from a perspective that does not involve a hypothesis or preconception (Husserl, 1970), but by focusing on the ‘how’ and ‘why’ of everyday intuitive lived experience — in this instance of ABI — rather than ‘how much’ or ‘how many’ of the scientific positivist position. Much debate remains within phenomenology and has done since Husserl’s time. Heidegger, for example, focused on perception (Heidegger, 1945) while Giorgi, uses a multidisciplinary approach where there is an intersection of phenomenological philosophy, science and psychology positing a humanistic view based in the interpretative paradigm (Giorgi, 1985). Van Manen (1990), writing about phenomenological research in education, relates ‘experience’ to our direct acquaintance of things, the intuitive qualities, impressions of, description of and interpretation of the everyday.
Previously it was explained that this study would look for blind spots by searching for the essence or nature of the lived experience, as revealed through the experience of individuals with ABI, in order to make this information available to people with ABI in an ABI learning resource. Phenomenology provides a philosophical perspective to understand ABI by understanding the way the individual defines and reflects upon their experience. Phenomenology seeks to search through layers of lived experience in order to rediscover the experience, then use beliefs and knowledge to make sense of the personal aspects of the experience of ABI.

4.9 Summary

This chapter has shown that intentionality is central to this study, which is based on the premise that meaningful behaviour is best grasped through the person’s narrative, through their own voice being heard. It is likely that participants will express widely varied everyday experiences and respect for this diversity is vital. It will be important to assist the participants to express how the challenges they face can be offset by positive factors in their lives, particularly in their lives after the ‘golden period’. In order to learn to feel better, learning to cope and adapt are essential. The review of qualitative studies and material written by people with ABI proposed that it is important to incorporate metaphysical concepts (love, hope, support and courage) in order to fully encompass the phenomena of coping. These factors have a knock-on effect on the methods and procedures to be adopted and more of these are considered in Chapter 5 to follow.

This chapter has examined ABI from the insider’s, body-subject or emic perspective of qualitative research and provided a contrasting view to that of outsider’s, body-object, etic quantitative perspective of Chapter 3. Through the examination of qualitative studies and narratives, another picture has emerged of the way the person with ABI can place their lives in the light while themselves growing in the process. From the insider’s perspective, involvement in qualitative and quantitative studies involve issues of power, control and opportunities to speak about what is deeply meaningful. Participant experience for those involved in quantitative studies where tests, scales and questionnaires are used differs from those involved in qualitative narrative studies, where the person would have the opportunity to express their opinions, and reflect on their experience. It can been seen that some of the research topics discussed in the quantitative studies in Chapter 3 (for example depression, self-awareness, coping, peer support and social identity) have also been identified in qualitative studies, where the studies reviewed focused upon coping, rather than deficits.
This review has also shown there is a large amount of information from the insider’s perspective contained in the literature from studies. Unfortunately, this information is not readily available to people with ABI or their families, unless they subscribe to academic journals that report on findings of studies. Tragically, the insight, wisdom or blind spots identified in this literature are not readily available to assist the person with ABI to have hope and understanding. This material does not appear to be translated nor does it trickle down to ABI support organisations’ websites to the same extent as data obtained from quantitative studies. Additionally, like the insiders’ perspective information in Chapter 1, this information is available only for ‘seekers’. Many people with ABI would not have the computer skills to sift through and find the resources that would help them. Indeed, some people with ABI do not have computers.

The findings from the qualitative studies echo my experience about the importance of love from family and friends, my hope and my belief that my life had been spared for a purpose, to help others with ABI. The findings from these studies also provide positive encouragement and hope for the person with ABI.

This thesis sets out to determine if there is a way to assist participants with ABI to reflect and ‘discover’ these perceptions/beliefs/strategies FOR THEMSELVES, to join the metaphysical with concepts and ideas that support them to learn to fare better. It is the necessity of providing an interface for reflection and learning that warrants further attention. The joining of metaphysical concepts with everyday life experiences is a product of lifelong learning. But for the person with ABI who is challenged to relearn (and to do so with as a new identity, with changed personal and social resources) as quickly as possible, they need a learning tool to assist them to reflect and learn.

In conclusion — How can people with ABI and their families learn of the good news — all the data about things that can positively affect their endurance/coping/recovery? How can people with ABI construct their own knowledge about ways of coping with ABI? This question will be explored in Chapter 5, a chapter devoted to learning principles.
CHAPTER 5

REFLECTION, UNDERSTANDING AND INSIGHT FROM THE EDUCATIONAL/LEARNING PERSPECTIVE: EDUCATION LITERATURE REVIEW

5.1 Introduction

Long term recovery from brain injury is not a medical problem. What is needed is relearning (i.e. education, rather than medicine). While the injured person may still be on some medication, the major problem has to do with things which are not unduly medical. The problem to be solved is how to help the injured person to relearn the process of dealing with their environment (restoring their External Affairs Department)… and to relearn the skills, which allow them to function as independently as possible (Freeman, 1998, p. 14)

Several authors who write about ABI state the need for people with ABI to ‘relearn’ (Durham, 1997; Freeman, 1998; Lewis, 2004; Rees, 2005). But ‘easy to read’ information that uses educational principles to inform, motivate and encourage people with ABI to learn to understand their lifeworld — the physical, emotional, social and metaphysical things (existence, cause and effect and possibility) that affect their quality of life and wellbeing — is not readily available. People with ABI need to relearn how they can adapt and adopt coping strategies to re-engage in their new life after the golden period where support and resources become withdrawn is an area yet to be researched, published and used.

Chapter 1 and Chapter 4 established that books written by people with ABI express their struggle to reconstruct themselves and their life, and to share what they have learnt, including their belief that their life was ‘spared’ for a reason, to encourage others. Responses from people who read Doing Up Buttons (Durham, 1997) demonstrated firstly that people could learn and reflect upon their own life by reading of the physical, emotional, social and metaphysical things that affected the quality of life and wellbeing of someone else as they adapted and adopted coping strategies to re-engage in their new life. Additionally, that there is a need for material that deals with the reconstruction of the ‘whole person’, or self, following ABI.

After rejecting the objectifying approach of body-object approaches in Chapter 3, much of the literature reviewed in Chapter 4 (body-subject qualitative studies) revealed connecting personal narratives around a wide range of factors that affected wellbeing, quality of life and coping as a whole person. Significantly, Kendall and Terry’s (2008) finding that while coping
produced benefits in short- and long-term *functioning*, it did not necessarily contribute in the same way to *wellbeing* and faring well. This reveals not only the complexity, but also the fragility of physical, emotional, social and metaphysical needs, the vulnerability of people with ABI and also the complexities of ‘reconstruction’.

In Chapter 4 it was posited that findings from these qualitative studies are not translated into ‘grey literature’ (e.g., ABI support web sites), nor made available for people with ABI to the same extent as information from quantitative studies (difficulties/differences/deficits of ABI). It appears that recent inclusions on these web sites of the stories of people with ABI demonstrate that encouraging people to write of their ABI experience, not only helps the writer ‘sort out their thoughts’ but can help people learn about vital issues as they reflect and reconstruct themselves and their lives.

In support of the position argued from my review of the ABI literature in this thesis, Freeman (1998) states:

> Medicine has very little to offer (to help the person function as independently as possible) in this direction. The way forward lies in education… in fact the medical model, as well as being superfluous in many cases and at most times in a person’s life, is also often counterproductive to follow. The medical model sees the patient as subservient to the professional. It sees the power of recovery lying in the hands of the physician, whereas the power for recovery lies within the injured person as they relearn their daily living skills… Education is the key. (Freeman, 1998, p. 14)

In my struggle to cope with ABI I yearned for a book to help me learn about, and understand, some of the ramifications of ABI, the consequences of injury to my brain. My only explanation of the crazy things that I did was that I had gone insane. It was terrifying, at times when I could not figure out what to do, to find myself intentionally doing something crazy. I did not understand why my head instinctively told my body to react in a certain way. An example is one day, crossing the railway tracks on my way to school, the boom gate came down to signal an approaching train. I didn’t know what to do and was astonished to find myself running across the tracks in front of the oncoming train. It sped past me with only a whisker to spare. ‘You stupid idiot’, I told myself ‘Why on earth did you do that?’ It took days of puzzling before I figured out an explanation of why I had done such a dangerous thing. I realised that I had been frantically searching my mind for what it meant when a horizontal barrier was placed across your path. Somewhere in my subconscious I remembered the ribbon at the finish of a running race when I was a child at school. I must have thought that a boom gate was like a finishing line of a race and this is the reason I ran.
Another puzzling action was my ‘drop your handbag’ reaction to traffic lights turning green when I was waiting to cross the road. I did not know what the change in the color of the lights meant and for some reason my unreliable brain told me the light turning green meant ‘drop your handbag’, so I would drop it on the pavement. I was aware that other people did not drop their handbag. I felt stupid, but least this action was not dangerous. I have not worked out why I did this, but the psychological ramifications of being unable to understand what is ‘the right/normal’ thing to do, or what to do when ‘the wires are crossed’ in your head and your mind tells you to do something you ‘feel’ is wrong, but you don’t know what ‘the right thing’ is, are not resolvable medically.

Frequently, cognition problems only surface once rehabilitation has been completed, when the person moves out of their comfort zone in hospital or home. The person may not have the words to explain problems or they may feel too ashamed to confess that they are either stupid or crazy. At that time I did not understand or have the words to express my difficulties. Even if I had had the words my shame would have prevented my asking about such situations. I did not know what to do when I did not know what to do. I did not know where to get information about doing crazy things. I had many hours to consider my stupidity. Crazy people did crazy things. I must be crazy. If only I could have read about the experiences of other people with ABI, and the strange things they did (in books or blogs that now exist) I would have seen the connection between my actions and the man who stopped at a puddle because he did not know what it was, or the person who chased emus, or the man who threw his typewriter in the creek. I would have felt comforted. I would have known that I was not the only person on earth who had these problems. Running in front of trains — or the multitude of other crazy things I’d done — are not explained on the ABI web sites reviewed in Chapter 1.

But education is more than information; it involves the learner doing something — engaging, making sense of, making connections, applying and considering how they can use their new understanding. These are the processes that I was grappling with as I lived through the challenges of my life with ABI, such as my story relayed about the railway crossing.

This chapter will change focus from specifically looking at ABI to examining educational and learning literature that underpins *Keys to the ABI Cage* as both a research method and a potential learning tool for people with ABI. As the discussion unfolds, relevant Headwork will point to how the literature informed the methodological approach and procedure. As in the previous chapters, this will be highlighted in separate figures.
5.2 Educational Theories about Motivation and Learning

This study developed *Keys to the ABI Cage* with the aim of motivating participants to reflect and learn more about ABI and things that helped them to learn to feel and fare better. Chapter 3 and Chapter 4 explored different philosophies/models/beliefs or paradigms through which ABI could be viewed and it was explained that the model through which the person with ABI is treated is influenced by the model used by the person dealing with or treating them. Additionally, the ‘production of knowledge’ in the research setting is influenced by the person’s dominant philosophical or ideological position and metaphysical beliefs about the nature of the world (Rubin & Rubin, 2005).

Philosophies/models/beliefs or paradigms are also influential in education where paradigms are changing from ‘being taught’, the analytic-empirical-positivist-quantitative paradigm (where the person believes that a separate material reality exists apart from the beliefs of the individual, group or societies — similar in concept to the medical model) to ‘learning on your own with guidance’, the constructivist-hermeneutic-interpretativist-qualitative paradigm (Schubert & Schubert, 1990). In this paradigm, ‘Truth is a matter of consensus among informed and sophisticated constructors, not correspondence with an objective reality (Guber & Lincoln, 1989, p. 44).

Alternatively, the educator may believe in the critical-theory-neomarxist postmodern-praxis paradigm where their focus is upon ‘questions of power, control, and epistemology as social construction with benefits to some and not to others’ (Muffoletto, 1993, p. 4). Educators working in the eclectic-mixed methods-pragmatic paradigm borrow methods from the other three paradigms to collect information to solve problems. Modes of enquiry are viewed as tools to better understanding and more effective problem-solving (Reeves, 1996).

Another way of viewing education is from the ‘Knowing is a process, not a product’ standpoint. Paulo Friere calls the paradigm of perceiving education as the transmission of fixed content the ‘banking’ concept of education. Education thus becomes an act of depositing, in which the students are the depositories and the teacher the depositor. Instead of communicating, the teacher issues communiqués and makes deposits that the students patiently receive, memorise and repeat. This is the banking concept of education, in which the scope of action allowed to the students extends only as far as receiving, filing and storing the deposits (Freire, 1966, p. 72).
Much of the seeker information on web sites provides information that is of this banking type, providing ‘the facts’ about ABI. But, as I have already shown, facts are uni-dimensional in perspective and can lack connection to people’s realities. This form of information transfer could be the reason the following question was posed on the Brain Injury Research eXchange (http://brain injuryrx.com/) webpage: ‘Do rehabilitation efforts harm more than help?’ and commenting further that: ‘Obviously, this is not a call to stop rehabilitation efforts. However, care should be taken not to let the rehabilitation plan become too routine, irrelevant, unnecessary, or misunderstood’.

This is an important point that fits well with the more constructivist approaches to contemporary learning theory. As Freire goes on to say:

They (students) do, it is true, have the opportunity to become collectors or cataloguers of things they store. But in the last analysis, it is men/women themselves who are filed away through the lack of creativity, transformation, and knowledge in this (at best) misguided system. For apart from inquiry, apart from the praxis, men/women cannot be truly human. Knowledge emerges only through invention and reinvention, through the restless, impatient, continuing, hopeful inquiry men/women pursue in the world, with the world, and with each other. (Freire, 1974, p. 58)

For Vygotsky (1987) knowledge is an internalisation of social activity. Piaget (1932) stresses the importance of experiences as the learner makes connections in an atmosphere of play with the teacher’s role as facilitator, mentor, consultant and coach. Bruner (1960, 1966, 1973) perceives learning as an active process where the learner forms new ideas from their past and current knowledge and makes sense of what they now know. The teacher’s role is to encourage, aid and allow students to ‘uncover’ or discover their own knowledge.

The present study, which employs Keys to the ABI Cage, is firmly positioned within the experiential learning theory: learning is a process grounded in experience, where learning is a holistic process of adaptation to the world (Freire, 1974, p. 32). From within such paradigm learning is a process of creating knowledge through the transformation of experience.

The German-American psychologist Kurt Lewin (1890–1947) first coined the term ‘action research’ and Kolb, (1984) considers the transformational process of learning as a process of adaptation and learning. This is different to a focus on content and outcome. Writing of the Lewinian model of learning Kolb states:

Learning, change, and growth are seen to be facilitated best by an integrated process that begins with here-and-now experience, followed by collection of data and observations about that experience. The data are then analysed and the conclusions of this analysis are fed back to the actors in the experience.
In this study, *Keys to the ABI Cage* is designed by drawing upon the constructivist educational paradigm. Constructivism is a broad, philosophical view about knowledge, understanding and learning that theorises about how people learn by constructing their own understanding and knowledge of the world through experiencing things and reflecting on their experience. Constructivism is based upon the belief that knowledge is constructed by the learner, not transmitted by the teacher. Consequently, knowledge construction is embedded in the learner’s interests and activities that are personally meaningful to them and the learner takes an active role in their learning.

It would not be possible for this chapter to examine *all* educational theories, nor would they be relevant, but the following nine key ideas, or selected theories, discuss ways people are motivated to engage with learning, and factors that affect the way people individually and collectively ‘construct reality’. This educational literature provides theoretical insights about how the person with ABI may engage with and learn from (construct their own knowledge) *Keys to the ABI Cage*. Another reason for the inclusion of this information is that some health professionals who are health and medically focused and trained may not be sufficiently familiar with the constructivist learning theories upon which *Keys to the ABI Cage* has been formed. Thus they have been briefly explained below.

### 5.2.1 Motivation and Engagement Are Crucial Elements in the Learning Process

Engaged students want to learn. Many people with ABI are not ready to learn for many reasons. For example, they may not acknowledge they are a person with ABI, they may still want to be (and pretend to be) as they were or they may feel there is stigma attached to having ABI (e.g., they feel they are different and ‘dumb’).

*Keys to the ABI Cage* was developed as a tool to facilitate learning by employing educational theories around motivation and engagement. A person may experience certain issues with learning and the person with ABI may need to be aware of and accept (acquire self-awareness) that s/he is a person with ABI. *Keys to the ABI Cage* provides each person with a model or an example of what it can be like to be a person with ABI, who may experience particular difficulties and differences, feelings, and also use similar ‘keys’ to feel better. *Keys to the ABI Cage* also demonstrates that they can ‘do’ something to help themselves to learn to feel and fare better (they are not reliant on something that is ‘done’ to them by people who are...
experts). Together these two elements should assist the participant to be motivated or feel empowered that they can use the tool to think about their experience.

Engagement is vital for learning to take place (Coates, 2005, 2010; Krause & Coates, 2008). Engagement is the person’s involvement with activities that are likely to generate high quality learning (Australian Council for Educational Research [ACER], 2008, p. vi) by their participation both within and outside the ‘classroom’. Likewise, it is hoped that the *Keys to the ABI Cage* is a tool that helps engage people with ABI to reflect both in the interview and give them a framework to use in everyday life.

Barkley (2010, p. 15) states that ‘motivation is the portal to engagement’; while Shulman’s (2002, p. 37) learning taxonomy states that ‘learning begins with student engagement’ and Edgerton (1997) also refers to ‘pedagogies of engagement’. *Keys to the ABI Cage* was used as a tool to engage the participant in the interview:

| **Keys to the ABI Cage** captures the attention and curiosity of people with ABI. |
| **Keys to the ABI Cage** provides an example of what it’s like to have ABI. |
| **Keys to the ABI Cage** shows them their input is important. |
| The complexities of ABI are simplified into three themes. |
| Participants are presented with the three steps to looking at the ABI experience three times so they understand what is required of them and they can become familiar with thinking about ABI in this way. |
| It is fun and different to examine a serious issue in this way. |
| Participants receive constant feedback that they are doing well. |

**Figure 5.1.** Headwork 14: How Keys to the ABI Cage addresses the issue of motivation.

### 5.2.2 Engagement is influenced by expectations and self-perceptions

*Keys to the ABI Cage* tool was developed to show people with ABI that they can share insights of things they do to help themselves to learn to feel and fare better and these ideas can help others with ABI. ‘[People] need to have confidence that, if they put in the effort, they can succeed. If there is no hope, there is no motivation’ (Barkley, 2010, p. 11). From this educational theory we learn that in order for the learner to engage in learning, they need to believe that success will result from their effort.

The participant is introduced to *Keys to the ABI Cage*, allowing them to identify issues from the concept and the talk-about cards. This process shows the participant that the process simplifies brain injury, it uses everyday (not medical) language, it identifies factors that can help them and ascertain strategies through which they could help themselves. This approach
can assist them to have success in their own learning and let go of pretending they do not need to learn.

Motivational theories that address student expectations include self-efficacy theories, attribution theory and self-worth models (Cross & Steadman, 1996). Self-efficacy theories state that the learner’s belief about their ability to succeed has *greater importance* than either skill level or task difficulty (Bandura, 1995, 1972; Corno & Mandinach, 1983). If the person has confidence in their ability to perform a task they will be motivated to engage in it. This theory holds an important message for professionals working with people with ABI and reinforces the point that setting a task that can be successfully accomplished, and encouraging the person as they attempt the task are fundamental in the learning process. By rehearsing the method to the participants in several different ways (seeing and touching) and reviewing the Introductory digital storage disk (see Chapter 6.2) they could see that they could contribute and succeed in sharing their thoughts.
Giving everyday examples and using everyday things as ‘Keys’ shows the task is not difficult or complicated. Recognising the importance of involvement and participation for learning to take place from constructivist and experiential paradigms. Thus the tool was devised to assist the participant to become involved and participate, think about their experience. The tool introduces a simple structure (1. Difficulties and Differences, 2. Feelings and 3. Keys) that can be used for further reflection not only in the ‘classroom’ (the research location), but also outside the parameters set for the research study. Letting participants engage in the tool from personal motivation — they will not be coerced to participate. Engaging the participants because it is interesting and different. Giving participants control over the direction of the interview.

**Figure 5.2.** Headwork 15: Keys to the ABI Cage addresses the issue of engagement and motivation.

### 5.2.3 Perceptions of attributing success or failure

Weiner’s attribution theory (1986) states that students attribute success or failure according to their perceptions of why they might have succeeded or failed in the past. This theory can be applied to people with ABI as well as students. *Keys to the ABI Cage* was purposefully designed to be different to any test or questionnaire the participant may have completed in the past so that they could not attribute success or failure from past experience to this task.

Weiner suggests that success or failure of tasks can depend on factors that include ability, effort, luck, fatigue, ease or difficulty of the task. If ‘success’ depends on attributes over which the person believes they have control, such as putting in an effort, students (people with ABI) are more likely to have confidence to be involved with the task than when success depends on external conditions over which they have no control, such as the difficulty of the exam (test, questionnaire).

The person with ABI may have experienced failure in every attempted task — in everything they do — they cannot walk, talk or even eat properly; the individual also faces failure in everything they think, they do not know what day it is, they forget names (including their own), they do not know what a cup or a hairbrush is, they cannot follow conversations. They attribute failure (and the resultant feelings of being dumb or stupid) to nearly everything. The person with ABI may believe that they do not have control over what they think and do, what others think about them, or control over circumstances, which results in the person assuming life and the future is hopeless. This can affect their motivation for learning and their engagement in learning. Having such attributes could also affect their willingness to engage with *Keys to the ABI Cage* and this study.
The importance of ‘self-talk’, which is associated with metacognition, is also evident in Weiner’s attribution theory, which examines the explanations that a person might use to explain their successes or failure in a task. Firstly, the cause could be internal (personal) or external (factors outside the person). Secondly, the success or failure could be stable (it is likely to be the same if the behaviour is repeated) or unstable (the outcome is likely to be different). Thirdly, the cause may be controllable or uncontrollable. The person with ABI, whose cognition, emotions, memory and confidence is damaged, may believe that failure is most likely because they attribute the situation to be dominated by external, unstable, uncontrollable factors.

In order to counteract these factors, the person with ABI involved with this study will be told in the advertisement, and during the pre-interview phone conversations, that their personal insights are important, their comments are valuable, they will be able to choose their input in order to encourage them to believe they can have success in being involved with this study. Barkley (2010) showed that these attributes can be encouraged when ‘success’ is built into a task: when there is no right or wrong answers, the person is encouraged and praised for their wisdom and the person has the power to control the discussion. Such understanding can be drawn in when working with people with ABI by allowing them to contribute their own experience and perceptions, rather than feeling they are forced to conform to expectations of the therapist.

<table>
<thead>
<tr>
<th>Being an unusual task so participants will not think ‘last time I did a test/questionnaire I failed, or I felt a failure.’</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are many different ways the person can feel successful — from putting a card in a box to discussing their experiences.</td>
</tr>
<tr>
<td>The participant is encouraged and praised for their wisdom/personal insights.</td>
</tr>
<tr>
<td>There is no right or wrong answers.</td>
</tr>
<tr>
<td>The participant is shown that success is built into the tool.</td>
</tr>
<tr>
<td>The participant feels they are in control of what they wish to talk about.</td>
</tr>
</tbody>
</table>

**Figure 5.3.** Headwork 16: Keys to the ABI Cage addresses the issue of attribution of success.

**5.2.4 People Are Strongly Motivated to Preserve Their Self-Worth**

*Keys to the ABI Cage* method was developed to allow the participant to preserve their self-worth because the tool acknowledges their enormous challenges in an empathetic way and asserts that they have special insight and wisdom, which they are invited to share with others with ABI. Self-worth models put forward the hypothesis that people are strongly motivated to preserve their self-worth.
When some students do not succeed they would rather let people think they are lazy (question their effort) rather than think they are dumb (question their ability). Some students do not even try because they believe there is a low possibility of success — Covington (1993) refers to these students as ‘failure avoiders’. Similarly, people with ABI have to overcome their abhorrence of admitting they do not know how to do up their buttons or tie their shoelaces and their self-worth and self-esteem is affected by their differences and difficulties. Fear of failing and being seen as dumb can block and inhibit learning.

Cross and Steadman (1996) also describe the ‘failure accepting students’ who are resigned to failure. They feel hopeless and respond to learning tasks with indifference (Cross & Steadman, 1996). To cope with failure in daily life people with ABI need to accept failure as a minute-by-minute, hour-by-hour occurrence. This was taken into account in Keys to the ABI Cage where success was assured (there was no right or wrong answers).

The goals and aims of the study are clear, and the steps to reflect upon things that positively affect lifeworld and the participants know they can understand more about their ABI through reflection. In the interview feedback is immediate, continuous, and relevant so that the participant is clear about how well they are doing. The challenge of reflecting on personal experience carefully balances skills and knowledge while stretching the participant’s capacities to reflect.

**Figure 5.4. Headwork 17: Keys to the ABI Cage addresses the issue of self worth.**

5.2.5 ‘Flow’

*Keys to the ABI Cage* was also devised to encourage what Csikszentmihalyi (1990, 1997) terms ‘flow’. Flow happens when the person becomes so absorbed in an engaging and interesting task that action and awareness merge. According to Wlodkowski (2008) in order to foster flow, firstly the goals must be clear and compatible, allowing the learner to concentrate even when the task is difficult. This links to ‘negotiated curriculum theory’, where goals are negotiated with the person. Secondly, the feedback is immediate, continuous and relevant so that the learner is clear about how well they are doing. Thirdly, the challenge carefully balances skills and knowledge while stretching the learner’s capacities (Wlodkowski, 2008, pp. 267–268). These concepts were incorporated into *Keys to the ABI Cage* tool to establish flow.
Clear goals.
Cards to help participant concentrate even when thinking about hard things.
The participant can decide what they want to talk about.
Feedback is immediate, continuous, and relevant.
The tool challenges the participant and carefully balances between what the participant knows while stretching them to think more about issues.

Figure 5.5. Headwork 18: Keys to the ABI Cage addresses the issue of ‘flow’.

5.2.6 Evasion Can Be a Coping Strategy

People with ABI could be compared to ‘at-risk students’. Barkley (2010) posits that these students have a ‘low level of confidence and expectancy of failure [that] have placed them in a state of almost chronic disenchantment’ (Barkley, 2010, p. 14). These learners recognise the value of learning to accomplish a task, but feel incapable because they ‘aren’t certain of what to do or how to do it or they doubt they can do it’ (Barkley, p. 14). By making excuses, denying that the task is difficult or by pretending to understand when they do not, they will do anything to protect their sense of self or ego. This can be applied to how the person with ABI may feel about attempting a task that they think will take them out of their ‘comfort zone’.

This educational theory that recognises that evasion can be a coping strategy was considered in the development of Keys to the ABI Cage. The interview aimed to have participants involved in reflection, not involved in trying to figure out how to evade questions they did not wish to speak about.
Looks like an interesting and fun thing to engage with. Helps the participant understand what they are asked to do (model it/rehearse it 3 times before they attempt the task). Provides constant positive reinforcement that they are doing well. The participant is not asked difficult questions. It is not hard to understand what is requested — to put a card in a ‘Do’ or ‘Don’t’ box and talk about the issue or something the card reminds them of if they wish to.

Figure 5.6. Headwork 19: Keys to the ABI Cage addresses the issue of evasion.

5.2.7 Active or Experiential Learning

‘Active learning’ principles were used in Keys to the ABI Cage. This half-century-old term that means the mind is actively engaged. Learning is taking an idea or concept and making it part of the personal knowledge and experience of the learner. This is done by connecting concepts and ‘accommodating’ (Barkley, 2010; Svinicki, 2004b) — fitting or altering the existing structure to accommodate the new learning. A dominant example of active learning, Kolb’s (1984) experiential learning, is a holistic model of the process of learning; it theorises that four learning styles make up a learning cycle, that four processes must be present for active learning to occur, that experience plays the central role in learning and that ‘knowledge results from the combination of grasping and transforming experience’ (Kolb, 1984, p. 41).

This distinctive view on learning is formed from combining the philosophical pragmatism of Dewey, the social psychology of Lewin and the cognitive development and genetic epistemology of Piaget (Kolb, 1984). The experiential learning model suggests that:

According to the four stage learning cycle immediate or concrete experiences are the basis for observations and reflections. These reflections are assimilated and drilled into abstract concepts from which the implications for action can be drawn. These implications can be actively tested to serve as guides for creating new experiences. (Kolb, Boyatzis, & Mainemelis, 2000, p. 3)

People grasp new information in different ways: some ‘through experiencing the concrete, tangible, felt qualities of the world’, relying on their senses and ‘immersing themselves in concrete reality’; some through ‘symbolic representation or abstract conceptualization — thinking about, analysing or systematically planning’; some through watching others and reflecting on what happens — reflective observation; some ‘jump right in and start doing things—active experimentation’ (Kolb et al., 2000, pp. 3–4).

With experiential learning an individual’s learning is ‘best conceived as a process not in terms of outcome, ideas are not fixed but are formed and re-formed through experience’ (Kolb,
Such a learning approach was reflected in this study as the participants were encouraged to examine different possibilities and adapt their ideas as the interview progressed, they were not asked to tick a box or state the right answer, because as they reflected on other issues, they might change their mind or opinion.

People with ABI who may have an unreliable memory might panic when they forget what they were told or instructed to do. But having the Cage in front of them and talk-about cards in their hands they had a way to review the issues that led to certain conclusions as they figured things out for themselves. Additionally, people with ABI can become stuck when trying to judge if they did give the correct answer, so they needed to know it was okay to revisit their ideas.

Using concrete experiences (of touch, and seeing) as a basis for the participant to share observations and reflections. As the interview progresses these reflections are assimilated and more abstract concepts explored from which they can draw implications for action. Implications can serve as guides creating new experiences. Providing a way for the participant to engage by using the senses — touch, through the use of symbols, through being able to observe what others do, by being able to jump in and have a go. Making the experience exciting/different.

Engage the participant in reflection and allowing pauses for reflection. Engagement with the materials in a way that encourages understanding and use of higher order thinking (analysis, synthesis and evaluation). Give participants something to do (physically) as they share and discuss ideas. Employing active learning techniques to support engagement and learning. Allow participants to feel and do (accommodating), think and do (converging), think and watch (assimilating) and feel and watch (diverging) (Kolb, 1984).

Figure 5.7. Headwork 20: Keys to the ABI Cage addresses the issue of active learning.

5.2.8 The Theory of Association

de Sousa’s (1987) theory of association was implemented in Keys to the ABI Cage where a combination of pictures, symbols, objects and words were used to provide a framework to support the participant’s ideas. The participant was assisted to emotionally respond to the process by the purposeful use of humour and being ‘different’ and eye-catching and a unique way to revisit their ABI experience. Emotions were acknowledged as an important element in the whole ABI experience as emotions can influence transfer and obtaining attention.

Brain scans have shown that retention can be improved when new learning makes sense and it can be connected to experience (Barkley, 2010). Memory difficulties affect every aspect of learning new information. By embedding strong emotional context, repetition and visual imagery learning is more likely to become part of long-term memories. Pictures and objects
were used to help the participant make connections so they made sense of and retained more than simply reading or being told information.

As retention of the learning needs ‘adequate time to process and reprocess information so that it can be transferred from short-term to long-term memory…this requires time and usually occurs during deep sleep,’ (Barkley, 2010, p. 23). By allowing participants to reflect further upon their concepts they were given ‘Some Further Thoughts’ sheets so that they could record any further thoughts they had in the days following the interview.

| Allows the participant time to think/understand. |
| Repeats information to allow time for assimilation. |
| Engages the participant by allowing them to examine the association between difficulties or challenges and how they feel. |
| Uses pictures/objects/symbols so the participant can put the concepts together. |
| Gives them ‘Some further thoughts’ sheets. |

Figure 5.8.  Headwork 21: Keys to the ABI Cage addresses the issue of theories of association.

5.2.9  Learning in a ‘Community.’

Many people with ABI feel as if they are the only person to experience what they experience. Knowing others ‘out there’ share common experiences can help them to not feel alone. Barkley (2010) writes about the importance of promoting synergy between motivation and active learning through creating a sense of classroom ‘community’.

In this study, a sense of community was used — not in a classroom, but with connecting the participant to the ideas and thoughts of other people with ABI — a ‘Community of people with ABI’. Much of what has been written about learning communities was applied to this study to develop a group of connected people with shared interests, goals and responsibilities towards one another (Brophy, 2004); the words on the talk-about cards were from other people with ABI and they were helping to develop material/resources to help others with ABI.

| Give them a sense of belonging to a group of people facing similar challenges. |
| Establish a ‘community’ feeling a resource from people with ABI for people with ABI. |
| Discuss the values of the participant’s insight for others with ABI. |
| Allow the participant to come to the conclusion that they are not alone or isolated with their issues. |
| Support self-reflection in a malleable way to allow any issue the person wants to ‘get off their chest’ to be talked about. |

Figure 5.9.  Headwork 22: Keys to the ABI Cage addresses the issue of participants feeling they are part of a community of people with ABI.
5.3 Educational Theories About Cognition and Learning

In order to engage with *Keys to the ABI Cage* ‘cognitive’ skills are required. The participant needs to think about concepts, reflect and express their opinion; but in Chapter 1 we learnt that people with ABI may have cognitive problems that include difficulty with short-term memory, concentration, confusion, slow thinking, slow processing of information, difficulty understanding, planning, organising, problem-solving, rigid concrete thinking and mental fatigue. We also learnt that impairment of memory is a significant impediment to people with ABI who are returning to work, however memory can helped through programs designed to assist memory (Raskin & Sohlberg, 2009). It is apparent that the one word cognition covers a plethora of meanings. *Keys to the ABI Cage* was developed to support the individual whose slow thinking and poor memory may limit their understanding and problem-solving.

5.3.1 Cognition

In the following sections different approaches to cognition are used to inform the further development of *Keys to the ABI Cage*. Given different approaches, this section is meant to draw upon leading paradigms within learning and rehabilitation practice.

5.3.2 Cognitive Rehabilitation

Cognitive rehabilitation is an established branch of rehabilitation where the individual practices various cognitive tasks to help attention, memory, and other problems with thinking. This may include doing arithmetic, solving logic puzzles and working on concentration and communication skills and executive functions.

Sohlberg, McKay and Mateer (2001) explain that just as cognitive abilities overlap each other they are also influenced by emotional difficulties such as anger, anxiety, or depression, behavioral difficulties such as impulsivity, frustration, and physical problems such as impairments to movement, sensory changes, headaches and pain. Sohlberg, and Mateer (2001) suggest that the artificial distinction among cognition, emotion and motivation has been steadily ‘eroded’ but it is still common in rehabilitation texts to see box diagrams in which cognitive problems are dealt with in cognitive rehabilitation and/or speech therapy, emotional and behavioral problems are dealt with in some sort of affective rehabilitation therapy (e.g., group counselling, individual psychotherapy); and physical problems are dealt with through medical management and occupational rehabilitation specialists.... Although the
notions of inter-disciplinary or even trans-disciplinary treatments attempt to bridge and coordinate various approaches, there has been very little written on or investigated with regard to how to practice this philosophy in patient interactions and not just in a paper trail. (Sohlberg & Mateer, 2001, p. 9)

More recently, we have begun to reap the rehabilitation benefit from collaborating and forming partnerships with families and caregivers. (Sohlberg & Mateer, 2001, p. xi)

Figure 5.10. Headwork 23: Keys to the ABI Cage addresses issues from cognitive rehabilitation.

5.3.3 Cognition/Thinking Involves Steps and Skills

Compared with cognitive rehabilitation, education views cognition within a framework of providing a scaffold or framework for learning. Anderson and Krathwohl’s taxonomy (2001) is a revised form of Bloom’s Taxonomy of Learning (1956). This taxonomy provides a comprehensive set of classifications to determine levels of learning included in a student learning task. It can also provide a useful checklist to view different ways people with ABI may engage with information. While it is tempting to view or treat the following taxonomy in a linear process for learning, this should be avoided. For example, inquiry or problem-based learning approaches often start at the complex end of the taxonomy (‘create’) to stimulate learning, and then work ‘backwards’ to examine the issue and deepen learning.

Table 5.1

Anderson and Krathwohl’s Learning Taxonomy (2001)

Learning involves:

- ‘Remembering’ involves recognising (identifying) and recalling (retrieving) information. This starting point can prove to be difficult when memory is affected.
- ‘Understanding’ involves the person constructing meaning from information: interpreting, illustrating, classifying, summarising, inferring, comparing and explaining.
- ‘Applying’ involves using the knowledge or procedure to a new situation or event.
- ‘Analyzing’ involves breaking the material or concept into parts by differentiating, organising and attributing.
- ‘Evaluating’ involves making judgments based on criteria and standards by checking and judging.
- ‘Creating’ involves putting elements together to form a functional whole; reorganising elements into a new pattern or structure — generating ideas — hypothesising, planning — designing and producing — constructing.
It could be generalised that good thinking involves gaining insight of an issue in order to have foresight to tackle similar issues. Thinking back to my experience with my ‘drop your handbag’ reaction to a green traffic lights or ‘running in front of an oncoming train’ reaction to a boom gate, I needed to understand by remembering, understanding, applying, analysing, evaluating and creating to develop ways to talk to myself next time I saw a traffic light or boom gate, and when I was confused about what to do.

The taxonomy was valuable in preparing resources for people with ABI. Rather than being filled like an empty vessel (which is not useful because people with ABI have memory difficulties), people with ABI need to learn to strengthen their cognitive skills across the lower order and higher order thinking spectrum. In using tools that are underpinned by such principles, people with ABI can then begin to engage with the variety of cognitive thinking levels.

Bloom’s (1956) taxonomy involves nouns — from knowledge, comprehension, application, analysis, synthesis to evaluation. Anderson and Krathwol’s taxonomy (2000) changes the nouns to verbs and changes the sequence to: remember, understand, apply, analyse, evaluate, to create.
Remembering: Start the process by obtaining simple remembering and recall of information.
Understanding: Lead them to make show they understand a concept by telling a story to illustrate the point.
Applying: Use the concept to make connections and apply the information to another idea.
Analysing the consequences of the information, and select other issues to distinguish a point.
Evaluating: helping them make a judgement about the issue by checking and judging.
Creating: generating ideas about how the information could be used in the future, hypothesise and plan for a further time.

Encourage synthesis where information gained can allow insight and foresight into problems.
Involving different ways of engaging with the material, recalling, talking about, applying a concept to something else, connecting, comparing and analysing the material until the person can talk about possible issues for the future and what to do about them.

**Figure 5.11.** Headwork 24: Keys to the ABI Cage provides steps for participants to engage in higher order thinking.

**5.3.4 **Learning Styles

Learning styles are various approaches or ways of learning (Kolb, 1984) that best assist the person to learn. The way that a person concentrates takes in, understands and stores and remembers new and information is defined as their learning style. Frequently, teachers assess the learning styles of their students and adapt their teaching methods to best fit their student’s learning style. Honey and Mumford (1982) posit that students learn best when they have an experience, they review the experience, they draw conclusions from the experience then plan the next step. This draws upon the concept of the student as ‘activist’, ‘reflector’, ‘theorist’ and ‘pragmatist’. Such a learning style approach was employed in *Keys to the ABI Cage*. Participants created their own knowledge by exploring the ideas drawn from other people with ABI and the ABI literature.

Participants had the experience of seeing the Cage, and watching the accompanying digital storage disk. They then reviewed the experience from their personal perspective. ‘Keys’ encourages them to draw conclusions from the experience and then plan how they could deal with issues and emotions in the future.

**Figure 5.12.** Headwork 25: Keys to the ABI Cage provides an experience for participants to review.

**5.3.5 **Multiple Intelligence.

Multiple Intelligences is a theoretical framework for defining/ understanding/ assessing/ developing people’s different intelligence factors. In his seminal work, Gardner (1983) conceptualised multiple intelligences as a framework that defines how we think, how we come to understand our world or how we generate knowledge. With this hypothesis in mind
*Keys to the ABI Cage* addresses many of these ‘intelligences’ in helping participants understand and generate knowledge (see below).

Prashnig (2011) states that both learning styles and multiple intelligences (see Gardner’s multiple intelligences below) need to be understood and acted upon for teaching strategies to become more useful and effective, and learning more enjoyable for students who struggle in traditional classrooms. Students can be assessed to determine their preferred learning style, which can then be used to assist their learning. For this study it was not possible to test each participant to assess their preferred learning style, but Gardner’s Multiple Intelligences were used to design the method used with *Keys to the ABI Cage*.

The models of disability outlined in Chapter 3 established pre-theorised versions of reality which, it has been argued, imposed, as a priority, a framework of meaning on the data. The phenomenological stance allows the data from people with ABI to ‘speak for itself’, to establish their meaning and, from this, to ground our understanding in those areas that have meaning and relevance to those with ABI.’

‘Multiple intelligences’ presents a panoply of vehicles through which learning can best be accomplished rather than a single theory reliant upon a limited range of learning styles. In this sense the approach offers a means through which people can meaningfully engage using the learning style they find most appropriate to their own engagement with knowledge’. It is argued that the concepts of learning styles and multiple intelligences can be helpful when working with people with brain injury because the person may have difficulty comprehending words, they may be suffering from aphasia to some degree and memory difficulties may limit their ability to remember the topic under discussion, whereas they may be more engaged if they have support for memory difficulties (they can hold the talk-about card in their hands), they can see and understand the whole picture of brain injury as they view ‘Keys to the ABI Cage’, and with the pictures and model in front of them they can see the progression of ideas and the direction of the discussion. At any time they can see where ideas fit in the whole concept. Reavey (2011, p.23) states that ‘remembering in everyday life is often facilitated via the use of visual images.’ This is very different to adopting any single learning style.

Thus the concept of multiple intelligences was used wherever possible in the study to assist the participant to remember and understand the activity/information involving the intelligence or intelligences they depend upon. Gardner’s intelligences are presented in Table 5.2.
Table 5.2

*Employment of Gardner’s Multiple Intelligences in Keys to the ABI Cage*

<table>
<thead>
<tr>
<th>Gardner’s Multiple Intelligences</th>
<th>Person’s Preferred Learning</th>
<th>How the Cage used the Intelligences</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The visual spatial intelligence</td>
<td>The person likes drawing and remembers visual landmarks</td>
<td>The cage uses spatial concepts, visual landmarks: it is a visual and memorable ‘landmark’.</td>
</tr>
<tr>
<td>2. The verbal/linguistic intelligence</td>
<td>The person likes to think in language or metaphor</td>
<td>Engaging with the cage involves using spoken and written language, and engaging in metaphor: talking as part of the interview, imagination is engaged with the use of metaphor.</td>
</tr>
<tr>
<td>3. The logical/mathematical intelligence</td>
<td>The person likes to compare and/or categorise information</td>
<td>Engaging with the cage provides an opportunity to compare and categorise information: the person can compare, categorise and ‘measure’ their own and other people’s experiences of ABI.</td>
</tr>
<tr>
<td>4. The bodily kinaesthetic intelligence</td>
<td>The person finds meaning in movement and touching</td>
<td>Engaging with the cage involves touching, and moving: touching the objects in the cage, moving things about in the cage, holding and placing the cards.</td>
</tr>
<tr>
<td>5. The musical/rhythmic intelligence</td>
<td>The person learns through rhythm and music</td>
<td>There was a rhythm established of taking up and placing the cards. For the learning resource rhythm/music will be used.</td>
</tr>
<tr>
<td>6. The interpersonal intelligence</td>
<td>The person sees the idea from another person’s perspective</td>
<td>Engaging with the cage led the participant to see the concepts from the perspective of other people with ABI. The talk-about cards held experiences from others and the CD recounted my own personal experience.</td>
</tr>
<tr>
<td>7. The intrapersonal intelligence</td>
<td>The person is aware of their own strengths, weaknesses and feelings and has insight</td>
<td>Engaging with the cage led the participant to become aware of their strengths, weaknesses and feelings and to develop insight. This was developed through the three key questions.</td>
</tr>
<tr>
<td>8. The naturalist intelligence</td>
<td>The person has a keen interest in the world of nature</td>
<td>The photos of the cage outside involved the world of nature. The bird, rocks and other contents were part of an ‘eco-system’ and used this as a metaphor for their experiences.</td>
</tr>
<tr>
<td>8½. The spiritual/ existential intelligence</td>
<td>The spiritual meaning of life is important to the person. It is 8½ because Gardner is still gathering evidence on this one</td>
<td>Engagement with the cage provided an opportunity for the participant to discuss their spiritual meaning of life. Metaphor was used.</td>
</tr>
</tbody>
</table>

Use of different intelligences could assist the person with ABI to learn and understand. Just as the traditional talk and chalk classroom (which relies upon the verbal/linguistic intelligence) is not the most expedient way for *all* students to learn, using the visual, logical/mathematical, bodily kinaesthetic, musical/rhythmic, interpersonal, intrapersonal, naturalistic and
spiritual/existential intelligences may provide learning assistance for a variety of learning styles.

Applying the concept of multiple intelligences to this study, a hypothesis is made that some people might find the physical presence of the cage and handling the artefacts (symbols) more helpful, while others might participate better with the digital storage disk, visual version in which the written word is required to express their response. *Keys to the ABI Cage* appeals to and engages all of Gardner’s multiple intelligences.

### 5.4 Summary

This chapter has identified literature in the field of education that was considered when devising *Keys to the ABI Cage*. A foundation of this study was that people are different, they learn in different ways and that different things can affect their learning.

*Keys to the ABI Cage* was devised to address people who are logical, critical, realistic and accurate by using structured activities, and allowing them to deal with the information sequentially, analytically, logically, factually and verbally. *Keys to the ABI Cage* was also devised to address the learning needs of people who learn through intuition, imagination, seeing the big picture, trying to understand and by discussing and sharing ideas. It is acknowledged that the issues discussed in this chapter may not be a prime consideration of ABI research, nor may the issues be the foremost focus in rehabilitation. This may be because of pressure of time constraints, limited funding, lack of resources, an absence of guidelines and the absence of appreciation of the significance of motivation and educational and learning principles.

The literature search suggested that there is a need for an interesting, structured, learning resource that employs concepts explored in this chapter. The resource could be used by the individual with ABI either privately, together with people who care for and support them or with their health professionals. The aim of this resource would be for the individual to achieve understanding and insight into ABI so they can learn to feel and fare better and make the best of living with ABI. This study aims to access lifeworld of people with ABI by inviting them to talk about their life in terms of a ‘commonwealth of concepts’ displayed visually in the tool, *Keys to the ABI Cage*.

Chapter 6 will explain the methods used for this study, synthesising information about education from this chapter with information about ABI obtained from the literature reviews.
in Chapters 3 and 4. Interpretative Phenomenological Analysis (IPA), the method used to analyse the data, will be explained, and an example of how IPA was used will be provided. Chapters 7 and 8 will then present the analysed findings.
CHAPTER 6
RESEARCH METHODS

6.1 Introduction

This study aimed to address the question ‘What issues need to be considered to design and test a method that employs educational/learning principles, to empower the participant with ABI to constructively reflect upon their ABI experience, to better understand themselves, so they can feel and fare better?’ Chapters 1, 3, 4 and 5 focused upon identification of issues that needed to be considered. Chapter 2 introduced Keys to the ABI Cage, the methodological shape and procedures devised to incorporate information from the review of literature. This study also aimed to test the method in order to identify the factors that positively and negatively affect the lifeworld of the person with ABI, and to discover if an individual may be ‘deepened’ by their ABI experience. The literature reviewed also focused on these concepts and informed the talk-about cards.

van Maanen’s concept of ‘Headwork’ was used in Chapters 2 to 5 to provide a catalogue of important issues and statements on the talk-about cards. The literature reviews in these chapters also pointed to a number of criteria that characterised this study:

- The most important consideration of this study was to preserve the rights, privacy, dignity and wellbeing of participants.
- I approach brain injury from the insider’s body-subject perspective — my role is as a person with brain injury and a visible researcher.
- As a professional educator I also approach it from the constructivist paradigm of education, where the individual themselves ‘constructs’ knowledge, with guidance. Knowledge is not something presented to the individual from a professional.
- Knowledge obtained from this study is for the direct benefit to people with brain injury, and will be made available to them through a book and web-based materials after the study.
- This study will seek positive things people with brain injury identify that help them as well as those things that pose a challenge.
- Participants were over 18 and at least two years post brain injury, when they were no longer in the rehabilitation setting.
Participants were not defined by their difficulties, differences and deficits, but by their courage and struggle. Respect was given to them as thinking ‘whole’ human beings.

From the position of a person with ABI, the body-object literature reviewed in Chapter 3 was conceptually inaccessible because of language used in the journal articles. It was physically inaccessible as it was presented in professional journals available only by subscribers. The information about studies mainly focused on deficits. The literature was written by and intended for professionals. ‘Power’ was involved in both the data collection and knowledge gained. In addition, for the person with ABI, the body-object literature has the potential to make them feel more disempowered. Information on ABI support web sites drew significantly from this literature. However, both qualitative studies and educational literature indicated important factors that could reduce the power differential between the researcher and the researched, and educational theories around motivation and cognition could be applied to research and rehabilitation.

Body-subject research around coping, quality of life and wellbeing did not appear to be translated for ABI support web sites to the same extent as the body-object research. Narratives in books and web sites offered more positive insights into living with ABI; however, synthesising ideas from these sources might be too taxing for most people with ABI. Therefore, constructive information from literature needs to be synthesised and translated, then reported in ABI support web sites to be read by people with ABI and their families.

*Keys to the ABI Cage* (refer to Chapter 2) had three purposes: to be used as a research tool, to gather data to inform a learning resource and to trial a learning resource that can continue to be used independently of this study. Therefore learning theories were examined in Chapter 5 to determine the role of engagement and motivation, to inform both the tool and the method.

The reader will now have a concept of, and a view of the physical object *Keys to the ABI Cage*, the talk-about cards (and their contents) from which each participant might choose to talk about their life in the interview, and (Appendix 6.1) ‘Handy Thinking Tools’, an alternate way to conduct the interview. The alternative format, the Reflection Kit, which used an interactive digital storage disk and ‘What ABI means to me sheets’, allowed access to rural people who might not otherwise be visited for an interview due to distance. This also offered the chance of a comparison of their engagement using a different form of media. The alternative format, reflection kit and digital storage disk are described shortly.
Just to reiterate, the interview or open-ended conversation, and the Reflection Kit led to the narrative, which explored three themes:

- My differences and difficulties can put me in the ABI Cage’
- ‘How I feel about my difference and difficulties can lock me in the ABI Cage’
- ‘Keys can release me from the ABI Cage’

Qualitative research studies experiences and engages participants using visual images to address research questions (Reavey, 2011). ‘Keys to the ABI Cage’ used images as Harper (2002, p.13) states that ‘The parts of the brain that processes visual information are evolutionary older than parts that process verbal information’

Previous chapters have presented the methodology, the theoretical framework including van Maanen’s Headwork; Clandin, Connelly, and Richardson’s narrative inquiry approach. This chapter now formalises the method used in this study and presents the procedures and analytic approach adopted for the data.

6.2 Introduction to the ‘Introductory Digital Storage Disk

In the same way that Chapter 2 provided an introduction to Keys to the ABI Cage to allow the reader to have a picture of the concept, a transcript of the Introductory digital storage disk (which introduced Keys to the ABI Cage to participants) is placed at this juncture (and is available as an attachment to the inner back cover of this document). It will allow the reader to obtain a clear description of how narrative is embedded in the method. The digital storage disk for interviews and the Reflection Kit were similar. Both contained colourful photographs and limited words.
**Keys to the ABI Cage Acquiring better insight into what it’s like to have ABI**

*The words on these talk-about cards are things people have talked to me about (and I’ve experienced myself.) You are invited to talk about these things. 1. How you are different to how you were, and the difficulties you have. 2. How you feel about your differences and difficulties. 3. Things that have helped you cope with your ABI.*

*I had my world turned upside down when I had a terrible car accident.*

*I Every day I still struggle to live with pain from my injuries, ABI, double vision and memory problems. So I do understand what life is like for you.*

*I I felt frightened and bewildered. I didn’t want anyone to ever feel as lost and scared as I was. So I wrote Doing Up Buttons.*

*I Here are my doves Lovey Dovey and Cloud. They couldn’t walk or fly properly so they weren’t proper birds. I felt wasn’t a proper person — I couldn’t even do up my buttons!! We were a good team!*

*I When I went on television to talk about my book I would put them in a cage to take them to television studios.*

*I ABI is just like being put in a cage. It feels like the cage is locked and the key is thrown away. There seems to be no way out.*

*I But pigs can fly! I have tried to stay hopeful! I decided to use (1) My old walking stick, (2) Lovey Dovey’s Cage, (3) A flying pig, to help you explain what living with ABI is like for you.*

*I Picture of the Cage*

*I Our Differences and difficulties can PUT us in the ‘ABI Cage’*

<table>
<thead>
<tr>
<th>Talk-about cards: Our Differences and difficulties can PUT us in the ‘ABI Cage’</th>
</tr>
</thead>
<tbody>
<tr>
<td>I forget where I live, I have terrible pain, I can’t walk properly, I dribble and choke when I eat, I forget my name, Rehab, I forget what things look like, I’ve lost my freedom — I can’t drive, I look like I’m drunk, I laugh and cry at the wrong time, I can’t talk properly, I can’t do things I used to do, Having to see lots of doctors, I’ve lost my family, I’ve lost my job, I can’t do up my buttons, Having to do lots of tests, I’ve lost</td>
</tr>
</tbody>
</table>

115
my friends, I can’t eat properly. My hands don’t work properly. I’m dependent and get lost, I’ve lost my memory, I feel sick and dizzy, I fall over and walk into walls, I forget what you’re saying or I’m saying, I’ve lost myself, I look different, I can’t see properly I can’t think properly.

*How we feel about our differences and difficulties can ‘lock’ us in the ABI Cage:

**Talk-about cards**: How we feel about our differences and difficulties can ‘lock’ us in the ABI Cage.

Bad: guilty, say and do the wrong thing, don’t understand.

Sad: depressed, disappointed, distressed.

Mad: angry, frustrated, ‘crazy’ and ‘nuts’.

Hopeless – the experts can’t fix me, crushed, scared, I hate myself.

*Keys that unlock ‘The ABI Cage’ These things help us cope:

**Talk-about cards**: Keys that unlock ‘The ABI Cage’ These things help us cope:


*Now we are going to look at your experience and things that have helped you turn a piece of poo into a rose.

**HOPE= Help Other Possibilities Emerge”**

**Figure 6.1. Introductory digital storage disk & Reflection Kit: Stars indicate individual slides and the words on the slides.**
Methods Part A: Data Collection

6.3 The Sample

6.3.1 Sample Sizes

This study was primarily about the experiences of people with ABI (over the age of 18) following the golden two years since injury period. These people were engaged in their everyday lives once again. Confidence in the findings of the study was more likely by data triangulation, the employment of three different types of participants (sources) and two methods of data collection.

Participants were to include 30 people with ABI, five people who care for and support people with ABI (note not referred to as carers — as the word carer implies unequal power) and five professionals. The latter two groups were included for the purposes of data triangulation (see 6.3.3). Foster (1997) asserts that a multidimensional perspective of the phenomenon will provide plentiful, balanced data that can be interpreted with a comfortable degree of assurance.

Data saturation was sought by the selection of the number of participants with ABI (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Saturation ensures trustworthiness where no new concepts are to be obtained and that participants are repeating concepts that had been found in previous interviews. Mason (2010) identified a mean sample size of 31 after examination of 560 studies that claimed saturation. Morse (1994) identified 30 to 60 as the number required for saturation; Creswell (1997) identified 20–30 for a grounded theory approach and 5–25 for phenomenological studies; and Bertaux (1981), in relation to qualitative research generally, identified 15 as the number of participants. Interpretative phenomenological analysis studies are conducted with a relatively small sample size — and some have said it is sufficient with a sample size of just one (Smith, 2004; Smith & Eatough, 2008, p. 39).

As well as singular theories induced from the data, this study aimed to establish a diversity of views. It was considered that the personal difficulties/differences/deficits of participants with ABI could misrepresent people with ABI in general, if less people with ABI were interviewed.

It will be seen in 6.10.1 that a number of qualitative analysis methods were trialled before interpretative phenomenological data analysis (IPA) was adopted.
Thirty participants with ABI and 10 family members/professionals would suggest that data collection and analysis would be time-consuming and lengthy. Nevertheless, I considered the views of a wide range of people were necessary in order to ensure that the data accurately represented the experiences of people with ABI.

6.3.2 **Type of Sample (Inclusion Criteria) of Participants with ABI**

Brain injury support organisations were contacted by phone and asked to place an advertisement (Appendix 6.2a) in their newsletter. This was then sent to the organisations along with a letter (Appendix 6.2b). People who were interested in being participants contacted the university who emailed me their details. I then contacted them by phone and if they fitted the inclusion criteria (see Appendix 6.3) they were sent a letter (Appendix 6.4) that set out the inclusion/exclusion criteria and Plain Language Statement. (The Consent Form will be found in Appendix 6.5).

As the main aim of this study was to do no harm to participants, ethical considerations informed the inclusion criteria: participants with ABI and people who care for people with ABI needed to be willing to reflect on the ramifications of ABI without becoming too distressed; if a person with ABI was taking part in the study the person who cares for and supports them could not take part in the study, or vice versa. Participants needed to be able to understand the plain language statement (Appendix 6.4) about the study, and be able to participate meaningfully with words or actions; they needed to be between the ages of 19 and 60 years of age; they should not be in a fragile state, stressed or in the midst of a crisis, nor awaiting a court case related to the accident associated with their ABI in 2009 (the year the interviews were conducted). Participants needed to be willing to have the interview tape-recorded. In order to reassure participants that their privacy would not be invaded, they were specifically not asked their age, occupation and so forth. The participants with ABI were to be between 2–14 years post-injury.

The sample was therefore a nonprobability sample and was purposive, requiring participants with particular characteristics to participate in the study. The sample might also be categorised as a criterion sample in that only a specific group, a group that met the study criteria from among the ABI population, was recruited for the study.

6.3.3 **Authenticity of Sampling — Triangulation**

Denzin (1970) suggests that methods that involve triangulation can increase trustworthiness, strength and interpretative potential. This study employed data source triangulation in time,
space and person (Denzin, 1970). Three different groups of people were involved in the data collection — 30 people with ABI, five people who care for and support other people with ABI (see Appendix 6.6 for letter sent to them and Appendix 6.7 Consent Form) and five professionals working in the field of ABI (Appendix 6.8 for letter sent to them and Appendix 6.9 Consent Form).

Methodological triangulation was also employed as different data collection methods were used (Lincoln & Guber, 1985): the interview alone, the Reflection Kit plus and interview and Reflection Kit alone, as I was striving to decrease the ‘deficiencies and bias that stem from a single method’ (Mitchell, 1986) and also testing whether the tool might be used as a resource in different formats. Within-method triangulation (Kimchi, Polivka, & Stevenson, 1991) therefore involved three data collection procedures from the same design approach, as summarised in Table 6.1. Ten participants with ABI were asked to provide data in two different ways — by completing the Reflection Kit, and later they took part in an hour-long interview.

6.4 The Interview

6.4.1 Reasons Why an Interview Was Used to Gather Data

Life stories are important to everyone as they provide an opportunity for the person to express who they are, their sense of self and allow others to understand who we are and how we got that way (Linde 1993; Widdershoven, 1993), therefore Keys to the ABI Cage was developed to scaffold the person’s thinking to tell the story of their experience.

The interview method was selected to allow people to tell their story in this phenomenological study, as interviewing involves exploration of and gaining understanding of the participant’s experiences and lifeworld. This was discussed in Chapter 4. Interviewing is initially broadly focused, process-orientated, context-bound, mostly in a natural setting and involves getting close to data (Holloway & Wheeler, 2010, p. 10) and the researcher/researched relationship is based on the concept of equality as human beings.

‘In-depth interviewing requires an interest and understanding of the lived experience of other people and the meaning they make of that experience’ (Seidman, 2006, p. 9). Interest and understanding was demonstrated by adopting Cresswell’s (1998) qualities seen as ‘caring’ nurses by their patients: the interviewer unsolicited gives of oneself, the participant will be viewed as a valued person and their comfort and security will be paramount with the meeting of their stated and unstated needs (Cresswell, 1998; see Appendix 6.10). Hermanowicz’s
important information regarding interviewing was implemented (Appendix 6.11):
listen carefully to ‘hear’ data … to have an ‘ear’ for what the participants are saying and focus
on what they find important or unimportant to them in their search for meaning. Searching for
meaning is a major reason to use the interview method.

Seidman’s (2006) suggestions were considered and followed, if applicable, with the
participants. Sixty minutes was selected as the length for the interview, although Seidman
suggests that three 90-minute interviews take place with each participant. This was considered
to be too taxing for people with ABI because of their fatigue, emotional, cognitive and
physical difficulties, and difficulty travelling to an interview, even at their local library. But
pre and post interview phone calls allowed rapport to develop and ‘Some further thoughts’
sheets gave the participants time to reflect on issues.

According to Seidman (2006), each interview should cover different topics: sharing life
experience, looking at details of their lived experiences and reflection about and finding
meaning attached to experiences. These three elements were addressed in this study through
phone calls, the interview and ‘Some further thoughts’ sheets. Seidman states that the
interviewer should listen on three levels (2006, p. 78) to internalise the meaning of the spoken
word, to listen to the unguarded intent behind the description of experiences and to watch for
nonverbal clues. These three levels of listening were undertaken in this study, and Seidman’s
tips to direct the interview (2006, pp. 81–93) were followed. These included:

• ‘Respond to the interviewee, but do not lead the response to the question.

Example (a) from this study: ‘Donna’ holding the ‘Rehab’ talk-about card:

From the word go I was terrified, so the only way I ever knew to face fear
was to understand it. I think some of the first words I found to say was
“educate me”…. I would say “I had trouble doing this, so I need help to do
that”. Because I knew they would have a checklist of what I had to achieve
to get home. So the goal was all about getting home. So I knew I would have
to stretch myself, feed myself, and medicate myself, so I worked through
that list. That’s all I could hold in my head, but that’s what I worked on…. I
was with other people with terrible problems, and I was saying, how would I
know if I was like this…. And I said to my family am I like this. Or people
who couldn’t remember their children’s names. Am I like this? Am I doing
this? Am I repeating myself as often? So I think I drove everyone around me
insane, by constantly saying the word “why”. Or is this me too?

• ‘Do not interrupt the participant while they are speaking — see Example (a)

• Ask them to tell a story about a particular part of the experience. Be patient; do not fill
the silences — give them time to think and respond.
Example (b). ‘Bernadette’: “Rrr.. yea, every day is.... a... new...... challenge”...[long silence]... “I ...feel.... isolated..... from .... people recently...” [Long, long silence].

As I was dealing with vulnerable people who were divulging ‘secrets’ about their experience, I did not follow Seidman’s suggestion to ask them to reconstruct the experience or ask for concrete details, as I was concerned that this could upset them.

Interviewing is a relationship between the interviewer and interviewee and involves rapport, distinguishing between private, personal and public experiences, differences of race, gender, status, language, age and positions of power (Seidman, 2006, pp. 95–106). As explained in previous chapters, status and power were carefully considered and, as I also had ABI, this assisted the development of rapport. Race was not an issue in this study.

6.4.2 The Introductory Digital Storage Disk

As well as having the physical object of Keys to the ABI Cage and talk-about cards for the participant to explore, a digital storage disk (see 6.2 for a transcript of this was developed and shown on a laptop computer. The purpose of this digital storage disk was to gain the interest of participants by explaining the story behind Keys to the ABI Cage, to familiarise the participant with what they would be asked to do in the interview and, for procedural purposes, all participants would be given the same introduction and instructions.

6.5 The Reflection Kit

The Reflection Kit was developed to widen the sample to include 10 people living in rural areas. It was also employed to test which method was preferred — interview and Kit (10 people), Kit alone (16 people). The Kit included a digital storage disk, instructions to use the digital storage disk (See Appendix 6.12) and ‘What ABI means to me’ sheets (Appendix 6.13). These sheets were to be filled in as the participant watched and listened to the digital storage disk, they then completed an evaluation sheet (Appendix 6.14). Once participants had completed the sheets these were returned to me (see procedure Appendix 6.17). ‘Some more thoughts’ sheet (Appendix 6.15) could be sent at a later date if they wished. Included in the Reflection Kit were contact numbers for people to contact if they needed to (6.16).

The digital storage disk PowerPoint presentation was similar to the transcript at the beginning of this section, and included slides with my voiceover; but three orange coloured slides were situated after the slides about the talk-about cards. When the participant came to this orange slide they were asked to pick up the ‘What ABI means to me’ sheets and answer the question
that corresponded to the talk-about cards (Difficulties and Differences, Feelings and Keys). The second difference was that at intervals throughout the presentation there were suggestions that if the person was upset by reflecting on their experience they should talk to someone who supports and cares for them, or to ring one of the phone numbers of support organisations listed on the sheets and digital storage disk.

6.5.1 Procedure re the ‘Reflection Kit’ Group

During the initial phone call (see Appendix 6.3) I had asked the participant if they had a computer, if they knew how to insert and use a digital storage disk and if they were willing to participate in this way (with or without an interview). After they had read the plain language statement and returned the Consent Form, a package was assembled and sent by mail, the Reflection Kit. This included an instruction sheet (see Appendix 6.12) for using the Reflection Kit, the digital storage disk and ‘What ABI means to me’ sheets (see Appendix 6.13) and a stamped addressed envelope to return the completed sheets.

A week after this package had been sent participants were phoned to make sure they had received the kit, that they were not having trouble with the process, or that they were upset by thinking about their experience. The completed ‘What ABI means to me’ sheets were posted by the participant to the university. They were then posted to my home address. Once I had received their sheets I phoned the participant to thank them and check that they were okay. A thank you card was sent.

6.6 Data from Interviews and the Reflection Kit

There was a great variation in the quantity and quality of data collected in the interviews and Reflection Kit. This will be discussed in Chapter 9. With the ‘What ABI means to me’ sheets some participants reviewed the sheets on several occasions to add to their thoughts, some wrote at length, some replied to the questions briefly, but with great thought. Analysis of data involved information obtained from both interviews and kits.

Table 6.1 summarises the methods employed and the participants who used each of these methods.
Table 6.1

Methods of Data Collection

<table>
<thead>
<tr>
<th>Group</th>
<th>Method</th>
<th>People with ABI (N = 36)</th>
<th>Family carers</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Interview only</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>B</td>
<td>Reflection Kit plus Interview</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>Reflection Kit only</td>
<td>16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Group A = Interview only — 10 people with ABI, five people who supported and cared for other people with ABI and five professionals.

Group B = Reflection Kit plus an interview — 10 people with ABI

Group C = Reflection Kit only — 16 people with ABI.

6.7 Procedure

All participants in this study (as shown in Appendix 6.17, Table 6.1) were recruited in the same manner. Initially, ABI support organisations were contacted by phone, the purpose and method of the study was explained and they were asked to place the advertisement (Appendix 6.1) in their newsletter. The participants then contacted me through the university, ensuring their confidentiality — the support organisation would not know that the person was involved in the study.

6.7.1 Recruitment Procedure

See Appendix 6.17 for greater detail of procedure. The elements of the process are presented in Table 6.2.
Table 6.2

Recruitment Procedure

<table>
<thead>
<tr>
<th>Procedure</th>
<th>People with ABI Interview</th>
<th>People with ABI Reflection Kit</th>
<th>People with ABI Reflection Kit and Interview</th>
<th>People who care for people with ABI</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read Advertisement</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Person contacts university</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Durham rings them</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Sent Plain language statement &amp; consent forms(2)</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Return consent form</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Phone call to organise interview</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Interview</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Reflection kit sent</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Phone call from Durham re kit received</td>
<td></td>
<td>*</td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Sheets returned</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Phone call to check OK &amp; Thank you</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Phone call 1 week later to check OK</td>
<td></td>
<td>*</td>
<td></td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Thank you card sent</td>
<td>*</td>
<td>*</td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

If interest was shown in the study a letter was sent (see Appendix 6.4, 6.6, 6.8) with an advertisement to be placed in their newsletters (Appendix 6.1). As can be seen from the advertisement, people with ABI, family carers and professionals were all invited to ring and register their interest at a remote phone at X university.

Once contact had been made from people with ABI, people who care for other people with ABI and professionals, I phoned the person using an untraceable phone number. I talked with them about the study and filled in the checklist (Appendix 6.3). If the person was still interested and fitted the criteria I sent them a letter and the plain language statement (Appendix, 6.4, 6.6, 6.8) along with two consent forms (Appendix 6.5, 6.7, 6.9) to be signed and witnessed — one to keep and one to return to me. Once I had received the signed consent sheet, forwarded from the university, I would phone and negotiate a time for the interview or send the Reflection Kit. I would also telephone them the day before the interview to make sure it was still suitable and remind them of the time and place of meeting.
### 6.7.2 Interview Procedure

(i) Preparation prior to each interview

Prior to each interview the following were taken by car and assembled at the interview location if possible (on several occasions the cage was assembled on the footpath or car park as it was too bulky to be assembled in a coffee shop):

- **Keys to the ABI Cage**, complete with walking stick, pole and talk about cards
- Two boxes (labelled ‘Do’ and ‘Don’t’), and a second set of the talk-about cards
- A laptop computer with the PowerPoint® presentation ‘Introduction to Keys to the ABI Cage’ ready to use
- The recording device
- The Ethics Consent Form
- The evaluation form
- A ‘Some further Thoughts’ sheet and self addressed stamped envelope (Appendix 6.15)
- Take home information about who to contact if the participant was upset by revisiting their past experiences (Appendix 6.16).

(ii) The participant arrived at the interview location

I introduced myself and my husband Edward, who drove me to each interview. Edward then moved to an area out of the way but within sight of (but out of hearing range) of the participant and I. We sat and chatted briefly about our phone conversations and they were put at their ease, and coffee was ordered (if in a location where coffee was available).

They were shown the Consent Form they had signed and returned to me. They had been asked to sign and have witnessed two copies of the consent form, one to keep and one to return the other to me in an enclosed stamped, addressed envelope. After changes to procedure I gave them a photocopy of the form they had signed and sent to me. I then read aloud the information on the form to make sure they had understood what they had signed. On the form they had signed a section to say that I was permitted to audio record the interview, they were asked again if it was okay to record the interview. Then the voice recorder was switched on.

(iii) Introduction to Keys to the ABI Cage

I introduced the participant to the **Keys to the ABI Cage** model, and talked about the three issues we would be discussing, and pointed out the various visual cues — and the participant
examined the Cage and the talk-about cards to become familiar with the concept and with what they would be asked to do.

Then the participants viewed the digital storage disk on a laptop computer. This described the three-step process of the interview to further familiarise them with the concept and what they would be asked to do (see 6.2 Methods).

(iv) The interview or guided conversation

The interview was broken into three sections as was explained previously.

The participants were now handed the second set of talk-about cards ‘Our Differences and Difficulties can put us in the ABI Cage’. They were invited to take each card, one by one, and put the card in the boxes labelled ‘Do’ or ‘Don’t’ and they could talk about the comment, or something the words reminded them of, if they wished to do so. While reviewing this section the participants added the following statements, which were turned into talk-about cards over the period of the 30 interviews: ‘I don’t know “new” me’; ‘I’ve lost “old” me’; ‘Police’; ‘Lawyers’; ‘Isolated’; ‘Very, very, very cold’.

The participants were now handed the second set of talk-about cards ‘Keys to the ABI Cage’, they repeated the process and they were invited to place the cards in the ‘Do’ or ‘Don’t’ box and talk about the issue on the card or any other issue the words reminded them of. These cards were illustrated with colourful pictures.

The set of talk-about cards fixed to the pole with the golden keys and the flying pig had little objects attached to them — a tiny cup, a tiny watering can, a tiny dog, ‘stretching my comfort zone’ had a rubber band wound round it. This captured the interest and attention of participants and caused a lot of smiles. The objects renewed the interest and helped participants to focus their attention on this section. They also renewed energy by providing a breathing space as they examined and discussed the objects. Most participants were fatigued by this time as we had been concentrating on issues for 45 minutes.

This list contained a wide range of things in order to show participants that there were many things that can help us feel better, or factors that have a positive effect on our lives. When participants held the stack of cards denoting Keys to the ABI Cage they had selected, they became aware of the large number of ‘keys’ that could help them feel and fare better.

(v) Conclusion and wrapping up
At the conclusion of the interview participants completed a brief evaluation sheet, they were given the ‘Some further thoughts’ sheet, and a stamped self-addressed envelope (at the university address) to take away with them, and a sheet of phone numbers of people to contact if they became upset as a result of participating in the study, which may have stirred up some negative experiences or memories. These phone numbers were on the information and also ‘What ABI means to me’ sheets (Appendix 6.13).

Then each participant was given a ‘Hope Stone’, a black polished river stone with a star affixed to it: the stone was a symbol of the hard things we can tackle; the star reminded them we can always reach for the stars.

(vi) Follow up after the interview

The day following the interview, or when I had received the ‘What ABI means to me sheets’ by mail, I contacted participants by phone to check that they were not upset by the process of reflecting on their difficulties. I also phoned them a week after the interview to make certain that they were not troubled by the issues their reflection might have brought to light.

A thank you card was sent. This contained two coloured photographs — one of the ‘ABI Cage’ and another of the ‘Pole of the Flying Pig’ — showing some of the keys that can release us from the ABI Cage, and additionally a bookmark of coloured paper with the phone numbers of professionals for them to contact if they were/became upset as a result of their participation in the study.

Eight participants returned ‘Some further thoughts’ sheets and had put an effort into telling about issues they had forgotten. Two others just wrote a few words, ten did not return the sheets.

6.8 On a personal note

As a person with ABI I still experience difficulties with double vision, memory, understanding time, numbers, juggling a number of tasks at the same time and fatigue. I had clearly set out the steps that would be involved in the period of time in which the interviews were conducted, but I had totally underestimated the complexities involved in the multitasking required.

I organised only two interviews a week, as they required detailed packing of the car, my husband driving me for up to two hours to the interview, conducting the interviews — which
were emotionally and physically draining, and the return journey of up to two hours. In order not to break the flow of the interviews field notes were made after the interview. Field notes were also made during phone calls to people who had contacted the university stating they wished to be involved in the study, and when making phone calls to organise interviews, and after the interview or when they had returned the sheets to check they were okay. At this same time I was also posting letters and consent forms, assembling and sending Reflection Kits, reading returned ‘What ABI means to me sheets’, sending thank you cards and checking with RMIT for returned forms and sheets. I experienced difficulty juggling so many different tasks at the same time.

Half-way through the interviews an ethical issue arose, which required attention and the study was suspended for a period of three months while this was resolved. The suspension of the interview program meant that I had some people already in the ‘pipeline’. I considered it important to honour my agreement to involve them in the study. But I must confess that I still experience great trouble with numbers and counting (setting the table still remains a challenge) thus, by mistake, an extra six people with ABI were sent the Reflection Kit — so 36 people with ABI, five mothers and wives and five professionals (46 people) were involved in the study. All participants were sent Christmas cards the year of the interview, as I was intending to recontact them to gain their feedback on the findings of the study. Unfortunately, the issues that involved the suspension of the study made me reluctant to make contact with participants again in case there could be another incident. This is unfortunate as I was intending to present the findings of the study to them and ask for their comments.

6.9 Ethics

Ethical considerations were of prime importance in this study. Many of the ethical issues were identified as important criteria in earlier chapters and reviewed at the end of Chapter 4. The section 6.3.2 discussed the inclusion criteria for participants with ABI and people who care for and support people with ABI.

This study sought to establish a balance between risk and benefit, both in the process of doing the work, and in terms of the long-terms gains (i.e., means and ends), to ensure that the potential benefits to the participants as well as potentially to others with ABI (i.e., public good) were accentuated in the way the research was carried out; to ensure the benefit was at all times as high as could be managed within a research process. A review of ethical considerations can be found in Appendix 6.18 (Tables 6.2–6.7) where ethical issues regarding the wellbeing of the participants with ABI were considered. The RMIT HREC ethics
submission approval letter for project No 04/09 was dated April 27, 2009 (see Appendix 6.19). After the incident, an amended letter was provided on October 8, 2009 (see Appendix 6.20).

‘All interviews will take place in a public space, no interview will take place in a private home’. In the Plain Language Statements this clause was inserted:

If you disclose something illegal or you tell Chris that you intend to do something to hurt yourself, or other people (or you have done so in the past), Chris will have a duty to report this to RMIT University, and the interview will be ended. If this happens the interview will be terminated.

My husband Edward was appointed a Support Assistant to assist by:

- Providing administrative services.
- Providing transport to interview and RMIT meeting locations.
- Providing technical support with computer, recording devices, interview room layout.
- Providing a presence and protection role for Christine throughout interviews in the event that a participant becomes emotional or aggressive.
- Edward will act with caution to ensure that no confidentiality is breached in any way.

Figure 6.2. Clause inserted in Plain Language Statement.

The incident that led to this project being suspended, re-emphasised the profound effect of the difficulties/differences/troubles of ABI.

As is usual, participants were provided with a plain language statement and an informed consent sheet, although the consent process was less a simple signing, than a process, (Cutcliffe & Ramcharan, 2002) as the issues were discussed on the phone, in the plain language statement, on the consent form, and the form was read to the participant before the interview was commenced.

I remained vigilant throughout the interview for any signs of participant’s discomfort such as tears in the eyes, sweating, distancing, shifting about in the chair, long pauses or becoming emotional. At all times I was supportive and believed the participants when they spoke of their perceptions. I did not ask for clarification but allowed the participant to lead the discussion.
The study sought to ensure anonymity and any names used in the following data analysis chapters are pseudonyms. The wellbeing of participants with ABI has been considered of prime importance in every stage this study. In the event that some participant searched out and read this thesis, they might recognise other participants who were known through ABI support groups. For this reason it was considered that pseudonyms alone would not fully accomplish confidentiality. As a further way to ensure confidentiality, statements in the first case have been split up, so it is not possible to trace through statements under one pseudonym in order to recognise a certain participant with ABI, either by people with ABI or by professionals who might identify a client by putting together statements under a particular pseudonym. Indeed, some of the places and identifying features have been changed without changing the meaning of what was intended, so as to ensure anonymity. The data (Cutcliffe & Ramcharan, 2002) were kept under pseudonyms on a password-protected computer.
Methods Part B: Analysis

6.10 Background

The audio recordings of the individual interviews were transcribed and I found myself swamped with over 150,000 words of data from the 30 interviews and 16 ‘What ABI means to me’ sheets. How should the phenomenological analysis of this data proceed?

I decided not to use a software analysis program for practical reasons: My computer skills are very limited because of my memory and vision problems. I experience extreme difficulty remembering how to use certain computer programs. For example, I could not use the Endnote program as my sight meant I had difficulty reading and placing information in the correct position. References were all completed manually. I type with only one finger while looking at the keyboard, as reading the printed word on the computer screen is a struggle due to my double vision — lines of typing intersect each other and move about the screen when I use both eyes; if I patch one eye my balance problems become more troublesome. Additionally, due to my left neglect (I still tend to neglect things on my left) each typed line would contain several errors as I frequently type the letter on the right side of the letter I intended to type, and because my left hand is still slow, generally after typing a capital letter my left finger would remain on caps lock too long and the second letter would also be capitalised. These problems have required arduous correction processes.

Another reason I did not choose to use a software program was to be true to phenomenology. This phenomenological study has been about ‘humanness’: the method that data was gained through interviews and conversations, with my role as a subjective actor, rather than a detached and impartial observer (Moustakas, 1994; Plummer, 1983; Stanley & Wise, 1993) suggested that I should use a phenomenological method of analysis. Participants had freely shared their deep metaphysical suffering with me and I was concerned that a software program might not capture the pain, shame and hope expressed by the participants.

6.10.1 The Phenomenological Approach to Data Analysis/Understanding

Chapter 4 (Section 4.8) discussed phenomenology as a philosophy and explained that this study would look for blind spots by searching for the essence or nature of the lived experience as revealed through the familiarity of individuals with ABI; through searching through layers of beliefs and perceptions of the lived experience. ‘Meaning is central, and the aim is to try to
understand the content and complexity of those meanings... through a sustained engagement with the text and a process of interpretation’ (Smith & Osborn, 2003, p. 66).

Phenomenology deals with human understanding, and this study explored the human understanding of the experience of ABI in a qualitative manner, searching through dialogue to uncover connections between issues and emotions, issues and insight and issues and how people coped or survived.

Phenomenological reduction involves leaving theoretical speculation behind and ‘bracketing’, cutting through the taken-for-granted and conventional wisdom about what it is like to have ABI — the blank spots. Instead, it focuses on the participant’s personal perceptions, understandings and knowledge — blind spots, to become ‘full of the world, full of the lived experience’ (Van Manen, 1990, p. 32).

According to Moustakes (1994) a common characteristic of human research is that it studies human experiences that are not approachable through quantitative approaches. Data analysis moulds ‘meaning from narrative’ (Moustakes, 1994) from the ‘clay’ of the words of the participants, this clay was how the person with ABI thought about their experience. Important but elusive strengths of the person with ABI were revealed in the discussions and transcripts demonstrated that symbols, stories and humour were an integral part of explanation and description.

There is no one phenomenological method and a number of phenomenological approaches were tentatively trialled, but as I progressed with each new method of analysis, I became dissatisfied with the practicalities of accomplishing analysis of the 150,000 words of transcripts. Initially, I made cursory attempts to analyse data using the methods of a number of authors (see below).

6.10.2 Struggles with Different Approaches

Following several readings of the transcripts, important passages were identified, underlined and notations recorded in the wide margin of the transcription. I commenced by employing Colaizzi’s (1978) seven-stage data analysis from ‘exhaustive description’; revisiting each person’s transcript to ascertain if the findings could be useful for the large amount of data I had for analysis (Colaizzi, 1978, pp. 59–61). Throughout the analysis there was a constant threading back and forth to write interpretative summaries and search for potential themes, and validate themes. With the seven steps, and the large amount of data, I found this method of analysis too unwieldy.
Then I trialled Diekelmann, Allen and Tanner’s (1989) analysis method, rereading the transcripts to gain a holistic impression, and writing interpretative summaries and searching for potential themes. By now I had accumulated a large number of themes. But as Diekelmann et al.’s analysis is formulated to be used by a research team this also was not suitable for this study.

After that I experimented using Giorgi’s (1985a, 1985b) four stages (Holloway & Wheeler, 1996, 2002,) rereading the transcript to make sense of the whole, grasping Gestalt (German for ‘essence or shape of an entity’s complete form’ or ‘wholeness’) to find the ‘structure of the experience’. Meaning units were identified and insights contained in the meaning units were noted. These were ‘transformed’ — units were then integrated into a consistent statement about the particular experience termed the ‘structure of the experience’. These were then formulated into unequivocal statements of identification of its fundamental structure — called essential structures of the phenomenon.

I now had substantial amount of organised data but as I returned to each participant, one by one, underlined and extracted phrases or sentences, and noted discrepancies I decided to search for a method that I could adapt to suit the aims of this study. I wanted to identify factors that negatively and positively affect the lifeworld of people with ABI, and a method that allowed me to interpret the meaning behind the words. That brought me to the work of Smith.

### 6.11 Adopting Smith

Smith’s (1996) interpretative phenomenological analysis (IPA) was eventually selected for several reasons: Firstly, because the method used in the interviews and the interviews themselves were from an insider’s perspective and IPA is concerned with a person’s personal perception and account of ABI (an event), rather than attempting to make any essentialist statement about ABI (the event itself) (Smith, 1996). IPA involves interpretation. As an insider I am in a good position to interpret statements: ‘explain the meaning, bring out the meaning, act as an interpreter’. Earlier chapters discussed the need for medical language to be interpreted for people with ABI. Here I am suggesting that the language of people with ABI needs interpretation for others to understand.

Secondly, data obtained involved narratives. IPA focuses on the narrative and involves formulating the connections between issues, emotions, insights and survival — Husserl’s
concept of phenomenology, and is connected to hermeneutics and theories of interpretation (Smith, 2007, 2008).

Thirdly, IPA is ‘not a prescriptive approach; rather it provides a set of flexible guidelines which can be adapted by individual researchers in light of their research aims’ (Smith & Eatough, 2007, p. 45). My research aims were to find data to inform people with ABI so they could help themselves feel and fare better.

Fourthly, Smith suggests that a study employing IPA might well enrich literature of an area previously only studied quantitatively. It is hoped that this study can enrich the ABI literature.


It was apparent that an adaptation of IPA was necessary to deal with both the amount, depth, breadth and the complexity of the data and the analysis process. Although IPA is generally used in studies with a smaller number of participants, Smith’s category analysis allowed adaptation to fit the complexities of the data.

Smith and Eatough (2008, p. 39) say that ‘recently we have increasingly been arguing the case for a sample of one’, but early on, the ‘researcher needs to make some critical choices, asking herself “Do I want to say something, detailed and nuanced about the particular person or more general about groups and populations?”’. Within the context of my study, the answer to this question was to find out about the lifeworld of people with ABI. Smith and Eatough state that some early career researchers

try to “play safe” by having a larger sample size, hoping they will therefore overcome the anxieties of examiners who might be more comfortable with quantitative research... this almost always misfires: it is too easy to end up in the trap of being swamped with data and only producing a superficial qualitative analysis but still not having an adequate sample to satisfy quantitative criteria. (2008, p. 39)

As explained in 6.3.1 the number of participants was chosen for specific reasons, not to play safe. As people with ABI were considered to lack self-awareness, and Keys to the ABI Cage was experimental, I could not be assured to gather sufficient data from say six participants — indeed, now, in hindsight after transcripts of the interviews and Reflection Kits have been examined, I could select six from which I would gain little information and another six that
provided a plethora of data. But prior to gaining the data I would not have been able to judge which group a prospective participant belonged to.

Indeed I was swamped with data, but each participant’s transcript was treated with the attention and respect it was due. The process of IPA aims to ‘explore in detail individual personal and lived experiences to examine how participants are making sense of their personal and social worlds’ (Smith & Eatough, 2007, p. 35). I examined the transcripts of all the participants with ABI. Then I examined the transcripts of mothers and wives who care for and support other people with ABI, then professionals’ transcripts were analysed. These two groups were designed for the purpose of data triangulation, although analysis of these groups demonstrated the different ways people perceive factors that influence the lifeworld of people with ABI. Participants tend to reflect on their own lifeworld, as mother, wife or professional, as they try to perceive the lifeworld of people with ABI.

The analysis followed the staged process described in Smith and Eatough (2007) and Smith and Osborne (2008), first for one transcript and then repeating the procedures for each transcript. I had already identified themes in the first case when I experimented with other data analysis methods. These themes were revisited and clustered together to form emergent themes. These themes were further clustered together to form overarching themes, which were finally clustered into superordinate themes. An example is set out below.

### 6.11.1 Applying Smith and Osborne (2008): A Practical Example

Transcription of each participant’s interview included a wide margin, which allowed for initial thoughts, observations and field-note comments to be recorded. The approach used is summarised in Table 6.3.
Table 6.3
Smith and Osborne’s Stages and Approach Used

<table>
<thead>
<tr>
<th>Smith’s &amp; Osborne’s Stages</th>
<th>Approach Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1. Looking for themes ‘in the first case’ for each individual participant.</td>
<td>Transcripts read a number of times. Became familiar with the account. Comments noted in margin. Reflection Constant comparison.</td>
</tr>
<tr>
<td>Stage 2. Clustering themes in the first case to find emergent themes. Each individual participant.</td>
<td>In other margin record emerging theme titles. Move response to slightly higher level of abstraction. Transformation of initial notes into themes.</td>
</tr>
<tr>
<td>Stage 3. Clustering of emergent themes to find overarching themes. Master list of combined emergent themes from all the participants.</td>
<td>Look for connections between themes. Try to make sense of the connections between themes — check with transcript. Cut and paste to compile directories of participants phrases that support related themes. Extracts moved, condensed and edited.</td>
</tr>
<tr>
<td>The process was repeated for each of the 46 transcripts.</td>
<td>Once each transcript had been analysed by the interpretative process, a final table of superordinate themes was constructed.</td>
</tr>
<tr>
<td>Stage 4. Clustering of overarching themes to find superordinate themes.</td>
<td>Examination of overarching themes — looking at richness of passage, how the theme helps illuminate other aspects of the account, prevalence of the theme and impact on the individual of the theme. Once superordinate themes were identified earlier transcripts were reviewed in light of the superordinate theme.</td>
</tr>
</tbody>
</table>

6.12 A Worked Example: Factors That Negatively Affect the Lifeworld of Participants with ABI

Firstly I read and reread the transcript of the first participant, Sally.

Stage 1: ‘Words in the first case’ (the participant’s direct words)

Sally’s transcript read and reread to identify factors that had a negative impact on her lifeworld. These were underlined and notes made.

It was many months...I think it was my GP, that actually diagnosed me. I think she said ‘are you angry?’ and that was one of my biggest problems. Cause I couldn’t control my anger. (9) I don’t think I realised that, because I didn’t know what was going on those first few months. But then I ended up getting referred to do rehab, so I was there for 6 months.

Sally’s underlined passages were each numbered (in this example (9) to facilitate re-visiting the statement in context.
Among all the underlined passages was one statement ‘I couldn’t control my anger’ (Sally statement 9) and this example will now be used.

Each one of Sally’s numbered statements were now copied and placed in the middle of a three columned table, as her words were central to the analysis and they were revisited as they were clustered in the left column with statements from other participants to form ‘Emergent Themes’. The right column ‘Overarching Themes’ were checked against her statements to make sure the meaning had not been lost. This was a circular process, starting and ending with Sally’s words in the central column (Step 1), clustering with other themes to form emergent themes (Step 2) and interpreting consequences of Sally’s anger and clustering it with statements from other participants to determine the overarching theme (Step 3). Finally, rechecking with Sally’s words to determine if Sally couldn’t control her anger would this affect her so that she felt she had ‘lost’ her old self, and she no longer felt ‘normal’ (Step 4). The arrows indicate the movement from step 1, 2, 3 and 4.

### Table 6.4

*Themes in the first case, emergent and overarching themes*

<table>
<thead>
<tr>
<th>Underlined points Themes in the first case – Sally’s words</th>
<th>Emergent Themes</th>
<th>Overarching themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1:</strong> I couldn’t control my anger (9) (the ninth statement in Sally’s transcript)</td>
<td><strong>Step 2:</strong> Anger Lack of control</td>
<td><strong>Step 3:</strong> Loss of my ‘old’ self Loss of feeling ‘normal’</td>
</tr>
<tr>
<td><strong>Step 4:</strong> To check if Sally couldn’t control her anger would this affect her so that she felt she had ‘lost’ her old self, and didn’t feel ‘normal’</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The underlined passages were cut and pasted on pages that were divided into three columns:

1. The middle column (the underlined points) — themes in the first case.
2. The left column — the emergent theme (first interpretation/abstraction of theme).
3. The right column was filled in with categories in common — these became the negative overarching themes.
This ‘reduction’ of data involved, as Smith suggests, ‘imagine a magnet with some of the themes pulling others in and helping to make sense of them’ (Smith, 2004, p. 71). Thus, emergent themes were collected and collapsed to form the overarching themes. These themes could be identified as having a connection to both ‘Themes in the First Case’ and the following stage ‘Superordinate’ themes.

**Stage 2: Clustering of emergent themes**

Sally’s emergent themes of ‘Anger’ and ‘loss of control’ were now cut and pasted onto a master list of emergent themes of all the participants with ABI.

**Table 6.5**

*Emergent Themes from Several Participants, Including Sally’s ‘Anger’*

<table>
<thead>
<tr>
<th>Anger</th>
<th>Frustration</th>
<th>Loss Of Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of Identity: The ‘New’ And ‘Old’ Me: <strong>Comparisons</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Can’t Understand</td>
<td>Can’t Control Emotions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disappointed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distressed</td>
</tr>
<tr>
<td>Crazy/Insane</td>
<td>Guilty</td>
<td>Stupid/Bloody Idiot</td>
</tr>
<tr>
<td>Embarrassed</td>
<td>Disempowered</td>
<td></td>
</tr>
</tbody>
</table>

138
Stage 3: Clustering of emergent themes to make overarching themes

Sally’s statement demonstrated that her inability to control her anger had a negative effect on her lifeworld. I, as the researcher, now became ‘more immersed...more responsive to what was being said’ (Smith & Eatough, 2007, p. 46). I revisited the participant’s words and my interpretation, to make sure their meaning was not lost when reduced to more abstract concepts.

By immersing myself in the words I was led to see this statement ‘I can’t control my anger’ implied several comparisons — between the ‘old’ Sally, who could control her anger, and the ‘new’ Sally who couldn’t control her anger. This could be further interpreted to the ideas that Sally could not trust herself to control her anger.

Sally’s statement also could be interpreted to show that she knew this loss of control of anger was not ‘normal’ — she compared herself to normal people who could control their anger. Her lack of control over her anger meant she did not feel normal. Clustered with similar statements from other participants with ABI the consequences of Sally’s inability to control her anger clustered together to form the emergent themes:

(i) Loss of identity: the phenomena of the ‘new’ and ‘old’ me.
(ii) Loss of understanding.
(iii) Loss of trust — I can’t trust myself.

The transcripts of other participants were then revisited and similar themes were clustered together to make the overarching theme ‘Loss of ‘self’ loss of the ‘old’ me’.

Table 6.6
Superordinate, Overarching and Emergent Themes

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ‘The Blind Spot Conglomeration’. Consequences of ABI can result in the person with ABI being (not just feeling) Afraid, Ashamed and Isolated but this is in their ‘blind spot’ and they are not aware of these factors that influence their wellbeing.</td>
<td>1. Loss of ‘self’ loss of the ‘old’ me</td>
<td>(i) Loss of identity: the phenomena of the ‘new’ and ‘old’ me: Comparisons</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(ii) Loss of understanding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(iii) Loss of trust: Can’t trust myself, other people, the experts, fate/God/luck</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(iv) Loss of faith/Religion/ being punished by God</td>
</tr>
</tbody>
</table>
Stage 4: Clustering of overarching themes to make superordinate themes

This process was repeated as the clustered overarching themes were cut and pasted together to form the superordinate themes. In this case, Sally’s inability to control her anger, contributed to the ‘The Blind Spot Syndrome’. The consequences of ABI can result in the person with ABI being (not just feeling) Afraid, Ashamed and Isolated but this belief is in their ‘blind spot’ and they are not aware of these factors that influence their wellbeing.

The ‘essence’ of the lifeworld of people affected by being unable to control their anger is very complicated.

6.13 Summary

This chapter has discussed data collection, sample size, type of sample, the interview procedure, the Reflection Kit procedure, ethical considerations of this study and the method employed (IPA) to interpret and analyse the data.

This was illustrated by a worked example that took just one comment from just one of the 46 participants and showed how this comment was, using a constant comparison of data, placed more abstractly in emergent and overarching themes through the process of analysis — Sally was afraid, ashamed and isolated but she was not consciously aware of this because it was in her ‘blind spot’.

As will be examined in Chapter 9 Discussion, learning and knowing this can take the issues out of the blind spot and empower the person with ABI to look for strategies and attitudes to help them feel and fare better, thereby affording a personally transformative engagement over time.

The following chapter will examine all the transcripts for factors that negatively affect the lifeworld of the person with ABI. Chapter 8 will at last come to the core of this study and identify factors that positively affect the lifeworld of people with ABI.
CHAPTER 7

FINDINGS OF THE STUDY: FACTORS THAT NEGATIVELY AFFECT THE LIFEWORLD OF PEOPLE WITH ABI

7.1 Introduction

Previous chapters have examined ABI from the body-object and the body-subject perspective, philosophy, theories and academic background that informed the tool *Keys to the ABI Cage*, the participants and the method of data collection and analysis. Chapter 6 provided a worked example of the analytic method adopted and the systematic way in which the study data were analysed in readiness for the presentation of study findings in this and in the following chapter.

The research questions of this study were: What issues need to be considered to design and trial a method that employs educational/learning principles, in order to empower the person with ABI to constructively reflect on their ABI experience, to better understand themselves, (gain greater self-awareness), so they can feel and fare better? This question has been explored in the previous chapters, and the next two chapters will also focus on people with ABI as learners — of things they have learnt about themselves and ABI:

- What factors positively affect the lifeworld of the person with ABI?

Can an individual gain something, be deepened, by the experience of ABI? If so, can this be used to help others experiencing similar life challenges?

- What factors negatively affect the lifeworld of the person with ABI?

This chapter and the following chapter will use interpretative phenomenological analysis (IPA) outlined in Chapter 6 to examine factors that negatively and positively affected the lifeworld of a person with ABI, where the place of intentionality is a vital component of the process. Others might choose to cluster or collapse the data in a different way. This interpretative analysis did not focus on every theme that emerged from the data, rather, themes were purposefully chosen because of their relevance to the research question — to discover factors that had a negative effect on the lifeworld of people with ABI, and to discover what the data suggests about their learning experience.
It has been established that people with ABI are known to lack self-awareness. This chapter will demonstrate that people with ABI can learn to have self-awareness, not in a linear straightforward way, but by a process of ‘learning circumnambulation’, by circling themselves and reflecting and learning from their experiences. *Keys to the ABI Cage* method encouraged participants with ABI to tell stories and reflect on things that had a negative effect on their life. At the beginning of this thesis it was stated that the focus of this study would be the ideas of insiders (people with ABI), and that concepts from outsiders (family members and professionals) would be included for the purpose of triangulation. There were a larger number of participants in this study who had ABI, and additionally this group identified a wider range of factors than some of the family members or professionals. Thus, a larger section of this chapter will deal with information from people with ABI. This will be discussed further in Chapter 9.

### 7.2 Participants with ABI: Factors That Negatively Affect the Lifeworld of Participants with ABI

#### 7.2.1 Overview of Factors

Appendix 7.1 demonstrates the wide range of themes and issues taken from the interview data that impacted on the lifeworld of the person with ABI, from the point of view of people with ABI, family carers, and professionals.

As the analysis proceeded I considered ways in which the words in the first case and emergent themes collapsed down to fit the broader overarching themes and, in turn, these collapsed down to the superordinate theme (see Table 7.1). This threading backwards and forwards between the three themes — superordinate, overarching and emergent — kept revisiting the words in the first case to keep the analysis grounded in the words of the participants.

The four overarching themes, loss, lost and trapped; no longer like a ‘normal’ person; damaged by emotional fallout and the rehabilitation experience didn’t suit me; collapsed down to the superordinate themes: ABI damages not only the person’s brain, body and beliefs, it also damages their hope, honour, trust and safety and security and learning is hard labour—it is a struggle to learn when the person is afraid, ashamed and isolated. This is shown in Table 7.1.
### Table 7.1

**Participants with ABI Overview of Findings**

<table>
<thead>
<tr>
<th>Superordinate Theme</th>
<th>Overarching Theme</th>
<th>Emergent Theme</th>
<th>Words In The First Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Loss, lost and trapped</td>
<td>Loss of identity: the phenomena of the ‘new’ and ‘old’ me: Comparisons</td>
<td>Loss of understanding</td>
<td>See Tables 7.2, 7.4, 7.5, 7.6</td>
</tr>
<tr>
<td>ABI damages not only the person’s brain, body and beliefs, it also damages their hope, honor and trust, and safety and security.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning is hard labour—it is a struggle to learn when the person is afraid, ashamed and isolated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. No longer like a ‘normal’ person</td>
<td>Can’t function normally</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t understand or communicate normally</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t control emotions normally</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Weird’ abnormal issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Damage from emotional fallout</td>
<td>(Sad) Disappointed; Depressed; Distressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Mad) Angry; Frustrated; Crazy/insane</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Bad) Guilty; Stupid/bloody idiot; Embarrassed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. The rehab experience didn’t suit me</td>
<td>Loss of hope</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found rehab disempowering</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professionals don’t know what it’s like (brain injury or the system)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bad rehab experiences</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was not a textbook case but I was treated like one</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of choice</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The remainder of this section (the perceptions of participants with ABI) will show how themes laid out in Table 7.2 were derived from the data and then how these were collapsed into emergent and overarching themes.
7.2.2 **First Overarching Theme: Loss, Lost and Trapped**

The four emergent themes: the loss of identity, understanding, trust and faith were clustered together to form the overarching theme ‘Loss, lost and trapped’ and are shown in Table 7.2.

**Table 7.2**

*First Overarching Theme: Loss of ‘Self’ the ‘Old’ Me*

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Loss, lost and trapped</td>
<td>Loss of identity: the phenomena of the ‘new’ and ‘old’ me: Comparisons</td>
<td>‘I wish I could have one more day without a brain injury just to be the person that died once more — to be with my family the way I used to.’ ‘... the frustration of not knowing who I am, and the lack of understanding of brain injury’. ‘I compare myself to my family/friends/peers/workmates; to what I want to do with my life and what I am capable of.’</td>
</tr>
<tr>
<td></td>
<td>Loss of understanding</td>
<td>When I don’t understand what people are saying I feel frustrated ... embarrassed.’ ‘I am not the person I would have been if I hadn’t had the accident’.</td>
</tr>
<tr>
<td></td>
<td>Loss of trust: Can’t trust myself, other people, the experts, fate/God/luck</td>
<td>‘I’m frightened because I can’t trust myself and I can’t trust other people and I can’t trust health professionals.’ ‘... but what I think is right really isn’t right’,</td>
</tr>
<tr>
<td></td>
<td>Loss of faith/Religion/being punished by God</td>
<td>‘I walked outside and never came back — what else might happen?’ ‘Man plans — God laughs’.</td>
</tr>
</tbody>
</table>

Participants with ABI did not approach the process of reflecting about experiences in a straightforward, linear way. But, as they held the talk-about cards, they reflected and came to realisations as they spoke. They circled and revisited ideas and came to further realisations, at times contradicting themselves.

The majority of participants told stories to illuminate the overwhelming effect of being a ‘different’ person as they struggled to function. They were overcome not only by physical, mental, communication and emotional difficulties and pain but they were also overpowered by a sense of loss. They were aware that they had lost the old self and were struggling to live with their new selves. Some participants spoke of the sadness of realising and accepting that they would never be their old self again.

In their struggle to make sense of themselves, most participants told stories about how they constantly compared their old and new self: how they thought they deserved to be treated by people including by their family, friends, health and legal professionals and how they
perceived that they were actually treated; and their slow recovery progress compared to the
effort they were making. Many stories demonstrated that life prior to their ABI seemed ‘more
fair’ than their post-ABI life, where they had no choice and little power. The complexity was
in many ways, therefore a product of comparing a new with an old me as shown in Table 7.3.

Table 7.3

Comparisons to the ‘Old’ and ‘New’ Me Taken from the Data

<table>
<thead>
<tr>
<th>‘Old Me’</th>
<th>‘New Me’</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I could walk, drive, work, go out, socialise, travel. I could chose to do anything I wanted to</td>
<td>I can no longer do these things. With my loss of physical, cognitive skills difficulties I’ve lost my choice — I have no power</td>
</tr>
<tr>
<td>2. I could talk, listen and understand</td>
<td>I can’t talk, listen understand and I have great difficulty communicating</td>
</tr>
<tr>
<td>3. I could eat easily</td>
<td>I don’t know when I’m hungry, I have difficulty chewing, swallowing — I can’t smell or taste my food</td>
</tr>
<tr>
<td>4. I could see</td>
<td>I can’t see properly</td>
</tr>
<tr>
<td>5. I could cope with life</td>
<td>I can’t cope with life and fatigue plagues my day — I get exhausted trying to cope with all by difficulties. This limits my life</td>
</tr>
<tr>
<td>6. I could control my emotions</td>
<td>I can’t control my emotions I make a fool of myself crying when I shouldn’t</td>
</tr>
</tbody>
</table>

A plethora of overwhelming and multiple losses compounded the feeling that the old self that
they knew, understood, trusted and depended on, had gone. The new self could not be
controlled, trusted or understood. These difficulties also cut the person off from normal
people, isolating them, making them feel like an alien. Without a personal identity and clarity
over their own self, the presentation of self becomes impossible and the self was constructed
in the way others treat them. This ‘looking-glass self’ was not a self with which the person
felt happy!

Most participants spoke about being bewildered, confused and lost because they could not
make sense of, or understand what people were saying, what they should do, or how they
should accomplish simple tasks. They could not understand the new self, the ‘stranger’ who
had taken over their body, brain and life. Just getting by was complicated, tricky, and
demanded all their attention and effort.

This new self could not be depended on; for example, they could do some things on one day
but not the next, at one time of day but not another time. A number of participants doubted
themselves and said that they felt guilty and asked me if I thought they were an ‘imposter’,

145
others stated they wished they were more damaged with broken limbs so people would understand they were ‘injured’ or ‘damaged’. Participants were generally confused and frustrated with their changed lifeworld and they told stories that illustrated the stigma of ABI.

As the participants held the various talk-about cards, stories emerged that clustered around trust. They could no longer trust themselves; they were aware that they did and said the wrong thing and, as a consequence, had lost confidence. They were aware they could not control their tongue — they were not tactful, their decisions were not right. Many participants had a ‘gut’ feeling that they could not trust themselves.

Almost every participant told of experiences that proved that they could not trust other people. They tried to hide their difficulties/differences/deficits from their family, friends, the public and medical professionals but they were ‘exposed’ and vulnerable. Most participants spoke of ‘disappointing’ encounters, when they thought people would understand/have empathy and sympathy with them for the difficulties they were experiencing. When people didn’t understand (and make allowances) participants became more wary of trusting others.

One third of the participants expressed disappointment with the way their family didn’t understand, some felt ‘scared’ of and had ‘lost trust’ in their families. Fred was ‘physically attacked…smacked by my wife’, Melissa was distressed that her parents would accuse her of being lazy but that she was trying hard and suffered from ‘bad fatigue’. A majority of participants had lost trust in their friends who did not ‘see what was really going on’, or who said they seemed to be ‘OK’. Pete said he wished he could reply ‘Oh yeah. Swap places with you then’.

Some participants had bad experiences with professionals and a great many participants expressed distress that they did not receive enough care or understanding from medical professionals. Their stories inferred that they thought professionals would be ‘the one group of people who would understand them’. A large number of participants were distressed because of the pessimistic outcomes suggested by professionals. This topic will be further explored later in this chapter.

For those who had religious beliefs, this had both a negative and positive impact on their lifeworld. Some participants had lost trust in God and many were struggling to make sense of why God was punishing them, or they queried whether God had caused their ABI to teach them a lesson, or if they could trust God to protect them the future. Over half the participants said that they were terrified they would have another accident (if it had happened once it
could happen again) and that they would not have ‘the will or the energy to fight brain injury when it happens again.’

The loss of trust (in themselves, others, God and the future) negatively affected their lifeworld.

### 7.2.3 Second Overarching Theme: Not Like a ‘Normal’ Person Any More

The second overarching theme clustered around losses and came together around a mass of data relating to a comparison between how participants perceived themselves compared to a normal person. Because they could not do certain things they thought they were no longer normal. These differences and deficits made life difficult and were also symbols that they were not like a normal person any more. None of the participants referred to themselves as disabled, although Goodley’s (2011, p.1) statement ‘to be disabled evokes a marginalised place in society, culture, economics and politics’ could be applied to them. Interestingly, participants with ABI did not readily identify with being labelled disabled. However, they told stories and compared themselves to other normal people and this comparison had a negative effect on their lifeworld. The supporting data are presented in Table 7.4 and discussed below.

The four emergent themes: Can’t function normally, Can’t understand and communicate normally, Can’t control emotions normally; and weird and abnormal issues, clustered together to form the overarching theme ‘Not like a ‘normal’ person any more’.
Table 7.4
Second Overarching Theme: Not Like a ‘Normal’ Person Any More

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Theme</th>
<th>Words In The First Case—Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Not like a ‘normal’ person any more</td>
<td>Can’t function ‘normally’ — to move, eat and sleep normally, fatigue</td>
<td>‘My hands didn’t work properly’&lt;br&gt;‘I forgot to eat. I didn’t have any appetite; I didn’t know when I was hungry and when I wasn’t.’&lt;br&gt;‘I scare myself — I must be a bit of a freak if I have to help myself swallow with my finger down my throat.’&lt;br&gt;‘My brain can no longer go to that special place called sleep but I had terrible fatigue.’</td>
</tr>
<tr>
<td></td>
<td>‘Can’t understand and communicate normally’</td>
<td>‘I have a great deal of trouble enunciating words — people find it hard to understand me’&lt;br&gt;‘I didn’t know how to tell the person … didn’t know the words to tell the person I couldn’t use the phone …’</td>
</tr>
<tr>
<td></td>
<td>Can’t control emotions normally</td>
<td>‘I cried all the time … at the drop of a hat. I was very emotional’&lt;br&gt;‘I went sort of the opposite, I just found everything hilarious. I was really extreme. I’d sit there and just laugh at everything. Well, I couldn’t help myself.’&lt;br&gt;‘I have not cried since accident — I feel like I need to cry to get it out you know — I’d love to cry — I have so much to cry about.’&lt;br&gt;‘I can’t cry — I don’t have tear ducts’.&lt;br&gt;‘… I can’t cry — but that’s — ok — because I never — was — a — big sook.’</td>
</tr>
<tr>
<td></td>
<td>Weird abnormal issues — balance, left neglect, distorted vision</td>
<td>‘If I was granted a wish today, it wouldn’t be to have my sight back. It would be can I have my left side back, to make me whole again. But the loss of sight loss I can overcome, workaround. The left loss…’&lt;br&gt;‘…like I knew how to do the dishes but I couldn’t work out how to do them’.&lt;br&gt;‘If a person was in the blind spot, I didn’t know that they were there … I couldn’t see them, but my body could sense they were they and I’d move away, so I was forever falling over. So I’d say … “walk over there, you’re on top of me, get away from me”, and she couldn’t understand.’</td>
</tr>
</tbody>
</table>

All participants could not function ‘normally’ to do a range of normal things such as walking, driving, working, going out, socialising or travelling. Most participants had balance problems which they described as ‘very clutsy’, ‘dodgy’, ‘fineline’. Some participants accepted their physical difficulties in a matter-of-fact way and they joked about the inability to walk normally for example, or ignored that they had difficulties. Impaired vision, loss of one eye or being legally blind was accepted stoically by several of the participants.

Several participants described how in the early months after their injury, they were ‘freaked out’, frightened and disturbed when they lost the basic normal ability to know how and when to eat, when they found themselves dribbling and choking, because their ‘brain had forgotten
how to tell the throat how to swallow’. These participants reported a tremendous loss of weight. Normal people can eat normally, they couldn’t. Meg still felt like a ‘freak’ as she still had to put her fingers down her throat to help herself swallow. Several participants spoke about their loss of smell and taste.

Sleeping was a problem for many participants. They had difficulty sleeping at night or, as one participant expressed it, as her brain ‘could no longer go to the place of sleep’. However, most participants had adapted to their fatigue, they ‘knew their limits’ and limited their daily activities to cope with the mental, physical and emotional exhaustion and weariness. They had accepted that coping with fatigue was part of their lifeworld with ABI.

Many participants spoke of how frustrated and embarrassed they were when they could not understand what people were saying or could no longer read. The inability to speak so that other people could understand was very upsetting. Holding the talk-about card with a topic in their hands helped some participants to hold a conversation about how they had difficulties speaking, listening and understanding.

Many themes were not isolated units in themselves; for example, the following issue could be placed under the ‘communication’ or ‘weird’ themes. Several participants discussed their puzzling inability to use the telephone, yet they did not remember this or ‘have the words to ask for help’ at an appropriate time. This made them doubt themselves, it was taken as proof that they were not normal and made them embarrassed, ashamed and afraid they were crazy. As Paula said:

It’s weird telling you … because you understand what I’m talking about … But then you forget that you couldn’t remember to use the phone, so you couldn’t actually get any help anywhere, because you couldn’t remember what you couldn’t remember. I think, looking back now, I thought there was something really really bad, wrong, and that I’d better not tell anyone. No, not that I shouldn’t tell anyone, but that I was embarrassed, ashamed … I don’t know, I think I was terrified.

For many participants a further symbol that they were not like normal people was the experience of uncontrollable crying (and laughing) in public. The next overarching theme ‘The emotional fallout’ considers the emotional difficulties in greater detail as it was a category that was sufficiently large and important to stand on its own. But uncontrollable crying and laughing were the outward emotional outbursts that caused participants public embarrassment and shame, and private shame and puzzlement.
It also emerged from stories from many of the participants that they were struggling with a variety of perplexing ‘invisible’ issues including ‘left neglect’, where they neglected the left side of their body and distorted vision. A small number of participants spoke about weird metaphysical issues, where they did not know who was talking (the other person or themselves). These invisible issues had a profound effect on their lifeworld. Several participants stated that their left neglect profoundly affected their wellbeing as it was strange and weird. One participant, who was legally blind, said that if she could have one wish, rather than regaining her sight she would want to get the sense of her left side back, so she felt whole.

Distorted vision, double vision, and seeing in other peculiar ways affected some participants. If vision was ‘confused’ it was ‘confusing’ to see things that were not there — if they couldn’t believe their eyes to tell them what was real — how did they know what was real? Tunnel vision meant the person had many blind spots — and this caused frustration and walking difficulties as they could sometimes ‘sense’ someone was in their blind spot, which was disconcerting. These strange and weird aspects of ABI affected the participants’ lifeworld.

7.2.4 **Third Overarching Theme: Grappling with Emotional Fallout**

All participants identified with the ‘Sad’, ‘Mad’ and ‘Bad’ talk-about cards (and their subsections) that were positioned inside the ABI Cage. These cards led them back to refer to stories they had previously told or they told new stories to illustrate their point of view. In Chapter 2 it was explained that the employment of these three small everyday words could provide a ‘softly softly’ approach (a nonpsychological, nonprofessional) way to broach profound, personal, serious matters. Participants ‘got’ the way the words were used and the words got them talking about the words, then themselves. Many commented that the words and their meanings made them really think and that it was an amusing way to think about how they felt. They thought it ‘was clever’ the way the different meanings were unpacked. The crushed soft drink can was widely recognised as an example of ‘myself’ (a crushed human being). Some participants opened the cage door so they could hold the crushed drink can. ‘This is me’ they said. The categories are shown in Table 7.5.
Table 7.5

Third Overarching Theme: Grappling with Emotional Fallout

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Grappling with emotional fallout — afraid, ashamed and isolated</td>
<td>Sad: Disappointed; Depressed; Distressed</td>
<td>‘Disappointed is an interesting word, it’s too mild for what I felt. I was probably disappointed with myself, disappointed with the doctors, and disappointed with everyone and everything for a while. Um, sad, distressed, and absolute abject despair and futility. Because I think brain injury it’s the unknown as well.’ ‘I’m so disappointed with life — my illness wasn’t my fault.’ ‘I’m still sad and depressed constantly.’ ‘I was depressed, and I was powerless.’</td>
</tr>
<tr>
<td></td>
<td>Mad: Angry; Frustrated; Crazy/insane</td>
<td>‘I was very angry, I had terrible anger’ ‘I’m so angry at the way I was treated — all professionals, even alternative ones are arrogant.’ ‘Probably mad/frustrated — that’s brain injury in a nutshell’. ‘Oh God I was really frustrated.’ ‘It drives you to distraction … trying to make your brain work’. ‘Feeling am I going mad? I think I am going mad.’ ‘I thought I was mad and everyone else was mad.’ ‘I’m going crazy. With the professionals, sometimes I felt like… are people doing this on purpose? Is this part of a stupid IQ assessment? Whether that’s a bit of paranoia or whatever’.</td>
</tr>
<tr>
<td></td>
<td>Bad: Guilty; Stupid/bloody idiot; Embarrassed</td>
<td>‘I feel guilty because I can’t trust myself — I’m not dependable — with good and bad days my thinking works in stops and starts.’ ‘I feel like I’m an imposter — I haven’t got it all together and things eat away at me — if I tried a bit harder I’d fix myself. ‘I feel bad because I’m slow and I can’t concentrate, I can’t understand things.’ ‘They say put the thing over there and I don’t understand — I’m lost.’ ‘I feel bad because people say things that I don’t understand and I feel bad — is it me or maybe the ABI just brought that out?’</td>
</tr>
</tbody>
</table>

Most participants placed the ‘Sad’ talk-about card in the ‘Do’ box. Many participants expressed disappointment with themselves and their lives, because they could now no longer achieve their dreams, the fact that day-to-day survival was difficult, that financially their future was changed for the worse, and that they no longer had careers they had loved, marriages had broken down — life was no longer predictable or controllable. They were ashamed and disappointed. They talked about feeling depressed, hating themselves, having contemplated suicide or disappearing, and feeling powerless. One participant spoke about the reluctance of professionals, family and friends to discuss their suicidal feelings with them.
Many participants also identified with the *distressed* talk-about card — that the ABI experience was distressing.

Anger was a big problem for many participants and they told stories of their terrible anger and rage, but the majority of respondents reported they had feelings of frustration, they felt annoyance rather than anger — at themselves, at situations they were put in because of having ABI and their loss of choice. Anger was expressed at the way the person was treated by professionals, another participant explained about their terrible uncontrollable anger where they wanted to put their hand through a glass window, and how they would kick things and hit their partner. One participant observed that he realised he was taking on the mood of people he saw.

All participants placed the ‘Frustration’ talk-about card in the ‘Do’ box. ‘mad/frustrated — that’s brain injury in a nutshell’ and their stories told of the struggle of trying to cope with a brain and body that does not obey the person. Of when they cannot understand why they behave in a certain way, when they are forced to rely on others, or to complete ordinary tasks when they are blind.

Many participants said that in the years following their accident they had believed they had gone mad or insane, that they often questioned if they were crazy, mad or nuts. They thought that everyone else was mad: Sharon said she thought the professionals were trying to make her feel insane on purpose, or, was what they were doing ‘part of a stupid IQ assessment’. These participants were profoundly affected by believing they were insane.

Most participants expressed *guilt* in some story or other — either about pain they were causing their family who they felt they had ‘let down’, for what they had put their family through, because they had not avoided the accident, because they couldn’t make themselves better, or because they had ‘let’ their ABI affect their life too much. Over half the participants felt guilty they had not ‘tried hard enough to make themselves better’. The linking of the other overarching themes can be observed in this theme — the first two overarching themes affect this theme of trying to grapple with the emotional fallout of ABI. By contrast, one participant identified that she avoided responsibility and guilt, but then she got more stressed and felt this was a trap. She said the only way was to acknowledge and move forward, which was a challenge for her every day.

Many male participants expressed feeling like a ‘bloody idiot’ when they did or said the wrong thing, when their poor balance meant they were unsteady when they walked and they
are accused of being drunk, stereotyped as being a loser, or get declined entry to bars. Women felt bad about other issues such as doing and saying the wrong thing; one participant elegantly called this the ‘loss of social graces’; others would query if the inappropriate action was due to their ABI or were they ‘just stupid?’ Not being able to complete simple tasks such as doing up their buttons resulted in them ‘feeling pretty stupid actually’, being embarrassed because they were ‘slow and can’t concentrate, or can’t understand things’. The participants were ashamed, afraid and isolated as a result of their emotional fallout.

7.2.5 **Fourth Overarching Theme: The Rehab Experience Didn’t Suit Me**

This study did not set out to critique rehabilitation and there was only one talk-about card that referred to rehabilitation: ‘Rehab’. It was up to the participant to simply place the card in a ‘Do’ or ‘Don’t’ box or to talk about their experience if they wished to. The participants were not asked to focus on expressing views on their rehabilitation experience. However, this was seen by the majority of participants as a significant area that they wished to speak about.

As many people who will read this thesis will be rehabilitation and health science professionals, I do not want to analyse the comments from participants, nor do I not want to criticise rehabilitation per se. But as over half the participants expressed opinions about how upsetting they had found rehabilitation experience, I will group the participants’ words in the first case for the reader to reflect upon.

Reviewing the data revealed issues around a perceived lack of understanding, power, truth, fairness and justice had profound long-term ramifications on many participants’ sense of wellbeing. Some participants had forgotten what was *said* and *done* in rehabilitation, but not how rehabilitation made them *feel*. They talked about people and events they did not want to think about, but found they could not forget.

This will be further examined in chapters 8 and 9.
Table 7.6

**Fourth Overarching Theme: The Rehab Experience Didn’t Suit Me**

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. The rehab experience didn’t suit me</td>
<td>I found rehab disempowering</td>
<td>‘In rehab I felt like a meal ticket.’</td>
</tr>
<tr>
<td></td>
<td>Loss of choice</td>
<td>‘... they were just like a Nazi camp to me ... ’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I wanted it to be about me. Well, all our problems were different. And I don’t like group therapy.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Some of those experts that I saw...didn’t inspire ... they made it harder’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Rehab was a waste of time.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Rehab was like being in jail — I was a copper.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I had to do rehab — I didn’t want to do rehab — but you’ve got to do what you’ve got to do...’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘My OT was hopeless — it just didn’t fit with what I felt I needed.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I wasn’t wanting an OT and I didn’t want to do the exercises.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I didn’t like anything done in groups.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘[Health professionals]...anyone who has made a difference? Nup sorry’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Professionals from rehab centre I don’t think played a huge role in my acceptance ... They focused on the physical’</td>
</tr>
<tr>
<td>Professionals don’t know what it’s like (brain injury or the system)</td>
<td></td>
<td>‘They don’t know what it’s like to actually experience the system.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘We want to educate the professionals.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘...lipservice ... they didn’t even believe what they were saying themselves ’We’ll say this to appease him and keep him calm’. I probably had more insight than what they had...’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I thought they didn’t know what they were talking about.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I felt it was suggested I was lazy, or my motivation damaged.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Integrity, that’s something about ABI.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘You can’t trust what they say...I was told I wouldn’t be able to do things that I’m doing now.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I’ve discovered that people judge you, they believed I was lazy.’</td>
</tr>
<tr>
<td>Bad rehab experiences</td>
<td></td>
<td>‘Rehab for 12 months oh poor me!’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Sexually inappropriate behaviour from professional people.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘They didn’t find some of the injuries until some months afterwards — they didn’t even know about it, and I kept on complaining...’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘The OT kept telling me I wasn’t trying enough. It made me mad’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘They thought I was slow — I was now deaf — what terrible mistake to make.’</td>
</tr>
<tr>
<td>I was not a textbook case but I was treated like one</td>
<td></td>
<td>‘Perhaps the professionals could treat us less like text book cases and consider us as human beings with thoughts and feelings a little more...we are not babies and do not need to be treated like we are.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘People in rehab were blind to our ability, they just concentrate on our disability.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I wish staff at rehab do a bit more than what they are doing — things I want to do.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Pretty frustrating — I don’t think the system catered for me to a degree because of my level of fitness.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Remember that we may have lost some of our bodies BUT help us to work out with the remainder. Abilities NOT disabilities.’</td>
</tr>
</tbody>
</table>

The following long quote has been included because the perception this participant had about the rehabilitation experience still upsets her years later.
Rehab was so awful actually I don’t…it’s something I don’t talk about, I don’t think about, if I do, I cry…I’ve always believed it was my own fault that I didn’t like rehab. In terms of that, I was in a terrible place, so it was always going to be bad…I was suffering…anywhere would be bad…but this was worse. ‘Cause it was bad at home, but this was really bad. And I think it’s the way, it’s a system that… it’s a hierarchy, it’s really structured, it’s really rigid, there’s rules, there’s no compassion, there’s no understanding, it’s not about the individual, it felt like you were in a factory…that you were just being pushed through, you were a number…you were just on this treadmill.

The majority of participants were informed that the brain heals for up to two years, then they plateau out. This two year rule took away their hope: ‘I was told all through my rehab and from other doctors, that the brain will only heal in the first two years, and after that there’s not much healing that happens’.”

A few participants said they had been damaged twice — firstly by ABI, and secondly by rehab. Positive comments about rehabilitation will be identified in the following chapter.

7.2.6 The Superordinate Themes of Factors That Had a Negative Impact on the Lifeworld of Participants with ABI

Long term recovery from brain injury is not a medical problem…Medicine has very little to offer in this direction. The way forward lies in education…the power for recovery lies within the injured person as they relearn their daily living skills. Education is the key. (Freeman, 1998, p. 14)

The arrangements and methods for this study have been premised on these words. In the examination of the transcripts and analysis of the findings four overarching themes were identified: (1) Loss, Lost and Trapped, (2) No longer a ‘normal’ person, (3) Damaged from emotional fallout and (4) The rehab experience didn’t suit me. These themes have collapsed into the two superordinate themes: ‘ABI damages not only the person’s brain, body and beliefs, it also damages their hope, honor, trust, safety and security’; and ‘Learning with ABI is hard labour — it is a struggle to learn when the person is afraid, ashamed isolated.’

The factors that had a negative effect on the life of the participants with brain injury came from stories they told as they discussed the words on each of the talk-about cards. The four superordinate themes were not on the talk-about cards although the cage was a symbol of being trapped. There was one ‘neutral’ card that said ‘rehab’ – the large response to this word was not expected. The literature reviewed in chapters 3 and 4 did not focus upon these themes, nor were the educational principles outlined in Chapter 5 utilized in the studies reviewed. In this study educational principles were employed to empower participants to reflect on factors that negatively affected their life. The moral and the social model of disability in Chapter 3 can be seen to influence the four overarching themes.
Table 7.7

Superordinate Theme: Learning with ABI Is Hard Labour. ABI Damages Not Only the Person’s Brain, Body and Beliefs, It Also Damages Their Hope, Honour, Trust, and Safety and Security

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI damages not only the person’s brain, body and beliefs, it also damages their hope, honour, trust, and safety and security.</td>
<td>1. Loss : lost and trapped</td>
</tr>
<tr>
<td>Learning with ABI is hard labour</td>
<td>2. No longer a ‘normal’ human being</td>
</tr>
<tr>
<td></td>
<td>3. Damage from emotional fallout</td>
</tr>
<tr>
<td></td>
<td>4. The rehab experience didn’t suit me</td>
</tr>
</tbody>
</table>

Most participants ‘got it wrong’, no matter what they did, many had only limited success, some were worn out with the struggle and were frozen. Chapter 8 will examine factors identified by participants that helped to counteract the paralysing effect of ABI — factors that helped them to live and learn.

Throughout the interviews many participants modified their statements as they reflected further about an issue. Most surprising were two participants who had stated that they had suffered from depression and been suicidal until recently. But later in the interview they stated that ABI had been the best and worst thing that had happened to them in their life. As will be seen in the following chapter, great challenges and satisfaction are not mutually exclusive.

Factors that have a negative impact upon people with ABI will now be examined from the perspective of family members.

7.3 Mothers and Wives’ Views of Factors That Have a Negative Impact on the Life of Their Loved Ones

The second group of participants was composed of three mothers of sons with ABI, Molly and Sue whose sons were in their twenties; Molly cared for her son at home, Sue’s son lived independently, both sons had support from carers. Jane’s son, a young teenager was at school. Also included in this group were two wives, Jo whose husband had suffered his ABI several years ago and their life had established a form and rhythm to accommodate his disability and Liz who was still learning to put in place structures to support her husband. These five women had had their lives totally disrupted by the ABI suffered by their loved one and they shared
common goal to provide a lifeline, to protect, encourage and support their loved one; and factors that affected their son or husband also affected them. Emergent themes were clustered from the plethora of issues, difficulties and differences they identified. The analysis proceeded in the same way as previously outlined.

### 7.3.1 Overview of Factors That Negatively Affect the Lifeworld of People with ABI from the Perspective of Mothers and Wives

The three overarching themes, the lack of understanding and guilt; being judged by others and the stigma of ABI; and the sadness for the future collapsed down to the superordinate themes: ‘It’s very hard being a person with ABI’; and ‘It’s very hard caring for and supporting a person with ABI’. This is shown in Table 7.8.

**Table 7.8**  
*Mothers and Wives: Overview of Findings*

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s very hard being a person with ABI.</td>
<td>1. The lack of understanding and guilt</td>
<td>Medical terms are hard to understand</td>
<td>See Tables 7.9, 7.10 and 7.11</td>
</tr>
<tr>
<td>It’s very hard being a carer of a person with ABI.</td>
<td>2. Being judged by others and the stigma of ABI</td>
<td>Juggling — giving him some independence, things can get out of control</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Others don’t understand—friends, school, the public</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Judged as drunk</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Judged as pretending</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Your whole life changes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. The sadness for the future</td>
<td>What will happen when I’ve gone?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sadness for the future</td>
<td></td>
</tr>
</tbody>
</table>

### 7.3.2 First Overarching Theme: Lack of Understanding and Guilt

The words in the first case from the mothers and wives that informed the emergent and overarching themes are shown in Table 7.9.
The words in the first case from the mothers and wives were collapsed into the three emergent themes: The lack of understanding and guilt, Being judged by others and the stigma of ABI, and The sadness for the future. These were further clustered or collapsed to form the overarching theme: Very hard things — The distress of being a wife or mother of a person with ABI.

Table 7.9

First Overarching Theme: Lack of Understanding, Guilt

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
</table>
| 1. Lack of understanding (personal & others) | Medical terms are hard to understand | ‘I mean medical terms are hard enough if you don’t have a brain injury but if you have an injury it becomes like a second language because I know a lot about medical terminology because I’ve done a medical receptionist’s course but before I did it, if you look at the medical terms it is a second language to you, you don’t know unless you’ve studied it …so imagine someone with an ABI it’s like hello, I don’t know what you’re talking about, yer…’
| | | ‘Needed information and training.’
| | | ‘I had the expectation he’d ‘grow out of’ or ‘get better’ but instead it led to depression.’
| | | ‘I felt thrown in the deep end.’
| | | ‘But it’s mind boggling, I mean you’re there with your loved one and there’s all these UVs and everything going on and these machines beeping and you think there really needs to be a non medical way to explain things...’
| Rehabilitation | | ‘The hospital was not keen to suggest rehab — they felt he would just be a nursing home person — I fought to get him rehab. I think it was our perseverance (you can’t give up, you can’t give up).’
| | | ‘He says ‘yes’ but next day nothing — no memory, no motivation no capacity...frustration needs masses of assistance ...’
| | | ‘...how much of this is behavioural, how much is...this tempestuous hormonal time, indecision...’
| | | ‘It’s very hard to persuade him...he has an opinion it is straight down the line — not swaying either side, and sometimes in the early days he couldn’t comprehend it.’
| Juggling — giving him some independence — things spiral out of control | | |

All the mothers and wives spoke about how medical terms are hard to understand and the difficulty they had obtaining information that they could understand, their need of information for family, friends, and school and sporting groups. They stated that they needed training so that they could learn how to help their loved one.

They all felt helpless in the early days in the hospital. They weren’t advised what they could or should do, they felt ‘thrown in the deep end’, and spoke with regret and anguish ‘[I] didn’t know what I was doing’, inferring that if they had known what they were doing then, he
might be better now. Some said that they did not understand about ABI and thought he’d ‘grow out of it’ or ‘get better’. All women had been told ‘this is as good as he’s going to get’.

All the mothers and wives held great hope in the power of the rehabilitation system to improve the outcomes of their loved one, although one mother observer there was ‘very little rehabilitation of the mind...is this a cup or a toothbrush?...but not a lot.’ Sue spoke about how the rehabilitation experience for her son involved too much time with no activity, which led to bad habits such as smoking. If therapies had appealed to her son his outcomes might have been better.

Molly and Liz had extreme difficulty trying to obtain some rehabilitation because their son/husband was considered unable to benefit from rehab. These women tenaciously ‘fought’ for rehabilitation for their loved ones, and went to extremes measures to learn how to care for them, even getting their private health insurance to pay for some time in a rehabilitation hospital so that they could learn how to physically care for them.

Sue identified a plethora of issues a mother with a son in his early twenties with ABI has to juggle. He was not a child, he had both good and bad days, he wanted his independence: this was a ‘recipe for disaster... he blew his settlement trying to buy affection and loyalty’. ‘Drugs — psychosis — from then on it has been hell — he couldn’t cope — life lost all reality — Everything he used to do and his dreams were gone’ (Sue). ‘I kept asking myself is it behavioural or is it something wrong with his head? Is it going to improve?’ (Jane).

Liz’s problems were becoming more apparent as her husband spent more time at home after leaving hospital. Jane’s son was refusing to attend school and Molly had fought and won many battles with authorities. Jo had experienced problems with the legal system, and friends were loath to testify in her husband’s defence. The five women had coped with and swallowed many ‘bitter pills’.

**7.3.3 Second Overarching Theme: Being Judged by Others — The Stigma of ABI**

A further theme related to being judged by others. Here, the stigma of ABI and the distress of loving a person with ABI were found to be key issues.
### Table 7.10

*Second Overarching Theme: Being Judged by Others — The Stigma of ABI, the Distress of Loving a Person with ABI*

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
</table>
| 2. Being judged by others: The stigma of ABI | Others (family, friends, schools, the public) don’t understand | ‘I know a lot of people who’ve never heard of ABI they wouldn’t have a clue…’
| | | ‘Friends… have had to come to court to be witnesses,…and they said to us, not in court. "There’s nothing wrong with him"… and they think it has all healed up…having to explain to everyone is hard.’
| | | ‘…but like his mother, you’d think like she’d understand a bit better but she doesn’t — she’s a nurse — and she’s in denial — she’ll always say “He’s fine — he might be a little bit injured but he’s fine”, whereas my mother, she has no medical training at all and she can see it when he’s tired (flagging)’
| | | ‘I want people to understand — more education about ABI — it would even be nice to have a TV ad…something about ABI, you know.’
| | | At school ‘this is how we will make him do things and bugger the injury and what problems he may have’.
| Judged as drunk | | ‘People talk about quality of life…I get really really irate about that because nobody has the right to tell what quality of life is to a person… he’s got quality of life that a lot of people would never have’
| | | ‘It’s very difficult when the world today is all about stereotypes and it isn’t very helpful about difference…many a time I think people have said “Is your son drunk?” because he lurches and spills things … the worst moment of my life…’
| | | ‘“Isn’t it disgusting, drunk at 11 o’clock in the morning” and he could hear that…so now he won’t go anywhere without a stick.’
| Judged as just pretending | | ‘I’ve had so many people say to me “Hey your husband is not injured — he’s fine, why does he have a disability sticker?”’
| | | ‘What injury do you have? It says here you have a brain injury but we can’t see it.’
| | | ‘We’ve been to concerts — people say “What’s your disability?” And he says’s “I’ve got an ABI” and they say, “You’re standing up, you’re walking you’re talking, you’re fine”. People need to be educated that there is such a thing as brain injury.’

All the women had stories that clustered into how difficult it was when people did not understand about ABI. It was particularly upsetting when family and friends could not, or would not acknowledge or were in denial about their difficulties. Jane spoke about how she was having trouble getting her son to go to school because of comments made by the teacher who told her son’s classmates that her son was just lazy, and the teacher aide was sent on other errands. Sue’s son had a ‘sort of aide’ when he tried to go back to university but she did
not understand about ABI. All the women said they want more people to understand, they wanted more education about ABI.

Having their son or husband accused of being drunk was a common occurrence. Sue spoke about ‘the worst moment of my life’ when a neighbour said to her face ‘you must be so embarrassed by your son’ who was accused of being drunk. Unsteady gait caused rejection, criticism, venom and stigma. Having a stick was seen as a way to show the son had a problem. Jo’s husband was told he was drunk at the supermarket, and people had taken advantage of him and short-changed him.

Stories emerged about how friends and strangers perceived them as ‘pretending’ or ‘cheating’ to get an advantage. This was very upsetting. Jo’s friends, who were to be a witness in her husband’s court case, privately told her that there was nothing wrong with her husband now. Strangers had made similar comments when they saw a disability sticker on their car or when they were in disabled seats at concerts.

7.3.4 Third Overarching Theme: Sadness for the Future

Table 7.11

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In the First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Sadness for the future</td>
<td>Your whole life changes</td>
<td>‘Your whole life changes, it’s just like that and you sort of think “well I’ll probably have to give up work”. You’ve got all those things and you’ve got your other kids to worry about…husband took it quite hard and that sort of caught up with him this year.’ ‘Because you’re Mum you fall into the habit of treating them as children, wanting to ‘fix’ them, and that’s really difficult not to do I constantly get reminded by my son now “Mum you’re doing it again” (laughter) so I have to stop and think.’</td>
</tr>
<tr>
<td></td>
<td>What will happen to him when I’ve gone?</td>
<td>‘When you talk to mothers do you get a common worry about when I’m not here that concerns me…that’s why I’m trying to put so many things in place now that he can exist.’</td>
</tr>
<tr>
<td></td>
<td>A bleak future</td>
<td>‘No girlfriend — no grandchildren. As a mother it’s sad to think he’ll be on his own — no love — how do you replace that? How do you make that spark happen with someone you can live a life with?’ ‘My son’s had a few tries at relationships but they’ve ended in disaster so I think he’s signed off from that… ‘On the love angle, we had a little granddaughter born recently … seeing my son with his brother and his nieces you could see that look “I’ll never have this” and he doesn’t drive because he can’t, he’s got so many lacks in his life comparative with and I know comparisons are odious but I just wonder…’</td>
</tr>
</tbody>
</table>
Mothers and wives spoke about how their life now revolved around the needs of the person with ABI. Some mothers spoke about the added difficulty of trying to support their husbands as they slowly came to terms with their son’s brain injury, cope with the needs of their other children as well as considering if it was possible for them to continue to work perhaps in a part-time capacity. The two mothers of the older sons were concerned about what would happen to their sons when they die. They felt pressured to put things in place so that their sons would be supported.

Sue spoke about her son’s loneliness, his relationships that have ended in disaster, and her sadness of watching him with his brother and his nieces and she could see that look ‘I’ll never have this’. She was acutely aware of all the things his life lacked, and was saddened to think that he would always be on his own with no love. She said:

T.S. Eliot — my biggest metaphor for ABI is the Hollow Man ... between the idea and the reality, between the motion and the act is the shadow (chasm), and that for me was with my son. He’d agree “I can do that, yes I’ll do that” — but the next day — nothing, no memory of it, no motivation no capacity and that becomes incredibly frustrating.

The reality that their son might only be able to do volunteering work was very disappointing.

Another mother had to make the decision to turn off her son’s life support. She spoke of her anguish:

As a mum it was the hardest thing...we told him that we really love him and we’d give him that choice and every one of us did that with him—they turned off the life support and he began breathing for himself ... he has fought so hard to be here.

7.3.5 **Superordinate Themes: It’s Very Hard Being a Person with ABI and Very Hard Caring for and Supporting a Person with ABI**

The factors that negatively affected the lifeworld of mothers and wives and their loved ones, the overarching themes, collapsed down to the superordinate themes: It’s very hard being a person with ABI, It’s very hard caring for and supporting a person with ABI. But once the whole story of the experience of the mothers and wives is considered in Chapter 8 - ‘Factors that positively affect the lifeworld’ - this experience will be seen to be not all negative. Positive factors, such as the sense of meaning and purpose, help to balance all these negative experiences.

It will be observed that there were many commonalities of issues identified by people with ABI, and mothers and wives of other people with ABI. These included the difficulty...
understanding ABI and the need for information in nonmedical language. Shame and guilt was felt by both groups and the stigma of ABI played a role in negatively affecting their lifeworld. The mothers and wives would commonly be called ‘carers’, however I have referred to them as ‘people who care for and support people with ABI’ because from the perspective of the person with ABI needing a ‘carer’ compounds the difference between you and a ‘normal’ person. The mothers and wives demonstrated that they believed that rehabilitation was vitally important. This belief in the effectiveness of rehabilitation, was not identified by over half the participants with ABI, who were disappointed in their rehabilitation experience.

The participants with ABI identified problems with rehabilitation that the carers had not identified.

7.4 Professionals’ Views of Factors That Have a Negative Impact on the Life of Their Clients

Group C comprised five professionals working in their professional capacity with people with ABI post the golden period. These were Mary, a psychologist; Ben, an advocate; Judy, a social worker; Phyllis, a community health liaison officer; and Kirstin a brain injury support worker. Together these professionals represented over 70 years of experience working with people with ABI and a wide range of different philosophies. Each person brought the expertise of their training and their experience to the study.

They were interviewed in order to triangulate the data about factors that they thought had a negative impact on their client’s life, and also to obtain their feedback about Keys to the ABI Cage information/learning tool and if it could be of benefit to their clients.

7.4.1 Overview of Factors That Negatively Affect the Life of Participants with ABI

Following the same approach as previously, the views of professionals are set out in the emergent, overarching and superordinate themes in Table 7.11.
Table 7.12

*Professionals Overview of Findings: Factors That Negatively Affect the Life of Clients with ABI*

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words in the first case</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI is a bugger</td>
<td>1. The losses of ABI</td>
<td>Loss of life as they knew it including physical skills</td>
<td>(see Table 7.13. 7. 14, 7.15)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss of cognitive skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I feel different — do I look different?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. People don’t understand ABI</td>
<td>The person with ABI doesn’t understand</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The family and friends don’t understand</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The public doesn’t understand</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Emotional challenges</td>
<td>Some health professionals don’t understand ABI</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>ABI is like a mental illness</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Misunderstandings — emotional problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bad weeks</td>
<td></td>
</tr>
</tbody>
</table>

### 7.4.2 First Overarching Theme: The Losses of ABI

In Table 7.13 some quotations from professionals that were collapsed into resultant emergent and super ordinate themes are presented.
Table 7.13

**First Overarching Theme: The losses of ABI**

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In the First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The losses of ABI</td>
<td>Loss of life as they knew it including loss of physical skills</td>
<td>‘(my client) has been locked up in a secure ward in a rehab hospital for 8 years.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘...he forgets things, he laughs, he cries.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘He’s a very cluey guy, and has lots of embedded knowledge (but can’t read)’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Recognise that there is a lot of loss — I think like they feel they’ve lost everything from relationships to especially work, driving a car, having to start all over again.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Memory and Fatigue are the main difficulties.’ (of our clients)</td>
</tr>
<tr>
<td></td>
<td>Loss of cognitive skills</td>
<td>‘They have lost the ability to know when they’ve been diddled — you know that and they just have to trust, that’s what it amounts to, by the way someone speaks to them there’s a limitation that involves trust because they no longer have those resources to alarm...’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Distrust ... can’t trust self—others, chip on your shoulder but no one deals with that’</td>
</tr>
</tbody>
</table>

Kirsten spoke of the losses associated with ABI — that her clients feel they have lost everything: relationships, work, being able to drive and needing to start life again. Mary identified that there was a limitation on understanding, so that the client relied on trust because they had lost the mental resources to raise an alarm if they were being poorly treated, and that they had lost the ability to know when they had been diddled or tricked. She stated that no one deals with their distrust of themselves.
Second Overarching Theme: People Don’t Understand ABI

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. People don’t understand ABI</td>
<td>The person with ABI doesn’t understand</td>
<td>‘Medical jargon is actually useless to you in the long run…not in diagnosis but what it means for life it’s actually quite useless information to families — education much broader than just information.’&lt;br&gt;‘They didn’t hear it…they weren’t in the space where they could hear it.’</td>
</tr>
<tr>
<td></td>
<td>The family and friends don’t understand — isolation</td>
<td>‘There can be a lot of misunderstanding, even within families.’&lt;br&gt;‘Families split up, divorce…’&lt;br&gt;‘They can’t relate to their friends because their friends have nothing to say to them and they have nothing to say to their friends’.</td>
</tr>
<tr>
<td></td>
<td>The public doesn’t understand</td>
<td>‘The person with brain injury may have experienced many people who do not understand ABI.’&lt;br&gt;‘People don’t realise how difficult brain injury is.’</td>
</tr>
<tr>
<td></td>
<td>Some health professionals don’t understand ABI</td>
<td>‘I know lots of people, lots of GP’s who don’t understand ABI’&lt;br&gt;‘A lot of people with brain injury have had a lot of poor experience with the medical profession.’&lt;br&gt;‘I’ve noticed with X over the years that he does have quite a mistrust for medical professionals and I’ve met other clients like that and that’s based on the poor relationships they’ve had whether it’s with GPs, or psychiatrists, psychologists.’&lt;br&gt;‘A lot of people with brain injury have had a lot of poor experience with the medical profession.’</td>
</tr>
<tr>
<td></td>
<td>People don’t understand the system</td>
<td>‘People with brain injury fall somewhere in the cracks between the criminal justice system and the mental health act which doesn’t seem to cater for them very well either.’&lt;br&gt;‘Some people have never been in the medical system — not necessarily a diagnosis of BI because they haven’t been in the health system — This is even more frightening because they are out there struggling on their own so I would see a local health practitioner based in a community health centre, promoted really well — people could easily make contact with those people at the community health centre.’&lt;br&gt;‘They need advice to see a counsellor for marital problems: marital counselling but people don’t that stuff and how are they ever gunna know that stuff if someone isn’t there to tell them’&lt;br&gt;‘People with ABI don’t want everything all at once — social workers like to tick boxes and you only have certain amount of time with them before they go to rehab or home the most important when they — show brain, take them apart, show them where damaged.’</td>
</tr>
<tr>
<td></td>
<td>The gap where they are left to sink or swim</td>
<td>‘Once they’re discharged from the health system, unless they’ve been linked up to some other agencies before discharge they are left to sink or swim.’</td>
</tr>
</tbody>
</table>

Four of the professionals identified that medical jargon is actually useless to people with ABI and their families in the long run. ‘It is useful in giving a diagnosis, but it doesn’t explain what it means for the life of the person and it’s actually quite useless information to families
education much broader than just information’. Several professionals spoke about the isolation of the person with ABI, that there was misunderstanding within families and that people with ABI can lose contact with their friends, they cannot relate to their friends and their friends have nothing to say to them and they have nothing to say to their friends.

Professionals stated that, in the main, the general public does not understand ABI and several professionals spoke of general practitioners who had little knowledge about ABI, and clients with ABI having poor experiences with medical professionals, and the way staff can treat young people like children.

Phyllis said people who had not been involved with the health system before their ABI needed to obtain help at their local community health centre. She stated that people with ABI were given too much information all at once because ‘social workers like to tick boxes and you only have certain amount of time with the client’. Ben was concerned that some people with ABI fall ‘somewhere in the cracks between the criminal justice system and the Mental Health Act, which doesn’t seem to cater for either of them very well.’

Once people with ABI are discharged from the health system, unless they have been linked up to some other agencies before discharge, they are left to sink or swim. Phyllis talked about the need to have an agency to support people once they had left hospital.

7.4.4 Third Overarching Theme: Emotional Challenges

Professionals identified that people with ABI can suffer from depression and emotional problems.
Table 7.15

Third Overarching Theme: Emotional Challenges

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Example Quotations</th>
</tr>
</thead>
</table>
| 3. Emotional challenges | Like a mental illness | ‘I think it’s almost irrefutable...certainly the research shows that if you’ve got an ABI your incidence of depression and other mental illnesses is very high.’
‘Isolation I relate it back to mental illness — they think they will get better and be the ‘old’ me, often in our work it is working towards a different state — I don’t think they are ever the ‘old me’. With brain injury you wouldn’t be the same again.’

Bad weeks | ‘They can have very bad weeks this makes them very fragile...emotional problems’.
‘There’s the down side of getting really depressed about the problems, but there’s the up side of these are all the amazing things of how you cope.’

Shame | ‘I think people can pretend very well, if it’s a small injury and they learn to compensate, but it comes out in the end when they do strange funny things because they don’t have the filter.’
‘The big issues are do I look different. How am I fitting in now? Do I look attractive anymore, women will feel it worst.’
‘We have lots of trouble modulating inappropriate behaviour. he realises...then he forgets...and he says “ooh sorry”.’

Isolation | ‘There can be a lot of misunderstanding, even within families.’
‘Families split up, divorce...’
‘They can’t relate to their friends because their friends have nothing to say to them and they have nothing to say to their friends’.

All the professionals spoke about the incidence of depression and other mental illnesses associated with ABI and how their clients’ bad weeks can make them very fragile. Judy, Kirsten and Mary said that some clients try to pretend they are okay but they slip up; women are concerned that they look different. All professionals spoke about how their clients were isolated from their family and friends.

Not all professionals identified all the losses and difficulties that people with ABI identified, although as a group most of the difficulties were discussed. Areas of expertise were apparent by the comments from the participants.

7.4.5 Superordinate Theme: Brain Injury Is a Bugger

The factors that negatively affected the lifeworld of clients with ABI, the overarching themes, the losses of ABI, people don’t understand ABI and the emotional challenges collapsed down to the interpreted superordinate theme: Brain injury is a bugger.
The professionals as a collective group identified most of the issues identified by the people with ABI, and mothers and wives, but a blind spot was their focus on the deficits, without a focus on how these deficits affected the hope and honour of the person or on their ability to learn. There was not a focus on teaching the clients to understand. Several practitioners focused on ‘fixing’ and not on issues around fear, shame, trust and power. A blind spot of some professionals was the fear and shame of the person with ABI and how this impacted on their lifeworld.

7.5 Summary

By using IPA analysis this chapter has identified the ways in which ABI is experienced by people with ABI, by family carers and by professionals. The triangulation of data that might confirm the common themes and experiences has actually only partially accomplished this task. Indeed, while there were some common categories of experience between the groups, there were also uncommon categories or blind spots.

Common categories participants with ABI, mothers and wives, and professionals identified were the physical, cognitive and emotional losses and challenges of ABI. The issues were complicated; they overlapped and affected other issues. The total catastrophic affect to the person’s life was identified by all groups, as was the isolation of the person with ABI. However, participants with ABI reported the profound effect their loss of trust and hope, and their shame and humiliation, had on their lifeworld. The participants with ABI were aware they had many blind spots. This included being able to understand ABI and the consequences of ABI to them; they needed to understand their emotional reaction to situations, their shame, their belief they were insane, their loss of trust of themselves and others.

One interpreted blind spot was the participant with ABI’s belief that it was the ‘professional’s job was to cure them’ — the same way as you go to a doctor to get medication or surgery to ‘get better’. A second important interpreted blind spot was their inability to see they could play an active role in helping themselves.

The statements made by the participants with ABI, reported in this chapter and in Appendix 7, demonstrate that they had awareness and insight of things that negatively affected their lifeworld. These themes left many participants swamped by their experience, but some participants had moved from feeling that life was not worthwhile to feeling that life was worthwhile, and a few participants felt enriched by their struggle. So these negative themes are not the whole story — participants with ABI had also discovered ‘Keys’ to release
themselves from the ‘ABI Cage’ — these discoveries will be explained in the following chapter. This current chapter has shown the often catastrophic, always challenging and complicated nature of ABI, and a conclusion could be reached that the story of people with ABI is bleak and hopeless. In Chapter 8 this view is tempered with the positive experiences of the three participant groups.
CHAPTER 8
FACTORS THAT POSITIVELY AFFECT THE LIFEWORLD OF THE PERSON WITH ABI: ‘KEYS’ FOR CHANGE

8.1 Introduction

It is with relief that at last we come to the heart and purpose of this study — to find the factors that have a positive effect on the lifeworld of people with ABI. It is exciting to be able to compile this collection: to lay out a ‘smorgasbord’ of ‘good’ things that have been identified by people with ABI, mothers and wives of other people with ABI and experienced professionals. The ‘dishes’ on this smorgasbord, are not of caviar, nor are they complicated concoctions requiring expensive ingredients. But they do contain ‘precious’ ingredients of love, hope, understanding, empathy and humanity. This information will be an important part of the Learning Resource.

The previous chapter appeared to express insurmountable difficulties. It was hard to imagine that there could be anything powerful enough to allow the factors that negatively and positively affect the ‘lifeworld scales’ to be weighted towards the positive. However, this second chapter of findings focuses upon the research question ‘What factors have a positive effect upon the lifeworld of people with ABI?’ and explores the positive factors, themes, or ‘Keys’ that helped people with ABI ‘escape’ from the ‘ABI Cage’ and balance the scales so that life felt worthwhile.

This chapter provides information to pass on to people with ABI in the hope it could give them a way to make the best of brain injury instead of feeling beaten and broken by brain injury. The purpose was not to cluster the data according to traditional quality of life, coping or resilience theories, which would be of academic interest, but to find information that could inform and empower people with ABI and their family.

It has been established that people with ABI are known to lack self-awareness, but the previous chapter demonstrated that Keys to the ABI Cage method encouraged participants with ABI to tell stories and reflect on things that had a negative effect on their life. This chapter will reveal the things they identified that helped them feel better; these things have the potential to assist them help themselves to learn to fare better. To these have been added the advice or views from wives and mothers of men and boys with ABI (the only people who care
for and support someone with ABI who were women volunteered to participate in this study) and the different opinions of professionals.

As with Chapter 7, people with ABI identified a wider range of factors than some of the family members or professionals. The latter groups addressed the issue with directness: they had definite established opinions. The participants with ABI did not address the issue of helpful things in a linear straightforward way, but in a roundabout way, by telling stories, making connections, revisiting ideas, changing their minds — a process of ‘learning circumnambulation’, by circling themselves and reflecting on and learning from their experiences. The Keys to the ABI Cage method encouraged participants with ABI to tell stories and reflect on things that had a positive effect on their life. This will be discussed further in Chapter 9.

An audit trail will be found in Appendix 8 and this demonstrates the wide range of factors that each participant group identified that impacted positively on the lifeworld of a person with ABI. As the reader has already read Chapter 7, they will be familiar with the way in which the analysis has been carried out and the ways in which sections reflect this analysis.

There were 35 talk-about cards under the heading Keys to the ABI Cage and these included ‘My Doctor’, ‘My health professionals’, ‘My OT’, ‘My Counsellor’.

8.2 Participants with ABI: Factors That Positively Affect the Life of People with ABI

8.2.1 ‘Keys’ to the ‘ABI Cage’ — An Amalgamation of Perceptions, Opinions, Emotions, and Factors That Positively Affect the Life of People with ABI

Chapter 7 identified just some of the perplexities and complexities of ABI for the person with ABI. For the rest of their lives, the person with ABI struggles to make their life more satisfactory: to progress from an unsatisfactory life (when they feel imprisoned by their ABI), to a more satisfactory life (when they have escaped from the ABI Cage). They may find they can escape the ABI Cage for a time then, hindered by new challenges (as they make progress, different challenges emerge), they find themselves back in the ABI Cage searching for new Keys to release themselves.

Keys are things that help people with ABI to move from being unsatisfied in their life during the months or early years after their ABI, to being satisfied (to some extent) in their life. This
study has established that there are a plethora of Keys that can help people with ABI unlock the ABI Cage and release themselves from feeling imprisoned.

As the overarching themes, Keys are phenomena that people with ABI can use to play an active role in helping themselves to find ways to cope with or live with the challenges of ABI. Keys are active not passive. Keys require the person to have ‘active acceptance’, the will and courage to accept Keys proffered by family, friends and professionals. Other Keys need the curiosity and effort of the person to find ways to regain their identity and reach equilibrium.

There are two superordinate themes of things that positively affect the lifeworld of the person with ABI: Firstly: There are many Keys that open the ABI Cage — there are a plethora of things that can help the person with ABI to feel better. Secondly, constructivist ‘circumnambulation learning can assist the person with ABI to learn to help themselves to feel and fare better’.

A handful of participants had constructed their own learning and discovered for themselves, after discussing their story, that they had been deepened by their suffering. They had gained something through their ABI experience: they were now aware of their strengths and weaknesses, they now really appreciated life, and this struggle to make sense of their life made them feel wise. This study has, therefore, found examples of Neitzsche’s deepening by suffering.

8.2.2 Overview of Factors That Positively Affect the Life of People with ABI

After this brief overview, the emergent, overarching and superordinate themes will be examined in detail. This overview provides a structure for the reader to observe how the words in the first case (selective quotations), emergent and overarching themes collapsed into the superordinate theme.

This basic map emerged out of systematic analysis of the data. It will be used to structure the rest of the chapter.
### Table 8.1

**People with ABI Overview of Findings**

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes ‘Keys’</th>
<th>Emergent Themes: Selective Quotes</th>
<th>Words in the first case</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There are many ‘Keys’ to open the ‘ABI Cage’</td>
<td>1. Hope: Learned optimism/resilience/coping</td>
<td>Determination</td>
<td>(see Tables 8.2, 8.3, 8.4, 8.5, 8.6)</td>
</tr>
<tr>
<td>2. Constructivist ‘circumambulation’ learning can assist the person with ABI to learn to help themselves to feel and fare better.</td>
<td></td>
<td>Wishful thinking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Love</td>
<td>Denial</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Learning to understand ABI and working things out</td>
<td>Religion/metaphysical things</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Learning to face the facts (acceptance)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Making progress: Brain injury is not all bad</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 8.2.3 First Overarching Theme: Hope

The emergent themes of determination, wishful thinking and denial collapsed down to the overarching theme of hope in various forms. Many participants told stories to illustrate their philosophy on life and to express the importance to them of believing ABI wasn’t going to beat them — they believed they’d improve. The consequences of giving up hope would mean they would no longer struggle against their difficulties/differences/deficits to try to improve. This is seen in Table 8.2.
Table 8.2

*Overarching Theme: Hope*

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
</table>
| 1. Hope           | Determination   | ‘Um, I guess I don’t use the word hope, I just think of it as bloody mindedness. Sheer determination, where I’m mad as hell and I’m not going to take this anymore.’  
‘I wasn’t willing to accept that I would be in a wheelchair in a nursing home for the rest of my life.’  
‘Hang on; I’m not going to let this beat me!’  
‘Proving professionals wrong — I’ve proved them wrong in a thousand ways.’  
‘There is nothing I can’t do I just haven’t found a way to do it.’  
‘Things change, you make it work. You need keys… I need to expand all the time. I joined this work (volunteering) … I was just drifting, [but] I didn’t want to sit at home and do nothing. So I joined the club.’ |
|                   | Wishful thinking| ‘They told mum that I’d never be able to walk again or do this or that have children — Luckily I didn’t believe them — you wouldn’t want to believe would you! (laughter) (drove to the interview, was married with children).  
‘The doctor was quite adamant that after two years you’ve reached your peak — it took away all my hope — I was frustrated because I thought I was going to get better…but then I thought I’m going to improve…” |
|                   | Denial          | ‘It just went in one ear and out the other.’  
‘I’ve never thought about these things.’  
‘I didn’t really think about anything.’ |
For many of these participants ‘hope’ involved what I have termed ‘wishful thinking’, because it involved a refusal to accept the considered opinions of professionals. Their refusal to accept that their life would be spent in a nursing home, in a wheelchair or that they could not have children assisted their recovery. The majority of participants had refused to accept the two-year rule. They had been informed that the progress will cease or slow down after the first two years but they refused to believe this.

If we view improvement or progress as life having more satisfaction than being unsatisfactory, there are many things that bring satisfaction to life, as will be seen later in this chapter. These things are independent of the two-year rule and allow the person some degree of success even though they had a ‘broken body’. Just to reiterate, some participants found ways to feel satisfied with their lives independent of their broken body being mended!

Some participants ignored or denied their difficulties, or made comments that their memory was never great but since their accident a poor memory is ‘quite normal’ and they had found ways to manage their difficulties. Several participants excused their difficulties by saying ‘everyone does silly things’. Hope encompassed many characteristics outlined in Seligman’s (1998) ‘Learned Optimism’ — the participants had learned to tell themselves just because they had failed at a given task that did not mean they would always fail in everything they
attempted and they could ‘excuse’ their failure or blame something else. Characteristics of resilience and coping were also apparent.

However, a few participants explained how wishful thinking (or the hope they would get better) allowed them to justify to themselves why they did not pay attention during rehabilitation session.

Several participants talked about how they obtained comfort and security from their religious belief and that this was very important to them, even if they were worried that God was punishing them. Nearly one third of participants expressed that nature and environment brought hope and comfort and a few participants spoke about seeking for symbols to show they were doing the right thing.

8.2.4 Second Overarching Theme: Love

Participants with ABI could be divided into two groups — half who spoke about how they were loved, supported and sheltered by their family and how their love for their family also caused them to work harder for the sake of their family — so they could have a life. For these participants the love was of prime importance.

The other half of the participants, who did not identify love as a Key, told stories of how they were estranged through divorce, or misunderstanding or lack of understanding. Many in the latter group spoke of animals who loved them unconditionally and who gave their life meaning. Several participants stated that they would have killed themselves but for their love of their animals and the way their animals ‘understood’ and loved them — animals provided the unconditional love they needed to survive. Several participants identified that taking responsibility and caring for their animals had been very important. Table 8.4 summarises the theme of love.
Table 8.3

**Second Overarching Theme: Love**

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
</table>
| 2. Love: a purpose| The two-way love of family and friends | 'Love is extremely important I believe that if I didn’t have my family and husband to come home to, I wouldn’t have worked so hard — I don’t think I did it for me, I did it so they could have a life...’  
'Encouragement and empathy was very important. the fact my family has held their breath when I try to do what I try to do,’  
'The understanding of my oldest and very dear friends and their ongoing support.’  
'Encouragement from my parents and siblings.’  
'I could stay in bed but I have a big black muzzle [of her guide dog] nudging me saying get up and feed me.’  
'I love my animals.’  
'My dog understood that I was crook and stayed by my side.’  
'I think if I didn’t have my 3 cats who loved me unconditionally, to talk to, I wouldn’t cope at all.’  
'Animals. I have lots — the cats are great, really affectionate.’  
'Taking responsibility and caring for something else (my animals) — I think it is very big.’  
'My cats saved my life I would have ‘disappeared’ but for my cats.’  
'I love going out — I’m terrified of my armchair.’  
'I always want to be out and doing things — doing new things.’  
'I love going to live shows.’  
'Going out to lunch on the weekend made me feel more normal.’  
'Fishing.’  
'Staying in: I’ve got a big TV, writing poetry, writing — recording my thoughts, feelings and daily events a surprise, a treat — reward self after I’ve achieved something, a glass of wine perhaps (laughter), talking books, cooking, listening to music, reading the newspaper, making jewellery.’  
'Writing all my thoughts down — everything...and they say stop this lunacy and I say I can’t stop...’  
'Painting — art is very important (couldn’t draw before) colour gets me excited.’  
'Gardening yep, I love gardening.’  
'Ah, gardening is a new thing I’ve taken up that I find a lot of peace, as a therapy... it’s a wonderful wonderful thing.’  
'A treat — yes — that’s part of the life process — it has to be achieved — a prize at the end of something. You’ve achieved something so now you can have a treat. Big or not so big — a cup of coffee shared with friends or family’  
'Exercise- Yes so important — I’m convinced the exercise side of things reduced the severity of the damage that was done significantly — simply having rich oxygenated blood flowing through the systems.’  
| They love to be able to help other people with ABI | ‘Helping people yea...’  
‘Being useful is absolutely necessary.’  
'I love being useful.’  
'Volunteering.’  
'I help people.’ |
Most participants identified things they loved doing, things that gave them satisfaction, and a purpose. The way they perked up and became enthusiastic about these things showed they were more than a diversion — they were fully engaged with their ‘passion’. A huge range of passions were identified: painting, fishing, knitting, live shows, writing, going out for coffee or lunch. Some men were very passionate about watching sport, the gym and exercise. Many women participants said they had discovered (or learnt) that doing cross-stitch/tapestry/knitting focused their thoughts, calmed them down and they felt productive as they watched their project progress. Several women referred to their craft as their ‘security blanket’ and they took it everywhere.

Once again participants could be divided into two groups — one group loved to stay home because they do not like crowds and they cannot take in too much information at one time, and the other group loved going out — one participant said that staying home was very detrimental, they had learned that if they get out of the house they feel a lot better.

The final category of things people love is another category of things that give people a sense of satisfaction and purpose — helping others — particularly others with ABI. This was most important as it allowed the person to use their sense of empathy and humanity that has been perhaps newly acquired — it is a positive new gift they can give. Being a volunteer to use their skills is meaningful, people click with the people they help, and participants spoke with pride about their volunteering. May expressed it beautifully: ‘I’m a volunteer I have a lovely lady to look after. She’s lovely, she loves me, she’s like a mum to me and I’m a mum to her’.

Love of people, pets and activities helped most participants belong and feel comfortable about themselves. Love supported progress from a life that was not worthwhile to a life that was worthwhile.

8.2.5 Third Overarching Theme: Learning to Understanding ABI and Working Things Out

Learning to understand is at the heart of this thesis. It is not possible to ‘give’ people understanding — they need to take on board ideas and information and learn to make sense of
ABI for themselves. Table 8.5 lays out how learning was discussed by the study participants and shows how the collapsing of categories took place.

**Table 8.4**

*Third Overarching Theme: Learning to Understand ABI and Working Things Out*

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Learning to understand ABI and working things out</td>
<td>Learning to understand ABI</td>
<td>‘Gain as much knowledge as you can about your brain injury to help you understand…’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘It was important to understanding my condition.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘If I’d had the CD earlier on it would have helped me to understand that I wasn’t going mad. And it certainly would have given me another way of approaching things too. And perhaps to even ask more questions. Because if I knew that was the situation, then I could relate that to other areas…’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Finding out what others with ABI have done.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘What other people with ABI have done this is massive to me — peer support — my writing group.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘What other people with brain injury have gotten up to, or survived. Um, it didn’t help to start with, because I was too interested in myself. But later on, to read stories of people who’ve survived was good.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Meeting you (Durham) at a conference in Sydney was another moving point for me and the rest of my life, as I feel that it is the survivors who can talk the talk to get others back on their feet after an injury, because we can walk in their shoes.’</td>
</tr>
<tr>
<td>Overarching Theme</td>
<td>Emergent Themes</td>
<td>Words In The First Case: Selective Quotes</td>
</tr>
<tr>
<td>-------------------</td>
<td>----------------</td>
<td>-----------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Things the person has worked out to help them cope</td>
<td>‘My life is down to just the basics of existence.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Try not to get impatient with myself.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Never be afraid to ask for help or get something wrong.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘The more ‘mistakes’ I made the more I learnt and recovered. Getting as much help from as many people as possible always puts you in the best position possible.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Whatever I’m doing gets all my attention.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Writing...recording my thoughts, feelings and daily events.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Tracking my progress and achievements.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Facing the fact I need to rely on my palm pilot diary’.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Everything is ‘slowly slowly’ and time has changed.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I made sure I had routine and that I was organised.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I was a very determined person, that part of my personality was entrenched.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I try to be the best I can at everything that I was good at before my ABI.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘My short term memory is getting better ... I have always practised my memory with mind games and developed strategies.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Repetition with a new task or learning something different — repetition is the only way to cement it until it becomes part of the fabric of your life.’</td>
</tr>
<tr>
<td></td>
<td>Teaching their body to work again</td>
<td>‘Speech therapists were great.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘My counsellor was great.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘The psychologist — she was just wonderful.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I did a lot of intensive rehab.... physio exercises at the gym. I devoted all my time to doing that, last year 6 days a week.’ (man)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘... physical rehab wonderful... ’ (man)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Rehab exercises was just brilliant.’ (man)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘My balance is a hundred times better with a lot of hard work and physios.’ (man)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I had a lot of rehab, it was extremely helpful. But taking control of it was… better. I was so determined to get home It was going to take too long to do it their way. It’s a long time to sit, if you’re just in hospital.’ (woman)</td>
</tr>
</tbody>
</table>

All participants with ABI had struggled and were still struggling to understand ABI for themselves. Not one participant remarked ‘I found this wonderful web site...booklet...I was given information from the hospital’, or that ‘Dr X explained ABI so that I suddenly understood’. No one spoke about understanding about ABI from information on brain injury support web sites or blogs, although now, two years after the interviews, maybe more people are searching the web.

All the participants wanted to find out more about ABI. About a third of the participants spoke about reading *Doing Up Buttons* and gaining greater understanding from reading the
story — it helped them make sense of their own personal issues. Almost all the participants said that ‘medical language’ was not helpful in helping them make sense of their experience.

About a third of the group spoke about the importance of finding out what other people with ABI have done and the value of peer support. An ABI writing group helped people share ideas, learn new skills and to express themselves. Some participants in ‘seeking to belong’ found joining ABI support organisations was helpful, yet others voiced the opinion they wanted to be normal mixing with normal people.

*Keys to the ABI Cage* helped many participants understand their ABI — one man said that he had ABI for 7 years and he denied it — but the cage had ‘showed him’ (he had gained self-awareness) and he now acknowledged his ABI; another said if he’d seen the cage earlier it would have helped him to understand that he wasn’t going mad, and would have given him another way to approach things and ask more questions.

Participants had discovered (taught themselves) a range of strategies through which they could work things out: for example, ‘patience’, ‘minimal stress’, ‘simplicity’, ‘routine/organization’, ‘structured living’, ‘quietness’, ‘a healthy diet’, ‘exercise’, ‘concentration’ and ‘tracking progress and achievements’. Participants also spoke about the effort required to teach themselves to make their body work again, and 12 positive comments about rehabilitation were obtained from the transcripts. Speech therapists, counsellors and psychologists were appreciated, and three men spoke about physical exercises being ‘wonderful’ or ‘brilliant’.

Empowering the person with brain injury to have a say was important. One man spoke about how ‘Letting me do what I want, and not what they think I want/need. One of my speech therapists used that theory on me and it allowed me to surge forward in my rehabilitation’.

### 8.2.6 Fourth Overarching Theme: Learning to Face the Facts (Acceptance)

This overarching theme I’ve called ‘Facing the facts (acceptance)’ could be seen as a subset of the previous overarching theme ‘Learning to understand ABI and working things out’, but it concerns a cluster of comments from participants about discoveries they had made about identity, self-belief, not giving up, a positive attitude and a sense of humour. The analysis categories are shown in Table 8.5.
Table 8.5

*Fourth Overarching Theme: Learning to Face the Facts (Acceptance)*

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
</table>
| 4. Learning to face the facts (acceptance) | Accepting that the person is not the same | ‘Coming to terms with the fact that I’m not the same person anymore.’
| | | ‘Redefining who I am and where I want to head to.’
| | | ‘Acceptance of events in the past and coming to terms with consequential responsibilities of future.’
| | | ‘Admitting to myself I have shortcomings (short-term memory) and learning to employ strategies to assist me with coping with these shortcomings.’
| | | ‘I now view the word from a changed perspective.’
| | | ‘I have changed careers/job to a completely different area.’
| | | ‘Remember the past, live the present, hope for the future.’
| | Recognising the positive things that have come because of ABI | ‘Being on the ball pushing, pushing...’
| | | ‘Changed me — learning new things.’
| | | ‘Recognising positive things from ABI experience.’
| | | ‘I have a much greater understanding of life and people.’
| | | ‘Learning to appreciate life.’
| | | ‘Don’t take life for granted.’
| | | ‘Believe in yourself.’
| | | ‘Looking at every part of my life post the brain bleed as a bonus.’
| | | ‘Saying I can do something.’
| | | ‘Focusing on the small goals that achieve bigger goals.’
| | | ‘To take very small steps and be patient in returning to “normal” life.’
| | | ‘It’s like I’m constantly finding new aspects of myself.’
| | | ‘Talking about things.’
| | The person’s sense of humour | ‘My sense of humour is the best thing I’ve got going for me.’
| | | ‘My optimism and sense of humour.’
| | | ‘My ability to find the funny side of things and to laugh.’
| | | ‘I was one of the court jesters at rehab — the nurses came to visit me when they finished their shift.’
| | | ‘[I was] sick of looking at the negative things — I turned things round — it’s a nice surprise to find $5 in coat pocket! [when you’ve forgotten it’s there.’

The reader of this thesis might feel a disproportionate amount of time has been spent on these two overarching themes. The reason why this has happened is because this was an area more participants with ABI talked about. This was important information they wanted to pass on to other people with ABI, many participants commented that they had never had the opportunity before to discuss these things — get them off their chests, and make sense to themselves of how they have ‘survived’ ABI.

In Chapters 2 and 5 I have explained that the two categories ‘My Differences and Difficulties can put me in the ABI Cage’, and ‘How I feel about my difficulties and differences can lock me in the ABI Cage’ were not the focus of this study. The focus was to discover the Keys to release people from the ABI Cage. Participants were eager to share the Keys they had discovered. By the time participants had come to the Keys and talk-about cards, flow had
been established and they were pleased to share how they had intellectually figured things out for themselves. These fit well with the learning factors identified in Chapter 5.

A small number of participants recognised that positive things had come from their ABI experience: an appreciation of life; a much greater understanding of life and people so that they feel wise.

Participant: Apparently I was supposed to be dead — that’s how bad it was.... I couldn’t walk, I couldn’t talk, I basically had to relearn to do everything — but I could breathe.

C. Durham: You’re doing pretty well!

Participant: …with the breathing part I am. (laughter)

Several of the participants were engaged in training to help people with ABI:

My recent training in the disability industry has helped me come to terms with some of the insult and pain that I have suffered the last 13 years. In fact I am doing work... I was a client/patient and now I am on the way to becoming a health professional... so there!!

The brain tumour was the worst thing that ever happened to me but because of the journey, my understanding it was also the best thing that ever happened to me too.

A thread that provided a connection to others was the way humour was used. Many ‘quick quips’ lightened the mood of the interviews. For example, when James held the ‘gardening’ talk-about card and said: ‘I don’t grow things — I just grow angry and I just grow old’. As Matt held the ‘Mad/frustrated’ talk-about card he commented: ‘Frustrated? with my ex-wife — a lot of married men have been frustrated by their ex-wives. I might be wrong but I don’t think so.’ (laughter).

The findings demonstrated the importance of accepting, self-belief, not giving up, a positive attitude and a sense of humour as setting important conditions for motivation, for engagement with others and with risk-taking and learning. These fit well with the learning factors identified in Chapter 5 and more will be said about this in the discussion chapter that follows.

8.2.7  **Fifth Overarching Theme: Making Progress — Brain Injury Is Not All Bad**

The burden of feeling ‘not normal’ and ‘different’ to others weighed heavily on many participants so being able to do normal things again was seen as a symbol of improvement and progress — and boosted their confidence, self-esteem and hope. The categories are shown in Table 8.6.
Table 8.6

**Fifth Overarching Theme: Making Progress: Brain Injury Is Not All Bad**

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Brain injury is not all bad</td>
<td>Being able to do ‘normal’ things again Making progress</td>
<td>‘Being able to talk to people and realise that I am still a ‘normal person.’ ‘Being a basketball coach and instilling some of my training into the team.’ ‘Knowing I am making a worthwhile contribution at work.’ ‘Returning to study.’ ‘Having a job makes you feel alive.’ ‘Now I’m in a job that I love more than anything I’ve done. So I think this has given me the opportunities to make those sort of decisions, and it’s been a really powerful experience.’ ‘Being able to revert back to old skills that could be reused in my new life.’ ‘Freedom to be able to drive again.’ ‘Getting my license again was freedom!’</td>
</tr>
</tbody>
</table>
Participants spoke about making progress in big and small ways. A handful of participants spoke of the freedom of being able to drive again. It was an exciting part of recapturing their life, and for Mary it was wonderful when she was actually able to put her left foot straight into her slipper.

Being able to work or be a volunteer, being able to make a worthwhile contribution, being able to reuse old skills in their new life led to participants move from feeling life was unsatisfactory to life was satisfactory. Some stories they told explained that they were thankful they had survived and they wanted to ‘give back’ to help others in the same predicament. Some participants stated they were now wiser as they had thought about and explored their lifeworld, they now have a much greater understanding of life and people, they feel older and in a lot of ways wiser.

I’m glad this happened to me. My mother is horrified when I say that. But I would say that I haven’t changed as a person, but I’ve learnt something...a little more courageous...I think this has given me the opportunities to make those sorts of decisions and it’s been a really powerful experience and I’m glad it happened.
Some participants expressed how lucky they feel to have survived: it has given them a chance to start their life again, they feel special because they have experienced so many unique and valuable things, they believe they are a newer better person and have become more aware, for example of the environment, pollution, good friendship, humanity to mankind, volunteering, service clubs and general sharing. Some have become highly sensitive to many things such as, noise, light, people, even feelings. Brain injury has been a really powerful experience for many of the participants.

What I say to them now is, there are two selves, there’s the person I was before, and no matter how much I grieve and think I’ve lost that person, I have not lost her she’s still here, she’s just been pushed back by this new self. There’s two selves, and there’s this new self, and the two of them have to learn how to get along.

8.2.9 Superordinate Themes: ‘Many Keys’ and ‘Constructivist Circumnambulation’

Participants identified a plethora of factors that helped them to feel and fare better. These ‘Keys’ to the ‘ABI Cage’ covered a wide range of factors from humble everyday things, to things that gave their life meaning and purpose. They were pleased to identify talk-about cards that were important to them and to tell stories about other hobbies or pastimes that brought them pleasure. Using Keys to the ABI Cage to talk about their experience helped them to made sense of ABI and construct their own knowledge about things that helped them to feel and fare better. These positive themes did not populate the talk-about cards nor were the themes a focus of the studies reviewed in chapters 3 and 4. These themes link to the social model of disability, and information about education in Chapter 5. In Table 8.7 the superordinate themes of (1) There are many “Keys” that can open the ABI Cage and (2) Constructivist ‘circumnambulation’ learning can assist the person with ABI to learn to help themselves to feel and fare better.

Table 8.7

<table>
<thead>
<tr>
<th>Superordinate Theme</th>
<th>Overarching Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There are many ‘Keys’ that can open the ABI Cage’</td>
<td>1. Hope</td>
</tr>
<tr>
<td></td>
<td>2. Love</td>
</tr>
<tr>
<td>2. Constructivist ‘circumnambulation’ learning can assist the person with ABI to</td>
<td>3. Understanding and making sense</td>
</tr>
<tr>
<td>learn to help themselves to feel and fare better’</td>
<td>4. Facing the facts (acceptance)</td>
</tr>
<tr>
<td></td>
<td>5. Making progress; brain injury is not all bad</td>
</tr>
</tbody>
</table>
8.2.10 *Triggers and Turning Points*

This study also sought to try to find ‘triggers’, turning points or epiphanies when the participant came to the realisation that life was going to be bearable, that it was worthwhile living. As they engaged with *Keys to the ABI Cage* participants told stories about a variety of different experiences and realisations about epiphanies, or turning points. I will allow the participants to explain:

Actually it was a flower that told me one day that the world is really worth being in. It was a memorable experience because I was walking around the side of my house and the world had been grey for a long, long time and I saw a red tulip, the bulb I’d put in a pot, and it had flowered red and honestly I stopped in my tracks, and it was like wow, and I’ll never forget that, and the world then had colour.

Yes yes I had a lightning bolt moment, an epiphany — in rehab I was in the ABI unit, surrounded by others — you start comparing yourself and you say “I’m not as bad as them”, and my family was saying “Oh my God, she isn’t really quite with it!” and I knew I could sit back and do nothing, and let people look after me and pamper me for the rest of my life, or I could take another road and have a life that I felt I had achievement in. I felt I was at the crossroads that it was up to me — one was the hard slog the other was the easy road but I don’t think I’ve ever taken the easy road.

I guess the secret to me, is to decide that this doesn’t have to be permanent, that it doesn’t have to be fully incapacitatory, and there’s a lot I can do about it and to never give up...and to try anything and everything.

I was told all through my rehab and from other doctors, that the brain will only heal in the first two years, and after that there’s not much healing that happens. And I refuse to believe that and I feel very lucky that I refused. So that really helped me to think I could keep getting better. I still believe it.

Believing the brain is a muscle — today the new term is neuro-plastic, but I was told all through my rehab and from other doctors, that the brain will only heal in the first two years.... That would be the one big change I would like to see in rehab or ABI treatment. I went for 10 years and I saw people who believed it — it was heartbreaking.

8.3 *Wives and Mothers: Factors That Positively Affect the Life of People with ABI*

8.3.1 *Factors That Positively Affect the Lifeworld of Sons and Husbands with ABI*

The following analysis examines the interview data from five mothers and wives of people with ABI. The analysis follows the usual approach in what follows. Table 8.8 sets out the range of emergent, overarching and superordinate themes upon which this section is based.
Table 8.8

Mothers and Wives’ Overview of Findings: Factors That Positively Affect the Lifeworld of Sons and Husbands with ABI

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes ‘Keys’</th>
<th>Emergent Themes: Selective Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>With love, hard work and the ‘right’</td>
<td>1. Love</td>
<td>Family — people who love them and people they love (see Tables 8.9, 8.10, 8.11)</td>
</tr>
<tr>
<td>attitude his life can improve</td>
<td></td>
<td>Things they love to do</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pets</td>
</tr>
<tr>
<td>2. Understanding — the ‘right’</td>
<td></td>
<td>Could understand, he could understand, others could understand</td>
</tr>
<tr>
<td>information</td>
<td></td>
<td>He then could accept assistance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hearing from others with ABI</td>
</tr>
<tr>
<td>3. Developing some quality of life for</td>
<td></td>
<td>Finding ‘good’ people to help</td>
</tr>
<tr>
<td>him</td>
<td></td>
<td>Developing confidence/self-esteem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some independence and happiness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whiteboards and phones if they can use them</td>
</tr>
</tbody>
</table>

8.3.2 First Overarching Theme: Love

As with people with ABI, family carers identified love as an essential overarching theme as shown in Table 8.9 below.

Table 8.9

First Overarching Theme: Love

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family: people who</td>
<td>‘The [family’s] love is important.’</td>
<td>‘He says ‘my family — if I didn’t have my family I couldn’t...’</td>
</tr>
<tr>
<td>love them and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>people they love</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things they love to</td>
<td>‘Being in the country — some freedom.’</td>
<td></td>
</tr>
<tr>
<td>do</td>
<td>‘To come down to the township with his</td>
<td></td>
</tr>
<tr>
<td></td>
<td>big brother to escape home.’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘Fishing.’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘Reading local paper — with all the town</td>
<td></td>
</tr>
<tr>
<td></td>
<td>gossip.’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘[I] try to make life as normal as</td>
<td></td>
</tr>
<tr>
<td></td>
<td>possible — take him out to friends</td>
<td></td>
</tr>
<tr>
<td></td>
<td>place in wheelchair...’</td>
<td></td>
</tr>
<tr>
<td>1. Love</td>
<td>Pets</td>
<td>‘His dog on his bed...’</td>
</tr>
</tbody>
</table>

189
Molly, Jane, Sue, Jo and Liz believed that their love, support and guidance were of prime importance. They also identified that ‘activities to fill his week’, hobbies and pastimes helped their family member feel better — whether it was fishing, pottery or reading. They were all trying to make life as normal as possible by taking ‘him out to a friend’s place in wheelchair...’ as they thought they became bored at home. Animals played a role in providing companionship and encouragement, and their sense of humour, also helped. These coincide with the views of participants with ABI.

8.3.3 Second Overarching Theme: Understanding — Getting the ‘Right’ Information

Table 8.10

Second Overarching Theme: Understanding — Getting the ‘Right’ Information

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case: Selective Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.Understanding—getting the ‘right’ information</td>
<td>Information I could understand, he could understand and for others</td>
<td>‘Information and not just give you a whole bunch of booklets — probably 5 months after his injury I started to read through some of these — my husband wouldn’t. Reading them sort of throws you because you think “Oh my God is he going to be like this — like that? Is he going to end up that way?” So it sort of makes you worry more — on the internet — much the same information it’s sort of repeated.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘I’ve had great support from friends — but I don’t think even my closest friends understand ABI or me — some days I’m just ragged; I need info for friends.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Hearing [about ABI in a way like Keys to the ABI Cage CD talk] — he needs to have ABI told in a humorous way — things he can relate to — things he can see and touch.’</td>
</tr>
<tr>
<td>Acceptance</td>
<td></td>
<td>‘He has developed some insight: He accepts assistance.’</td>
</tr>
<tr>
<td>Hearing from others with brain injury</td>
<td></td>
<td>‘He accepts he needs to use his mobile phone.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘[He] accepts it’s good to talk to someone else with ABI.’</td>
</tr>
</tbody>
</table>

Mothers and wives stated that it was vital to obtain information that could be understood — this was not simply information from a ‘bunch of booklets’ or the internet as they repeat all the negative issues. The families and the person with ABI needed to hear about ABI in a way that they could understand, a way they could relate to, not in medical language. Jane, Sue, Jo and Liz thought that Keys to the ABI Cage would be a way to explain about ABI ‘in a
humorous way — with things their family member could relate to, things he could see and touch’. All women said they needed information so their friends could understand and that information was needed so that schools and sporting clubs can understand ABI, as was explained in the previous chapter.

Mothers and wives talked about the breakthrough once their loved ones understood about ABI, developed some insight and then accepted assistance, or accepted he needs to use his mobile phone. Brain injury support groups and talking to others with ABI was seen as valuable.

Looking at the things people talked about, it is possible to see a movement away from information about the ABI to information about how to establish meaning to life and in doing so, how to counterbalance the challenges faced. This is a source of information in the metaphysical realm of hope, love, trust and dignity as well as about the practical helping tasks. And this is no less a message for people with ABI than other groups and, furthermore the population at large. This theme will be revisited in the discussion chapter.

8.3.4 Third Overarching Theme: Developing Some Quality of Life

Several themes contributed to the development of quality of life. These are shown in Table 8.11.
Table 8.11

Third Overarching Theme: Developing Some Quality of Life

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finding ‘good’ people to help — proper treatment, suitable housing etc</td>
<td>‘Find good people’ ‘We got a psychologist who came to see him and she was very helpful.’</td>
<td>‘Get help with transition from hospital to home.’ ‘If [the guardian] hadn’t intervened he’d be dead.’ ‘...got onto proper medication , for depression ...Housing that suits the young person is important.’</td>
</tr>
<tr>
<td>Development of confidence/self-esteem</td>
<td>‘...learning by his own mistakes, but not on tight leash ... but supported and shadowed.’</td>
<td>‘He works 16 hours a week; Sympathetic understanding work is important.’ ‘You should see him on the phone ‘I’m an artist now’... this has helped his self esteem — he feels like he’s out there and contributing to society and he’s made friends with others who have ABI, [with] similar injuries to himself,[it’s] easier when people understand.’</td>
</tr>
<tr>
<td>Some independence/happiness</td>
<td>‘He’s got his mind and memory; I think he values what he’s got — he doesn’t think about what he hasn’t got.’ ‘My son said “Now ‘I’m perfectly happy”’.</td>
<td></td>
</tr>
<tr>
<td>Whiteboard/signs/mobile phones</td>
<td>‘Whiteboards, he’s only just started to use a diary, he couldn’t before, he tried but he wouldn’t know what day it was but now...’ ‘When he’s tired he might forget where the toilet is so not just for him it’s for others, there’s signs toilet this way...’ ‘...he lives with a mobile phone ringing ...we just program it in and it rings and tells him what he does at a particular time.’</td>
<td></td>
</tr>
<tr>
<td>Attitudes</td>
<td>‘I take it just one day at a time.’ ‘We’re lucky to still have him.’ ‘Appreciate the small gains and events.’</td>
<td></td>
</tr>
</tbody>
</table>

The participants who were mothers and wives all identified that it was vital to find ‘good’ people who could help in different ways — a psychologist, a guardian (who took over managing Sue’s son’s life — ‘If she hadn’t intervened he’d be dead’), obtaining proper medication, ‘proper’ accommodation. Jo spoke about the difference at work when there were signs for her husband to find the toilet. Jane needed good people to help her son at school, Liz was in the process of locating good people to help her husband. Molly had built up a good team to help her care for her son. Sue spoke about whiteboards and mobile phones as valuable aids if the person with ABI can use them.
These tenacious women spoke with pride about the way their family member coped; Jo how her husband’s work contributed to him feeling like he’s out there and contributing to society; Sue’s son also did volunteer work several hours a week and was learning by his own mistakes; Liz’s husband was striving to communicate. Even when the son or husband was badly injured by ABI their mothers/wives saw hope even in simple things such as their family member could eat and enjoys their food, and that their family member values what he has. Sue’s son had recently told her ‘Now I’m perfectly happy’.

The women had realised that the lifeworld of their loved one was affected by their attitude — they needed patience to ‘just take one day at a time’; ‘Just think you’re lucky to think you still have him’ and appreciate small things ‘Every little thing is a gift.’

8.3.5 **Superordinate Theme: With Love, Hard Work and the ‘Right’ Attitude Life His Life Can Improve**

Clarity over the importance of love, understanding and developing quality of life, even through small engagements that accomplish change, are what set the conditions for giving meaning to life and are separate from the cold and clinical environments of rehabilitation. For example, the mothers and wives believed in the importance of love; information that they could understand, that he could understand, that their friends could understand and schools and sporting clubs could understand.

The themes of professionals who work with people with ABI will now be examined to determine the factors that they believe help their clients.

**8.4 Professionals: Factors That Positively Affect the Life of Clients with ABI**

The psychologist, the social worker, the advocate, the community health liaison officer and the brain injury support worker, each brought to the study their expertise and experience about things that help people with ABI to learn to feel and fare better. They brought valuable insight into this area of the study. Overarching themes identified by clustering of emergent themes provided a new angle on the importance of the family ‘the support team’ of the individual. Themes allow a triangulation of the data.

Very different views were put forward by different professionals again calling into question the use of triangulation as ‘confirming themes’. This involved marking up the different meanings professionals had compared with those whose engagement with ABI exists within
the everyday world, the world at which it is not possible to switch off and go home at 5.00 p.m. each evening. Views among professionals also differed along these lines and I will call them the X and Y groups. The X group focused on the place of the professional. The Y group focused on the ‘humanity’ of the professional. These different areas will be identified by X and Y in the following table.

8.4.1 Overview of the Professionals’ Perspectives of Things That Positively Affect the Life of Clients with ABI

Table 8.12

Professionals: Overview of Findings

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words in the first case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group X: The professional provides guidance to fill the gap when the person leaves rehabilitation.</td>
<td>1. Group X The gap is filled by professionals when the person leaves hospital/rehabilitation</td>
<td>A home visit (see Tables 8.13, 8.14, 8.15)</td>
<td>Someone professional there Services Providers Training</td>
</tr>
<tr>
<td>Group Y: The humanity of the professionals — they can help by encouraging hope, providing connection, socialisation and empathy, this can support the person to have a purpose, and break down isolation.</td>
<td>2. Group Y The person’s hope, acceptance and attitude is important</td>
<td>Hopes and dreams Sense of humour Understand ABI and accept they have ABI Moving forward This has happened for a reason — a wakeup call Palm pilots/mobile phones</td>
<td></td>
</tr>
<tr>
<td>3. Technology and specific social groups help both group X and Y</td>
<td></td>
<td>More Headway-type brain injury social meeting groups</td>
<td></td>
</tr>
</tbody>
</table>

From this overview the two different concepts of things that positively affect the lifeworld of the person with ABI can be observed. Some professionals thought the keys to unlock the ABI Cage were for more professionals to be involved in the gap transition time, and to ‘walk beside’ the person and their family. The other group saw empathy, understanding, humour, hopes and dreams as the keys to unlock the ABI Cage.
8.4.2 First Overarching Theme (Group X): The Professional Fills the Gap After the Person Leaves Rehabilitation

Table 8.13

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Emergent Themes</th>
<th>Words In The First Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals walk beside families</td>
<td>‘To walk beside families once they’re discharged from the health system because they can feel like they are being left to sink or swim — discharge planning actually caters for a way of being followed up.’</td>
<td></td>
</tr>
<tr>
<td>Professionals keep an eye on providers</td>
<td>‘People with brain injury need help with not the medical needs but follow up needs — I think none of the current models work well that’s why they often struggle and their families struggle because the health bit ends at whatever point they think that your rehab is finished...’</td>
<td></td>
</tr>
<tr>
<td>Training for families</td>
<td>‘The needs of the family surrounding that person often are not looked at or managed or addressed...’</td>
<td></td>
</tr>
<tr>
<td>Group X the gap is filled by professionals when the person leaves hospital/rehabilitation</td>
<td>‘Someone keeping an eye on providers and making them a bit accountable for the decisions they’ve made.’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘What we need to start saying is rehab doesn’t start till 2 years or 5 years post-injury but we have this system where things have to be very set and very structured, again if you don’t fit the pigeonhole you don’t get...’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘We need regularly training for family carers. Current training is often just for the professional and service providers.’</td>
<td></td>
</tr>
</tbody>
</table>

Professional Group X saw that the most helpful thing for the person with ABI and their family was to have home visits by professionals to fill the gap between hospital and home and have regular contact with the family, to manage or address problems. A health officer to contact them and basically says ‘How are you? Is there anything I can do? Is there anything you need? Are you coping?’ These health officers could also make sure providers are doing the right thing and regular training would be available for family carers.
Second Overarching Theme (Group Y): The Person’s Acceptance and Attitude Is Important

Table 8.14

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case</th>
</tr>
</thead>
</table>
| Group Y the person’s hope, acceptance and attitude is important | Hope, love and dreams | ‘People with brain injury need hope — when the doctor says you’re going to be a vegetable, or that you’re only going to improve for 2 years or 5 yrs... people need to have hope.’  
‘His self worth — there’s a light inside him it may be masking other issues but it’s still a form of self-esteem.’  
‘He has hope that he’ll improve — constantly.’  
‘I absolutely have no doubt that you can improve...that cells regenerate and that you’re learning like all of us can go on for ever...I do not believe at all that there is a limit, I’ve seen evidence of this in my work. In my work I see the contrary to that (that people only improve for the first two/five years).’  
‘If they get the basic and primary health care that they need and once you provide situations for people to thrive in, they will do that, and I’m always amazed that how far that can go.’  
‘I want to temper my comments because even when I think ‘oh my god, you don’t get [understand] this at all’ in fact I am often surprised with people given the right sorts of circumstances’. |
| Understanding | ‘Medical jargon is actually useless to you in the long run...not in diagnosis but what it means for life it’s actually quite useless information to families — education much broader than just information.’  
‘An important hurdle for them is having an understanding of the impact of the ABI on themselves.’  
‘What I’ve been really working with, employment skills and studies, so they have some foundations for whatever they chose to do next. It’s slow work’. |
| A sense of purpose | ‘Help with the creation of purpose — purpose I think is an absolute key to everything we’re doing.’  
‘The “switch” to get people going again It’s the same things that everybody else does — their kids, their partners, their work it’s all those things that we all value — what makes me feel good? What makes me get out of bed every day and come to work?’  
‘People really want to connect and if it’s an animal — the primary thing is people want to connect and love and be loved — because it’s lonely having ABI — you think you’re mad and all of those things ...’  
‘There’s something about recreation that I think it’s important for a long time for people to be involved, but I think, the sense of purpose is so enormous in human beings, that to have lots of time, and nothing to do with it, no sense of purpose, is worse... it’s torture.’ |
Professionals in Group Y saw the individual with ABI as having the power to affect their outcome by having hopes, dreams, understanding and purpose. These professionals identified that understanding the impact of ABI on the individual was an important component and that people needed education. This was much broader than about the getting better, about rehabilitation and overseeing providers. As examined in Chapter 7, they said that medical jargon is actually useless, not in diagnosis, but what it means to life in the long run.

Clients might have information but they cannot absorb it. They need be able to identify issues to tackle and what they will do to improve. Two professionals were working with employment skills so that their clients would have some foundations for whatever they chose to do next.

Some professionals identified how a sense of humour helped their clients and how, as professionals, they needed a sense of humour. Clients needed to think about ‘alternatives to watching television’. Three professionals saw the potential of Handy Thinking Tools, to help people re-engage with thinking about issues, which I briefly explained to them. I had prepared ‘Handy Thinking Tools’ (Appendix 6.1) as an alternative to Keys to the ABI Cage in case a participant was not interested in using the method to unpack their ideas. Kirsten stated that some people embrace the difficulties of ABI and others fight them, but the embracing gets you further in the end. Some people have a view of the world that ABI has happened for a reason, and that they needed to ‘embrace whatever this learning and this opportunity’ have
provided for them. ABI can be seen as a wake-up call, it can help some people refocus their life and priorities.

8.4.4 **Technology and Specific Social Groups**

Professionals spoke about the importance of technology being used if the person could use it, and that brain injury support groups were helpful.

Table 8.15

**Overarching Theme 3: Technology and Specific Social Groups**

<table>
<thead>
<tr>
<th>Overarching Themes</th>
<th>Emergent Themes</th>
<th>Words In The First Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technology and specific social groups</td>
<td>1. Helpful technology</td>
<td>‘Palm pilots and a lot of mobile phones — they’ll use them like alarms, and also as sending themselves messages to remember things.’</td>
</tr>
<tr>
<td></td>
<td>2. More Headway type groups</td>
<td>‘More Headway-type groups where they can go and hang out.’</td>
</tr>
<tr>
<td></td>
<td>3. Other social groups</td>
<td>‘What they want is not to be in ABI groups. They want to be out with everybody. And that’s what we’re moving towards.’</td>
</tr>
</tbody>
</table>

Professionals from both Groups X and Y identified that Palm Pilots and mobile phones can be helpful if the person is able to use them. Several professionals stated that there needed to be more groups like Headway, where the person could go to just ‘hang out’. In one country town location, a travel cost of $90 a week meant belonging to an urban group would not be viable financially, especially as a taxi was required to get the client to the centre. On the other hand some people do not want to be in an ABI group. They want to be out with everybody.

8.4.4 **Professionals: Superordinate Themes (1) ‘Fill the Gap’ and (2) Needs to Understand, Accept and Have Hope’**

There were two different superordinate themes, each with a very specific focus. Group X focused on how the gap is filled by professionals when the person leaves hospital/rehabilitation by providing connection to the correct organisations. Group Y considered the humanity of the empathetic professional — they can help by encouraging hope, helping them understand, supporting the person to have a purpose.

8.5 **Summary**

This chapter has shown in spite of catastrophic, complicated affects of ABI, Keys can help the person move from being unsatisfied with their life during the months or early years after their
ABI, to being *engaged* in a meaningful life. This study has established that there are a plethora of Keys that can help people with ABI unlock the ABI Cage so they can release themselves from feeling imprisoned and find a satisfaction in their lives.

The keys exist in the metaphysical world as well as in the world of practical help and clinical attention to getting better. Indeed, the notion of getting better establishes a particular type of opportunity structure for hope that may never be realised. The meaning of hope, love, caring, trust and the warmth in offsetting the challenges lies deep in us all, but cannot be accessed through any hope that services can play this role. The Keys are a way of understanding this and a way of beginning to see what is important to people and thus, what should then also be important to professionals.

Keys ‘open doors’, they are one step in the process of moving from one place to another. Keys involve a complex mix of coexisting perceptions, opinions, emotions and behaviours. Keys can be used by people with ABI so they play an active role in helping themselves to find ways to cope with or live with the challenges of ABI. These Keys can release people from feeling bleak about brain injury and beaten by brain injury, so they can make the best of brain injury. The learning resource will pass on these Keys to people with ABI, their family and professionals.

Keys are active not passive; all these Keys require the person to have active acceptance — the will and courage to accept Keys proffered by family, friends and professionals. Other Keys need the curiosity and effort of the person to find ways to regain their identity and reach equilibrium. The personal stories of participants with ABI revealed that, for some, the brain injury brought a fresh appreciation of life, an awareness of their strengths and weaknesses and wisdom.

Mothers and wives of people with ABI believed that love, understanding, and patience could assist their loved ones. Some professionals suggested professional expertise is valuable in guiding the person with ABI (and their family) on the ABI ‘journey’, other professionals identified empathy and compassion as being of prime importance. All participants identified the importance of the person and their family gaining understanding about ABI.

It is thus that we come to the phenomenological heart of this study. This thesis commenced by explaining I was going to look for a way to acquire better insight into ABI in order to find a way to help people feel (and fare) better. ‘Understanding’ was the common and universal theme that helped people move from feeling that life was not worthwhile to feeling that life
was worthwhile. In order to understand people need to work with Keys they can easily identify and Keys that are meaningful to them.

I can now agree with Freeman’s words that ‘education is the key’. This concept will be examined in the following discussion chapter.

I end this chapter with some of the key quotes made by participants with ABI that shared their insight (self-awareness) into their lifeworld and in presenting their ‘wishlists’, said:

…It’s hard to trust people.
… listening to people is important.
…stick at what you’re doing — don’t ever give up.
…life is good and interesting.
…I have to set my goals myself.
…I’m slowly getting better than I was a month ago.
…I can walk, talk and write.
…I’m using to use my brain better.
…I use my normal eye extremely well.
…you need to look at the semi-trailer coming towards you, not the cow!
…going out to pubs and clubs is bad because I see all these attractive females and I realise I’m married!
…sometimes I put my clothes on back to front.
….I tend to take longer to think and reply, although perhaps I give a better reply.
…we can’t help but ask “Why me?”
…I need to hear of other people’s experience.
…you must think before you speak — you can never take back words.
…everyone needs a hug a day.
… I’m always asking “Why?” I’m always looking for an answer.
… we might be able to help others understand.
…I want to be seen as me, an individual, regardless of any disability.
CHAPTER 9

DISCUSSION

Long term recovery from brain injury is not a medical problem. What is needed is re-learning... the power of recovery lies within the injured person as they relearn their daily living skills. Education is the key. (Freeman, 1998, p. 14)

9.1 Introduction

The previous two chapters explained factors that negatively and positively affected the lifeworld of participants with ABI, who could describe these concepts as ‘golden threads’ (important issues from their perspective); or blind spots (from the medical perspective). Part A of this chapter supports data in chapters 7 and 8 and the foundational work set out in the earlier chapters. Superordinate themes are discussed with reflections on the literature and other studies, while areas for further research are identified. Part B of this chapter will discuss Keys to the ABI Cage as a tool for reflection and learning from the multiple perspectives of the different participant groups.

The aim of this study was set out in Chapter 1: to design and trial a method that employs educational/learning principles to help people with ABI acquire better insight into ABI.

The secondary research questions were:

- What factors negatively affect the lifeworld of the person with ABI?
- What factors positively affect the lifeworld of the person with ABI?
- Can an individual gain something, ‘be deepened’, by the experience of ABI? If so, can this be used to help others experiencing similar life challenges?

This chapter reconnects the findings from chapters 7 and 8 with the literature introduced in the first five chapters. This study focused on the participant from the body-subject perspective and the findings reflect how brain injury injures more than the brain – it affects the life of the person as they meet the challenges of living in society. The findings illuminate factors that negatively and positively affected their life. This is different to findings from the body-subject perspective, where deficits are isolated and examined for example the studies reviewed in Chapter 3.
Part A: ‘Golden Threads’ and ‘Blind Spots’

9.2 Discussion of Factors That Have a Negative Effect on the Life of People with ABI

At the beginning of this thesis I stated that even though every brain injury is biologically different, the way people feel about their injury contains many similar themes. The purpose of this study was to identify and tease out ‘golden threads’, themes and factors that could be woven together to form a prototype ‘safety net’ to support people with ABI as they help themselves.

A theme in this thesis has been that academic work has focused upon what has been identified as ‘golden threads’ by professionals, working within certain paradigms. The ‘threads’ may be isolated from other threads, and, even if ‘golden’, a single thread is liable to snap. Although they provide an initial lifeline for the person, they may not be sufficient, nor indeed suitable, to support the person for the rest of their life.

To discuss the findings of this study from the perspective of insiders I have classified the ‘golden threads’ identified by people with ABI. These threads could be viewed as ‘blind spots’ of some health professionals, but have practical implications for the person with ABI: learning about these ‘golden threads’ could help them acquire better insight into ABI, and provide them with some threads to weave together as they construct their own safety net. These threads also have theoretical implications for the professional to consider as they conduct research and programs and in their day-to-day contact with clients.

This study identified that some participants had constructed their own safety net. They had constructively circumnambulated around the phenomena of ABI and worked things out for themselves: they had learnt that there were many keys to the ABI Cage, that certain things affected their quality of life and that they had different ways of coping with their challenges. The ‘powerful experience’ of ABI had led them to acquire better insight into life. They felt wise. This is powerful information to pass on to others experiencing the life challenges of ABI.

9.2.1 Golden Thread/Blind Spot 1: ABI Damages More Than the Brain

The first superordinate theme revealed that hope, honour and trust, and safety and security play a pivotal role in the lifeworld of the person (see Chapter 7.2.2, 7.2.3). Metaphysical concepts around ways the person perceives the world and their core beliefs/understandings
profoundly affected their life. This is an important finding because the absence of hope, honour and trust can affect how the person not only perceives life but also how they engage in learning.

Chapter 7 revealed that many participants, as well as dealing with physical losses, had also lost their understanding of the world. They were not only trying to rebuild their body’s abilities but also their connection with the world. They were searching to understand what was ‘true’ in life, and they were distressed that their integrity had been questioned (see 7.2.4, 7.2.5). The majority of participants with ABI, (and mothers and wives of people with ABI) had been told (or it had been inferred), that they and their family member were cheating or lying. This led them to become suspicious, to withdraw, to be cautious and to doubt other people’s integrity. A most unfortunate repercussion was the fear they could no longer believe themselves. The result was fear, shame, disappointment, distress and hopelessness that affected their daily life. Professionals have reported their clients are fearful, depressed, anxious and agitated (Jorge et al., 2004; Rapoport, McCullagh, Streiner, & Feinstein, 2003). The medical model recognises and classifies these beliefs/feelings/perceptions, (as was shown in Chapter 3) as cognitive impairment (Parker & Rosenblum, 1996; Yudofsky & Hales, 2008), depression (Fann, Uomoto, & Katon, 2001) or posttraumatic stress disorder (PTSD) (Ben-Ari, Koren, & Klein, 2005; Bryant, 2000; Harvey & Bryant, 1998, 1999; Schneiderman, Braver, & Kang, 2008).

Education has been shown to be valuable in the treatment of PTSD: ‘The treatment of PTSD involves educating the patient about the nature of the disorder, and providing them with a safe and supportive environment so they can discuss the traumatic events and how they impacted on them’ (Yehuda, 2002, p. 102). Participants in this study revealed they valued an opportunity to talk about how they felt about their experience, and the impact of ABI on their life using the Keys to the ABI Cage. Some of the issues identified by this study included the following.

9.2.1.1 Different perceptions of fear

A large number of participants in this study divulged that they believed they had gone mad, crazy or insane and they also queried if they really had ABI (see 7.2.1; 7.2.2; 7.2.3; 7.2.4). They said they could no longer believe their own ideas. This contributed to their fearfulness. Fear is ‘a particularly distressing emotion aroused by impending danger, which plays a profound role in a number of philosophical texts and thesis’ (Honderich, 1995, p. 291). Fear is also identified as a personality disturbance (Prigatano, 1993). Maslow’s (1954) ‘hierarchy of
needs’ identifies freedom from fear as a step towards self-actualisation. Ehlers and Clark (2000) posit that people who survive trauma may have insufficient cognitive resources to manage their memories of the trauma, engage with adaptive coping strategies, or stop ruminating.

9.2.1.2 Different perceptions or delusions

Participants had ‘proof’ or reasons for many of their fears that affected their lifeworld, (7.2.1; 7.2.2) however, often these fears were treated as ‘paranoid’ or ‘delusional’ by the professional. From the perspective of the professional, some of the fears expressed by participants with ABI could be placed upon a sliding scale from extreme sensitivity, to paranoid to delusional. However, in the same way we saw that avoidance could be a coping strategy (in Chapter 5), McKay, Langdon and Coltheart (2007), and Bortolotti, (2010) state that persecutory delusions can serve the defensive function of retaining self-esteem. What can be seen by others as purely negative and/or destructive behavioural issues can be performing a very valuable and protective function for vulnerable people on the long-term road to learning to live with ABI.

Fuchs (2005), writing about delusional mood and perception from a phenomenological perspective, draws on Husserl’s (1952) intended perception and Merleau-Ponty’s (1996) embodied perception and uncovers our ‘intimate connection with the world mediated by the lived body’ (Fuchs, 2005, p. 138). The outsider does not have the lived experience of the person with ABI, thus what is the truth may be different for the insider’s and outsider’s perspectives. This suggests that empathy and consideration needs to be fostered around a person’s beliefs. The experiences and actions of participants were affected by their beliefs.

This is an important but complex finding and needs further investigation. Participants said they were disturbed that professionals did not understand what it was like to have ABI (see 7.2.4). Indeed, when they told professionals about their fears/beliefs/feelings/perceptions they were either told not worry, they were not taken seriously (it was minimised) or they were taken too seriously and the issue was blown out of proportion (it was maximised) when they simply wanted an opportunity to discuss the issue with someone who understood (see 7.2.4). This study showed that many people with ABI are therefore burdened by their beliefs.

9.2.1.3 Different perceptions of courage

Participants initially glossed over their difficulties as they were trying to appear brave or courageous; they were showing they were courageous, persistent and honest. But many
outsiders treated them as dishonest cowards, only pretending to have ABI, which meant they then saw themselves from the outsider’s perspective (see 7.2.1; 7.2.2; 7.2.3). These contrary beliefs had contributed to the isolation of the person.

Aristotle posits in *Nicomachean Ethics* that how one manages one’s fear is a measure of courage. Positive psychologists assert that good character is something measurable. Peterson and Seligman (2004) attempted to identify and classify positive psychological traits by surveying global religious and philosophical traditions. They identified six universally endorsed strengths or ‘encompassing virtues’ — wisdom, courage, humanity, justice, temperance and transcendence. They define courage as the person having strength to undertake goals in the face of opposition — bravery, persistence, integrity.

Evans (2011) posits that Positive Psychology (PP), the scientific study of positive emotion and wellbeing, has shifted from understanding the factors that contribute to wellbeing to developing and evaluating interventions to improve wellbeing. This is relevant to brain injury rehabilitation as ‘much of our current (best) practice is consistent with the principles of PP, but there remain areas where brain injury rehabilitation practice could draw further on the specific methods of PP’, (Evans, 2011, p. 117).

### 9.2.1.4 Shame and loss of status

Participants were ashamed because they were unable to control their body, brain or beliefs (see 7.2.1; 7.2.2; 7.2.3; 7.2.4). They felt guilt (self-scrutiny and self-condemnation) and shame (self-accusatory, through the eyes of others). William James (1890) in the *Principles of Psychology* wrote about the ‘fiendish punishment’ experienced if people did not notice us or ‘cut us dead’. James suggests that the consequences would be ‘rage and impotent despair’ (cited in de Botton, 2004), the person with ABI may daily experience the ‘torture’ of being a ‘nobody’, being held in low esteem, invisible or ignored. Positive regard, empathy and kindness from others are needed by the person with ABI who has to endure rejection by a society that does not understand ABI.

Another important finding of this study was that many of the negative comments made about rehabilitation were based on ‘perceived’ lack of positive regard, empathy and kindness, and not practical outcomes of therapy (see 7.2.4). Earlier in this thesis it was explained that some people see themselves reflected as they appear to others in the ‘the looking-glass self’. de Botton states that if a person believes others see them as a failure, unimportant and dim, this affects their self-image — they think: I am a disgrace, a nobody, I am stupid.
de Botton also posits that people ‘consider themselves fortunate only when they have as much as, or a little more than their friends and acquaintances’ (de Botton, 2004, p. 16). Participants with ABI stated that they constantly compared themselves not only to the old me (and loss of identity, see Chapter 7 overarching theme 1), but they also compared what they were doing to what their friends with normal lives were doing. This comparison impacted negatively on their lifeworld. de Botton states that ‘what we understand to be normal is critical in determining our chances of happiness. Few things rival the torment of the once famous actor, the fallen politician...’ (2004, p. 55). To this statement could be added ‘the person with ABI’. The person’s dashed expectations and diminished self-esteem affects their day-to-day life and their learning because self-esteem plays an important role in motivation and learning (see Chapter 5). Uprichard (2010) stated that people with ABI felt judged and less valued by society.

9.2.1.5 Time passing may not mean the person’s life gets better

Some people in this study felt less afraid, ashamed and isolated over time as their physical difficulties and health improved and they slowly learnt to compensate and adjust to physical, cognitive and emotional difficulties. Other participants felt more afraid, ashamed and isolated as time passed because they had not made what they considered satisfactory process, they had lost all their old friends and had experienced greater feelings of panic as they understood more about their losses (see 7.2.1; 7.2.3). A number of studies have shown that life can improve for the person: Bulinski’s (2010) study showed that there was deep social isolation, loneliness, and sadness, but involvement in the ‘Academy of Life’ reduced social dysfunction; self-efficacy may contribute to overall subjective wellbeing (Cicerone & Azulay, 2007). Life satisfaction after TBI appears to be related to attaining healthy and productive lifestyles (Corrigan, Bogner, Mysiw, Clincholot, & Fugate, 2001) while ‘some researchers found that life satisfaction was not related to the extent of impairment or disability but was associated with several dimensions of societal participation’ (Corrigan et al., 2001, p. 2).

9.2.1.6 Relevance and implications of these findings

*Practical implication - Professionals:* As well as treating the body of their clients it is vital that professionals take into account the beliefs/feelings/perceptions of their clients, and concepts of PP. It is also vital that clients are treated in a respectful, kind manner.

*Practical implication - People with ABI:* Learning information is needed for personal use and/or for use with groups at support organisations including information about PP and
PTSD. The person with ABI needs the opportunity to talk about things that concern them. Ideally an ABI educator could teach people about ABI and some of these concepts.

_Theoretical implication:_ Treatment of people with PTSD has demonstrated that through education, people can learn to change their beliefs and therefore behaviour and emotional responses. Sensitive qualitative investigation is needed to determine ways that can help people learn to understand the fear, distress, disappointment and shame that accompanies ABI so the person does not believe they are mad. Suitable information explaining the consequences of ABI is needed, so that people can learn about these issues, and that this is just part of the whole lifeworld as positive factors will be discussed below.

The learning resource will contain stories about how some people with ABI feel. It will be written in simple nonmedical language, using narratives to help people with ABI understand that others also experience conceptual difficulties. This may help people to identify issues that are disturbing them and help them to work things out for themselves.

### 9.2.2 Golden Thread/Blind Spot 2: Learning Is Hard Labour

This superordinate theme revealed that when a person has ABI, learning is hard labour. It is a struggle to learn when the person feels afraid, ashamed, isolated and is trying to understand and cope with the ideas discussed above (see 7.2.1; 7.2.2; 7.2.3; 7.2.4). However, the person needs to understand ABI in order to gain self-awareness and acceptance; they need to learn about ABI and how it has affected them physically, emotionally, cognitively and on a metaphysical level.

Chapter 5 identified some of the crucial factors needed in order for a person to learn: engagement, motivation, association, learning styles and multiple intelligences. Anderson and Krathwol’s taxonomy (2000) showed that there were a series of steps in learning. The first step was ‘remembering’. Thus the person with ABI is confronted with a significant challenge at the first step - because they have memory difficulties, they may forget they have ABI, they need to learn new strategies, or they may forget everything they are told by professionals. This first step to learning can be assisted by the person being engaged and motivated to learn, by taking into account the person’s preferred learning style and the ‘intelligences’ that best help them learn (Gardner, 1983). These learning styles are the visual, logical/mathematical, bodily kinaesthetic, musical/rhythmic, interpersonal, intrapersonal, naturalistic and spiritual/existential. Just as the traditional ‘talk and chalk’ classroom (which relies upon verbal and linguistic intelligence) is not the most expedient way for all students to learn,
direct instruction from a professional may not be the most expedient way for a person with ABI to learn (as it also relies upon the verbal/linguistic intelligence).

The second step in learning according to Anderson and Krathwol (2000) is ‘understanding’ and information (the information must be understandable). However, an important finding of this study was that all participants — people with ABI, mothers and wives, and professionals, identified that there was a need for information in nonmedical language that helps people understand and learn about ABI. All three groups stated that people with ABI, their families and the general public and some health professionals do not understand ABI. Further study is needed to determine different ways to identify suitable information for people with ABI, written in a way that is interesting to them and understandable. For example, in the Learning Resource there will be several different analogies made to help people understand ABI (similar to the crushed can etc) used in Keys to the ABI Cage as used in this study.

Anderson and Krathwol’s (2000) third step is ‘applying’ the knowledge. Here the person with ABI needs to talk about their experience and make links and connections between the information and knowledge they have about ABI and how ABI has affected them. The fourth step, ‘analysing’, means the person needs to break the knowledge they have into meaningful steps or parts If their interpersonal intelligence is strong, they could describe what they have learnt to someone experiencing similar difficulties. For the fifth step ‘evaluating’, the person with ABI needs to evaluate what is the most helpful skill or strategy to address a problem or challenge, and the sixth step ‘creating’ involves the person generating ideas about how these concepts could be used in the future. This is an example of circumnambulation around an idea — and is very different to being told to do something and having to obey instructions.

Chapter 5 also stated that engaged students really do want to learn. We have seen from this study that many people with ABI are however not ready to learn for a plethora of reasons. The statements made by the participants with ABI, reported in Chapter 7 and Appendix 7 showed they felt swamped by the losses they had incurred because of their ABI. Overarching themes demonstrated they were lost and trapped by ABI, they no longer felt like normal people, they were damaged from emotional fallout of feeling sad, bad and mad. They were ashamed, afraid and isolated and over half the participants were disempowered by their rehabilitation experience — they were not in the right ‘head space’ to learn. Some participants admitted they had denied that they had ABI. Self-awareness is an important area that has been the focus of studies examined in the literature review in Chapters 3 and 4. It is a complex phenomenon that can impede the rehabilitation process and outcome (Fleming, Lucas, & Lightbody, 2005).
Assisting people with ABI to understand about ABI (gain self-awareness both positive and challenging) in a constructive way was an important component of this study.

The interviewed mothers and wives felt guilty that initially they were unable to understand ABI and if they had understood ABI earlier they would have done things differently. ‘Suitable’ information would have helped them learn about ABI. Statements made by professionals identified most of the physical and cognitive losses and some of the emotional difficulties. However, most professionals revealed a blind spot: they focused on ‘fixing’ the deficits of their clients without focusing on how these deficits affected their client’s self-esteem and self-belief, their ability to learn, nor issues of trust and power. The client’s fear and shame were not issues that were readily talked about. Learning could be termed a blind spot of the medical model, it was not a focus of the professionals, nor studies about ABI. However, this study has demonstrated that the combination of the total of the overlapping difficulties/differences/deficits affected the ability of the person to learn.

A significant, surprising finding of this study was that many participants with ABI had a deep understanding of their situation: they could identify issues that affected them when they were provided with the opportunity to discuss ideas through using Keys to the ABI Cage. They demonstrated they could learn to acquire better insight into ABI. This indicated that learning theories can be applied to assist the person with ABI to learn about and understand their ABI. Learning concepts from Chapter 5 were successfully applied to motivate and engage people with ABI to learn.

9.2.3 Golden Thread/Blind Spot 3: Negative Effects of the Rehabilitation Experience and Medical Terminology

Data indicated the way the person was treated by professionals, including the focus on testing, contributed to the person feeling powerless, losing trust in themselves, others and the world. The protagonist in Graham Greene’s story The Moment of Truth reveals that:

...[he] thought doctors and surgeons are not necessarily good psychologists; perhaps, because their interests are so concentrated on the body that they forget the mind, they don’t realise how much a tone of voice reveals to the patient. They say “there’s always a good hope” but what the patient hears is “there is very little hope if any”. (Greene, 1990, p. 37)

Another blind spot identified by this study was that many participants with ABI did not get the best out of their rehabilitation experience (see 7.2.4). They believed rehabilitation should involve not only getting the body working to the best of its ability, it should also help them understand ABI and themselves, and discover and develop their own skills, talents and hopes.
They thought the focus revolved around the professional’s skills and talents to ‘fix’ them. The practitioner needs an ability to lead them to learn about their new selves through education, encouragement and motivation.

Participants’ inability to ‘connect’ with rehabilitation professionals were disclosed when they stated they were ‘treated like a leper’, ‘like I’m dumb and stupid’. The perceived lack of empathy and understanding of the professional was a common thread running through many stories, and again accentuated the gap between practical help and helping the person regain their self-esteem. There were extremes to which the rehabilitation experience impacted and still impacts on the lives of participants. These participants would be in accord with the findings of Simpson’s study (2000) that identified that attentiveness, friendliness and guidance from rehabilitation staff was valued. Another interesting finding of this study was that some people took on the emotions of people they saw.

9.2.3.1 Mistrust

One interesting finding of the study was the legacy of mistrust of rehabilitation and the testing process for some participants (see 7.2.4). They had been ‘burnt’ by being ‘tricked’ in tests. This was revealed very forcefully to me during the last stage of the first few interviews. I had made two sets of talk-about cards that were very similar: ‘Being useful’ and ‘Helping’; and ‘A cup of tea’ and ‘A cup of coffee’. I was astonished at the reaction of the first five participants to these cards. They said: ‘Being useful is the same as helping!’ ‘A cup of tea or coffee — what’s the difference — did you think I had forgotten I had already chosen one’. They became hostile and asked me if I was trying to trick them or catch them out. For a short time the friendly atmosphere that had been built up during the 45-minute interview was destroyed. As I attempted to explain that I had no intention of tricking them, the participants explained they were sorry for their reaction but it was a legacy of feeling tricked in tests and the mistrust they had about tests. As the first five participants reacted in a similar way I removed the ‘Helping’ and ‘A cup of tea’ cards because the main aim of this study was to do no harm and not to upset the participants. This was the only example where the study design upset that aim.

9.2.3.2 Terminology

Further issues identified by the participants included difficulty around the use of certain terms including ‘mild ABI’ (see 7.2.4). In daily use the word ‘mild’ means ‘slight, minor, unimportant, and insignificant’. Mild ABI is inadequate to describe the state of people impacted by ABI on an ongoing significant way. Additionally, the adjective mild encourages
unrealistic expectations of recovery. This leads to subsequent disappointment and self-blame as the individual views themselves as a failure when faculties are not readily recaptured.

The term ‘plateauing’ was not helpful. The word implied that their condition would not improve. This term does not take into account the person as a whole and how learning information that allows them to make sense of ABI can allow them to move forward in cognitive and emotional ways. Participants also abhorred the term ‘constant or persistent vegetative state’. This is an example of how terminology has the potential to dehumanise people.

9.2.3.3 The Two-Year Rule

The majority of participants were informed by professionals that the brain would only heal during the two years following their ABI (7.2.4). This statement caused loss of hope and anger. The two-year rule does not take into account recent studies on the plasticity of the brain and the real time needed to make gains, the ability of the person to learn, or that the person can learn to feel better when they understand more about ABI. The two-year rule was most unhelpful as it put a perceived limit on progress.

This study has demonstrated that there are many ‘keys’ to help people learn to feel and fare better. Understanding ABI, hope, making progress, being treated in an empathetic way all positively influence the lifeworld of the person. So their lifeworld can improve after two years as they learn to live and cope with ABI.

9.2.3.4 ‘You Will Never...’

Many participants explained how they had been told they would never walk, work, drive or have children (7.2.4). Despite the strong and dire predictions they received from rehabilitation professionals to the contrary, some participants were pleased that they had proved that these predictions were wrong. People at ABI support groups have informed me that they had done things they were told they would never do. Telling a person that they will never do certain things negatively affects their lifeworld, hope and motivation.

9.2.3.5 Relevance and Implications

This section has focused upon trust, hope, fear, guilt, courage and examined concepts of truth and integrity. Questions were posed about the ‘truth’ of the ‘two-year rule’. Doidge’s (2007) book documents examples of neuroplasticity of the brain. This new paradigm posits that the adult human brain is able to change its own structure and functions, rather than being fixed
and unchanging. This provides a ‘new truth’ about the brain and this study, and my personal experience, demonstrate that the brain can be neuroplastic.

*Practical implication - Professionals:* The professional has the ability to greatly affect their client’s lifeworld and wellbeing. Care needs to be taken to treat them with respect and kindness and help them to understand ABI. Clients should NEVER be told they will only improve for two years, or that they will NEVER do certain things.

*Practical implication - People with ABI:* Need to understand that the two-year rule is wrong and that they will continue to have their lifeworld improve as they learn new ways to deal with ABI. People with ABI should be allowed to CHOOSE areas that are important to them to focus on in rehabilitation.

*Theoretical implication:* Sensitive qualitative research is needed to determine how people experience the rehabilitation system, things that could be put in place to help them engage in activities and ways devised that could help them fill in the empty hours.

Suitable information using learning principles need to explain the consequences of ABI, so that people can learn about ABI in a constructive way.

The theoretical implication of both the ‘validity’ and ‘value’ of test results as indicators of the way the person with ABI will cope with the future should be reviewed.

Investigation is needed into the value of people with ABI being given IQ tests. Is the purpose to indicate their capacity to cope? As seen in findings of this study, most people with ABI experience a negative emotional outcome from being obliged to complete tests that highlight their impairments. If the person’s IQ score is ‘lower’ than it would have been pre-injury, does this indicate they will experience difficulty coping? If this is so, should people with ABI be taught different ways of coping? People need to be able to employ higher order thinking in order to identify strategies they use. Is this influenced by IQ? Does that mean that the participants who had found ways of coping had lost less IQ points, or had started with a higher IQ, or was it their emotional intelligence (self- and social awareness and management) not IQ that played a role in the way they worked things out and accepted and coped with their ABI? If studies prove this to be the case this could be addressed through learning. In Chapter 5 the concept of multiple intelligences was explored and the idea that there are other intelligences that IQ tests do not measure — emotional intelligence and metacognition are not measured in IQ tests although these other intelligences may play a more significant role in learning and better life for people with ABI.
9.3 Discussion of Factors That Have a Positive Effect on the Life of People with ABI

Fortunately, the negative superordinate themes discussed above did not tell the whole story of the lifeworld of people with ABI, or their ability to learn: participants with ABI also identified a plethora of Keys that had helped them to release themselves from the ABI Cage. Many participants had moved from feeling that life was not worthwhile, to feeling that life was worthwhile. A few participants even felt enriched by their struggle — they had worked things out for themselves and they believed they had attained and employed wisdom, courage, humanity. This section will discuss issues that culminated in these beliefs.

This finding was in agreement with the idea that although concepts of the ‘personhood’ as ‘lost’ or ‘shattered’ have dominated discussions in the literature, this ‘perspective is a crude representation of the post injury experience of self, and the aspects of stability, recovery, transcendence and moral growth are also involved in this process’ (Gerlich & Dejardins, 2011, p. 62). This finding also is in line with Nochi’s (2000) categories, which show how a person can come to terms with their new self and a series of coping strategies identified in Chapter 4 (Kendall, Kendall & Muenchberg 2009 and, in particular, Linge’s, 1990, suggestion to focus on small achievements).

*Keys to the ABI Cage* aimed to help people with ABI discover and come to terms with the new self (self-actualisation) by helping them to understand ABI, to feel safe, to belong to the ‘brother/sisterhood’ of people with ABI, to recognise their achievements and to have their achievements recognised by others. Identification of factors that positively affected their lifeworld assisted them to see their ABI experience with ‘new eyes’.

9.3.1 Golden Thread/Blind Spot 4: The Positive Effect of ‘Humanity’

Blind Spot 3 examined how, for some people, rehabilitation left them feeling ‘more wounded’. For these people the rehabilitation experience did not make them feel safer, they felt greater fear, they felt less likely to belong and their self-esteem was further eroded by their experience. So even if they could now walk, make a cup of tea or cook more easily, the rehabilitation ‘process’ and the professionals had eroded their fragile and vulnerable self-esteem.

Kirsten, a participant in this study, a professional with many years’ experience working with people with ABI, provided an answer to many of the negative comments about rehabilitation
and health professionals recorded in Chapter and Appendix 7. She remarked ‘What I like about the stuff you are doing — the humanity of it — with all these things it’s about humanity...’. Kirsten said that the professional should encourage hope because in many years working with people with ABI she has seen people improving past the two- or five-year period: once you provide situations for people to thrive in they will thrive. She stated that helping the person to have a purpose is vital, and the ‘switch’ to get people ‘going again’ is the same things that affect everybody — ‘their kids, their partners, their work and those things that they value, things that make them feel good, that make them get out of bed every day’.

Kirsten exemplifies the centrality of family friends, empathy, touch and reassurance. Indeed, she explained that people get isolated in acute hospitals, in rehabilitation and when they return home, maintaining connection with their family, friends, community and workplace is vital. She said that empathy is important:

I touch people — I might not be able to fix whatever but I put my hand on their arm — I just try not to have a difference between my professional and my personal self, I think I try to connect on a human level.

She explained that she had

spent a lot of years not touching people, not connecting with them, maintaining “professional” boundaries and doing all that those kinds of things. Recently I thought “No, that’s crap” (laughter) and for the rest of my career I’ve just been myself. Recently one client said “I can see your heart”, another client said “I consider it an art” which I consider one of the nicest compliments I’ve had as a worker, it’s the only way you can connect and be honest.

Kirsten’s approach to her work is reflected by others in the area of rehabilitation, for example, Fuhrer (1992) states that life satisfaction in regards to medical rehabilitation requires subjective wellbeing from individually held expectations, rather than externally defined criteria. The subjective wellbeing can positively affect the lifeworld of the person with ABI. Rees (2005) writes about ‘connoisseurship’ people who understand ABI and can assist people with ABI:

The greater the number of persons who become connoisseurs, the greater is the chance of promoting understanding effective learning, and inclusion...Connoisseurs will have intimate familiarity with the phenomena of people with brain injury. They respect and are committed to their inclusion in society and understand the factors influencing rehabilitation. Connoisseurs typically present narratives that advance community understanding of the difficulties, but also the skills and talents, of people with brain injury. (Rees 2005, p. 5)
9.3.2  **Golden Thread/Blind Spot 5. Many ‘Keys’ to Open the ‘ABI Cage’**

Participants with ABI identified that there are many Keys that open the ABI Cage: Love, hope, learning to understand ABI and working things out, learning to face the facts and accept ABI, and making progress (see 8.2.3; 8.2.4; 8.2.5; 8.2.5; 8.2.7). They identified many other Keys that can help the person with ABI to lean to feel and fare better. These Keys can be passed on to others with ABI in the Learning Resource and through ABI support organisations. Mothers and wives identified Keys as being love, understanding, having the right information, and their son or husband developing some quality of life. One group of professionals said that professionals should fill the gap when the person left hospital and returned home. The second group thought that encouraging their clients to have hope, their client’s acceptance and attitude were vital Keys.

Data indicated the perplexities and complexities of ABI; therefore, for months, or years (depending on the person and the injury) during which time the conditions were not suitable for people to move from feeling life was unsatisfactory, to feeling that life was satisfactory. Support and learning is needed for people to find the Keys that help them feel satisfied with life.

9.3.2.1  **A satisfying life**

Asplund and Astrom’s (1992) study demonstrated that those who showed improvement showed improved life satisfaction and vice versa. Positive ways of producing conditions that improved life satisfaction emerged from participant’s stories (see 8.2.3–8.2.7). Rees (2005, p. 15) states that ‘the appropriateness and validity of the question ‘What is a satisfying life?’ requires close examination. It is a fundamental goal for effective rehabilitation.’ *Keys to the ABI Cage* allowed people with ABI to easily identify phenomena that contributed to a satisfying life for them — to their psychological wellbeing, happiness and hope for the future.

This study also set out to discover if some people are deepened by suffering (Nietzsche, 1887); if an individual may actually gain something by the experience of ABI. Several participants felt that their life was enriched by their ABI experience; they now appreciated being alive, they were aware of their strengths and weaknesses and they now felt wise (8.2.7). These beliefs or understandings emerged through the interview process of learning about ABI and applying it to themselves, reflecting on their life and gaining insight. This appeared to be a turning point for some participants in terms of their self-understanding and new pride in what they had achieved and overcome.
The Keys (talk-about cards) chosen by some participants reflected some deepening of understanding. Interpreted this using Maslow hierarchy of needs, this might be seen as the accomplishment of self-actualisation. From Peterson and Seligman (2004) it might be construed as character strengths and virtues and from a Positive Psychology premise it shows that personal fulfilment is constituted by more than absence of problems and deficit — it focuses on ‘what is strong, not what is wrong’. The participants chose and talked about virtues and strengths such as: wisdom and knowledge, courage (accomplishing goals in the face of opposition), humanity (strengths of tending and befriending others), justice, (fairness), temperance (forgiveness and mercy, humility and modesty, self-regulation and self-control) and transcendence (appreciation of beauty, gratitude, hope, humour and playfulness and spirituality). These findings will be made available to people with ABI to encourage them to reflect and gain insight and have their own ‘Eureka moments’. But they are at the very heart of this thesis and of the humanity we all share.

It will be remembered that one study reviewed in Chapter 4 showed that ‘functional independence did not correlate with life satisfaction whilst depressed mood, income and time after injury, age, race/ethnicity and impairment affected life satisfaction’ (Corrigan et al., 1997, p. 544). Kendall (2009) posits that data obtained from studies using quantitative and qualitative methods around quality of life and life satisfaction have differed and that studies of the connection between the psychosocial wellbeing and coping of people with ABI has been limited and the results have been inconclusive. The results of this study would indicate that it is neither one nor the other. The two are interdependent and necessary. The final ingredients lie in finding the keys, in the understanding that there is hope and movement towards goals, however small, a person’s positive approach to the future and the centrality of feeling love, connection, trust and understanding.

The person’s subjective wellbeing involves their perception and emotional judgment of their expectations, rather than externally defined criteria (Fuhrer, Rintala, Hart, Clearman, & Young, 1992). Thus, the subjective wellbeing of the person with ABI is influenced by not only their physical, cognitive, emotional impairments but also by their perception and how they feel about their lifeworld. This could vary if the person was experiencing a time of greater difficulty or pain. From the outsiders’ perspective, the ultimate proof that a person with ABI has a satisfying life and that they have developed successful coping strategies would be if the person has been able to successfully return to employment. For many people today, employment represents an important expression of who they are as a person. Five participants were working in different areas to their pre-injury jobs, two participants expressed job
satisfaction, and four were studying. Some participants wished they could have career opportunities or work longer hours. Others who were not working wished to gain some employment and many had tried with great persistence to obtain work but could not.

Thus, unfortunately, few of the participants in this study felt they had recovered sufficiently to be able to claim they had a ‘healthy and productive lifestyle, or had returned to work’. If only two out of the 36 participants were satisfied with current employment this is indeed a grim reality for the future of this group of people with ABI if life satisfaction and coping equates to being able to live as they lived and worked before their ABI. Coming to terms with this and finding positive factors to balance out this part of their identity was clearly one of the harder things to accomplish for many people.

The participants from this study differ from other groups of people with ABI involved in other studies. This may be because of the way the participants were recruited: they were not recruited from specific hospital, rehabilitation or university sectors, by professionals they had had contact with. They volunteered from reading the advertisement in brain injury support organisations’ newsletters, and were from both city and rural areas. More research is needed across a wider sample of people with ABI.

### 9.3.2.2 Quality of life

If Keys are things that enhance life satisfaction, they are also things that affect quality of life (see 8.2.3–8.2.7). The dominant paradigm at present rests on splitting life quality into domains for objective measurement (Cummins, 2005; Schalock, 1990). In contrast, Brown and Vandergoot (1998) state that quality of life (the general wellbeing of the person) can be viewed as residing in the ‘insider’s’ judgement of the “goodness” of his/her life, based on cognitive processes or on emotion-based response (1998, p. 4). Brown and Vandergoot argue that outsiders (family members, professionals and researchers) may decide which elements they consider most affect the ‘goodness’ of the person’s quality of life, and the professional or researcher has the power to decide which factors will be focused upon.

In this study, the participant was given the choice and power to determine things that were important factors to them — things that negatively and positively affected the goodness of their life. The process also moved the interview away from the ‘medical illness lens’, which is a ‘relative narrow swathe of the person’s life-space, with the aspects of illness and impairment at the centre of attention’ (Brown & Vandergoot, 1998, p. 4). Meaningful and positive
relationships affect quality of life — good relationships make people happy and happy people enjoy more and better relationships than unhappy people.

9.3.3  **Golden Thread/Blind Spot 6: ‘Keys’ Can Assist the Person with ABI to Learn Coping Skills**

The second positive superordinate theme identified that ‘constructivist circumnambulation’ learning can assist the person with ABI to learn to help themselves to feel and fare better’. This finding could assist people with ABI, their family and professionals to examine ABI in a roundabout way. Keys included things that helped people learn to cope, manage, handle, deal with, survive, get by and tip the balance from life being worthless to life being bearable. There are a plethora of studies about coping that include a range of behaviours such as adaption and adaptive functioning, mastery of skills, defence or realistic problem solving (see Chapter 4 for a review). Determining the style of coping that contributes to psychosocial adjustment can reveal information that can be used in rehabilitation (Kendall et al., 2009, p. 129).

9.3.3.1  **Coping**

Findings from *Keys to the ABI Cage* study have similarities to other studies such as Kendall et al. (2009), as will be examined below. Only a few participants interviewed mentioned the word coping, however they could identify Keys that could be classified as coping strategies (see 8.2.3–8.2.7). Lazarus (1993) broadly defined coping as a ‘person’s cognitive and behavioural efforts to manage psychological stress’ (1993, p. 62). Lazarus and Folkman’s (1984) seminal work and Smith and Lazarus’s (1990) work centres round the notion that emotions are influenced by evaluations (appraisals) of events that cause specific reactions in different people. Shepherd’s (2007) study of coping styles showed that people who cope in an active way showed less depressive symptoms than people who cope in a passive way. For the person with ABI to cope with a wide variety of differences and difficulties a plethora of coping strategies must be employed at different stages of their post-injury life. Keys identified in this study could be classified according to coping strategies. Denial of specific difficulties and differences may be a positive way for the individual to live life — otherwise they would be constantly comparing their life pre- and post-ABI. Lazarus (1993), writing about people with heart attacks, suggests that denial has different consequences at different stages of this illness.

Lazarus (1993, p. 236) states that the coping strategy of, say postsurgical breast cancer patients, depends on whether they are dealing with threats by feeling endangered by the
disease at the time. In the same way, asking a person with ABI about their coping strategies depends on firstly their memory — if indeed they remember they have ABI and if they can remember abstract strategies they have in place. Secondly, it depends on their general state of health, both physical and mental; and thirdly, what difficulties they have encountered in the time prior to being asked about how they cope. Many of the participants in this study had experienced difficulties before the interview — dressing, remembering the interview (in spite of a reminder call the previous evening), finding the location, understanding time allowance to arrive on time, having to organise someone to escort them, arriving very early and waiting (due to time difficulties), having to concentrate all their attention in locking up their bicycle and so forth.

People with ABI need unique ways to cope with multiple challenging situations at one time; physical danger; emotional spin-offs including their loss of confidence and loss of trust; and their belief that they are sad, mad and bad, afraid, ashamed and isolated and fatigue. Lazarus (1993, p. 236) states that ‘what is most needed in coping measurement is to describe what a person is thinking and doing in the effort to cope with stressful encounters’.

As the purpose of Keys to the ABI Cage was to report back to people with ABI in a simple user-friendly way in the learning resource, Cohen and Freedenberg’s (1993) ‘Eighteen Coping Strategies’ were used in the hope that these strategies would be in a language that might be easier for people with brain injury to understand.

However, this study unravelled complexity whereas coping inventories do not. It allowed choice by the person of those things that they could or might use as ‘appraisal’ devices and buffers against stress. The keys therefore allowed the collection of diverse experiences and provide a ground for a choice of how people can engage. By drawing on the talk-about cards, which represent the range of experience, people can reflect on strategies and approaches they do not presently use but ones that may be open to them.

People with ABI in this study wrote about a wide variety of coping strategies — more extensive than those recorded in most coping self-report inventories (see Chapter 4), indicating that self-report inventories may fail to assess the full nature of coping. The problems associated with self-report inventories have been documented extensively in literature, yet the use of these inventories to assess coping is still widespread (Kendall, Shum, Lack, Bull, & Fee, 2001). Such inventories represent a quick method of assessment that is easy to analyse. However, the current study has indicated that self-report measures are likely to miss rich and subtle aspects of coping, (Kendall & Muenchberge, 2009, p. 137). Cohen and
Frydenberg’s coping scales have been used to examine data gathered under the Theme 3 *Keys to the ABI Cage*.

Keys fit under these areas:

- Seeking social support
- Focus on solving the problems
- Working hard to achieve
- Worry
- Invest in close friends — engaging in particular intimate relationship — this strategy was not a common strategy
- Seek to belong
- Wishful thinking
- Social action
- Tension reduction
- Not coping
- Ignore the problem
- Self-blame
- Keep to self
- Seek spiritual support
- Focus on the positive
- Seek professional help
- Seek relaxing diversions
- Physical recreation

Additional strategies identified by participants in this study included:

- Nature
- Animals
- Symbols
- Helping others
- Further study
- Achieving hard things
- Sense of Humour
- Employment
- Doing ‘normal’ things/feeling a ‘normal’ person
- Success
- Attitude
- Doing things for myself

It is important to note that the findings from this study differ from the findings of other studies focusing upon how people cope with ABI because this study was looking for factors that had a positive effect on the lifeworld of a person with ABI. It was not focusing on coping, which was not foremost in participants’ minds, but reflecting on what has helped them cope in the past could provide the basis for development of a ‘tool box’ of coping strategies. The individual could keep a journal (if they had writing skills or a family member could help them by recording thoughts for them) to refer to and use as a guide if they could remember.

**9.3.4 Golden Thread/Blind Spot 7: Some ‘Keys’ Involve Optimism**

Some participants could be said to have displayed ‘resilience’ (8.2.7). This is an active process that includes positively adapting in spite of significant adversity (Garmezy, 1991; Luther & Ziegler, 1991; Masten, Best, & Garmezy 1990). Garmezy and Rodnick’s study (1973) investigated competence, adversity and resilience. Adversity can be applied to people with ABI, but competence is problematic if you are not competent to walk, talk, think or even eat as you once did. Positive adaptation involves skills, attitudes, awareness, acceptance of deficits, taking steps to adapt. These are not the normal attributes of a person whose life is changed by ABI.

Perlesz, Kinsella and Crowe (1990) stated that few studies explore the experience of coping well and resilience after traumatic injury and this still seems to ring true. Ponsford and Crowe’s (2000) study provided evidence that coping strategies are associated with emotional outcome and Uprichard (2010), using the person-centred global approach, found that participants felt less valued and judged by society and wanted the focus to be on enablement rather than disablement. This also is the finding of Keys to the ABI Cage study.

The Resilience Research Centre (RRC) brings together experts from across six continents and from many fields (including social work, sociology, psychiatry, health statistics and measurement, psychology, medical anthropology, child and youth studies, and epidemiology) and identifies a multidimensional model of resilience. Most commonly, the term resilience has come to mean an individual’s ability to overcome adversity and continue his or her normal development. However, the RRC uses a more ecological and culturally sensitive definition. ‘In the context of exposure to significant adversity, resilience is both the capacity
of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being (Ungar). Given this definition and what was said about the use of Keys to the ABI Cage in providing a toolbox for coping, the same may be asserted around resilience. The cage maximises the chance that people may find the resources through which to sustain their wellbeing.

As we have seen in Chapters 6 and 7, people with ABI are repeatedly told by professionals that there is no cure for ABI, this can lead to a pessimistic outlook. Seligman (1992) refers to ‘explanatory style’ (p. 40) to explain the way people think about the causes of misfortune. Seligman’s question ‘Who never gives up?’ and posits that

```
Learned helplessness is the giving-up reaction, the quitting response that follows from the belief that whatever you do doesn’t matter. Explanatory style is the manner in which you habitually explain to yourself why events happen. It is the great modulator of learned helplessness. (1992, p.16)
```

The way a person explains bad events (their permanence, pervasiveness and personalisation) is termed ‘explanatory style’. As many participants were humiliated, disempowered, stigmatised by ABI, Seligman’s concepts could provide a method to assist people to move towards resilience.

### 9.3.5 Relevance and Implications: Research Is Needed

**Practical implication: Professionals.** The professional has the opportunity to explain to their client about coping, things that contribute to quality of life, to encourage them and give them hope.

**Practical implication: People with ABI.** People can learn about coping strategies, resilience, the benefits of optimism and how to increase their quality of life. They want the focus to be on enablement rather than disablement (Uprichard, 2010).

**Theoretical implication:** Sensitive qualitative research is needed to determine an in-depth understanding of how the wealth of the client’s experiences can be harvested without splitting their lives into fine threads that are difficult to weave into something stronger. The findings of this thesis point to the importance of the person finding Keys to their ABI Cage, remaining positive and realising the value of love, trust, nurturance and meaningful relationships are supported because they are glue that holds the fabric of their lives together.
A catalogue of strategies could be a valuable resource for people with ABI who have forgotten coping strategies they employed as the old me. These will be supplied in the Learning Resource to be developed from this thesis.

Another issue that could be investigated is determining the benefit to people with ABI talking or writing about their trauma. Pennebaker and Chung (2007) discuss the links between expressive writing and mental and physical health — people who made progress writing about their experience of a traumatic event showed increasing insight and their health improved over the next year. Creating a meaningful story can help the person to reappraise the experience. Hait (2006) states ‘human thinking depends on metaphor. We understand new and complex things in relation to things we already know’ (Hait, 2006, p. 2).

The success of Keys to the ABI Cage does not seem questionable. However, in the section to follow this is considered more closely.

Part B: The Research Tool and method

9.4 Keys to the ABI Cage

This study set out to find a method to ask new questions to illuminate ‘blind spots, areas in which existing theories, methods and perceptions actually keep us from seeing phenomena as clearly as we might’ (Wagner, 1993, p.16).

“If I have lost confidence in myself, I have the universe against me.” (Ralph Waldo Emerson)

The main aim of this study was to identify issues that needed to be considered in order to design and trial a method that employed educational/learning principles to empower the person with ABI to constructively reflect upon their ABI experience, so they could better understand themselves (gain greater self-awareness) and to help them to learn to feel and fare better.

The first four chapters of this thesis identified the many issues that were considered to construct the learning/interview tool Keys to the ABI Cage. Headwork boxes isolated issues that were considered as of concern to the welfare of the participant with brain injury. The list of issues derived from the Headwork boxes (refer to Chapters 1, 3, 4 and 5) could be used as a checklist by other researchers when they conduct studies, or professionals who work with people with ABI. Keys to the ABI Cage was designed specifically in response to the need to ask questions of vulnerable people who may have lost confidence in themselves.
Chapter 5 identified educational/learning principles that were considered in the construction of *Keys to the ABI Cage* that were used to engage, encourage and empower people with ABI so that involvement in this study would be a positive experience. The quantity and quality of data gathered from participants with ABI demonstrated that the tool engaged both their interest and provided a vehicle for them to reflect on and make sense of their ABI experience.

The literature review identified that people with ABI may lack self-awareness (see Chapter 3.5.8). However, this study demonstrated that participants with ABI, by engaging with *Keys to the ABI Cage*, were led to reflect on their experiences in a constructive circular way (circumnabulation) and through this to potentially gain further awareness and insight. This was done at their own speed, by allowing them to tell stories as they focused on factors that they considered were important.

All the participants with ABI who engaged with both the Reflection Kit and interview, said that they thought it was preferable to have both methods, the Reflection Kit followed by the interview, no one had a preference for interview only. This perhaps indicated that for many the Reflection Kit acted as a prompt to start thinking about their lives prior to the interview. For many the chance to step outside of their everyday reality and reflect upon it may have seemed alien and given them pause for thought.

This study was very different to a quantitative study. It could be because it used a metaphor or because it was different in relation to politics and power, or the participants were different to participants in other studies. It could also be because the participants were more honest in divulging the difficulties they experienced coping with ABI without fear of loss of status or feeling inferior (as they knew I also had ABI). There was mutual trust and empathy between the participants and myself and the majority of participants at some time during the interview voiced the opinion, ‘You understand’, when trying to articulate specific problems. When they ‘got lost’ or forgot what they were speaking about (in spite of having talk-about cards in their hands) they would ask for reminders stating the fact they knew I understood their difficulties.

### 9.4.1 Strengths of Keys to the ABI Cage

The ABI Cage generated interest, humour, understanding and showed empathy and encouraged and supported participants to open up and share their thoughts. In the interview situation, *Keys to the ABI Cage* allowed people with ABI to tell stories and share their experience. Information on the talk-about cards clearly showed that I had understood, respected and acknowledged their difficulties and challenges and positive things that helped
them feel and fare better. Many participants expressed thanks that I had recognised that they may be feeling fragile and that I was concerned that the interview might bring up memories of difficult things. Participants who completed the Reflection Kit expressed thanks that these points were raised several times on the digital storage disk and the accompanying sheets, indicating that rehearsal or practice or a run-through was also important to some people in engaging meaningfully. No participant contacted me to express distress about reflecting on their ABI experience.

The participants were curious and interested in the method and they were prepared to discuss issues because the process was completed in a spiral pattern: they become familiar with the concepts by first looking at Keys to the ABI Cage, secondly by watching and listening to the introductory digital storage disk and finally they held and placed the talk-about cards in the ‘Do’ or ‘Don’t’ box and spoke about the issue if they wanted to.

Keys to the ABI Cage was also trialled at three different ABI Support Group sessions. Each session had up to 15 people with ABI. The tool worked well in the group situation and encouraged group discussion. One support group wanted to use the digital storage disk with a group of people using computers at the centre with the aim of viewing the digital storage disk once more in a year’s time to review the individual’s progress. It is interesting to realise that there could be many different uses of the ABI Cage and the digital storage disk.

The use of objects (e.g., the crushed soft drink can, the flying pig, the rubber band on the ‘stretch outside my comfort zone’ talk-about card) created interest and the small objects on the Keys talk-about cards (e.g., miniature watering can, dog, sun, moon, mushroom, flower) created amusement. This all helped to maintain the focus and keep the session relaxed.

I was curious about how participants who were vision impaired would react to the tool but they carefully touched the cage and objects while I described them. One legally blind participant joked that the pig would have difficulty flying as she had felt the wings and said they were made from fly wire. This participant said that having a mental picture in her head of Keys to the ABI Cage helped her imagine her ABI. For vision impaired participants I read the talk-about cards and placed them in the ‘Do’ or ‘Don’t’ box as directed. At the completion of each theme I handed the participants their pile of cards. Holding the cards in their hands they remarked that they now realised that they had found ways to cope with many difficulties. This reflective activity appeared to be a powerful way for them to understand and acknowledge the things they had learnt to cope with.
The talk-about cards were invaluable. When the participants held the talk-about cards they were empowered because they were encouraged to speak not only about the words on the card, but to talk about things the words reminded them of — they decided what was important to discuss, not the interviewer.

Holding the cards also gave participants a prompt to refer to as they talked about issues. Placing the cards in ‘Do’ or ‘Don’t’ box focused their attention and gave them a physical way — an action — to express their thinking. It was interesting that some participants wanted to place the talk-about cards in order and they took care to balance some cards between the ‘Do’ and ‘Don’t’ boxes. Several participants said they wished they could spend hours ordering the importance sequence of their talk-about cards and discussing their realisations with me. Some participants expressed relief when they held cards and remarked how comforting it was to learn that others have had these difficulties too — they had not been imagining things — they were not alone, they were not mad.

The talk-about cards were also of value when participants were taking too long dwelling on a specific issue. I would comment on how many cards we yet had to look at. This did not infer I was not interested in what they had to say and allowed me to remind them that the purpose of the interview was to find the Keys. The talk-about cards provided a nonconfrontational way to move the participant along.

I had been concerned that participants who completed the Reflection Kit and then had an interview would be bored, but this was not a problem. Some participants said they had forgotten what they had written on the Reflection Kit by the time they came to the interview; others said that revisiting the material at the interview was not boring; other participants greatly valued the opportunity to add to what they had written. Providing the participants with a copy of their comments would have been of value for further reflection. Some participants valued ‘Some further thoughts’ sheets as it allowed them to record further insights.

*Keys to the ABI Cage* was also introduced to several groups of professionals during presentations at national and international conferences and workshops and the reaction of these participants was most positive. However, feedback from one presentation to rehabilitation professionals clearly indicated that they were surprised that this was how people with ABI felt! I had assumed that professionals would be aware of many of the factors shown through *Keys to the ABI Cage*.
9.4.2 Weaknesses of Keys to the ABI Cage

The logistics of packing up, moving and setting up the Keys to the ABI Cage was not easy, but the reaction by participants made the effort most worthwhile. Because of the bulk and large size of the cage (66 cm wide by 100 cm tall, the pole was 150 cm tall — refer to Chapter 2) it was not possible to take it into cafes or libraries for interview purposes. Participants were shown the set up Cage in a car park or on the pavement. This problem has been addressed by purchasing a smaller cage (25 cm wide by 66 cm tall) that fits into a suitcase. This cage accompanied me to the Brain Injury Congresses in Washington and Auckland.

A poster has been made of Keys to the ABI Cage which could be another method to use the tool.

9.4.3 Possible Uses for Keys to the ABI Cage

As reported above, an ABI Cage could be a useful learning tool at ABI groups or rehabilitation hospitals. There is no doubt that a freestanding cage creates a lot of interest, but an alternative could be a large poster with a picture of the Cage with an associated kit containing talk-about cards. However, the tactile experience would be lost in doing so.

As part of the learning resource Keys to the ABI Cage could include a discussion starter for ABI groups, a learning tool for people with ABI and carers, a tool with sheets for personal reflection.

Keys to the ABI Cage could be trialled as a useful tool to make sure the people with ABI/family carers/professionals were ‘on the same page’ — were aware of the major problems the person was dealing with.

Keys to the ABI Cage could be a useful tool to introduce health science students to ABI as well as professionals.

9.4.4 Keys to the ABI Cage Reflection Kit Digital Storage Disk and Fill-in Sheets

The digital storage disk and ‘What ABI means to me’ sheets proved to be a useful way to gain reflective, thoughtful information from people with ABI. It has particular relevance for people in rural areas. Some participants spent considerable time writing on the sheets and sending more information, while others only wrote a few words. The digital storage disk and sheets were a suitable way for people with ABI to reflect on their experience in a guided way taking as much time as required.
Several participants had difficulties with computer skills (even though they had indicated during the phone call that they had and could use a computer and insert a digital storage disk). Some participants had old second-hand computers that did not have the PowerPoint® program. This demonstrated that the Reflection Kit is not the most suitable method for all people with ABI. Because of computer difficulties, 5 of the 26 people with ABI who completed the Reflection Kit did so at computers accessed at ABI support groups. The presentation was set up and the participants were shown how to move through the PowerPoint® program, and then they worked through the presentation and ‘What ABI means to me’ sheets. Three participants could not write and needed scribes to record their thoughts.

People with ABI who had speech difficulties preferred the digital storage disk to the interview as they could take their time thinking and coming back to the sheets on several occasions or to add more information.

9.4.5 Some Comments from Participants with ABI About Keys to the ABI Cage

All participants with ABI had circled ‘Yes’ on the Feedback Sheet to three questions: (1) When you received this digital storage disk (or came to this interview) did you want to understand more about your ABI? (2) Did Keys to the ABI Cage help you think things through and understand more about your ABI? (3) Was Keys to the ABI Cage an interesting way to do this? Some comments were:

If I’d had the CD (Keys to the Brain Injury Cage) earlier on it would have helped me to understand that I wasn’t going mad. And it certainly would have given me another way of approaching things too. Perhaps then I could have asked more questions. Because if I knew that was the situation, then I could relate that to other areas. It would have helped me tracking my progress/achievements.

I thought this was a helpful way to do the questions and it prompted my thoughts as I was reading the cards.

I’m still walking round dragging my cage but I can see I’m getting somewhere.

The talk-about cards brings back a lot.

I love the Cage, it’s a very beautiful cage, I want it, I want the whole thing, I love it.

I feel locked up inside the ABI Cage.
9.4.6 Some Comments About the ‘ABI Cage’ from Mothers and Wives of People with ABI:

It sets things out, it’s very interesting once you start realising it’s a tool for reflection.

I think the CD would be terrifically helpful for my son.

Something like this earlier on would have helped him come to terms with ABI because it’s in user friendly language and not in medical terms.

Viewing the Cage and cards:

... I was just thinking that he has done a lot — when you’re there every day you don’t notice things (holding a stack of cards) — this is what he’s achieved so far.

9.4.7 Some Comments About the ‘ABI Cage’ from Professionals:

The leader of an ABI support group reflected that ‘It was fantastic...and I think it really resonated with every person in this room, who really got it. It’s perceptions that change once you’ve got a metaphor’, Other reflections from the group of professionals included:

...The talk-about cards led to discussions and realisations.

Oh, they were very interested. I suppose the major thing was because you’ve been a teacher as well, you come at it with not an emotional view that probably someone, very emotionally overwhelmed by what they feel would get upset. You come at it from a humorous point of view of putting out all that information. A lot of the information was familiar but I think a key was seeing the talk about cards in the cage, and that feeling of being. Because I don’t have a brain injury, so I don’t have that same perception, but that gives me something to always be talking about now, the keys, looking for the keys.

C: Has this been positive?
B: Fantastic, yes.
C: What can I do to improve it?
B: I would say, keep it as it is, it’s just beautiful.

... your cage is a wonderful example of feeling they are locked in and trapped in that cage and there is actually no way forward or out. I think you’re right, I think human beings generally do have the ability to um to find a way forward um against all odds, that’s what people with ABI tell you it was against all odds without someone particularly helping us.

C: I was interesting that acknowledging my problems seemed to validate things for the PWABI in the group.
B: Absolutely. And I think every one of them, as I watched, thought ‘That’s me’. So everyone felt like they were in the centre here, as part of all of this, which was really lovely.
With visual cues and card cues—I think if you have issues with your memory centre anything that helps you remember things surely must be a good thing.

### 9.5 Information to Inform a Learning Resource:

Another aim of the study was to obtain data to inform the creation of a learning resource to assist people to help themselves to make progress so they learn to feel and fare better; to help people who care for them to understand so they can better support their family member; and for health science students/professionals to more easily understand the phenomenon of ABI so they can better aid their clients.

This aim has been achieved by finding a plethora of issues to unpack and explain in the learning resource. Ways to make the information of benefit to people with ABI was constantly considered throughout each stage of this study and information obtained will be made available in a book, to be published by Australian Academic Press; a Learning resource kit including a poster of ‘The ABI Cage’, talk-about cards, and a digital storage disk, and a web site.

It has been shown that body-subject research around coping, quality of life and wellbeing, did not appear to be translated for ABI support web sites to the same extent as the body-object research. Narratives in books and web sites offered more positive insights into living with ABI. This constructive information will be synthesised and translated, then reported in the learning resource and to ABI support web sites to be read by people with ABI, and their families.

### 9.6 The Need for More Information Was Identified by All Participants

Participants with ABI said they needed to be given information from health professionals presented in a way that they could understand their condition in nonmedical language.

Participants with ABI identified information about ABI that would have been of benefit.

They wanted information for family and friends (in nonmedical language) so that they would understand. They also wanted the general public to understand more about brain injury (suggested an advertising campaign) and information for police, sporting clubs and schools.
Specific areas these participants identified included: better information during the initial weeks in hospital — ‘where I was/why people were doing horrible things to me/how this had happened’, brain injury and suicide risks, and resulting health problems. Also identified were ways to track their progress and achievements, help with contacting people who previously had ABI, positive stories of others with ABI, information about Centrelink (government support agency), ‘take home’ information to refer it when they left rehabilitation.

My therapists in X, they would go through those sorts of things with me. But it sort of decreased and decreased and decreased, til it got to the stage where when I was released from there, I ended up with nothing. No idea, no information, no nothing, I had to find it out myself, and I’m still struggling to do that.

People who care for and support people with ABI want information they can understand in layman’s terms because medical terms are like another language. One participant, whose son has ABI said that when they see a professional ‘I write it down in English, in our terms’. Carers did not know what they were meant to do and felt thrown in the deep end, and were often informed ‘this is as good as he’s going to get’.

Professionals identified the need for information that people could understand as evidenced in their comments such as: ‘Medical jargon is actually useless... what it means for life it’s actually quite useless information to families — education is much broader than just information’. Some clients could not ‘hear’ the information as they were not ‘in the space’ where they could hear it. But one professional said that the ‘information you give, depends on the level of brain damage — some people I think you could confront with information others would not understand’.

We have been tutored into thinking in the modern day age that information is central. The findings of this study indicate that, while important, the unspoken by-product of a society that values pragmatic and utilitarian processes is the creation of a blind spot of major proportions. It is in the realm of hope, of trust, of love and of finding a meaning to life that the major gains are to be found — this should be a central part of any information resource. It is at the heart of the life of each person on this earth.

9.7 Summary

ABI damages not only the person’s brain, body and beliefs it also damages their hope, honour and trust, and their security and safety. This study has identified that from the insider’s perspective the loss of hope, honour and trust, and security and safety profoundly affected the
goodness of their life. Lack of understanding affected the way they saw themselves and the contact they had with people (their hope and honour). ALL participants said there was a need for information (in non-medical language) so that people could understand ABI. Further sensitive research is needed to determine additional ways these issues could be addressed, the time and place information could be given, and ways rehabilitation and brain injury support organisations could address these issues.

The triangulation of gathered data demonstrated that although many of the physical and cognitive difficulties of people with ABI were identified by outsiders — family members and professionals — the importance of hope, honour and trust (fear and shame) was not generally recognised by outsiders. People with ABI, family members and one professional identified the importance of love, hope and purpose while, generally speaking, professionals focused upon ways they could ‘fix’ problems. This indicates, as Brown and Vandergoot (1998) argued, that outsiders, professionals and researchers have the power to decide which factors to focus on, factors they consider most effect the goodness of the ‘insider’s’ quality of life. These people need to be informed of the findings of this study.

This study has shown that acceptance encompasses a plethora of issues including dealing with denial, humiliation, status anxiety, feeling vulnerable, defensive, issues of trust, and unresolved grief. It is clear many people struggle to accept that they have ABI because this can seem like ‘giving up’. But acceptance is a vital step in moving forward as the new me, of accepting that we cannot change the past but we can choose to change the way we tackle the future. Findings identified the importance of hope, love and understanding, thinking and doing normal things, and provide a guide for people with ABI and a checklist for people who care for and support them. Many of these issues could be addressed by professionals. For the professional to demonstrate empathy and kindness and allow clients to retain a sense of hope does not require expensive programs, equipment or medication, but could enhance the goodness of the person’s life. The learning resource will contain information about issues raised by participants that will help people learn about positive things they could do to help themselves.

Using the learning tool Keys to the ABI Cage has demonstrated that just one hour spent reflecting on their experience, with someone who understood, could start the process of the person regaining some hope (they could identify the Keys they used and could use) and honour (holding a handful of difficulty/differences and feelings cards, participants were proud they survived the day-to-day challenge that is ABI). The depth and breadth of information
obtained from participants showed that, over time, they had acquired insight into ABI, but they did not know how to use their insight, they had no framework by which to make sense of their ideas. The metaphor of the cage helped them review their knowledge. This study demonstrates that people with ABI can learn to feel and fare better.

Pete, a participant with ABI, said that he had been denying that he had ABI for seven years. One hour spent with Keys to the ABI Cage showed him that yes, he did have brain injury. Learning and understanding about ABI could be a way for people to find a new meaning and purpose in life, and learn to feel wise.

The study has at least started the process of identifying golden threads that can help to form a safety net to catch, support and encourage people, whose life hangs by a thread, because of ABI.
CHAPTER 10

CONCLUSIONS: FINDING A BALANCE

While modern medicines may occasionally have an almost magical effect on a person’s life, the time has come to move beyond our rather arrogant clockwork model of the brain, within which a clinician has only to isolate some faulty cognitive gear and repair it. We have to begin to think of the brain as a self-organizing ecosystem, one of such staggering complexity and delicate balance that almost any aspect of a patient’s life may be relevant to a diagnosis or essential to treatment. (Ratey, 2001, p. 354)

10.1 Introduction

This study has exposed the staggering complexity and delicate balance of the brain and also of that of the lifeworld of the person with ABI trying to cope with damage to their brain, body and beliefs; their hope, honour and trust, their security and safety. Weighing up the plethora of complicated and complex difficulties participants with ABI experienced in their day-to-day lives, it appeared impossible that anything could balance the scales so that life could be tolerable. However, it was demonstrated that it was possible for some participants with ABI to achieve a balance: that the negative factors of physical, cognitive, emotional differences, difficulties and deficits of ABI could be balanced by the positive influences of hope, love, understanding, learning to work things out for themselves and even small everyday things. The latter were those key things that conferred a meaning and purpose to life that is essential in maintaining a positive stance. Some participants believed that ABI was a really powerful experience that had let them experience unique and valuable things, so that they now had a fresh appreciation of life, they were aware of their strengths and weaknesses and were now a wiser, better person. The implications of these findings can provide a lifeline for people with ABI who are feeling swamped by things that negatively affect their lifeworld.

Although information from this study will be made available in a book, to be published by Australian Academic Press, and a learning resource kit will be developed to include a poster of Keys to the ABI Cage, talk-about cards, a digital storage disk and a web site, further research will be carried out to find ways that the information obtained from this study could be of greatest help with people with ABI.

This study showed that there are many Keys to open the ABI Cage. Hope, love, learning to understand ABI, working things out for themselves and learning to face the facts were identified by participants as factors that helped them learn to feel and fare better. The finding that there were many things the person could do the help themselves needs to be made
available to people with ABI and their family through rehabilitation hospitals and brain injury support organisations.

This study identified an abundance of issues around ABI and education. The tool, *Keys to the ABI Cage*, supported the participants with ABI to share their insight into ABI as they told stories about their experience and identified factors that negatively and positively affected their lifeworld. A conclusion that can be drawn from this study is that although people with ABI may be considered to lack self-awareness, participants demonstrated that by using *Keys to the ABI Cage* they could reflect on their difficulties, differences and feelings and identify keys - factors that could help them learn to feel and fare better in a constructive, positive way.

Moreover, the term ABI itself refers to the brain sustaining injury, but it been shown that the brain is but part of the ‘person’ that requires attention. In many ways, it is itself a misnomer. When we think of a person who is identified as having an ABI we need to be thinking of the broad spectrum of their life and not just about ‘mending’ their brain and the physical losses of ABI. Mending lives is infinitely as complex and equally as important as mending brains and bodies.

### 10.2 Recommendation One: Information So That People Can Learn About ABI

*Information That Can Be Understood in Non-Medical Language*

All participants with ABI, mothers and wives of people with ABI, and professionals stated that people with ABI, their families and the general public and some health professionals do not understand ABI, and that there is a need for information in non-medical language. Lack of understanding about ABI had a negative effect on the lifeworld of most of the participants with ABI. It was disappointing that so many participants had felt that they had gone mad or insane and did not realise the consequences of ABI, in spite of being involved in the medical system. Professionals need to provide the person with ABI and their family information presented in a way that they can understand ABI.

This study has shown that constructivist circumnambulation learning can assist the person with ABI to learn. This finding could assist people with ABI, their family and
professionals to examine ABI in a circular roundabout way. Further research into ways to allow people with ABI to learn about ABI is needed.

**Positive Information**

People with ABI and their families need to have some information about positive things they can do, so they can learn what people with ABI have done to help themselves. A catalogue of coping strategies could be a valuable resource for people with ABI who have forgotten coping strategies they employed prior to their ABI. These will be supplied in the learning resource. Further research is needed to find factors that help people with ABI, and help people with ABI learn about different coping strategies that could help them cope.

Positive information from studies about ways people cope with ABI, ways to improve memory, factors that improve quality of life etc need to be ‘translated’ into everyday language and made available to the person who sustains a brain injury, their family and support organizations.

**An ‘ABI Educator’**

There is a need for an ‘ABI educator’ who would teach the person and their family about brain injury and positive things they can do to help them learn to feel and fare better. This needs further investigation.

10.3 **Recommendation Two: Addressing Factors That Negatively Affect the Life of the Person with ABI**

*To cease putting the 2-or 5-year timeline on ‘recovery from ABI’*

This study provides evidence that people with ABI learn ways to adapt and cope with living with brain injury, year in and year out, so their life improves to some degree as the years pass. It is never ‘as good as it gets’ since things are always changing; a small gain is made here or there, circumstances change, people come and go and so forth. The ‘Two-year rule’ is unhelpful and causes people to lose hope (something they need if they are going to learn to live with ABI).

If there was just one change that could happen from this exhausting and exhaustive study it would be that no one is ever told they will only improve for two or five years.
The words ‘vegetative state’ and ‘plateau’ should not be used, other terms should be employed. The term ‘mild ABI’ does not adequately describe the difficulties a person may encounter, nor that an easy recovery will not necessarily follow, as is the case in most ‘mild’ illnesses. These three terms can have a negative effect on the lifeworld of the person with ABI.

To carefully examine the reason for and benefit of every test/questionnaire given to people with ABI

The comments from participants about the negative impact of being required to complete a battery of tests needs to be considered by professionals. If the person is given a test they should be given the opportunity to have their test result explained to them, along with positive action that will be taken by professionals to address the issue and things they could do to try to overcome the difficulty. This needs to be in clear written form. Further research into the value to the client of doing tests needs to be undertaken.

Studies need to be undertaken to ascertain the value to the client of IQ tests and whether there is a replacement for them. A hypothesis has been formed after interviewing people with ABI that if some of the time taken completing tests was spent learning about ABI, having difficulties explained, being given strategies to address issues, this could positively affect the lifeworld of people with ABI.

10.4 Recommendation Three: Addressing Factors That Positively Affect the Life of the Person with ABI

To focus on the emotional wellbeing of the person with ABI

This study has established that many people with ABI believe they are mad and bad and that they are afraid and ashamed. There is a stigma and humiliation associated with being a person with ABI. The emotional welfare of the person with ABI should be of primary consideration for all contact by professionals, whether in the research, rehabilitation or medical setting.

To address this issue, the curriculum of the health professionals should concentrate on this issue, and professional journals and conference presentations should focus on the importance of ‘humanity’ as a basic value held by the brain injury professional. All professionals involved in this study could identify the physical and cognitive
consequences of ABI, but they were not as focused on how the person with ABI felt as a whole person, not just a focus on the deficits of ABI.

For ethical and humane reasons all professionals working with people with ABI should have a ‘reminder checklist’ to refocus their attention on how the client may feel. The ABI professional needs to show humanity and understanding to their clients. This could enrich and strengthen the rehabilitation experience for clients. Professionals need to have a broader understanding of the consequences of ABI, not just their specific area of expertise. This also requires further investigation.

*To teach people with ABI and their family members of the factors that could increase the emotional wellbeing of their family member with ABI*

This study demonstrated the need of information in everyday language that is discussed with the person and their family, about the range of things that can improve the wellbeing, satisfaction and quality of life for person with ABI, and the importance of learning new things. Family members need to work with professionals in supporting and helping the person understand things they can do to help themselves live with ABI. Constructive information from other people with ABI about attitudes, understandings and emotions that have helped them learn to feel and fare better needs to be provided to the person and their family.

The person with ABI and their family need information about practical everyday things that can help them learn to feel better. This includes the importance of finding an activity that the person loves doing (from knitting and sewing to gardening and playing computer games), the company and companionship of pets, and being able to contribute by helping at home and helping other people with ABI.

Love, hope, understanding and everyday things can help the person with ABI to make progress from a life that is unsatisfactory, when they feel imprisoned in the ABI Cage, to a more satisfactory life, when they have discovered keys to unlock the ABI Cage.

10.4 A Final Few Words

This thesis has provided a new lens through which to view ABI. It has shown that participants with ABI had insight into their difficulties, differences and feelings and the many Keys that opened their ABI Cage. As they reflected they realised that their hope, acceptance and attitude had helped them to learn new ways to help themselves feel and fare better.
This study has shown that educational principles can be applied to empower people with ABI to learn to acquire better insight into ABI.

The power of recovery lies within the injured person…Education is the key. (Freeman, 1998, p. 14)
REFERENCES


246


Cutcliffe, J. and Ramcharan, P. (2002) Levelling the playing field? Exploring the merits of the ethics-as-process approach for judging qualitative research proposals, Qualitative Health Research, 12, 7, p.1000-1010


Kaplan (1999)


Moulton, G., & Van der Loo, J. (1986). My friend Lucy. Canada: Scholastic TAB.


Webster, B. J. *Lost & found: Caps, sunglasses, and earplugs*. Youngsville, NC: Lash & Associates.


282