
Perceptions and Expectations of Rehabilitation and Recovery Following Acquired Brain Injury

Rosemary Gravell

Department of Human Communication Sciences

University of Sheffield

Submitted for the award of PhD

February 2015

Contents

Abstract	19
Acknowledgements	21
List of Tables	23
List of Figures	24
Chapter One : Introduction	
<u>1.1 Introduction: Identifying the research question</u>	25
<u>1.2 Research Aims and Objectives</u>	26
<u>1.3 Thesis Structure</u>	26
1.3.1 Stylistic conventions	27
<u>1.4 Definitions and Context</u>	28
1.4.1 Acquired Brain Injury (ABI)	28
1.4.1.1 <i>Stroke</i>	29
1.4.1.2 <i>Traumatic brain injury</i>	29
1.4.2 Rehabilitation and The Care pathway	30
1.4.3 The Research Context	31
<u>1.5 Literature Review</u>	32
1.5.1 Rationale	32
1.5.2 Search strategy	33
1.5.3 Perceptions, meaning and experience of people following ABI	34

1.5.3.1 <i>Stroke</i>	34
1.5.3.2 <i>TBI</i>	35
1.5.3.3 <i>Communication Impairment studies</i>	36
1.5.3.4 <i>Summary</i>	36
1.5.4 Stage in the pathway	37
1.5.4.1 <i>Summary</i>	38
1.5.5 Prospective studies of expectations of rehabilitation and recovery	38
1.5.5.1 <i>Perceptions of rehabilitation</i>	38
1.5.5.2 <i>Perceptions of recovery</i>	39
1.5.5.3 <i>Expectations</i>	39
1.5.5.4 <i>Summary</i>	41
<u>1.6 Chapter Summary</u>	41

Chapter Two : Research Design

<u>2.1 Introduction</u>	43
<u>2.2 Ontological and Epistemological Considerations</u>	43
<u>2.3 Methodological Considerations</u>	43
2.3.1 Methodology : Choosing a qualitative approach	46
2.3.2 Methodology : Choosing Grounded Theory	47
<u>2.4 Method</u>	50
2.4.1 Method : Sampling in Qualitative Research	51
2.4.1.1 <i>Principles and pitfalls in Qualitative sampling</i>	53

2.4.1.2 <i>Sampling in Grounded Theory</i>	55
2.4.2 Method : Data Collection Techniques	56
2.4.2.1 <i>Interviews in Qualitative Research</i>	56
<u><i>Epistemology and Methodology</i></u>	57
<u><i>Collaborative construction of meaning</i></u>	58
<u><i>Type of interview</i></u>	58
<u><i>Interview Schedule</i></u>	59
<u><i>Analysing Type of question</i></u>	60
<u><i>Analysing Interviewer's Responses and Technique</i></u>	61
<u><i>Summary</i></u>	62
2.4.3 Method : Data analysis in Grounded Theory	62
2.5 <u>Reflexivity</u>	63
2.6 <u>Judging the Quality of qualitative research</u>	65
2.7 <u>Ethical Issues in Acquired Brain Injury Research</u>	67
2.7.1 Obtaining informed consent in health research	67
2.7.2 Consent and People with Aphasia	69
2.7.3 Consent and Cognitive Impairment	71
2.7.4 Proxy Consent and use of Surrogates	71
2.8 <u>Chapter Summary</u>	72
Chapter Three: Research Design	
3.1 <u>Introduction</u>	73

3.1.1 Aims	73
3.1.2 Ethics	74
3.1.2 The Context of the Research	74
<u>3.2 Reflexivity</u>	74
3.2.1 Epistemological and methodological	75
3.2.2 Personal characteristics	75
3.2.3 Researcher behaviours	76
<u>3.3 Sampling Strategy</u>	77
3.3.1 Sample selection	77
3.3.2 Sample size	80
3.3.3 Recruitment Procedure/Process	80
<u>3.4 Adapting Consent Forms and Information Provision</u>	81
3.4.1 Content and Design	81
3.4.2 Presentation of information	83
3.4.3 Verification of understanding	83
<u>3.5 Data Collection</u>	83
3.5.1 Interviews and Transcription	83
3.5.2 Exploratory Phase	85
3.5.3 Interview Content	85
<u>3.6 Data Analysis</u>	86
3.6.1 Coding	86
3.6.1.1 Initial Coding	87

3.6.1.2 <i>Tentative categories/Focused Coding</i>	88
3.6.1.3 <i>Theoretical coding</i>	90
3.6.1.4 <i>Modelling</i>	91
3.6.2 Analysis Reliability	92
<u>3.7 Chapter summary</u>	92

Chapter Four: Findings

<u>4.1 Introduction</u>	94
<u>4.2 Participant Characteristics</u>	94
<u>4.3 Analysis : Categories and Sub-categories</u>	98
4.4 HOPING-DESPAIRING SPECTRUM	101
4.4.1 <i>One hundred percent – Hoping and expecting</i>	101
4.4.2 <i>My mojo’s not coming back – Doubting</i>	102
4.4.3 <i>I’m trying to keep them at bay – Hiding the doubts</i>	104
4.4.4 <i>I just want to lie down and die - Despairing</i>	104
4.5 MAKING SENSE OF WHAT HAS HAPPENED	105
4.5.1 <i>Pre-morbid beliefs/knowledge</i>	105
4.5.1.1 <i>I wish I’d been more understanding</i>	105
4.5.1.2 <i>You really don’t pay attention</i>	106
<i>Family experiences</i>	106
<i>Severity of brain injury</i>	107
<i>Media knowledge</i>	107

<i>Links to other conditions</i>	107
<i>Knowledge of rehabilitation</i>	107
4.5.2 <i>Life context</i>	108
4.5.2.1 <i>A Double Whammy</i>	108
<i>Life stage</i>	109
<i>Employment</i>	109
<i>Finances</i>	109
<i>Home life</i>	109
<i>External factors</i>	109
4.5.3 <i>What's going on? Post-morbid questioning</i>	110
4.5.3.1 <i>It just came out of the blue</i>	110
4.5.3.2 <i>What's all the fuss about</i>	110
4.5.3.3 <i>I was on another wavelength or planet</i>	111
4.5.3.4 <i>I'd love to know why, so I don't get it again</i>	112
4.6 MOVING FORWARD	113
4.6.1 Perception of Progress	113
4.6.1.1 <i>I say time....time.....</i>	113
4.6.1.2 <i>My first miracle</i>	114
4.6.2 Beginning to adapt	115
4.6.2.1 <i>It's just not coming</i>	115
4.6.2.2 <i>If I started to cry I didn't think I could stop</i>	115
4.6.2.3 <i>Making adaptations</i>	116

4.6.3	Recognising positives	117
4.6.3.1	<u><i>I'm over the moon</i></u>	117
4.7	WHAT CAN I DO?	118
4.7.1	<i>Being the same but not the same</i>	118
4.7.1.1	<i>I'm the same person - but I'm not</i>	118
	<i>Helpful qualities</i>	119
	<i>Past-Present Self</i>	120
4.7.1.2	<i>I'm so glad I wasn't like that</i>	120
4.7.1.3	<i>What no blood? - Feeling judged</i>	121
	<i>Visible changes</i>	121
	<i>Hidden changes</i>	121
	<i>Hiding problems</i>	122
	<i>Being too good</i>	122
4.7.1.4	<i>I've caused so much stress to everybody</i>	123
4.7.2	<i>Taking stock</i>	124
4.7.3	<i>Doing What I can</i>	125
4.7.3.1	<i>I am the director</i>	125
	<i>Taking control</i>	126
4.7.3.2	<i>Nobody's going to do it for me</i>	126
	<i>Self-motivation</i>	127
4.7.3.3	<i>I'm up for the challenge</i>	127
4.8	TRUSTING/DOUBTING OTHERS	128

4.8.1	<i>Early Experiences</i>	128
4.8.1.1	<i>I just wanted to get out of there</i>	129
	<i>Information</i>	130
	<i>Predictions of recovery time</i>	130
	<i>Information about conditions</i>	131
	<i>Transfers</i>	131
	<i>Other patients</i>	131
	<i>Assumptions</i>	132
	<i>Communication</i>	132
4.8.1.2	<i>Rehabilitation experiences</i>	132
	<i>Being Heard</i>	133
4.8.1.3	<i>A Stepping Stone</i>	134
	<i>Not knowing what to expect</i>	134
	<i>Information about specialist help</i>	135
4.8.2	<i>Experiences and Expectations of Family Support</i>	135
4.8.2.1	<i>To do their best. To do their best</i>	135
	<i>Practical help</i>	136
	<i>Emotional support</i>	136
4.8.3	<i>Expectations of services: expertise</i>	137
4.8.3.1	<i>I was expecting someone the next day, but....</i>	138
4.8.3.2	<i>There's no shame in it</i>	138
	<i>Roles and responsibilities</i>	139

<i>Specialist help</i>	139
4.8.3.3 <i>Guidance is the word</i>	140
4.8.3.4 <i>If they wanted me to</i>	141
4.8.3.5 <i>I wish I'd known that a bit sooner</i>	141
4.8.3.6 <i>I've got to trust</i>	142
4.8.4 <i>Expectations of services: Therapeutic alliance</i>	143
4.8.4.1 <i>She said it didn't matter</i>	143
4.8.4.2 <i>I needed to talk to someone</i>	144
4.8.4.3 <i>I just needed someone to care</i>	145
4.8.4.4 <i>Look I'm not stupid</i>	145
4.8.4.5 <i>You're doing really well</i>	146
4.8.5 <i>Expectations of services: family support</i>	146
4.8.5.1 <i>She's got it 24 hours a day</i>	146
4.9 ACCEPTING	147
4.9.1 <i>No delusions of recovery</i>	147
4.10 <u>Chapter summary</u>	148

Chapter Five: Evolution of the Model

<u>5.1 Introduction</u>	149
<u>5.2 Exploratory Phase Model</u>	149
<u>5.3 Model based on participants 1-10</u>	153
<u>5.4 Participants 1-15</u>	156

<u>5.5 Chronological Model Participants 1-17</u>	159
<u>5.6 Efficacy Model Participants 1-17</u>	160
<u>5.7 Engagement Model</u>	163
<u>5.8 Implications for rehabilitation</u>	166
<u>5.9 Chapter summary</u>	167

Chapter Six: Hope

<u>6.1 Introduction</u>	169
<u>6.2 Hope: A review of relevant literature</u>	170
6.2.1 What is hope?	170
6.2.1.1 <i>Associated terminology</i>	170
<i>Hope, expectation or wish?</i>	171
<i>Hope or optimism</i>	171
6.2.1.2 <i>Models of Hope</i>	172
6.2.1.3 <i>Hope and despair</i>	173
<i>Despair or Depression</i>	174
6.2.2 The experience and importance of hope	175
6.2.2.1 <i>Hope as a Coping Strategy</i>	177
6.2.3 What contributes to hope and despair?	178
6.2.3.1 <i>Personality</i>	179
6.2.3.2 <i>Meaning and Self</i>	180
6.2.3.3 <i>Psychological factors</i>	180

<u>6.3 Beliefs and Hope</u>	180
6.3.1 Belief in progress/recovery	181
6.3.1.1 <i>Perceived progress</i>	181
6.3.1.2 <i>Time</i>	181
6.3.1.3 <i>Stage in the care pathway</i>	182
6.3.1.4 <i>Information</i>	182
6.3.2 Self-efficacy	183
6.3.3 Belief in Others	185
6.3.3.1 <i>The attitudes and beliefs of Therapists</i>	185
<i>False Hope</i>	187
6.3.3.2 <i>The Therapeutic Relationship</i>	188
6.3.3.3 <i>Relationships outside rehabilitation</i>	189
6.3.4 Combining Beliefs in self and others: The Tripartite Efficacy Model	190
<u>6.4 Chapter summary</u>	191

Chapter Seven: The views of clinicians

<u>7.1 Introduction</u>	193
7.1.1 Ethics	193
7.1.2 Context	193
<u>7.2 Review of Literature</u>	194
7.2.1 Philosophical differences	194
7.2.2 Judgements and motivation	195

7.2.3	Goal setting	195
7.2.4	Pressures on staff	196
7.2.5	Hope	197
7.2.6	Summary	197
<u>7.3</u>	<u>Methodology and Method</u>	197
7.3.1	Focus Groups: Background	198
7.3.2	Sampling and recruitment	199
7.3.3	Data collection and analysis	200
7.3.4	Reflexivity	200
<u>7.4</u>	<u>Participant Characteristics</u>	201
7.4.1	Staff focus group	201
7.4.2	Additional comments	203
7.4.3	Overall: Characteristics of participants included in analysis	203
<u>7.5</u>	<u>Findings</u>	204
7.5.1	Factors affecting recovery	205
7.5.1.1	<i>Brain injury factors</i>	205
7.5.1.2	<i>Pre-morbid factors</i>	205
7.5.1.3	<i>Client's Personal resources</i>	206
7.5.1.4	<i>Beliefs about rehabilitation efficacy</i>	208
7.5.2	Expectations in rehabilitation	208
7.5.2.1	<i>Expectations of rehabilitation services</i>	208
	<i>Timeliness</i>	208

<i>Quality and quantity</i>	208
<i>Bespoke services</i>	208
<i>Therapeutic Relationship</i>	209
<i>Expertise/specialism</i>	209
<i>Information provision</i>	209
7.5.2.2 <i>Expectations of clients</i>	210
7.5.2.3 <i>Expectations of others</i>	210
7.5.3 Beliefs about discharge	211
7.5.3.1 <i>Reasons not to discharge</i>	211
7.5.3.2 <i>Long Term Care</i>	212
<u>7.6 Comparison of staff and client beliefs/expectations</u>	212
7.6.1 Factors affecting recovery	213
7.6.2 Expectations in rehabilitation	214
<u>7.7 Discussion and Therapeutic Implications</u>	216
7.7.1 Recovery	216
7.7.2 Rehabilitation	218
<u>7.8 Chapter summary</u>	219
Chapter Eight : Discussion	
<u>8.1 Introduction</u>	220
<u>8.2 Revisiting the models: Interview data</u>	221
<u>8.3 Engagement</u>	223

8.3.1	What is engagement?	223
8.3.2	Associated concepts	225
8.3.2.1	<i>Engagement and motivation</i>	225
8.3.2.2	<i>Readiness to engage</i>	225
8.3.3	Barriers to engagement	226
8.3.4	What contributes to engagement?	227
8.3.4.1	<i>Belief in recovery</i>	228
8.3.4.2	<i>Belief in Self/Personal factors</i>	228
8.3.4.3	<i>Belief in Others/Rehabilitation factors</i>	230
8.4	<u>Linking Hope and engagement</u>	232
8.5	<u>Revisiting the model: Incorporating the literature</u>	234
8.5.1	Implications of the Revised Engagement Model	234
8.5.2	Case Studies	236
8.5.2.1	<i>Group A: Hoping and ready to engage (Simon)</i>	236
8.5.2.2	<i>Group B: Doubting but ready to engage (Andrew)</i>	237
8.5.2.3	<i>Group B: Accepting and ready to engage (Harry)</i>	238
8.5.2.4	<i>Group C: Hoping but not ready to engage (Shirley)</i>	240
8.5.2.5	<i>Group D: Despairing and not ready to engage (Billie)</i>	241
8.5.2.6	<i>Summary of case studies</i>	243
8.6	<u>Revisiting the model: staff view</u>	243
8.6.1	Expectations within rehabilitation	243
8.6.2	Expectations of recovery	245

<u>8.7 Implications for clinical practice</u>	246
8.7.1 The Philosophy of rehabilitation	246
8.7.2 Therapy Factors	247
8.7.3 Clinical implications/Hope	248
8.7.4 Clinical implications/Readiness to Engage	250
8.7.5 Applying the research findings: a summary of therapeutic implications	252
<u>8.8 Chapter Summary</u>	254

Chapter Nine: Conclusion

<u>9.1 Introduction</u>	255
<u>9.2 Clinical implications</u>	255
<u>9.3 Limitations of the study</u>	258
<u>9.4 Quality Evaluation</u>	259
9.4.1 <i>Statement of research aims</i>	260
9.4.2 <i>Qualitative methodology</i>	260
9.4.3 <i>Matching design to aims</i>	260
9.4.4 <i>Recruitment strategy</i>	260
9.4.5 <i>Data collection</i>	260
9.4.6 <i>Reflexivity</i>	261
9.4.7 <i>Ethical issues</i>	261
9.4.8 <i>Data analysis</i>	262
9.4.9 <i>Statement of findings</i>	262

9.4.10 <i>Research value</i>	263
<u>9.5 Future Research</u>	263
9.5.1 Transferability	263
9.5.2 Evaluation of the model	264
9.5.3 Evaluation of clinical recommendations/implications	265
9.5.4 Time in long term recovery	265
9.5.5 Expectations of carers/families	265
<u>9.6 Summary</u>	265
References	267
Appendices	
List of Appendices	304
Appendix 1 – Ethical Approval Documents	305
Appendix 2 – Information sheets, questionnaires and consent forms	309
A2.1 Standard information sheet	309
A2.2 Standard Questionnaire	313
A2.3 Standard Consent Form	315
A2.4 Adapted information sheet	317
A2.5 Adapted Questionnaire	324
A2.6 Adapted Consent Form	326
Appendix 3 – Interview	328

A3.1 Interview schedule	328
A3.2 Exploratory Phase Interview reflections	329
Appendix 4 – Sample research diary pages	334
Appendix 5 – Transcript and analysis example	336
A5.1 Sample Line by line analysis (Shirley)	336
A5.2 Categories (Shirley)	349
Appendix 6 – Comparison analysis example	367
Appendix 7 – Sample Memos	377
A7:1 Memo: Shirley	377
A7:2 Memo: Expectations of Recovery	380
A7:3 Memo: Expectations of Rehabilitation	384
Appendix 8 – Focus Group information sheet and consent forms	387
A8.1 Information sheet	387
A8.2 Consent Form	390
Appendix 9 – Focus Group Questions	391

Abstract

It is widely acknowledged within rehabilitation services for people with Acquired Brain Injury, that there is considerable variation in the degree of engagement, and that this has the potential to affect outcomes. While it is recognised that subjective beliefs are an important factor in engagement, little is known about how clients perceive their experience, what expectations they have in relation to recovery and rehabilitation, and how their perceptions impact on engagement with rehabilitation.

This research aimed to explore clients' perspectives and increase knowledge of clients' expectations of recovery and rehabilitation, prior to beginning community based rehabilitation; and to develop a theoretical explanation, upon which improvements in service delivery and practice can be based.

The research aims were explored through a qualitative methodology, using a symbolic interactionist theoretical perspective to grounded theory, to facilitate the process of theory generation (Glaser & Strauss 1967, Charmaz 2006). Twenty-one people were interviewed prior to being seen by community rehabilitation services, including people with communication and cognitive impairments

The central theme that emerged was hoping-despairing, with five further main categories: making sense of what has happened, moving forward, what can I do?, trusting/doubting others, and accepting. An explanatory framework was developed and a model was proposed, by which belief in self/others and belief in recovery interact to generate hope and readiness to engage.

A focus group consisting of specialist rehabilitation therapists was conducted, to compare the expectations of clients and therapists.

The findings suggest that expectations and beliefs at this stage in the rehabilitation pathway influence the degree of engagement with rehabilitation services, and that this has implications for clinical intervention. While the context of qualitative research is critical in interpreting findings, it is felt that there are wide implications for ABI services and other areas of health care.

Acknowledgments

Most of all I want to acknowledge my gratitude to the twenty-one people, and their families, who gave of their time and energy, and welcomed me into their homes, to enable this research to take place. They did this in the hope that their contribution might lead to improvements in clinical rehabilitation in the future, and with no expectation of personal gain and at a traumatic period in their lives.

I would like to thank my supervisors – Professor Shelagh Brumfitt and Dr Richard Body, for their time, expertise and encouragement. I am proud to be able to claim that I am Shelagh's first and last student, as she was my under-graduate tutor in her first year at the University of Sheffield, and retired as this research was nearing completion.

My colleagues, in the ABI service which was the context for this research, have been encouraging and supportive throughout, and I am especially grateful for their involvement in the focus group. In particular I want to thank the two Rehabilitation Team Coordinators – Nicole Cocksedge and Julie O'Brien – who referred clients to the study, and to the Clinical Administrator, Sandra Blyth.

My thanks also go to Dr Kate Fryer, who provided a second opinion on my data analysis; to Dr Carole Pound for her advice; and to Frances Ludlow, the Librarian who gave of her time to teach an old dog some new tricks.

My family and friends have encouraged me throughout the experience. My husband, Oliver, and my four sons, Benedict, Archie, Hugo and Oscar, have probably been bored rigid by my constant concerns and worries, but have – to a man – tried not to show it! The process has led to some interesting discussions on grammatical pedantry and the work ethic needed to study.

I would like to dedicate this thesis to the many clients who have attended the rehabilitation centre in which I work, as a Speech and Language Therapist and as a Counsellor, and those who will come to us in the future. I hope that this research will in some small way contribute to improving services, engaging people and families more effectively, and raising the quality of life for those who face the life-long trauma of Acquired Brain Injury.

This research has convinced me that it is crucial to support our clients in retaining hope. While writing this thesis I came across two very different quotations which seem relevant:

'Whatever semantics we favour, we mustn't stop hoping. Because without hope in this world we are nothing, the whole lot of us. Fears of disappointment, failure and death exist for everyone. But we shouldn't give them too much sway. So gun the tank, or proceed calmly. But don't stop hoping.' Melanie Reid; The Times Magazine

*'Take a longshot if that's all there is,
And put it in a very safe place,
Where your doubt can't get to it,
Cos once you're certain that all hope is gone,
A longshot is better than none.'* Megson; The Longshot

List of Tables

- 3:1 Initial Line by Line Coding
- 3:2 Focused Coding
- 3:3 Focused Coding across Transcripts
- 3:4 Theoretical Coding
- 4:1 Characteristics of people refusing to participate
- 4:2 Characteristics of Participants
- 4:3 Categories
- 7:1 Focus Group by Role
- 7:2 Focus Group by Professional Background
- 7:3 Additional Comments by Discipline
- 7:4 Overall Number of Comments by Discipline
- 7:5 Overall Number of Comments by Role
- 7:6 Categories
- 7:7a Comparison of Clinician/Client Expectations about Recovery
- 7:7b Comparison of Clinician/Client Expectations about Rehabilitation
- 8:1 Shared Factors Influencing Hope and Engagement

List of Figures

- 3:1 Sampling Framework
- 5:1a Exploratory Phase Model (1)
- 5:1b Exploratory Phase Model (2)
- 5:2 Main and Exploratory Study Model: Participants 1-10
- 5:3a Participants 1-15
- 5:3b Expectations of Rehabilitation/Self/Others
- 5:4 Chronological Model: Participants 1-17
- 5:5 Efficacy Model: Participants 1-17
- 5:6a Engagement Model
- 5:6b Engagement Model (2)
- 8:1 Data Collection Stages
- 8:2 Engagement Model
- 8:3 Revised Engagement Model (2)
- 9:1 Revised Engagement Model (2)

Chapter One : Introduction

1.1 Introduction: Identifying the research question

In 2010, I was asked to see Mary, a 40 year old woman who had had a stroke. She lived with her family in the community, and attended appointments at the rehabilitation centre, but the interdisciplinary team working with her reported that she did not follow through any advice or home programmes. Her motivation was questioned repeatedly, and discharge was discussed as she appeared not to respond to any of the offered intervention, despite having the necessary cognitive and physical skills. While she seemed low, she was not thought to be clinically depressed. In my dual role in the team as Speech and Language Therapist and Counsellor, I had the opportunity to talk to her about her motivation and explore her perception of her situation.

Mary believed, absolutely, that if you had one stroke you would have another, and that it would be more severe and possibly fatal. This would happen within five years. By the time she attended the rehabilitation centre, she was resigned to this, and did not question it.

This thesis is the direct result of that interview. It led me to reflect on the beliefs that people have before they enter community rehabilitation services, and how these perceptions might impact on the process of rehabilitation. As a clinician, how many assumptions was I making about the beliefs my clients held about their situation and what their expectations were of recovery and of rehabilitation? If clinicians had a better understanding of the client's starting point, could we improve both the experience of rehabilitation and outcomes for our clients?

The resultant research, described and evaluated in this thesis, is clinical in its focus. Vivar et al., (2007) consider the starting point of research as identifying the topic of interest and what has already been studied in that area, and considering how the proposal would contribute to knowledge in the field. These questions lead on to identifying the most appropriate design and model by which to interpret the data. Sensitising concepts and general disciplinary perspectives 'provide a place to *start*, not to *end*' (Charmaz 2006, p17).

The topic of interest in this study arose from the interview described above, but this did not occur in a vacuum. The experience of being part of an interdisciplinary clinical team working with adults who have acquired brain injuries had led, frequently, to observations that the

degree and nature of impairment was not the only factor in peoples' responses to therapy, and that there is considerable variability in engagement with the rehabilitation process. The understandable tendency in busy and underfunded clinical settings to accept that not everyone is motivated, rather than exploring the underlying reasons, often results in early discharge and poor outcomes. This background experience, triggered by the interview with Mary, led to the research question: might the beliefs and expectations people bring to therapy be an important aspect affecting engagement?

The research question developed from this point - could increasing knowledge about the expectations and beliefs people bring to rehabilitation inform clinical decisions, potentially having a positive impact both on engagement and outcomes? An assumption was made that it would be more effective to understand expectations at the beginning of the rehabilitation process, and not to attempt to do so retrospectively, when people were already judged not to be engaged. Knowledge about factors leading to positive engagement would be as important as factors affecting those who do not engage. The exploration of this question would be within a specific service, and the question would therefore be related to post-acute, community based rehabilitation.

1.2 Research aims and objectives

The overall research objective was to improve clinical decision making by developing a framework or model of engagement. The starting point was to learn more about peoples' perceptions and expectations, so the primary research aim was therefore to explore the client's expectations and perspective, and increase knowledge of the client's experience, following discharge from acute services, as he or she prepared to begin a community rehabilitation programme. Developing a theoretical explanation was the second aim, upon which improvements in service delivery and practice could be based.

1.3 Thesis structure

This introductory chapter will set the scene, by defining the context and relevant terminology, and clarifying the stylistic conventions that will be adopted. It will also offer an initial, pre-data collection literature review, as the first step in the process was to establish

whether the research question had already been addressed and therefore whether the research could potentially add usefully to the knowledge base (Vivar et al., 2007).

Chapter two takes the literature review further, by looking at evidence and knowledge which would influence the decisions on appropriate research design. This gives the background and rationale for the specific methodological decisions outlined in chapter three.

Central to the thesis is chapter four, which describes and illustrates the findings of the research study, and chapter five develops this further by explaining the evolution of the model/framework as the study progressed. Chapter six then integrates the model and findings with existing literature.

As the research progressed, and bearing in mind the study objective - to improve clinical decision making, an additional area of importance was recognized – the need to know if clients' expectations and perceptions of recovery and rehabilitation were different from those of clinicians in the field. Chapter seven therefore describes how the views of clinicians were explored and compares the findings to those of the main study. It also incorporates relevant literature comparing the perspectives of clients and clinicians.

Chapter eight is a discussion of the various findings and literature, and of the implications for clinical practice. The concluding chapter then offers a summary and considers quality issues relevant to this research.

The thesis structure adopted reflects the research process followed in answering the initial question, and achieving the research aims. For example, it is clear from the outline structure above that the literature review is not offered as a single discrete chapter, but permeates the process, which fits the methodological choices and research design.

1.3.1 Stylistic conventions

Qualitative research reports vary in the style of presentation more than quantitative reports, which tend to adopt a conventional structure – with a literature review, method, results and discussion – and are written in the third person. In contrast some qualitative researchers choose to present their findings in the first person, reflecting the importance of the researcher in the process.

This thesis will maintain the traditional third person style, apart from those sections which are – in line with qualitative studies – specifically about my reflections as a researcher, and in chapter five which describes the evolution of the model from a personal reflective perspective.

The term clinician is used to refer to members of the multidisciplinary team involved in rehabilitation following Acquired Brain Injury, including speech and language therapists, physiotherapists, occupational Therapists, neuropsychologists, counsellors, social workers and rehabilitation assistants.

1.4 Definitions and context

This research focused on a specific population (Acquired Brain Injury), at a specific point in the care pathway (post-acute and preceding community rehabilitation) and in a specific location (highly specialist community rehabilitation service), so it is important to define and explain the terms used and the context in which it has been undertaken.

1.4.1 Acquired Brain Injury (ABI)

Acquired Brain Injury (ABI) is a term that is difficult to define in terms of scope, as it can be due to a wide range of causes and can lead to impairments and disabilities of varying types and severities. There have been numerous attempts to define the term, depending on the purpose – for example if within health policy or administrative/legislative areas, in studies of prevalence/incidence, or in clinical settings. The National Policy on Services for People with ABI (Australian Dept of Human Services and Health 1994, p.xii) defines it broadly:

Acquired brain injury is injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke. These impairments..... may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.

The inclusion of degenerative conditions reflects the broad nature of this definition, and in practice – and for the purposes of this study – it will be defined as not including brain damage that is developmental or progressive in nature. That is, ABI will refer to injury of sudden onset.

The incidence of ABI is often based on hospital data, and Fortune and Wen (1999) note studies suggesting incidence at between 100 and 270 per 100,000. There are many possible causes, in addition to those listed above, but the most common ones within this study (which reflect the referrals into the service) are stroke and traumatic brain injury.

1.4.1.1 Stroke

A stroke is a brain injury due to a disturbance in the blood supply, as a result of haemorrhage or ischemia. The World Health Organisation (1988, p108) defines it as 'rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin'. Approximately 85% of strokes are ischemic and 15% haemorrhagic (Royal College of Physicians 2012).

The incidence of stroke in England is 178 men and 139 women per 100,000 with higher figures in Scotland (202 and 160 respectively) (Townsend et al., 2012). The same study gives the prevalence of stroke as 2.4% men and 2.2% women in England. The National Stroke Strategy (2007) states that 110,000 people in England have a stroke each year, and there are over 900,000 people living in England who have had a stroke, a third of whom live with moderate or severe disability as a result. There is an increase in incidence with age, and of survivors about two-thirds have some permanent disability (Bronstein 1991)

1.4.1.2 Traumatic brain injury

Traumatic brain injury is defined as 'an injury to the brain caused by trauma of some sort, such as a road traffic accident, a fall or an assault. In clinical terms TBI is a sub-category of acquired brain injury' (Research in Practice for Adults 2007, p 1). In other words it is due to external force, and is classified according to severity, whether due to a closed or penetrating head injury, and according to whether damage is diffuse or focal. The definition includes altered level of consciousness at the time of the incident (Carroll et al., 2004). Incidence is difficult to estimate, and varies with age and gender among other factors. The most common causes in civilian life are road traffic accidents and assault/violence.

The annual incidence of traumatic brain injury is partly difficult to establish because of the wide range of severities and variation in definitions used in studies (Roozenbeek et al., 2013). A meta-analysis of reports from 23 European countries cited hospital admissions due to TBI at 235 per 100,000 population, but there was significant variation depending on criteria used

(Tagliaferri et al., 2006). There were nearly 170,000 admissions to UK hospitals with 'non-superficial' head injury in 2011-12, and between 10,000 and 20,000 severe traumatic brain injuries per year in the UK (National Health Service Health and Social Care information Centre 2012).

1.4.2 Rehabilitation and the care pathway

The care pathway may differ depending on available facilities and provision, but ideally would involve an acute stage of hospitalization with specialist in-patient rehabilitation in a hospital or other residential setting. This stage varies considerably in length, both for service based and client based reasons. On discharge from the acute sector, clients may be referred for community rehabilitation. In practice in the UK, this may take the form of early supported discharge teams; individual community or out-patient appointments with one or more therapeutic disciplines; or specialist interdisciplinary team based intervention.

Rehabilitation may be offered at any stage in the pathway, although in the UK long term support is more likely to be provided through voluntary organisations, such as The Stroke Association or Headway. The stage in the pathway relevant to this study is the post-acute period.

Rehabilitation is 'a reiterative, active, educational, problem solving process focused on a patient's behavior (disability)' (Rosewilliam et al., 2011, p 502). Prigatano (2011) suggests three levels of brain injury rehabilitation – to remediate the underlying impairments, to improve functional outcome (via compensatory strategies and environmental changes), and to find ways to explore the individual's phenomenological state. This third stage would explore the personal experience of impairments and resultant disability, in order to re-establish meaning.

Rehabilitation is not a simple process following ABI. Dowswell et al., (2000, p508) highlight this when they stress the complexity of designing interventions, stating 'recovery from stroke is complex and multi-dimensional. While physical, psychological and social facets of recovery are inter-linked, the exact relationship between these factors is poorly understood.' Anderson (1993, p217) states 'a sound, effective and ethical approach...must lie in awareness of and attention to the experiences, values, priorities and expectations of patients and their carers.' This chimes very much with Prigatano's views (2011).

1.4.3 The research context

The study is based in the context of a community rehabilitation service, for adults who have an acquired brain injury. The service is part of a national charity, and is not part of the NHS, although statutory health services are the primary purchasers of the service. As has been discussed above, within the service Acquired Brain Injury is defined as a non-progressive, acute onset brain injury. Aetiologies include stroke, sub-arachnoid haemorrhage, traumatic injury, encephalitis, anoxic injuries, and abscess.

The service offers highly specialist rehabilitation and to meet referral criteria clients must be over 18 years old, and have complex problems, either encompassing multiple areas of need or a single issue of great complexity. Referrals must be made within six months of discharge from acute services following stroke and within twelve months of discharge from acute services following other brain injuries, including sub-arachnoid haemorrhage. Outside this time scale, clients may be seen but a special case for funding has to be agreed by the local health/social care authorities.

The service is non-residential and clients are seen in the centre, at home or in the community depending on the identified need. The referral system is open – that is referrals can be accepted from any source. Following receipt of the referral, clients are placed on a waiting list until an assessment place is available. At that point the client is screened by the Rehabilitation Team Coordinators. This screening is conducted by telephone, with the client, carer and/or professionals involved, depending on the client's level of ability. If suitable for the service, the client is invited for assessment by the clinical team, and appropriate therapy/management intervention is undertaken. The time scale between screening and assessment is usually 2-3 weeks.

The service operates through an interdisciplinary team, which includes Speech and Language Therapy, Occupational Therapy, Physiotherapy, Neuropsychology, Counselling and Social Work, with Rehabilitation Assistants and a Consultant Neurologist.

Clients must have a GP in the county, which is geographically the eighth largest county in the UK, but has few large towns and is largely rural. The population is approximately 670,000 (Keeble 2011). It has a higher percentage of elderly people than the national average, and fewer of working age. The ethnic mix is limited - in 2011 the population of the county was

more than 89% British white, but this reflects a change from nearly 97% in 2001 (Fenton et al., 2011).

1.5 Literature review

1.5.1 Rationale

The initial literature review in qualitative research is an area of some controversy, in relation to when to engage in it and where to include it in the written report. Dunne (2010) summarises the debate clearly, between those who believe that early engagement with existing literature risks creating preconceptions which may stifle or contaminate theory development, and those who believe it can provide a rationale and context. Charmaz (2006, p165) suggests delaying the literature review can help to avoid importing and imposing pre-conceived ideas on the work, so that the researcher's own ideas can flourish: 'delaying the review encourages you to articulate *your* ideas.'

A pragmatic approach has been adopted in this study. A characteristic of qualitative research is that it is data-led, and therefore there is no clear sense of what may emerge in the data – thus a focused literature review is difficult. However, it is important, at the same time, to ensure that the study has not already been done and that there is a gap in existing knowledge (Chiovitti & Piran 2003). Coffey and Atkinson (1996) indicate the dangers of re-inventing the wheel, as a result of ignorance of the field. Therefore, in order to evaluate whether the proposed research study could potentially add to the knowledge base, an initial literature search was undertaken.

The questions asked of the literature review at this stage were:

- What qualitative studies have been done on the perceptions, meaning and experience of people following Acquired Brain Injury, including those with communication impairments?
- What stage in the pathway has been the focus of the existing literature – acute, post-acute, or longer term?
- To what extent have studies specifically considered – prospectively – expectations of recovery and rehabilitation?

1.5.2 Search strategy

The main databases searched were Medline, Cinahl, Cochrane and Psychinfo, and limited to peer-reviewed journals in the English language. The initial search terms were *qualitative research, recovery, rehabilitation, and expectations*, combined with *ABI, Stroke, and TBI*. No time limitation was placed on the search, but this was considered when reviewing the abstracts. When relevant papers were identified, a further strategy was to hand-search the reference lists. This literature search was undertaken prior to the research *per se* and it should be noted that there have been numerous studies published subsequently, such as Kuluski et al. (2014).

It quickly became apparent that there has been a significant increase in qualitative studies over recent years. There appear to be many more qualitative studies specifically related to the impact and meaning of stroke than other ABI diagnoses and, for this reason, in this initial phase of the literature review, it was decided to consider stroke research separately from other ABI. It was also decided to include a section on the experiences of people with communication impairment, as much of the research into the experience of stroke/ABI excludes people with communication impairment as they are difficult to interview, and the generalizability of some research to this population is therefore doubtful (Townend et al., 2007).

Some studies were identified that specifically addressed perceptions of recovery and rehabilitation, which again was critical in establishing whether this study could offer new insights, and these – although few in number compared to general experience of stroke/ABI – are also discussed. Finally general research in ABI related to expectations is outlined.

The nature of qualitative research is considered in more detail in Chapter two, but it is worth noting the differences in the analyses undertaken - some are descriptive, while others attempt a more interpretive analysis. In terms of the conclusions drawn there is a range from practical, functional issues needing to be addressed, to existential and abstract issues, which can make comparison difficult or inappropriate.

This brief review is not intended as a comprehensive description of existing qualitative literature in the field, but to give a flavour of the range and scope of studies. Each of the questions above will be considered in turn.

1.5.3 Perceptions, meaning and experience of people following Acquired Brain Injury

This section considers stroke, TBI and communication separately as this reflects the literature, but there are common themes and issues. The studies also have in common that they are all retrospective, asking about the meanings and perceptions of the individual's experiences to the date of the interview.

1.5.3.1 Stroke

As has been stated, there has been a plethora of qualitative research papers addressing the lived experience of stroke over recent years. As an indication, Satink et al., (2013) searched for qualitative studies reporting the views of people post-stroke and identified 494 records. In addition to individual research, a number of systematic or meta-synthetic reviews have explored the impact of stroke, often focusing on demographic or thematic issues – Lamb et al., (2008), for example, looked at psychosocial spiritual experiences in older people after stroke. Satink et al., (2013), having operated various exclusion criteria, included 33 studies to look at the impact of stroke on roles and the self. McKeivitt et al., (2004) considered 95 qualitative studies, in relation to the scope of research (rather than offering a formal metasynthesis of findings) and suggested four broad areas were covered – recording experience of stroke, identifying needs, barriers to care, and the different priorities of staff and clients.

In 2008, Salter et al., undertook a metasynthesis of qualitative research and identified five general themes – change, transition and transformation; loss; uncertainty; social isolation; and adaptation and reconciliation. Since then other studies have reinforced these findings, and other themes have been developed.

Change, often related to the discontinuity with former life, is viewed as sudden, profound and comprehensive (Lawrence 2010, Murray and Harrison 2004, O'Connell et al., 2001, Dowswell et al., 2000, Ellis-Hill 2000) Change in people's perspective of the meaning of their lives is explored by Kessler et al., (2009) and Hilton (2002). Loss encompasses loss of control, confidence, and sense of self, among other aspects, as evidenced, for example, by Clarke and Black (2005), Carlsson et al., (2004) and Kvigne et al., 2004.

There are frequent references to the uncertainty of life after stroke, and people experience this as time passes with no clear answers or predictability of outcome (Carlsson et al., 2009, Alaszewski et al., 2006, Kvigne & Kirkevold 2003, Burton 2000). McKeivitt et al., (2004) noted

frequent themes related to loss and uncertainty. Social isolation and broad issues of social relationships are also identified in numerous studies, including Erikson et al., (2010), Lynch et al., (2008), and Murray and Harrison (2004). The fifth of Salter et al.'s themes is adaptation, illustrated by Jones et al., (2008), Wallenbert and Jonsson (2005) Clarke (2003) and Folden (1994).

While these themes seem to be a consistent thread in qualitative research into the meaning and experience of stroke, some studies have considered specific aspects, such as the experiences of younger stroke survivors or gender (e.g. Lawrence 2010, Dale Stone 2005, Kvigne & Kirkevold 2003) and the different perspectives of clients and staff (e.g. Bendz 2003, Mold et al., 2003).

1.5.3.2 TBI

Howes (2005) identified similar themes to those in Salter et al.'s metasynthesis of stroke studies, including change and adaptation. Discontinuity has particular relevance in relation to the experience of memory gaps or voids at the time of the incident (e.g. Nochi 1997). Conneeley (2003) looked into issues affecting quality of life up to one year post discharge, following a traumatic brain injury and noted that it is not just the impact of TBI that affects quality of life, as some have a poor quality of life pre-morbidly. This illustrates the need to recognize that the experience of living with a disability has different meanings for different individuals (Crisp 1993).

Possibly the strongest theme to emerge from studies of people's experience following TBI is the impact on the sense of self (e.g. Nochi 1997, 1998a). Hill (1999, p841) wrote a personal narrative 8-9 years after his brain injury, commenting 'my being in an existential sense was severely traumatized. I know that I am no longer the same....hence there is little to be gained in comparing with the previous being in terms of the progress that I have made'. Another theme related to this is that of perceived judgments and loss of self in the eyes of others (Nochi 1998b). Highlighting the importance of learning about the experiences of clients, Haggstrom and Lund (2008) considered participation in people more than three years post-injury, and concluded that it is not possible to judge by performance but only subjective experience is valid.

1.5.3.3 Communication impairment studies

Grohn et al., (2012) noted that thematic analysis of stroke and TBI studies may not be relevant to people with aphasia, as communicatively impaired people are often excluded. They identified five themes – a need to do things, social support and relationships, rehabilitation, adaptation and making adjustments, and positive outlook. This again resonates with the general stroke research findings, and many authors have highlighted the importance of social support (e.g. Brown et al., 2010, Dalemans et al., 2010, Hilari et al., 2010, and Andersson & Fridlund 2002,). Quality of life is another theme explored in relation to people with aphasia (e.g. Cruice et al., 2010).

Ferguson (2010) studied use of metaphors to explore the subjective experience of aphasia, finding a wide range, but most commonly *journey*, *battle* and *product* metaphors. In their often cited text 'Talking about Aphasia', based on the experiences of 50 people with aphasia more than five years post onset, Parr et al., (1997) described constructing an 'account of what has happened', incorporating pre-stroke biography. Hinckley (2006) urges Speech and Language Therapists to listen to people with aphasia and their narratives to understand how best to offer support, recognizing the importance of the personal perspective.

In a rare study of people with cognitive-communication disorder (CCD), O'Flaherty and Douglas (1997) studied their subjective experience within interpersonal settings, in people 2-18 years post injury. They found persistent changes, altered dynamics in the dyad, reduced social/leisure opportunities, difficulties in employment, time to appreciate changes, and long term needs. There is a paucity of studies that look at the experience and perspective of people with communication disorders other than aphasia following ABI, and the views of people with cognitive-communication disorder or dysarthria have been neglected.

1.5.3.4 Summary

This brief review indicates that there is a considerable amount of research into the meaning and experience of ABI, particularly in stroke, and that there are certain repeated themes, regardless of aetiology. The literature search does not suggest that there is a need for further general retrospective studies into the experience of stroke, although perhaps further research in the experiences of people with other causes of ABI and into people with communication disorders would be valuable. The second question to consider is in relation to the point in the pathway at which studies are undertaken.

1.5.4 Stage in the pathway

Although the current study samples the population at a point in the pathway, rather than specifically in terms of length of time post onset, many more studies define their populations by time post onset. There is clearly an overlap, in that the length of time post ABI relates to the care pathway.

The timing of qualitative studies after any type of ABI varies, but there seem to be many more studies that focus on long term experience. Some research does consider perceptions early in the process, that is within the first six months, (e.g. Olofsson et al., 2005, Nilsson et al., 1999, Folden 1994, Dolittle 1992). This relatively early stage in recovery has also been addressed specifically in relation to the experiences of people with aphasia (Grohn et al., 2012, Hilari 2010, Pringle et al., 2010). Aphasia per se was not a predictor of distress, but a higher proportion of people with aphasia experienced high psychological distress. Some of these early studies focus on or include the stage of discharge from acute services, which is seen as a crisis point. Satink et al., (2013)'s thematic synthesis suggested that participants saw going home as a 'rehabilitation goal, giving hope of return to a normal life,' but 'discharge was also perceived as a loss of supportive environment' (p1177).

The six month to twelve month period is explored by some authors (Erikson et al., 2010, Carlsson et al., 2009, Wallenbert and Jonsson 2005, Conneeley 2003). However, as has been stated, there is a larger body of research that is longer term, investigating peoples' perceptions retrospectively often many years after the event (e.g. Kessler et al., 2009, Haggstrom and Lund 2008, Lynch et al., 2008, Howes et al., 2005, Stone 2005, Carlsson et al., 2004).

McKevitt et al., (2004) reviewed 95 qualitative studies of stroke, and concluded that there is 'a sizable body of qualitative research that seems to document the longer term impact of stroke on patients'. The long term impact of having a chronic condition and the 'narrative wreckage' (Alaszewski et al., 2004) resulting from the destabilization of life plans and sense of self is increasingly well recognized. The trajectory of illness is a term often applied to chronic conditions and the experience of time. Faircloth et al., (2004) looked at narratives of recovery as a way of making sense of life events - past, present and future.

Research thus seems to address long term coping after ABI – often years after the event – and to a lesser extent the acute and immediate post-discharge period, but there are relatively few studies that focus on community services (McKevitt et al., 2004).

1.5.4.1 Summary There seems to have been a preponderance of research looking at the long term impact of stroke, and, although there are examples of studies earlier in the pathway, none were identified that particularly considered the perspective of people post discharge from acute care, who are waiting to begin community rehabilitation. The earlier studies, including those related specifically to discharge, are retrospective in nature. Potentially, therefore, the current study will offer a new perspective.

1.5.5 Prospective studies of expectations of rehabilitation and recovery

1.5.5.1 Perceptions of rehabilitation

A number of studies have explored subjective client views of the rehabilitation process, at different stages after onset, and focusing on such issues as goal setting, availability of services and satisfaction. Lewinter and Mikkelson (1995a) interviewed participants 3-12 months after discharge from hospital, on their experience of rehabilitation after stroke, and note that adjustment ‘takes longer than a stay in a rehabilitation ward. Hence patients upon discharge as well as admittance are in a process; and their own expectations may be difficult to accommodate, no matter how empathic a staff’ (p9). Possl and von Cramon (1996) note that even when goals (expectations) were mostly realized in rehabilitation, people still wanted further progress.

Goal setting has been the focus of qualitative research by Brands et al., (2012), Rosewilliam et al., (2011) and others, and goals are viewed as beneficial, giving reassurance and motivation. At the same time patients and carers often felt passive, despite meetings and collaboration efforts by staff, and there is an apparent difference between the perspectives of clients and staff. Other authors have also found this difference (e.g. Rosewilliam et al., 2011, Bendz 2003, Mold et al., 2003), and it was one of the themes identified by McKevitt et al., (2004) in their review of 95 qualitative studies.

Mold et al., (2003) did a literature review to evaluate the inequalities of service provision, from both client and professional perspectives. They identified 55 articles, and relevant

issues included conceptualizations of stroke and age; socioeconomic factors; resource allocation; information; and identity. Tistad et al., (2013) found that continuity in rehabilitation was associated with self-reported met needs and related to severity of stroke, but not associated with amount of rehabilitation or location of the provision.

1.5.5.2 Perceptions of recovery

Studies of recovery seem to agree that it is their subjective experience, not objective measures or professional views, which matter to clients. Levack et al., (2010) undertook a metasynthesis of the lived experience of recovery, looking at the best outcome measures. The themes identified were the central experience of loss, reconstruction of lives, and resources. Another metasynthesis (Salter et al., 2008) focused on adaptation and reconciliation, with recovery described by clients in reference to the pre-stroke self and abilities.

Research seems to indicate consistently that people measure their own recovery against their pre-stroke lives, and what has individual and personal meaning, rather than against professional views, external norms or objective measures. Dowswell et al., (2000) note that two people with the same level of progress on objective measures may have very different experiences. People judged the impact relative to another time or person, saw progress as not absolute but personally defined, and had a holistic view. Bays (2001) stated that hope was reinforced by the achievement of personal goals, rather than by what professionals said.

Burton (2000, p304) followed six patients for a year, and states 'Individual reference frames for recovery were complex and highly specific to each informant'. In a review of four studies of patient experience of stroke, Hafsteindottir and Grypdonck (1997) found that people often hold clear goals against which progress is measured, and will not accept professionals' views if lower than their own aspirations. Recovery is seen as very much about what has meaning for the individual, and being able to return to a life that is perceived as having meaning (Dolittle 1991).

Further support for this separation of personal and professional perspectives on recovery is offered by Folden (1994) who also stressed that his 20 participants saw recovery as accomplishing personal goals, rather than the goals set by rehabilitation staff. The reasons for recovery after stroke were investigated by Jones et al., (2008, p507) who noted that the 'domination of physical measures of recovery (*used by professionals*) can be misleading'.

The value of biographical work is highlighted by Kaufman (1988, p218), who notes the intersection of illness with the 'interpretation of pressing life issues at the time the illness occurs'. Kaufman's analysis leads to three categories – discontinuity of life patterns, failure to return to normal, and the re-defined self. The paper discusses the belief of patients that they are in some way different from their pre-morbid self, even if they achieve a 'perfect' performance in therapy. Similarly Clarke and Black (2005, p320) found what they note has been termed an apparent paradox 'whereby individual perceptions of well-being and life satisfaction are often discordant with objective health status and disability'. Factors implicated were residual impairments, adaptations, health services and resources, social supports, and effect of time and uncertainty. The authors note that time post-stroke affected the results, and interpreted this as meaning people were 'likely to become more successful over time.'

O'Connell et al., (2001) explicitly acknowledged a retrospective view of recovery in their study of people some years post-onset, with participants describing the stroke via themes of 'the end of life as they knew it'; life after stroke; losses and frustrations; and emotional and social issues.

1.5.5.3 Expectations

In 2007, Bains et al., stated that no studies had investigated patients' expectations of ABI rehabilitation up to that point, and questioned whether there is a link between beliefs about rehabilitation and engagement. They also hypothesised that if the family believe in rehabilitation, the client will engage better, because of the need to meet the expectations of significant others. Acknowledging that the clients were already in rehabilitation programmes at the time of the study, they stated 'future work needs to focus on predicting engagement in people who are new to rehabilitation.' This is exactly the area of interest in this study and, in recognising the gap in knowledge, reinforced the need for research in the area.

The literature search did not identify many studies that prospectively examined expectations of either recovery or rehabilitation, although some explored expectations retrospectively. There are problems with studies that use this approach as it is likely views will alter during the process of rehabilitation – Giorgi and Giorgi (2008) suggest that retrospective description risks error or deceit on the part of the participant. Hafsteindotir and Grypdonck (1997) also warn of the problem of retrospective studies.

Haggstrom et al., (1994) looked at expectations, and identified worries about the future including fears of long term residential care being needed. Participants had positive, negative and incomplete expectations, with uncertainty, sadness, gratefulness and isolation featuring. The approach taken was interesting, as it involved narrated stories based on photographs of people being fed or eating independently, rather than the more usual interviews of personal experience. Metaphors were used to illustrate the meaning of living with stroke, based on weaving a tapestry (life) and the weaving pattern being disrupted (stroke). Worrall et al., (2011) looked at what people with aphasia want, identifying goals in areas including, among others, return to pre-stroke life, communication, information, and altruism and contributing to society.

An attempt to look at expectations prospectively, albeit in a very specific area, as part of a larger randomized controlled study, was made by Dowswell et al., (2002). They investigated expectations prior to beginning a course of physiotherapy one year after stroke, and found that participants either did not have any expectations or had them in relation to specific abilities based on immediate post-stroke rehabilitation they had received. Wiles et al., (2002) also looked at physiotherapy in relation to the information exchanged with clients and its impact on their expectations of recovery, and concluded that better communication strategies could be beneficial.

1.5.5.4 Summary

Qualitative research on both rehabilitation and recovery seems to be largely retrospective, and there are almost no studies that attempt to look at expectations prospectively. The literature search seems to endorse the claim that the current study will provide a new perspective, by considering the expectations of rehabilitation and recovery of people following ABI prospectively and in relation to community based rehabilitation.

1.6 Chapter summary

From this review it is apparent that there have been numerous qualitative studies looking at the meaning and experience of having an ABI, especially in relation to stroke and to long term impact. Despite differences in themes and categories identified, there are some common threads. Change and uncertainty, impact on self, loss, and social isolation all feature consistently.

While there are studies that focus on the point of discharge and early months post-onset, the initial literature search and review indicates that, with the exception of Dowswell et al., (2002), there seem to be no studies that seek to understand more about what expectations people have *before* beginning community based therapy.

The current study therefore does seem to have the potential to offer new insights into the experience of ABI, by focusing on the expectations people have prior to engaging in specialist community rehabilitation. No study has been identified that seeks to explore, prospectively, expectations of recovery and rehabilitation, at the post-acute stage following ABI.

Prigatano (2011) states that the first principle of neuropsychological rehabilitation is to 'begin with the patient's subjective or phenomenological experience....in order to engage them in the rehabilitation process'. This study will add to the knowledge base about what people's subjective expectations in relation to recovery and rehabilitation, following ABI, and consider this in relation to engagement in the rehabilitation process. Chapter two will consider the question of how best to meet the stated objective and aims of this research, using relevant literature to explain and justify the decisions made in designing the study.

Chapter Two – Research Design

2.1 Introduction

This chapter will consider the literature and knowledge base that informs the research design, to best address the research question. The ontological and epistemological underpinnings of the research are described, and the process of deciding to adopt a qualitative, grounded theory methodology explained. Having chosen this approach it was necessary to look at the specific method that would best answer the question. This chapter therefore goes on to discuss the background literature in relation to sampling, data collection, data analysis, reflexivity and quality evaluation. In chapter three the specific research design for this study, informed by this literature, will be described. Finally chapter two considers the specific ethical issues in obtaining informed consent in this population.

2.2 Ontological and epistemological considerations

Denzin and Lincoln (2000, p157) define a paradigm as:

‘a basic set of beliefs that guide action. Paradigms deal with first principles, or ultimates. They are human constructions...These beliefs can never be established in terms of their ultimate truthfulness’.

There are four concepts encompassed in this approach – ethics, epistemology (the relationship with the known), ontology (the nature of reality and being in the world) and methodology.

Carter and Little (2007, p1316) argue that ‘three fundamental facets of research – epistemology, methodology and method – should provide the framework for planning, implementing, and evaluating the quality of qualitative research’. A possible limitation of their argument – as they acknowledge – is in not including ontological considerations in this statement. So what do these terms mean, and how are these concepts important in research design?

Ontology is the nature of reality – is there an absolute truth or reality that can be ‘discovered’ or is there no absolute truth or foundation of knowledge? Carter and Little (2007) take a pragmatic approach, recognizing that, in order to undertake research, there must be an

acceptance that concepts are 'real enough' to be investigated. Mason (1996), among others, sees the researcher's first essential task is to question his or her ontological position.

Epistemology is the study of the nature of knowledge (Schwandt 2001), that is, theory of knowledge, and for Carter and Little (2007, p1319) choosing one's epistemological position is the first decision of the researcher. They criticise articles that are 'silent and, worse, sometimes internally inconsistent with regard to epistemology', and discuss the influence the epistemological stance has on methodology, implementation and presentation. Epistemology, they state, is 'inescapable. A reflexive researcher actively adopts a theory of knowledge. A less reflexive researcher implicitly adopts a theory of knowledge'. In contrast, Bryman (1988) questioned whether the decision about which approach to take should rest in the epistemological foundation or should be a technical decision regarding the suitability of the method to the research question. Although researchers disagree about the importance of considering epistemological issues in making decisions, there must be an influence of the researcher's underlying beliefs about the nature of knowledge on the approach.

The predominant position in social, behavioural and physical sciences in the 19th and 20th centuries has been positivism, which is based in the belief that there is a discoverable, objective truth that exists and can be explained. At the other extreme is the belief that there is no objective truth - relativism. The positivist approach underlies quantitative methodologies, but Mays and Pope (1995) comment that the question of the relationship of research to an underlying truth applies to all social research – quantitative and qualitative. Daly et al., (1992, p177) state that:

'one of the greatest fallacies of the last half century in social research is the belief that science is a particular set of techniques; it is, rather, a state of mind, or attitude, and the organizational conditions which allow that attitude to be expressed'.

Statistical representations still depend on the judgment and skill of the researcher and the appropriateness of the data to the question, and all research is selective in that it cannot capture the literal truth of events, but operates through methodological prisms (Mays & Pope 1995).

The development of qualitative research was in reaction to this strongly positivist approach, and reflected moves away from the ontological and epistemological position it espouses. Lincoln and Guba (2000) see 'objectivity as a chimera; a mythological creature that never

existed, save in the imaginations of those who believe that knowing can be separated from the knower' (p181). Denzin and Lincoln (2000) celebrate the emancipation from 'a single regime of truth and from the habit of seeing the world in one colour' (p162).

There has been a growing awareness that people act on the basis of meanings and interpretations. Historically qualitative research was viewed for a long time as second-best within health research, with the positivist approach leaning towards quantitative, generalisable studies. Pope and May (1995) note how qualitative research is often 'viewed as the antithesis of the quantitative method' and that quantitative and qualitative approaches are 'frequently presented as adversaries in a methodological battle' (p43). Bryman (1988) also wrote of the tendency to exaggerate the difference between quantitative and qualitative research by viewing them as separate paradigms based in different epistemological positions.

There are a number of epistemological stances that have been claimed within qualitative enquiry – for example, Schwandt (2000) discusses three of these – interpretivism, hermeneutics and social constructivism. The former encompasses intentionalism, phenomenology and Wittgenstein's language work, which all see it as possible to understand subjective meanings in an objective manner. Hermeneutic philosophy assumes interpretation of meaning is negotiated not simply discovered – understanding is lived or existential rather than rule based. Social constructionism sees humans as not able to 'find or discover knowledge so much as we construct or make it' against 'a backdrop of shared understandings, practices, language and so forth' (p197).

Another stance is symbolic interactionism which 'views social life as an unfolding process in which the individual interprets his or her environment and acts on the basis of that interpretation' (Bryman 1988, p54). Thus people act, say and think differently because the interpretations/ meanings they place on events will depend on their experiences and the context, in a dynamic process. The interest is in the perspective people take rather than 'truth' – Thomas and Thomas (1928) described this nicely – 'if men define situations as real, they are real in their consequences'. Gubrium and Holstein (2000) see analyses of reality construction as engaging with cultural and institutional contexts of meaning making and social order.

It is clear that quantitative research falls into the positivist epistemological position, in that it presupposes there is a discoverable 'truth'. My own stance has most in common with the

symbolic interactionist / social constructivist approach, recognizing that reality is not a single discoverable entity but is constructed within a contextualized social world, which is dynamic and changing. However, I do not adopt an extreme relativist position, in that I do believe there are commonalities that affect human behavior, and knowledge about how we construct the world can have value. Specifically I believe that knowing how people perceive the world in particular contexts can have ethical, moral and political implications. This epistemological choice makes a qualitative methodology the logical next step.

Having explicitly claimed a social constructivist approach and accepted that a qualitative approach is consistent with this, what specific methodology would be best able to address the research aims? The need was to explore meanings and perspectives, but also to generate a theory or formal framework that could be used to advise service delivery and planning.

2.3 Methodological considerations

2.3.1 Methodology : Choosing a qualitative approach

Harding (1987, p3) defines methodology as ‘a theory and analysis of how research should proceed’, that is, it is a justification of the methods used. In general terms qualitative methodologies have been increasingly accepted (e.g. Sandelowski 2004) in a variety of functions – to enhance quantitative methods, for preliminary or exploratory study of complex areas not amenable to quantification, or within mixed methodologies. Vivar et al., (2007) consider qualitative approaches especially valuable when there is little known about a phenomenon and where no current theory adequately explains the concept. Hagner and Helm (1994) discuss the use of qualitative methodology in rehabilitation research and identify four areas – studying behaviour in naturalistic contexts, looking at the meaning of events and perspectives for participants, exploring new phenomena, and describing complex social processes.

Most qualitative methodologies share some common aspects in that they are naturalistic, exploratory, contextual, and interpretive. Methods are of emergent design, flexible, inductive and both give a voice to the participants *and* acknowledge the role of the researcher in what is seen as negotiated reality (Mintz 2010). Charmaz (2004) stresses the need to consider meanings, which are often ‘liminal, unstated and unacknowledged’ (p982) and actions, in a dynamic and reciprocal relationship. She states ‘we live in separate settings

and times in a global world' (p986), recognizing the contextual nature of meanings and processes.

The goal of qualitative research, according to Pope and Mays (1995, p43), is:

'the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of all the participants.'

Jones (1995, p2) states that qualitative research 'should begin to close the gap between the sciences of discovery and implementation' – thus enabling researchers to consider the beliefs and understandings that mean 'results of (quantitative) research are often not implemented in clinical practice'. Selikoff (1991, p1465) draws attention to this, saying that 'statistics are human beings with the tears wiped away'. Statistically significant findings are not necessarily clinically useful and qualitative findings are said to show the tears that statistical accounts wipe off (Selikoff 1991).

The task of the qualitative researcher is to capture the way in which people see their world (Taylor & Bogdan 1984), but there are three components in this – the way the participants see the world, the researcher's interpretation of that, and the researcher's construction of his or her interpretation in the final presentation (Bryman 1988).

This discussion underlines the relevance of a qualitative approach to the research aims, which were to look at participants' perceptions/interpretations of their experience, in a largely unexplored area, within a complex social process. The next decision was to select the most appropriate methodology within the various qualitative approaches.

2.3.2 Methodology : Choosing grounded theory

Qualitative research is often treated as a unified field but it is not, either at the level of data collection or methodology. There are many diverse approaches which fall into the broad grouping of qualitative research – such as phenomenology, grounded theory, heuristic enquiry, discourse analysis, conversation analysis and case study. There is also much variety in the standards applied to research and the claims made by authors in the field. It is easy to get enmeshed in the issue of which qualitative methodology is best, as there is considerable overlap both between the epistemological underpinnings and the practical tasks. Willig (2008) believes that there are no right or wrong methods, but that methods of data collection

and analysis can be more or less appropriate to the research question. Giorgi and Giorgi (2008) in a similar vein suggest that all methods have limitations and there is a point at which choice cannot be entirely justified.

Sandelowski and Barroso (2003) critiqued many so-called qualitative studies by looking at the degree of transformation of raw data, rather than evaluating against epistemological and ontological claims made in published papers. They draw a continuum from pure data, through topical surveys, thematic surveys, conceptual description, to interpretive explanation.

The contribution methodology makes to the research is central, involving a two way interaction between the methodology and the research aims/question and design (Carter & Little 2007). For example, if the aim is – as in this case – to propose changes in service delivery, the methodology needs to allow the development of a usable theory.

Starks and Brown Trinidad (2007) compare three qualitative methodologies – phenomenology, discourse analysis and grounded theory – and suggest that there is a central coming together at the point of analytic methods and the role of the researcher, but greater differences in the history/philosophy and goals at the beginning of the process, and in the framing of findings at the end. They describe this as an ‘hour glass’ model, which indicates the similarities of analytic methods across qualitative approaches. Grounded theory sets out to develop an explanatory theory of basic social processes. Whereas many qualitative approaches (including grounded) seek better understanding of processes and to describe the meaning of lived experience, few develop this into a theoretical framework.

This characteristic of grounded theory stood out in relation to the research aims - that is, that it sought to generate a theory or framework by which to understand the phenomenon – not just to describe it, but to explain (Marshall et al., 2007). In line with Willig (2008) the research question also met the criteria for a grounded approach in that it was open-ended, identified the phenomena of interest without making (too many) assumptions, and did not engage existing constructs. It sought to gain understanding of participants’ ideas without imposing the researcher’s own. Kennedy and Lingard (2006, p106) see the strength of grounded theory in health research as its ‘clearly articulated analytical process and its emphasis on the generation of pragmatic theory that is grounded in the data of experience’.

What then is grounded theory, and does it offer epistemological consistency with the stated approach of this study? In its original form (Glaser & Strauss 1967) it broke the mould in that it offered systematic strategies for qualitative research, countering the then current view that scientific research should be quantitative, focusing on concrete objective 'reality' (positivism). It married positivism and pragmatism (Charmaz 2006). The two original authors then developed the theory in different ways – Strauss looked at a more prescriptive development of technique and procedure, while Glaser continued to view it as a discovery process, seeing techniques as stifling and restrictive. Since then grounded theory has been used often more as an approach than in its pure form, with many studies using it to describe, rather than to seek to develop theoretical models of, the processes being considered. Dixon-Woods et al., (2004) note that the tendency to create ad hoc and a la carte approaches is very unhelpful in terms of judging the quality of research.

Various researchers have moved grounded theory away from the post-positivism of its early versions, and argued that its basic guidelines can be used with methodological assumptions and approaches more usual in the later twentieth century (Charmaz 2006). Most influential in the development of the approach has been the social constructivist movement, which has its epistemological base not in the positivist antecedents of the approach, whereby 'reality' exists objectively to be discovered, but in seeing 'reality' as constructed through the influence of past and present interactions and contexts. It is explicit in this that the researcher's philosophical and methodological choices will shape the process and the findings – thus the final theory generated will represent only one possible reading of the data. The original theory has moved from a positivist beginning, to post-positivist manifestations (reality exists but can never be fully apprehendable), into the post-modernist consideration of there being many realities that are constructed within social interaction. Charmaz (2000) has developed grounded theory within this social constructivist perspective.

Eaves (2001) notes that most grounded research initially is context based and may generate a substantive theory, which can then be tested out within other contexts to develop a formal theory. The current research was set in a single context and as such aimed to generate a substantive theory.

Grounded theory methods may be viewed as bridging interpretive analysis with positivist assumptions – that is interpretations from the inside with a positivist external reality (Charmaz 1995). The aim is to provide as dispassionate and objective an account of the

phenomena as possible, but recognizing the interaction of observer and observed. In grounded theory, Mays and Pope (1995, p111) state that:

‘findings must be rendered through a systematic account of a setting that would be clearly recognizable to the people in the setting...while at the same time being more structured and self-consciously explanatory than anything that the participants themselves would produce’.

Three questions about grounded theory are posited by Willig (2008) – what kind of knowledge does it seek to produce, what assumptions does it make about the world, and how does it conceptualise the role of researcher? The answers to these questions would undoubtedly have been different in its early positivist manifestation from the current social constructivist model. It still seeks to produce theories grounded in data, but the reality it explores is negotiated and constructed. The researcher now is not a discoverer of an objective truth, but a co-creator in developing a fuller understanding of a phenomenon.

This discussion seems to indicate that, although other qualitative methods may also have had a value in addressing the research aim to explore the client’s perspective, a grounded theory approach was particularly suited to the development of a theoretical model that may be used to inform future services. However, there is much debate about the use of qualitative methods becoming too rigid and the need for flexibility and creativity.

Janesick (2000) writes of the choreography of qualitative research : the warming up stage is asking the research question and preparation of method, followed by exploration and ‘exercising’ to practice and refine the techniques and instruments. The cooling down phase is for illumination and formulation. Janesick goes on to advise against ‘so-called ‘methodolatry’ which is a slavish attachment and devotion to method, which so often overtakes the discourse’ (p390). While this is important, there is still a need to ensure some measure of quality.

2.4 Method

Having considered the rationale for choosing a qualitative, grounded theory methodology, in keeping with the stated epistemological and ontological position, the underpinnings were in place for the development of the detailed research design. The following sections on sampling, data collection, data analysis and reflexivity offer a review of the literature and

current knowledge relevant to the final design, the implementation of which is described in chapter three.

While the methodology is the theoretical basis for research, the method is the action needed and encompasses the techniques for gathering evidence (Harding 1987). It is the actual methods that reveal the underlying methodology and epistemology, and which determine the end result (Carter & Little 2007). Different methodologies vary in how prescriptive the method choice. In grounded theory there are a number of characteristic methods or techniques.

2.4.1 Method : Sampling in Qualitative Research

The goal of quantitative research is to test pre-conceived hypotheses, whereas qualitative research seeks to gain deeper understanding of naturally occurring psychosocial phenomena. It is crucial to consider how best to achieve this through an appropriate sampling strategy, so relevant literature was explored.

Broadly sampling falls into two groups – probability and non-probability. Probability sampling is commonly applied in quantitative research, and stems from the belief that there is a single, apprehendable reality or truth (positivistic approach) and that a sample can be controlled in such a way as to allow findings to be seen as representative of the relevant population. Quantitative sampling thus aims for a representative sample which can be used to generalise. This is described as random sampling, but as Wellington (2000) points out sampling “always involves a compromise” and “we can never be absolutely sure that a random sample....is representative. We can only estimate a certain probability that the part represents the whole” (p58). Statistical analysis is used to indicate how likely it is that the sample represents the whole.

Non-probability sampling is used in qualitative research, where the purpose is to gain a deeper understanding of complex psychosocial issues. In this approach random sampling is not appropriate, as Marshall (1996) indicates, because of the small sample size; the impossibility of knowing the characteristics of the whole population; the fact that there is no evidence that values, beliefs, attitudes and so on are normally distributed; and the recognition that people are not equally good at observing, understanding and interpreting their own and others’ behaviours.

Mays and Pope (1995) state that statistical representativeness is not the prime requirement when seeking to understand social processes. The need is to engage groups of people who have certain characteristics or live in specific situations relevant to the social phenomenon being studied. This indicates that a non-probability sampling strategy, involving people who have shared the experience of ABI, would be necessary. There are considerations beyond this basic decision, however.

Numerous writers have offered lists of types of non-probability sampling, and there appears to have been some confusion in the literature over definitions and the use of terms interchangeably. Coyne (1997) refers to the 'plethora' of terms used. The basic principle is that qualitative sampling is purposeful (Patton 1990) – that is, samples are chosen in order to illuminate or understand the chosen topic, so cases are selected from which we can learn a great deal about issues of importance and relevance to the research. Coyne sees purposeful and selective sampling as terms which are used interchangeably, and Glaser (1978) defines the latter as 'the calculated decision to sample a specific locale according to a preconceived but reasonable initial set of dimensions (such as time, space, identity or power)' (p37).

Sandelowski (1995), Morse (1991), Patton (1990), and Strauss and Corbin (1990) have all outlined sub-categories of purposeful sampling, although they have variously described them as types, strategies, stages or kinds. Strauss and Corbin (1990) suggest stages of open, relational/variational and discriminate sampling, which align to some extent with their open, axial and selective coding in analysis of data. Sandelowski (1995, p182) includes 'phenomenal variation' and states that the decision to seek this is often 'made a priori in order to have representative coverage of variables likely to be important in understanding how diverse factors configure as a whole'.

Theoretical sampling is an important concept in qualitative research, which is sampling done in order to develop theory. Initially there is a need to identify a selective sample – 'the researcher must have some idea of where to sample, not necessarily what to sample for, and where it will lead' (Coyne 1997, p625). Qualitative research, most notably in grounded theory, involves simultaneous collection and analysis of data. This early selective sample is analysed and leads directly to theoretical sampling, whereby sampling is specifically to develop the emerging theory. The current study therefore incorporated purposeful sampling and theoretical sampling.

2.4.1.1 Principles and pitfalls in qualitative sampling

There seems to be some consensus in the literature that certain principles can be applied in qualitative research sampling, and also that a number of criticisms can be levelled against much of the published research. It seemed important to consider possible pitfalls prior to making final decisions on the strategy.

Most important is the need to match the sampling strategy to the research question/goals. Kearney (2007, p299) emphasises the need for sampling to be broad enough and the data rich enough to match the aims of the study. Basing the selection of sampling population on the purpose of the study – “will yield the clearest understanding of the phenomenon under study” (Maykut & Morehouse 1994, p56). It is not appropriate to judge quantitative and qualitative methodologies by the same criteria, as they serve different purposes.

Matching the sample to the research question will be inextricably entwined with other methodological decisions – for example if the goal is to generate theory (substantive or formal), then theoretical sampling will be important, and there will be a need to cover the range of possible relevant perspectives. Lincoln and Guba (1985) stress that in qualitative research it is crucial that the design is flexible enough to allow any avenue to be followed as the data unfolds. Sofaer (2002) suggests that researchers should be open to surprises, as qualitative research cannot be entirely predictable.

Although the sampling strategy needs to match the question, sampling and data collection is often, at best influenced by and sometimes driven by, practical and situational factors such as funding, the nature of the study (e.g. PhD), time, access and ethical restrictions (Maykut and Morehouse 1994). Higgingbottom (2004) acknowledges the role of theoretical perspective as a factor in sampling, for instance in the predominant qualitative methodologies such as grounded theory, ethnography and phenomenology.

Sample size has led to much debate, but needed to be considered in relation to the current research design. Quantitative researchers often fail to value study of small samples, because of what Marshall (1996, p523) describes as the ‘misapprehension that generalisability is the ultimate goal of all good research’. It is of course important to gather enough data to allow a valid analysis, but in qualitative research, it is difficult to predict the necessary sample size as the aim will be to continue sampling until the data is ‘saturated’ – that is, no further useful information is to be gained. Higgingbottom (2004), Tuckett (2004) and Rubenstein (1994) all

make the point that the number of cases cannot always be specified at the outset of a qualitative study – there is no hard and fast rule about numbers. Saturation may not simply be about number of individuals included in the study, but refer to number of interviews or extent of other information and data included. The sample size may not be large, but it does need to be broad enough to capture the many facets of a phenomenon (Kuper et al., 2008). In applying for ethical approval it was necessary to suggest a maximum figure but the number needed for saturation could not be predicted.

Another principle (and common pitfall) is the need to ensure a systematic approach to sampling. This is an area of debate because of the need to retain flexibility, but a systematic approach may involve a clear framework or logic, without being too prescriptive. Thompson (1999, p818) points out that few of the studies he reviewed ‘have an explicit framework for sampling informants and settings on the basis of their likely contributions to the theory or description being developed.’ Tuckett (2004) offers a framework which encompasses consideration of physical/organisational context, research aims and practicalities/logistics.

Duncan (2008) argues for a systematic selection of cases within a demographic approach. He cites examples that suggest that a priori theoretical explanations about what constituted interesting or uninteresting cases ‘proved depressingly inaccurate’ and looks for a random sampling approach within qualitative studies, or within a mixed-methodological approach. However he also draws attention to problems with this – such as omitted variable bias.

Associated with the need for a systematic approach, is the need for clear procedures which are well-defined and well-explained (Collingridge and Gantt 2008). Numerous writers highlight the failure of many qualitative papers to meet this criterion. Kuper et al., (2008) stress that limitations to the sample must be explained and justified, within context. If sampling is not fully described as Coyne (1997) points out, interpretation of findings will be difficult. In this study the decisions on method in chapter three provide a clear description as to the systematic procedures adopted.

Pope et al., (2002) raise the issue of validity and reliability. They feel that internal validity is high, almost by definition, as the phenomenon is being explored through the eyes of the respondent, but that reliability is harder to judge. A clear description of the sample will enable readers to judge the ‘evidence, interpretations and transferability’ of findings. Transferability is a more relevant concept than generalisability in qualitative research. Kearney (2007, p299) states that ‘It is not expected that these embedded stories, relatively

few in number, represent all individuals with that illness condition....instead, each personal constellation is a set of findings unto itself, from which conclusions about similar combinations may be drawn’.

Non-probability sampling, as adopted in this study, will apply only to the specific population under investigation. Therefore the sample size is not determined by trying to ensure generalisation, but by getting data and information that explores the phenomenon as fully as possible (Grbich 1999). It may be representative or typical of other clients or settings that share basic properties of the study context.

Collingridge and Gantt (2008) suggest that generalisation can be understood in different ways. An alternativeanalytical generalisability involves making a ‘reasoned judgement about the extent to which the findings in one study can be used as a guide to what might occur in another situation’ (Kvale 1996, p.231). Thus ‘assertional logic’ is used to judge whether the context of a study is similar to other natural examples of the phenomenon. This seems to relate to the concept of transferability. Possible biases in sampling need to be considered and explained. Stewart et al., (2004) highlight necessary strategies to protect against bias and enhance reliability, including clear purposive sampling. The current study, therefore, in line with the literature, had a clear, transparent and systematic sampling strategy, which continued until saturation.

2.4.1.2 *Sampling in Grounded Theory*

In grounded theory the conceptual framework, literature and researcher background guide the initial selection and then theoretical sampling is used to widen the scope as new concepts emerge from the data (Gibbs 2007). Thus, as Coyne (1997, p625) describes, the ‘initial sample is determined to examine the phenomena where it is found to exist’ and then theoretical sampling ‘to test, elaborate and refine a category is done for verification or to test the validity of a category’. Thompson (1999, p816) describes this as using ‘tentative theoretical jumping off points from which to begin theory development.’ Discussion of this jumping off/selective sampling typically includes description of the population, sample size and recruitment strategies (Draucker et al., 2007).

Draucker et al., (2007) reviewed articles referencing theoretical sampling and point out that there is little clarity and consistency of approach. Their guide is the basis for the framework illustrated in figure 3:1, and draws on Strauss and Corbin (1990)’s approach to grounded

theory, which connects specific theoretical sampling strategies to the three coding types they identify for data analysis. Open coding occurs with open sampling – that is purposeful sampling to gather data which illustrates as many categories as possible. Axial coding and selective coding occur on later data from theoretical sampling. This model will be considered further in Chapter three.

The sampling strategy needed, in the light of this discussion, to be purposeful/theoretical and ensure selection of participants who had the necessary experience to contribute to deepening knowledge. The systematic selection strategy needed to be clearly explained, and this is described in chapter three. The sample size, rather than being pre-determined, was dependant on saturation.

2.4.2 Method : Data collection techniques

Having used the literature to ensure the sampling strategy adopted was in line with good research practice, it was necessary to consider how best to obtain the data relevant to the research aims. The interview seemed to be the most effective route, so this was explored further, both to determine its applicability to the aims and in relation to the practical questions of how the interview should be planned and conducted.

2.4.2.1 Interviews in qualitative research

The interview is a crucially important tool in qualitative research. Kvale (1994, p149) defines the qualitative interview as ‘an interview the purpose of which is to gather descriptions of the life world of the interviewee with the intention of interpreting the meaning of the described phenomena’. Taylor and Bogdan (1984, p81) see it as a form of conversation which is:

‘subject to the same fabrications, deceptions, exaggerations, and distortions that characterise talk between any persons. Although people’s verbal accounts may lend insight into how they think about the world and how they act, there can be a great discrepancy between what they say and what they actually do’.

The interview is, of course, artificial, and does not allow access to the individual in his or her daily life, so the interviewer does not have full contextual knowledge. It is important to bear this in mind when making claims about the truth of data thus obtained.

The basic concern was whether the use of interview data helps in addressing the research topic, and there did not seem to be any other method that would allow access to individuals' subjective experience of a particular event, such as brain injury.

Epistemology and Methodology The researcher's theory of knowledge will inform the methodology and use of the interview process. What the interview transcript represents will, as Willig says (2008) depend on the theoretical framework, as informed by the epistemological stance.

Silverman (2000) suggests five questions that qualitative researchers should ask themselves, most of which apply to the analysis stage. However two are relevant in preparing the interview, in that they relate to the epistemological stance of the researcher - 'What status do you attach to your data?' and 'Are you making too large claims about your research?' He suggests (p823) that;

'by abandoning the attempt to treat respondents' accounts as potentially "true" pictures of "reality", we open up for analysis the culturally rich methods through which interviewers and interviewees, in concert, generate plausible accounts of the world'.

In reflecting upon the interview process, therefore, it is relevant to consider what Willig (2008) calls 'epistemological reflexivity' – that is, the assumptions about the world, knowledge and 'truth' made by the researcher. Reflexivity is about exploring 'the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research' (Nightingale and Cromby 1999, p.228). As well as considering epistemological issues, the researcher needs to look at personal aspects, which will be considered later in the discussion. Kvale (1994) argues against over-playing the dichotomy between the polarity of objective reality and 'anything goes' relativism, and careful reflection will facilitate achieving a balance.

Grounded theory has been developed since Glaser and Strauss first explained their approach (1967). It was designed to identify and explicate contextualised social processes, by allowing concepts/categories to emerge from the data, and thus had a realist orientation. Social constructivism has informed the work of researchers such as Charmaz (2006) who describe a symbolic interactionist version, which assumes realities are negotiated and interpreted – that we all act on the basis of meanings, which are social products. It does not, as within an extreme relativist ontology see the world as lacking in 'laws' or orderliness. Willig (2008) sees

the world as constantly changing and in flux, so to reflect its dynamic nature grounded theory attempts to look at process and change.

The social constructivist approach stresses the role of the researcher more than Glaser and Strauss's early model. Charmaz goes so far as to say that grounded theory does not capture any extant social reality, but is itself a social construction (1990). Earlier in this chapter, the epistemological beliefs of the researcher were discussed, which underlie the whole study.

Collaborative construction of meaning An interview cannot take place in a vacuum, and both interviewer and interviewee will influence the process, over and above the wording of questions. Neutral questions do not result in an interview without influences, according to Charmaz (2006), but reflect both people's past and immediate identities, present impressions of each other and the relationship formed. The 'interviewee will appraise the interviewer, assess the situation, and act on their present assessments and prior knowledge' (Charmaz 2006, p27).

Interviewing is person-dependent. Kvale (1994) mentions this as a standard criticism of qualitative interviewing, and accepts that different interviewers will have varying sensitivities and abilities and therefore obtain different 'nuances and depths'. He describes the interviewer as 'the primary methodological tool'. All types of interview still involve some formality in terms of expected 'rules of engagement'. The cultural milieu of the client is likely to impact on how they deal with the interview situation. A client from a professional background may be used to interview style interactions more, for example, than a manual worker.

Reflecting on the researcher's own part in the interview process is an important part of qualitative research. This recognises that the interview is a collaborative process and that both participants are involved in constructing meaning. Personal reflections on the interview process will be offered in chapter three, acknowledging the importance of the researcher within the process in line with the literature on interviewing.

Type of interview The three main categories of interview are structured, semi-structured and open/depth. There is considerable overlap between them in practice. Relevant literature was again considered in deciding what type of interview would be most appropriate to the current research aims. A structured format is not appropriate to a grounded approach, or indeed to most qualitative research.

Semi-structured interviews, according to Britten (2006), are based on open-ended questions that are pre-decided; while depth interviews focus on one or two issues in detail and questions are based on what is said in the moment. In-depth interviews are used to explore, rather than used like a clumsy interrogation of so-called facts (Charmaz 1991). Smith and Osborn (2006, p59) suggest that semi-structured interviews still need a schedule, as 'producing a schedule beforehand forces us to think explicitly about what we think/hope the interview might cover', pre-empts possible problems and allows focus on what is said.

Willig (2008, p23) states that 'Semi-structured interviewing is a method of data collection that is compatible with several methods of data analysis (e.g. Discourse analysis, grounded theory, interpretative phenomenology).' Holstein and Gubrium (1995, p14) see the interview as a collaborative process, whereby both interviewer and interviewee are engaged in constructing meaning. They suggest the active interview has two purposes – 'to gather information about what the research project is about and to explicate how knowledge concerning that topic is narratively constructed'. The interviewer 'seeks to understand the topic and the interview participant has the relevant experience to shed light on it' (Charmaz 2006, p25).

Interview schedule It was, based on the above discussion, decided that a semi-structured interview, with a schedule, would be adopted as the data collection method. In relation to how this would be used, consideration was given as to whether to have a schedule to use in the interview. It may be that having a schedule to hand for early interviews helps to build confidence and also to allow focus on what is said, rather than becoming distracted by thoughts about what to ask next (Britten 2006). Having pre-formulated questions can help to avoid more directive, clumsy questions formed 'in the moment'.

In the literature regarding best practice, the interview schedule tends to start with easy to answer, factual questions (what Willig 2008 calls 'public' questions), and proceeds to more sensitive, personal matters. In a grounded approach the interview schedule needs to be used flexibly. New questions can be introduced within or between interviews with different clients. Smith and Osborn (2008) talk of funnelling, as a technique to move from general to specific. Charmaz (2006) suggests slanting ending questions towards positive responses, to allow the rhythm and pace to return 'to a normal conversational level before ending'.

Charmaz (2006) advises having a few broad open-ended, non-judgemental questions, then inviting detailed discussion, reflection and clarification by following up. She is comfortable

with the interviewer being flexible enough to act on intuition and shift the conversation. This flexibility is important. She also endorses returning to earlier points when appropriate, restating to check accuracy/understanding and validating participants' humanity, thinking and behaviours.

There is a risk of forcing data into preconceived categories (Glaser 1978) which is perhaps more of a risk because of the flexible nature of semi-structured or depth interviewing, and the grounded approach which collects and analyses data simultaneously. This needs to be guarded against increasingly as more interviews are conducted and as the theory takes shape. Taking the literature into account, in the current study, a schedule was used. It began with factual questions and moved to more sensitive areas, but was used flexibly.

Analysing type of question Detailed attention needed to be given to the interview questions used. Charmaz (2006) recommends using questions that reflect the epistemological underpinnings of symbolic interactionism, emphasising the desire to learn about participants' views, experiences and actions. Questions in qualitative research are designed to explore the client's perceptions, and it is therefore important that care is given to the topics/form of questions. Various classifications of question types have been offered. Patton (1987) defines types as behaviour/experience based; opinion/belief; feelings; knowledge; sensory; and background/demographic. Spradley (1979) with some overlap suggests descriptive; structural; contrast; and evaluative.

Smith and Osborn (2008) encourage researchers to look at individual questions in the schedule and subsequent transcript, and ask such questions as whether they are leading, open, value laden, or confusing. They also suggest considering whether too much data is generated from specific follow-up questions, which might suggest the participant is being forced into your world rather than *vice versa*, and if assumptions are being made about the interviewee's knowledge.

Kvale (1994, p155) states 'Bias in research cannot be completely avoided, but counteracted by carefully checking for effects of bias in subjects and researchers'. There is risk of unintentional bias from the interviewee (for example, trying to please the interviewer or give the 'right' answers) and from researcher. There may also be deliberate deception (Giorgi & Giorgi 2008) but this was not seen as an issue in this study.

There is much evidence, in many fields, that leading questions can sway answers, via wording, especially with suggestible clients, but Kvale (1994) suggests they can also serve a useful function in checking the reliability of answers:

‘the task is, again, not to avoid leading research questions, but to recognise the primacy of the question and attempt to make the orienting questions explicit, thereby providing the reader with a possibility of evaluating their influence upon the research findings and assessing the validity of findings’.

Thus in looking at the interview, if there are leading questions do they lead in important directions and bring out new knowledge?

Bearing in mind the importance of the type of question and possible biases, it was decided to use Smith and Osborn’s (2008) questions as a basis for evaluating the schedule in an initial exploratory phase.

Analysing interviewers’ responses and technique Whyte (1982) suggests a six point scale of directiveness by which to analyse interview technique, from making encouraging noises (least directive), reflecting on remarks made by the informant, probing remarks or ideas expressed earlier, to introducing a new topic (most directive). Britten (2006) points out that the amount of directiveness should be appropriate to the style of research, and does not mean that most directive is least effective per se.

The literature highlighted a number of concerns, which were taken into account when conducting the interviews, such as sensitivity to the client’s comfort, validating responses and being prepared for questions and unexpected responses.

The interviewer needs to respond both to the client’s words and non-verbal behaviour, and prioritise the client’s comfort above collecting what Charmaz (2006) calls ‘juicy data’. Paying close attention can identify when it is appropriate to probe further and when to pull back, being sensitive to the client’s responses, so that the situation is not abused by delving too deeply and making the client uncomfortable.

Validating what is significant to the client contributes to the development of the relationship. Picking up on or ignoring cues/words from the client makes a huge difference to the depth of data gained, so the interviewer needs to remain active and alert to leads. Giving enough time to respond is critical, so the pace can be set by the client.

Taylor and Bogdan (1984) comment on the need to let people talk, to pay attention, to be sensitive and to communicate empathy and understanding via a non-judgemental approach. In terms of responding to clients, they acknowledge using probes to clarify meanings and elaborate points; and using cross checks to explore possible distortions, contradictions or exaggerations.

It is important to take care not to assume 'that the interviewee's words are simple and direct reflections of their thoughts and feelings' (Willig 2008, p23). There needs to be sensitivity to the language and concepts used by the interviewee. One cannot assume that terms are understood and used in the same way.

Another issue that Britten mentions (2006) is that of being asked questions – as he states 'the problem with this is that in answering questions, clinical researchers may undo earlier efforts not to impose their own concepts on the interview' (p16). He suggests one possible, albeit not ideal, method is to promise to return to the question/issue at the end of the interview.

Summary The interview seemed to be the most effective method for data collection to meet the research aims. This review of the literature indicates the importance of reflecting in general on the influence of the researcher on the interview process, clarifying the type of interview, having a clear rationale for the interview schedule, considering the type of question used, and being aware of – and specifically reflecting on – the interviewer/researcher's behaviour within the interview. Chapter three describes how these considerations were taken into account in practice.

2.4.3 Method: Data analysis in grounded theory

There are certain accepted principles for analyzing data within a grounded theory paradigm. Charmaz (1995) sees grounded theory as using logical, systematic procedures for the collection and analysis of data, which aims to develop theory and specifies its defining characteristics as:

- Simultaneous collection and analysis.
- Codes and categories are developed from the data not preconceived hypotheses.
- Middle range theories are used to explain behaviour and processes.

- Analytic notes or memos are taken throughout.
- Theoretical sampling is used to develop theory not to be representative
- Literature review is delayed until the analysis is completed to minimize the influence of preconceptions.

The constant comparison method is used to look at data within and across subjects and context (Glaser and Strauss 1967). These principles were adopted in the current study, and a detailed description of the data analysis used in this study will be given in chapter three. The controversy surrounding when to engage with the literature was briefly discussed in chapter one.

2.5 Reflexivity

Reflecting on the researcher's own part in the interview process is an important part of qualitative research, and it therefore must be given appropriate focus in the current research. This recognises that the interview is a collaborative process and that both participants are involved in constructing meaning. In taking a social constructivist approach, it is a given that research is seen as a joint product of researcher and researched (Ashworth 2008). As Willig states (2008, p7) 'Social Constructivist research is concerned with identifying the various ways of constructing social reality that are available in a culture, to explore the conditions of their use and to trace their implications for human experience and social practice'. Epistemologically and ontologically this flows on from the belief that reality is not a single truth that can be discovered.

Taylor and White (2000, p35) discuss the issue of reflexivity in a broader way than research, looking at clinical involvement and practice, and note 'We are not interested simply in what we have done and how we have gone about things when we reflect on our practice, we must also concern ourselves with the (tacit) assumptions we are making'.

Guba and Lincoln (1989) state that the observer cannot and should not be disentangled from the observed, and the 'findings or outcomes of an inquiry are themselves a literal creation or construction of the inquiry process' – 'they do not exist outside of the persons who create and hold them; they are not part of some objective world that exists apart from their constructors.' (p143). Scheper-Hughes (1992) writes 'We cannot rid ourselves of the cultural

self we bring with us into the field any more than we can disown the eyes, ears and skin through which we take in our intuitive perceptions' (p28).

Grounded theory in its early incarnation was criticised for not considering reflexivity enough, but the more recent social constructivist approach has redressed that imbalance, recognising that categories can never capture the 'essence' of a concept in its entirety (Dey 1999). Charmaz (2006) believes that categories and theories do not emerge from the data, but are constructed via the researcher's interaction with that data. As a result 'the theory produced constitutes one particular reading of the data rather than the only truth about the data' (p45).

One of the concerns about qualitative research historically has been the risk of bias, but this in part relates to the claims made, and the epistemological and ontological foundations of the researcher. Olesen (2000) suggests that 'if the researcher is sufficiently reflexive about her project, she can evoke (these biases) as resources to guide data gathering or creating and for understanding her own interpretations and behaviour in the research' (p165).

Marcus (1994) differentiates essential and derived (ideological) reflexivity, seeing the former as an integral feature of all discourse. Willig (2008, p18) draws attention to what she calls personal reflexivity (the influence of one's own background and values) and epistemological – that is, how the research design influences the findings, and the need to think about the assumptions made in the course of research about knowledge and truth. She goes on to state – 'it encourages us to foreground, and reflect upon, the ways in which the person of the researcher is implicated in the research and its findings'. Factors to consider include class, sex, age, nationality, race, ethnicity, social distance, role/authority imbalance, the status of the interview in different cultural milieus, linguistic variability and ideology (e.g. Willig 2008, Britten 2006, Charmaz 2006,).

In terms of evaluating the quality of qualitative research, Yardley (2008) indicates that reflexivity is 'an important part of the transparency of the study....the term used for explicit consideration of specific ways in which it is likely the study was influenced by the researcher' (p250). Others before and since also stress reflexivity as an attribute of good qualitative research (e.g. Elliott et al., 1999, Henwood & Pidgeon 1992). Elliott et al., (1999) include 'owning one's own perspective' in their list of criteria pertinent to qualitative research quality. Within this, they suggest that there needs to be acknowledgement of theoretical

orientation, methodological orientation and personal orientation, relevant training and experience, and – if appropriate – initial beliefs about the phenomenon.

The discussion above stresses that reflexivity is an important consideration in good practice and, in line with this, both the epistemological and personal aspects will be outlined in chapter three.

2.6 Judging the quality of qualitative research

Madill et al., (2000, p2) suggest evaluation of an analysis should be ‘by the logic of justification entailed by its stated epistemological stance (as opposed to the nature of the data or method of analysis per se)’. They go on to state : ‘Qualitative researchers have a responsibility to make their epistemological position clear, conduct their research in a manner consistent with that position, and present their findings in a way that allows them to be evaluated.’ They consider three epistemological strands which, they believe, carry different implications for evaluation of the research. Carter and Little (2007) believe that if the epistemology, methodology and method are internally consistent, there is no need to seek to insist on any one qualitative approach is better than another.

Mays and Pope (2006) looked at quality of qualitative research and whether the same criteria can be applied as in quantitative work. Some see the two as entirely distinct, but others recognize a ‘subtle-realism’, that is, there is an underlying reality that can be studied, and so modified versions of the same criteria can be used. Mays and Pope see the distinction between the two in relation to validity and reliability more as ‘one of degree than of type’.

The two main areas considered in evaluating research traditionally, within the positivist framework, are validity and reliability. Britten and Fisher (1993, p271) state that ‘there is some truth in the quip that quantitative methods are reliable but not valid and that qualitative methods are valid but not reliable’. There is some disagreement over what makes good qualitative research, with – as has been noted - some fearing that formal criteria would ‘stifle interpretive and creative aspects’ (Dixon-Woods et al., 2004, p223). Criticisms often applied to qualitative research are the risk of researcher bias, lack of reproducibility and lack of generalisability.

Rigour in qualitative research is clearly important – Tuckett (2005) sees this as paralleling traditional positivist studies, albeit with different language and terminology: validity is referred to, for example, as ‘trustworthiness’. Mays and Pope (2000) cite strategies to promote rigour as having a systematic and ‘self-conscious’ research design, a clear account of method and data that can stand independently, and a plausible and coherent explanation of the phenomenon. Meyrick (2006) offers a model for assessing rigour via two core principles – transparency and systematicity.

If one accepts the need for criteria which will allow judgments to be made about the quality of research, then validity, relevance and reliability need to be considered. Validity encompasses validation (such as triangulation), transparent method, reflexivity and attention to negative cases. Jootun et al., (2009) highlight reflexivity and the need to discuss the impact of the researcher on the study, recognizing that any findings are co-constituted. ‘Relevance’ asks whether it adds to useful knowledge bases and whether the findings are transferable (e.g. Estabrooks 2001). Reliability requires meticulous records covering data collection and analysis – a clear audit trail.

Elliott et al., (1999) suggest some tentative and ‘evolving’ guidelines for reviewing qualitative research, listing seven aspects shared with quantitative research, and seven especially pertinent to qualitative approaches. The latter are: owning one’s perspective, situating the sample, grounding in examples, providing credibility checks, coherence, accomplishing general or specific tasks, and resonating with readers.

Even this brief discussion makes it apparent that there have been numerous attempts to set out criteria by which to judge qualitative research, but in common seem to be the need for explicit methods (including sampling strategy, data collection and analytic procedures), contextual information, attention to contradictory cases, reflexivity, and enough original data in the report to justify the interpretation offered (e.g. Collingridge & Gantt 2008; Kuper et al., 2008; Mays & Pope 2006). In reading qualitative papers, the question is whether enough information about context and method has been given to allow judgments to be made about transferability to another setting.

Smith and Deemer (2000) make the following statement: ‘We enquire, we make judgments about enquiries, we must give reasons for our judgments, offer up these reasons to others and simply attempt to do the best we can’ (p891); and go on to say ‘As finite beings all we can do is construct social and educational worlds, social and educational constructed

realities, for which we are morally responsible' (p891). As Elliott et al., (1999, p216) state : 'ultimately, the value of any scientific method must be evaluated in the light of its ability to provide meaningful and useful answers to the questions that motivated the research in the first place'.

Much of this chapter has focused on issues that are important to the evaluation of the quality of this research. Employing relevant literature on good practice, in sampling, data collection and analysis, at this early stage in the research, before making final decisions as to design and method, ensured the quality of the research. Chapter nine will consider this quality, and limitations of the current research, in the light of the literature cited above, and using the Critical Appraisal Skills Programme (1998) as an evaluation tool.

2.7 Ethical Issues in Acquired Brain Injury research

The nature of Acquired Brain Injury means that there are specific issues that need to be considered in obtaining consent. Relevant literature was reviewed and is discussed here, as it was used as the basis for the consent materials described in chapter three and included in the appendices.

2.7.1 Obtaining informed consent in health research

Informed consent is defined as 'full disclosure of information from the researcher to the potential participant, voluntary participation, competence, and comprehension' according to the Nuremburg Code and the Declaration of Helsinki (Nelson-Marten & Rich 1999). It involves therefore more than cognitive capability, but the ability to 'understand and appreciate the context and implications of the decision, and also involves the capacity to translate the decision into action' (Slaughter et al., 2007, p30). Stein and Brady-Wagner (2006, p42) state 'True informed consent requires that the patient demonstrate understanding of the medical procedure under discussion and also that the patient have a genuine opportunity to pose questions exploring aspects of the decision that he or she seek to understand better'.

Wear (1993) stressed how important informed consent is in enabling people, as the power has for so long rested with medical authorities. The World Medical Organisation declaration

of Helsinki (1964) sets out the ethical principles that guide medical research; and respect for the right of individuals to be involved in decisions about their healthcare is enshrined within the NHS as a key principle (NHS Constitution 2010). Despite this there is evidence that research participants do not always understand fully (Flory & Emanuel 2004).

Appelbaum and Grisso (1988) define the specific and necessary functional abilities for decision-making as being comprehension; manipulation of the options and their consequences in relation to personal goals and values; the ability to reason through a decision; and communication of a preference.

In relation to comprehension, Flory and Emanuel (2004) cite evidence that a high proportion of people do not understand disclosed information. They undertook a systematic review of research on interventions that might improve participants' understanding. They found that the use of multimedia and enhanced consent forms had only limited success, but that having an individual spend time talking through the research one-to-one seemed to be the most effective approach. This, as they suggest, would support the idea that 'informed consent is more than just the action of reading a form and signing it. It is better thought of as a process, ideally a dialogue, which takes place over time and largely depends on interaction between human beings' (p1599). Their review did indicate that educational or reading level and mental health were factors at the individual level, and that this should also be taken into account.

In relation to the reading level required, Young et al., (1990) found that many consent forms expected a high level of ability, affecting comprehension, and that subjects with lower levels of education have poorer understanding even when information is simplified. They recommended all researchers to use shorter and simpler sentences; improve organization of the material; use more familiar terminology; and define technical language in layman's language. They also suggest combining written and verbal presentation.

Richards and Schwartz (2001) discuss the risks for participants in health services research as anxiety/distress; exploitation; misrepresentation; and identification in research publications. The issue of exploitation encompasses the power balance within health care, which may lead people to feel pressured by a sense of duty, and confusion with therapy. They suggest using both verbal and written information, giving time for reflection and asking questions, ensuring there is opportunity to withdraw at any stage, and making the researcher's role clear. It must be transparent and explicit that refusal will not have an adverse effect on care.

Some have called for the use of questionnaires as a check on understanding, with the proviso that it needs to be done in a timely way so that understanding rather than memory is being verified. Wirshing et al., (1998) consider consent in two phases – provision of information and decision making. In the latter phase it is presumed that the participant has understood enough to make a rational and informed decision. They made use, with schizophrenic participants, of a questionnaire to check understanding – when an item was failed that aspect was re-explained. Most clients needed two or more reiterations to master the material.

There are therefore broad issues in relation to improving potential health research participants' understanding, but there are, in addition, very specific issues for people who have communication difficulties and/or cognitive impairments. Stineman and Musick (2001) refer to the ethical principle of justice, and the importance of including people with cognitive disabilities in clinical research – or indeed other vulnerable groups – so that clinical benefits are available to all. Similarly Slaughter et al., (2007, p28) state 'It is morally unacceptable not to do research with vulnerable participants'.

2.7.2 Consent and people with aphasia

It is common for research studies to specify aphasia in exclusion criteria, in part because of the difficulties in interviewing people with aphasia, such as difficulty understanding instructions. Townend, Brady and McLaughlan (2007) for example found that many studies of post-stroke depression exclude people with aphasia, thus limiting generalisability and potentially impacting on the planning and providing of services. According to Braunack-Mayer and Hersh (2001) there are three difficulties in relation to aphasia – that it is poorly understood, in part because it 'impairs both the individual and the collective voice'; that aphasia can mask competence normally revealed in conversation; and that of practical issues, such as lack of time. Assessment of competence to give consent is often tied up with language skill.

Palmer and Paterson (2011) propose a screening of people's level of competence with spoken and written material so that information can then be matched to that level. They suggest four levels, from highlighting key ideas, through use of aphasia friendly text conventions, to a total communication approach, and – at the most severe level – the use of

available techniques in combination with input from the carer/relative. This final level endorses the suggestion of Stein and Brady Wagner (2006) of a facilitated consent process, whereby the proxy participates in the process and can ask questions when needed – acting therefore as an advocate – but the patient makes the final decision.

Consent, competence and capacity are often evaluated through formal testing, but Braunack-Mayer and Hersh (2001) point out the danger in solely using this approach, and the need for what they call a ‘sensitive and multi-faceted approach’. The strategies they endorse are:

- Allowing sufficient time, as it may be necessary to rephrase, repeat and slow down explanations.
- Presenting information through more than one modality – written, pictorial, gestural and so on.
- Balancing simplifying information enough to allow people with aphasia to understand the options, restricting the amount of information in line with what professions assume is needed.
- Using tailored consent forms, perhaps with pictures, symbols, enlarged print and short sentences/key words.
- Discussing the form before the interview (Fadan & Beauchamp 1986)
- Checking at the time the information is presented, so that comprehension rather than memory is being verified.

Kagan and Kimelman (1995, p65) ask ‘Does the nature of aphasia preclude the ability to make informed consent?’ The authors worked together to redesign standard consent forms to increase the accessibility for people with aphasia, noting the importance of distinguishing between ‘those for whom competence itself is in question and those for whom competence is masked’.

The question is whether information *can* be provided in an accessible form to people who may find a text-based form difficult. As has already been stated, this extends beyond people with specific impairments – Sachs and Cassel (1990) found that consent forms generally require at least a college education to be able to understand – which fits in with the review by Flory and Emanuel (2004), referred to above.

In looking at people with aphasia, Kagan and Kimelman (1995) stress that using an adapted form is only part of what is needed to obtain properly informed consent. Skill and training are needed to use the form as a basis for dialogue. Techniques must also be used to reinforce the message, such as writing key words, drawing, and constantly checking comprehension through as many channels and modalities as possible. Various authors endorse the need to use a trained facilitator to aid people with aphasia in making informed decisions (e.g. Braunack-Mayer & Hersh 2001; Kagan 1995).

2.7.3 Consent and cognitive impairment

Brady Wagner (2003, p276) highlights the complexity of ethical dilemmas when a person has a cognitive communication disorder. People with diminished cognitive-linguistic competency 'are inherently more vulnerable to losing their right of self-determination (autonomy)'.

Cognitive impairments (for example inattention, memory and executive functioning) may affect comprehension, the ability to reason and the ability to make judgments, and thus affect the process of giving informed consent. While Brady Wagner (2003) notes more research is needed on addressing the value of using cognitive techniques to aid decision making capacity, Kim et al., (2002) cite some evidence that utilizing educational strategies and reducing the amount of information given at one time may be helpful.

Hunter and Jensen (2003) consider the question of getting consent from individuals with cognitive impairment, although she only addresses dementia, delirium and depression, rather than the cognitive impairments that result from acquired brain injury.

2.7.4 Proxy consent and use of surrogates

Proxy consent has been considered in relation to people with aphasia and those with cognitive impairments. A study by Warren et al., (1986) found that consent was sometimes given by proxies even when they believed the person would not have given consent if able, or when they would not take part themselves. McCormack (2002, p118) considers proxy consent in relation to people with dementia, and discusses a number of ethical problems with this approach – if proxy input is essential he suggests it is treated 'as another narrative

that serves to confirm the other person's decision or to provide important information towards reaching an effective decision'.

Kagan and Kimelman (1995, p67) found that patients and surrogates do not always agree on proposed treatment options, and cite emotional responses from people with aphasia when asked about proxy consent –

Interviewer : So you think the person should be making decisions about themselves

Marg : That's right! That's right!

However, Stein and Brady Wagner (2006) suggest that surrogate decision making is acceptable when comprehension is severely impaired and that this is 'clear and broadly accepted'. However, there needs to be very careful attention paid first to the accessibility of information and underlying competence before such a decision is made.

2.8 Chapter summary

This chapter has explained the ontological, epistemological and methodological choices that lie behind the specific research design for this study. The literature that has been relevant to the decisions about methods of sampling, data collection and analysis has been described, and particular attention paid to the ethical issues of obtaining consent from people who have acquired brain injury resulting in communicative and cognitive impairments. Chapter three will relate this more abstract discussion to the design and practical implementation of this study.

Chapter Three – Methods

3.1 Introduction

While chapter two introduced the general issues relevant to the design of this study, this chapter describes the actual methods of sampling, data collection, and data analysis used. It has already been stated that the fit between research questions and method is paramount, so the chapter will begin by returning to the question and the aim/objectives of the study. It has also been made clear that information about the context of the research is crucial in qualitative studies, to enable interpretation of findings, and allow the question of transferability to be addressed, so there is a brief repetition of the description of the context in which the research has been carried out. All the decisions about method described in this chapter have been justified within the literature review offered in chapter two.

Reflexivity will be addressed as it is important to have an appreciation of the researcher's influence upon the findings described in chapter four. This topic is addressed early in the chapter, as it is recognised that personal beliefs and characteristics influence many, if not all the decisions in designing qualitative research and analysing the data, from epistemological to practical. The specific methods of sampling, data collection and analysis are then described.

3.1.1 Aims

The aim of the research was firstly to gain a deep understanding of the perspective of clients who have an acquired brain injury about their expectations of recovery and rehabilitation, following discharge from the acute hospital setting. Secondly the aim was to generate a theoretical model upon which to base suggestions for clinical practice. As has been covered in chapter two, these aims fit with a qualitative grounded theory approach, and with non-probability sampling strategy, data collection via interview, and analysis that seeks to interpret rather than merely describe or label (Willig 2008).

During the course of the study an additional aim was incorporated, which was to explore and contrast the perspective of clinicians working in specialist ABI services. It was decided this

would further inform any suggestions regarding clinical practice. This aspect of the research is described and discussed in chapter seven.

3.1.2 Ethics

Ethical approval for the study was obtained through the University of Sheffield, with full managerial and team support from the Rehabilitation Service in which the research was undertaken.

The clinical protocol used within the service for responding to clients who express suicidal ideation was employed when necessary. This ensured the client's safety, by engaging in exploration of the risk factors with the individual, and involving neuropsychology and other medical services immediately after the interview, to establish an appropriate course of action.

3.1.2 The Context of the Research

As has been explained, the study is based in the context of a community rehabilitation service, for adults who have an acquired brain injury. Acquired Brain Injury has been defined as a non-progressive, acute onset brain injury resulting from a variety of aetiologies, including stroke, sub-arachnoid haemorrhage, traumatic injury, encephalitis, anoxia, and abscess. People with any of these conditions may be referred to this service. Clients will have been screened to identify those who meet the criteria for referral to the service, and, at that point, invited to take part in the study, prior to beginning any element of the assessment process and rehabilitation. Chapter one provides a fuller description of the context.

3.2 Reflexivity

Chapter two highlighted the importance of reflecting on a number of levels. The researcher not only influences the process of data collection, through interview, but is – within this paradigm of qualitative research – a co-constructor of the final analysis. It is hoped that this discussion will offer some insight into the influences that may impact on the researcher's analysis and therefore the study findings, as well as the initial design. This section will be written in the first person as it is appropriate to emphasise the subjective nature of the reflective process.

3.2.1 Epistemological and methodological beliefs

My theoretical, epistemological and methodological basis has been described in chapter two and determined my research design and influenced my analysis/findings. My stance was informed by empiricism to some extent, in that my approach did assume that there is an underlying discoverable 'truth' within the data, so a theory can be constructed to make sense of the data. However, I believe – in line with a social constructivist approach – that what we perceive and experience does not represent an absolute truth but is contextual and interpretative. The kind of knowledge I believe can be obtained through interview is an interpretation of interviewees' reality, who have made sense of events (in this case the experience of brain injury) they have experienced/perceived, in a particular social and temporal context. I agree with Charmaz (2006, p27) who states that 'Interview stories do not reproduce prior realities'.

I also, like Fontana and Frey (2000), would stress the role of the interviewer in influencing the interaction, in agreement with Holstein and Gubrium (1995)'s statement : 'To say that the interview is an interpersonal drama with a developing plot is part of a broader claim that reality is an ongoing, interpretive accomplishment'(p14).

3.2.2 Personal characteristics and beliefs

In relation to the method, data was collected via interview. My personal characteristics and role will affect the interview process and relationship, directly impacting the data. I am female, from a white/British background, of professional class/status, middle aged and hold professional qualifications both in Speech and Language Therapy and Integrative Counselling. I have worked in the field of adult acquired brain injury for more than 30 years.

In the research I had a dual role – as research interviewer and also as a member of the rehabilitation team by whom the clients are waiting to be assessed. This presented some concerns. The latter role could have resulted in clients giving responses to meet what they perceived to be the interviewer's expectations/wants (Britten 2006). This potential power imbalance may have been more relevant in some cases than others, if, for example, a client had past experience of power relationships that engendered distrust or fear, or of relationships that developed trust and enabled disclosure. It was not possible practically to

involve others in the collection or analysis of data, so it was crucial to give consideration to the potential issues resulting from my involvement in the research process.

As will be described more fully later in this chapter, an initial exploratory phase of the study was undertaken with three participant interviews. These allowed early reflection on my role within the interview process, as a result of which I noted some potential issues. To illustrate the nature of my reflections, it seems appropriate to offer these exploratory interactions as examples.

One client was a white/British male, in his 40s, with no professional training. Comments made in the interview suggested he came from a professional family but, as a result of long standing mental health issues, saw himself as less able. The experience of mental health care also meant he had probably had extensive experience of interview situations that had a clear power and status imbalance. As a man interviewed by a woman, he did not seem to be reticent to discuss emotional issues – an issue identified in the literature (e.g. Arendell 1997) but again his past may well have been a factor.

The second client was a white/British male of 55 years old, who worked in a manual job. He was from a working class background and spoke with a strong Northern English accent. He seemed less forthcoming in terms of emotional or underlying concerns, and tended to stick more to 'facts'. His comments in the interview suggested a lack of comfort with role/power imbalance based on age and sex. The final exploratory phase client was a white/British local woman of 40, who was professionally trained, but her training followed years of lower status work and she was from a non-professional family. She spoke with a local accent. She appeared comfortable with the interview format, and was able to express her emotional/deeper concerns openly – this was partly related to the organic damage, but also to her past experience, and may have also related to being comfortable talking to another woman.

3.2.3 Researcher behaviours

In addition to considering the interplay of the background personal characteristics of researcher and participant, I also needed to consider my behaviour during the interview.

One issue of which I needed to be aware was the danger of counselling rather than interviewing, a great temptation to a qualified Counsellor, especially with those participants who raised emotional or psychological concerns. For example, one client became distressed, and it was difficult not to interrupt the interview by taking a more active role in responding to her distress. In fact, in this case, I promised we would return to the issue after the recording was completed, as a way to ensure her concerns were not dismissed but that the interview did not turn into a counselling or information giving session, which would have affected the data adversely.

There was also the risk of presenting one's own perspective and risking biasing the interview. In interviewing one client, asking a question about his expectations of recovery led to a response that referred to the question – *'if you asked that you must mean I might not recover'*. On reflection the question was too directive and could have been worded more neutrally.

Further reflections on the researcher's role in the interview are included in the appendices.

3.3 Sampling strategy

3.3.1 Sample selection

As is apparent in the above description of context, clients would already have been 'selected' on the basis of the referral criteria and screening protocol. In defining the sampling strategy the question of using other criteria to identify potential participants was considered. Further selection on factors such as age, gender, diagnosis, family context, employment, or communication/cognitive abilities would presuppose the relevance of such factors rather than grounding any conclusions/theories in the data. It would create a false group in terms of the client population in this study.

At the same time, practical issues in relation to data collection from this client group could not be ignored. The majority of data would be obtained via interview and this population presents certain potential difficulties. Additional conditions frequently seen may mean data collection is problematic and information gathered would be restricted. Examples are :

- Severe communication disorder (especially aphasia where understanding is impaired),

- Severe cognitive impairment affecting recall of events/insight etc.
- Significant post-traumatic or retrograde amnesia
- Primary mental health issues e.g. psychosis, substance or alcohol abuse

Exclusion of these groups would limit the open-ended nature of exploring client views and risk pre-disposing towards certain themes.

A further factor to consider was that inclusion of all diagnostic groups would necessitate a much wider literature review, as much is focused either on Stroke or TBI, rather than the inclusive ABI population, which would have a time/resource implication. These terms have been defined in chapter one.

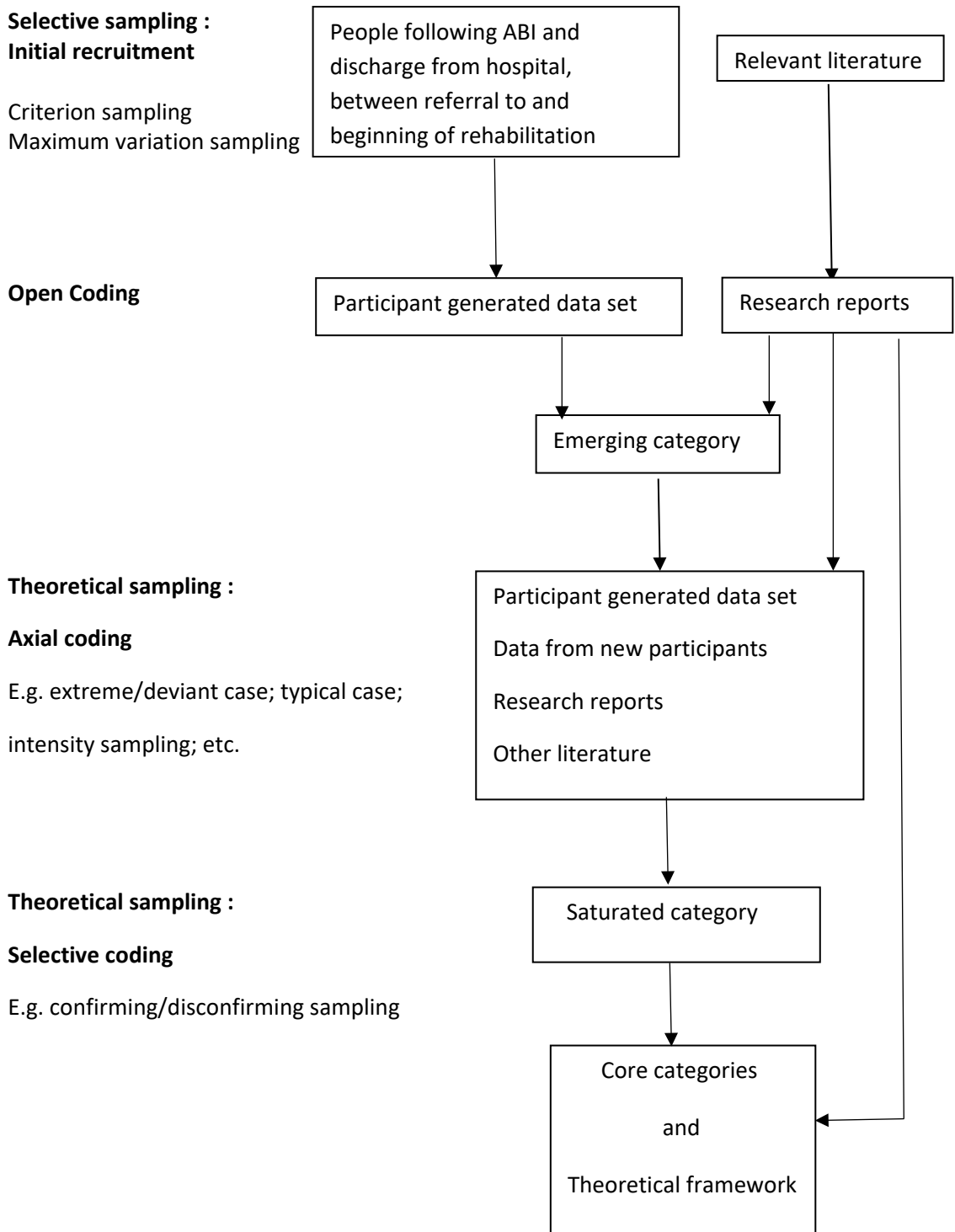
On reflection it was decided that sampling in the main study should not exclude clients on the basis of potential practical difficulties in gaining data. The advantage of gaining a broad range of perspectives outweighed the difficulties and seemed more in keeping with the research aim and context. The initial approach was therefore to identify clients purely on the basis of appropriate referral to the service and, thereafter, on agreement to take part (in line with ethical considerations). The only other criteria were that participants should have mental capacity and not need an interpreter if English was their second language. Tuckett (2004, p49) suggests that the decision not to exclude can increase capture of 'a multiplicity of perspectives'.

The specific recruitment strategy – for example to invite all those referred in a certain time frame, to invite every fifth referral, or to fit in with the practical time constraints of simultaneous data collection and analysis – and size of initial sample needed to be considered. In practice it proved unnecessary to define this specifically, as a result of the process for recruitment which will be outlined later in this chapter.

Purposeful, criterion based sampling at the initial stage, led on to theoretical sampling. Brown and Lloyd (2001, p351) describe the 'relation between sampling and explanation as iterative and theory led'. The suggested strategies are represented in the framework (figure 3:1), based on Draucker et al.,'s model (2007).

However, having made the decision not to exclude 'difficult to interview' clients, It was felt that exclusion of these groups in the initial phase of research might offer useful information on the proposed process, that could allow more focused/supported interaction with such clients at a later stage, through the development of more structured questions based on

Fig 3:1 Sampling Framework (Based on Draucker et al., 2007)



initial responses from other clients. Therefore, while the intention for the full study was to include any client who met the criteria for referral to the service, and specifically not to exclude clients with communicative or cognitive impairments that make interviewing difficult, it was decided to undertake an initial exploratory study. This would allow evaluation of the interview schedule and process, and potentially enable refinements and adaptations that would facilitate later interviews with less able clients. The initial three clients were, therefore, selected on the basis of meeting referral criteria for the service *and* being able to take part in a verbal interview – that is, they did not appear to have significant communication or cognitive impairments.

The full study included clients with communication and cognitive impairments and consideration was given to the specific issues involved in recruiting, getting consent and interviewing such clients.

3.3.2 Sample size

As noted in chapter two, it is difficult in qualitative research of this nature to define clearly at the outset how many participants will be interviewed, as data collection continues to saturation. At the same time it is accepted that sample sizes are small, with perhaps 8-12 participants. It was decided to request ethical consent for a maximum of 24, in addition to the three participants in the exploratory phase of the study.

3.3.3 Recruitment procedure/process

During the screening, Rehabilitation Team Coordinators assessed clients as to whether they met the initial referral criteria for the service and established whether there was any doubt about mental capacity. Appropriate clients were then asked if they would be prepared to be contacted by the researcher. Those who agreed were telephoned and asked if the researcher could visit them at home, to explain the project.

The flow of referrals proved manageable as there was a proportion who refused to take part (details of which are reported in chapter four) without needing to specify further strategies, but no record was kept of cases where the coordinator did not refer to the study.

At the explanatory visit clients were given verbal and written information. In line with Flory and Emmanuel (2004), there was opportunity to ask questions and enter into dialogue, and the reading level of material was considered. It was made clear to clients that they could refuse to take part at any point. Clients were contacted 3-5 days following the visit for their decision, by a service administrator rather than the researcher, as it was agreed this would reduce pressure on them to agree to take part. If the individual agreed to be a participant, a time was arranged at his or her convenience, for the interview.

3.4 Adapting consent forms and information provision

An Information sheet and a consent form were drawn up, which would be appropriate for clients who were able to read. However, the discussion in chapter two considering the issue of informed consent with people with aphasia and/or cognitive impairments, led to the following decisions:

- Proxy consent should not be sought. If a person did not have capacity they would not be included in the research study. However, in the case of people with severe levels of communication/cognitive difficulty, it may be appropriate to involve a carer/relative or other advocate in the consent process, to facilitate understanding.
- A suitably adapted form should be used, based upon research into aphasia friendly materials, which would consider the content and design of the form.
- The form should be presented and discussed on a one-to-one basis with each potential participant, by someone trained and skilled in using multi-modal methods in a flexible way, and allowing time properly to cover issues at the individual's level.
- A comprehension verification should be undertaken, at the time the material is presented.

3.4.1 Content and design

Having made the decision to adapt consent forms and information giving in order to facilitate those participants who had a significant communication and/or cognitive impairment, the question remained as to how best to do this. There has been an increase in interest in the need for so-called 'aphasia friendly' materials recently, stemming from studies finding how little material was available, making accessibility hard for people with aphasia. Aleligay et al.,

(2008) for example, found that readability levels of written health materials given to people with aphasia were inappropriately high, and there was a lack of sufficiently modified information.

Various authors have suggested principles and guidelines for making information more accessible (e.g. Rose et al., 2011; Dalemans et al., 2009; Pound et al., 2001). However, as Brennan et al., (2005) point out, such advice is not always evidence based. They looked at the effect of recommended formats on reading comprehension in people with aphasia, and found that overall they do improve comprehension. However the value of pictures – despite widespread recommendation – was unclear. They offer several possible explanations for this, such as distraction, preference, clarity, relevance and age-appropriateness of pictures used.

They consider the importance of both content and design, suggesting, for example, that typography is a form of paralanguage – ‘that is, the relationship of typography to written expression may be analogous to the relationship of gesture and tone of voice to verbal expression’ (p 707). Rose et al., (2011) looked at content and design characteristics through interviews with people with aphasia, so that both understanding and preferences could be considered. They identified facilitators and barriers within content (amount of information, amount of text, language and relevance) and design (typography, layout, emphasis, document type, colour and graphics). While they do draw attention to the fact that there will still be individual preferences and no one formatting style will suit all, their paper offers valuable guidance. They also note that dialogue can support or hinder understanding of written materials.

There is a need for further research into the best ways by which to make information more accessible to people with aphasia, and a lack of a definitive evidence base. There is an almost complete absence of specific advice for use with people who have cognitive impairments following acquired brain injury, but there seem to be many principles relevant to both groups – such as limiting the amount of information, avoiding distracting layouts and so on. Therefore, based on current evidence and consensus within speech and language therapy, a set of guidelines was developed covering content and design. The information sheet and consent form were adapted in line with these guidelines, and are in the appendices.

3.4.2 Presentation of information

As mentioned in chapter two, the recommendation of Brunack-Mayer and Hersh (2001), Richards and Schwartz (2001), and Kagan and Kimelman (1995), among others, is that information should be presented by suitably trained and skilled people, who can adapt to the needs of people with communication disorder. They also advocate allowing time for clients to consider and question the information, raise concerns and make a decision within a dialogue.

The adapted materials were presented by the researcher, who is an SLT experienced in working with brain injured clients. There is a potential conflict in that the researcher is also a member of the rehabilitation service to which the potential subjects have been referred. Attention was given to ensuring that people understood the roles and did not fear any negative consequences on their therapy from refusal to take part.

3.4.3 Verification of understanding

It was important to be sure that participants were making informed decisions about taking part, and as suggested by Wirshing et al., (1988) a short questionnaire was used to check understanding. This was also developed in line with the guidelines, and is in the appendices. A questionnaire was also used with those who were able to read the standard information sheet.

3.5 Data collection

3.5.1 Interviews and transcription

An interview is a directed conversation (Lofland & Lofland 1995) which permits an in-depth exploration of a topic, with a person or people who have had the relevant experience to shed light on it (Fontana & Frey 2000). Based on recommendations discussed in chapter two, interviews were conducted in the client's home and lasted between 50 -60 minutes. Clients were informed that this time could be shortened in recognition of the fatigue experienced by many people following brain injury. The interviews were audio-recorded and followed a flexible interview schedule.

There is a general acceptance that interviewees feel most comfortable if the interview can be conducted in familiar surroundings. These interviews all took place in the client's own home, as did the initial explanatory visit to seek consent. Interviewees chose where in their home to locate the interview and placement of chairs and recording device.

It was decided prior to the interview that there would be an audio recording, using a small recorder to be as unobtrusive as possible, and that there would not be notes made during the interaction – partly to reduce the client's sense of being recorded/studied and also to allow greater focus from the interviewer on what was said. It is accepted that this means some details may be missed, but it was felt the better compromise. Videoing was felt to be more intrusive and more likely to affect the client's level of comfort.

Suitable adaptations were made for participants who had communication disorders, including additional written information, availability of resources such as pen/paper, and – in two cases – at the participant's request their partner remained during the interview to offer support/interpretations.

O'Connell and Kowal (1994, p103) state the 'primary goal of transcription is not really readability but usability of the transcribed data for purposes of scientific analysis.' The recordings were transcribed verbatim as soon as possible following the interview, and immediately after the interview field notes were made of the researcher's perceptions and observations. Silverman (2011, p279) suggests that 'there cannot be totally "complete" data any more than there can be a perfect transcription'.

In the transcripts, in order to maintain anonymity, for the purposes of this study, clients were given pseudonyms; initials in alphabetical order were used for children to indicate their position in the family (ie. The first child was A, second B and so on); and other named individuals or places were given initials.

The interviewer's words were transcribed in italics. Overlapping speech was indicated by the use of brackets around the relevant words. If utterances were indistinct, open brackets were used. Descriptions of non-verbal behavior, such as crying or laughter, were in italics and bracketed. Pauses were indicated by, giving a suggestion of the length, but were not timed. However timings were appended to the transcript at 30 second intervals to indicate the speed of discourse.

3.5.2 Exploratory phase

Initially three interviews were undertaken as an exploratory phase, the aim of which was to justify the decisions made in relation to research design, and to evaluate the appropriateness of the method of data collection and analysis in relation to the research aims and questions initially identified. The method did seem to allow the collection of rich data, the analysis of that data, and findings relevant to the aim of understanding more about individual perceptions and experiences.

Following the exploratory phase, the researcher undertook a detailed reflection based on the transcripts of the interviews, and in the light of the literature on interviewing in chapter two – for example relating to the type of question and the responses and technique of the researcher (Smith and Osborn 2006). This was felt to be useful as a learning exercise, in order to approach the main study with greater awareness of the process. No major changes were considered necessary. This reflection can be found in the appendices.

3.5.3 Interview content

The interviews fall between semi-structured and open/depth. There was a clear schedule, including prompts, which directed the interviewee to certain areas reflecting the research question/focus. However, there was the intention to allow the interviewee to develop discussion within these areas via use of open questions and the least directive interventions (Whyte 1982). The schedule was evaluated against the recommendations in chapter two (e.g. Smith and Osborn 2006). In relation to the specific format and questions included on the schedule, the introductory and closing sections were designed in line with the guidance/advice in terms of starting and ending with less sensitive areas. The questions were open and not too explicit and free of jargon (other than the deliberate use of the word 'rehabilitation' in order to check their understanding of the term). The schedule sought to ensure that questions followed in a logical order, and therefore could lead in to the next area. The suggested prompts worked effectively. As a result of the exploratory phase, minor alterations were made to the schedule - more neutral wording and avoidance of one leading and one yes/no question.

Field and Morse (1989) offer a list of eleven common pitfalls in interviewing, such as interruptions, summarising too quickly, presenting one's own perspective and jumping

between subjects. Another issue that Britten mentions (2006) is that of being asked questions – as he states ‘the problem with this is that in answering questions, clinical researchers may undo earlier efforts not to impose their own concepts on the interview’ (p16). He suggests one possible, albeit not ideal, method is to promise to return to the question/issue at the end of the interview. This technique was used on a number of occasions.

It was decided that the researcher would have the schedule for referral during the interview, to facilitate the consistency and flow of interaction. The interview schedule is included in the appendices.

3.6 Data analysis

3.6.1 Coding

The analysis procedure remained the same following the exploratory phase of the study, as it provided a clear and transparent system, and the grounded theory method of analysis used, based in the social constructivist approach of Charmaz (2006), generated a tentative model and categories relevant to the research question. There was internal consistency between the stated epistemological, methodological and method decisions made.

The question of whether to use a software programme to facilitate analysis, such as NVivo, was considered, and the programme was investigated in order to evaluate its potential within this study. The decision was taken not to use a computer programme to assist in the coding/categorisation of data, as it was felt that the researcher would gain more by immersion in the data and that this would enable implicit and ‘hidden’ meanings to be accessed, rather than merely frequency of codes, and could take into account non-verbal behaviour and field notes of relevance. However, the programme was used as a check on categories, as will be explained later in this chapter.

To ensure immersion in the data, the researcher transcribed all the interviews personally, and data was read and re-read prior to the initial coding. Each interview was separately coded. In addition to the transcript, field notes were made immediately following the interview. Memos were written throughout the process.

3.6.1.1 Initial coding

Charmaz (2006, p43) defines coding as ‘naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data. Coding is the first step in moving beyond concrete statements in the data to making analytic interpretations. We aim to make an interpretative rendering that begins with coding and illuminates studied life’.

Table 3:1 Initial Line by line coding

<p>Hoping for a friendly environment Acknowledging never good at going to new places Being concerned about first visit</p>	<p><i>So you don't really know what to expect. Do you know ...do you have any particular hopes for it rather than expectations?</i> Well I hope it'll be a friendly place I'm not very good – I never have been – at going somewhere strange...of going you know into a crowded place. I'm not very good with – I suppose I'm not I'm just not very good with being there as a first time, so I find that concerning. I find the idea that transport is being provided and that</p>	<p>31:00</p>
<p>Worrying that transport means she has to stay until allowed to go home Feeling trapped/not in control</p>	<p>kind of makes you feel as if you've got to stay until they can bring you home, even if you don't want to. <i>So that feels a bit trapping?</i></p>	<p>31:30</p>
<p>Seeing transport as taking control away from her Being controlled by centre Not wanting to be controlled</p>	<p>It does – it feels as if I've got to be there for a specific time because that's your decision...or their decision rather because you're not part of it, so it will be their decision if I'm going to stay x number of hours or whatever and I would rather not be in that position.</p>	<p>32:00</p>
<p>Wanting to be able to leave at her choice Feeling centre would be in charge and she would have no say Fearing what she thinks would not matter</p>	<p><i>Sure</i> Because you know you feel like you need to get up and go when you've had enough. <i>So it sounds as if you sort of expect that they will be in charge?</i> They....Yes I feel as if they are in charge and that I've got to do whatever they want me to do and I feel as if they are in charge of me...where I've got...you know I suppose you know what I think doesn't matter.</p>	<p>32:30</p>

Initial coding of the data was done line-by-line, and – as recommended by Charmaz (2006) – invoked the ‘language of actions’, using actions and processes as descriptions, and avoiding use of pre-existing categories. Constant comparison method was followed (Glaser & Strauss

1967) to establish analytic distinctions, within each interview transcript and subsequently between transcripts. Attention was paid to the clients' own use of language and some codes were in-vivo (that is, used the participants' language). An example of line-by-line coding is shown in Table 3:1.

3.6.1.2 Tentative categories/focused coding

The second major phase in coding is focused coding. Glaser (1978) describes these codes as more 'directed, selective, and conceptual'. Developing line-by-line codes allowed systematic searching for significant and recurring items of interest and themes. The line-by-line codes from each interview were printed out and also sorted by hand. Codes were compared and grouped into tentative categories. The intention was to reflect as many nuances as possible at this stage, not to reduce to a few codes.

Table 3:2 Focused coding (Shirley)

Seeing rehab as teaching you normal Having to come to grips with normality	SEEING REHAB AS MAKING NORMAL
Hoping to recover completely	HOPING TO RECOVER FULLY
Having hope she can improve Hoping to improve life Hoping to improve physically Hoping to improve memory	HOPING TO IMPROVE
Questioning if she needs rehab as feels normal Having the impression the centre was a good place before the accident Not knowing why the centre would be good Being told centre can help her Feeling isolated by not knowing what centre can do	NOT KNOWING WHAT REHAB SERVICE CAN DO
Being concerned about first visit Thinking best in home environment as in control Being told they could sort it out for you Feeling taken over Feeling controlled	FEARING BEING CONTROLLED BY REHAB

The focused codes were then compared across transcripts, and the initial transcripts re-examined to check the adequacy of the codes. Charmaz (2006, p57) states that ‘focused coding requires decisions to be made about which initial codes make the most analytic sense to categorize your data incisively and completely’. Table 3:2 illustrates this stage within an individual transcript, and Table 3:3 illustrates the comparison of transcripts across participants as data collection continued.

Table 3:3 Focused coding across transcripts

SEEING REHAB AS MAKING NORMAL NOT KNOWING WHAT REHAB SERVICE CAN DO	Not knowing about rehab
HOPING TO RECOVER FULLY HOPING TO IMPROVE	Hoping
FEARING BEING CONTROLLED BY REHAB (AS IN HOSPITAL) WANTING COMFORTABLE/ FRIENDLY SETTING WANTING PROMISES TO BE KEPT EXPECTING HELP WITH SPECIFIC AREAS FEELING EXAMINED BEING ENCOURAGED WANTING TO FEEL THERAPISTS ENGAGED/ INTERESTED NEEDING PEOPLE WHO CARE NEEDING TO TALK FEARING HAVING NO VOICE WANTING HONEST INFORMATION NEEDING CLEAR LANGUAGE NOT MEDICAL JARGON	Expectations of services
WANTING TO BE IN CONTROL TRYING HARD DOING AS TOLD/ACCEPTING ADVICE	Expectations of self

Strauss and Corbin (1998) describe a third type of coding – axial coding – which ‘relates categories to subcategories, specifies the properties and dimensions of a category and reassembles the data you have fractured during initial coding to give coherence to the emerging analysis’ (Charmaz 2006 p60). This stage offers, in Strauss and Corbin’s terms, a framework which researchers can apply in analysing data. This stage was not formally followed, as it was felt that greater flexibility would be beneficial, rather than using a pre-set structure. However, links between categories and subcategories were developed as sense was made of the data. Constant comparison of codes and categories was undertaken throughout the study.

3.6.1.3 Theoretical coding

Charmaz (2006, p63) defines theoretical coding as ‘a sophisticated level of coding that follows the codes you have selected during focused coding’ and specifies ‘possible relationships between categories’. It moves the analysis in a theoretical, more abstract direction – from the specific to the general.

The focused codes developed by constant comparison within and across transcripts were re-examined and memos written to refine conceptual categories. The resulting categories were then checked back against the original data and further refined. This process was continuing alongside collecting further data, so new data was fed into the process constantly. Table 3:4 shows an example of categories developed at the end of the data collection/analysis stage, with comparison across the data from all 21 participants (numbers indicate the number of clients whose data fell into the various categories).

While NVivo software was not used in the main analysis, it was employed as a means of checking the validity of the categories as applied to each transcript. The original transcripts were imported to the software programme and the tentative categories were applied to the data. This ensured that all the data was incorporated within the final analysis, and that the final categories did not omit areas or aspects of significance to the participants.

Interviews continued until saturation was reached, and no further new information was discovered. Table 3:4 illustrates the linking of categories in formulating the main category ‘Hoping-Despairing’, and includes a numerical indication of the number of client interviews in which the codes appeared. The first code – expecting/hoping for full recovery – for example, was found in 18 of the 21 interviews.

3.4.1.4 Modelling

As the categories were developed, they were used to model the process based upon the data. In modelling, the theoretical categories were further refined and the final six categories described in chapter four were developed. The model described later in this thesis is based upon these. The six categories are: HOPING-DESPAIRING; MAKING SENSE OF WHAT HAS HAPPENED; MOVING FORWARD; WHAT CAN I DO?; TRUSTING/DOUBTING OTHERS; and ACCEPTING. A separate chapter (five) addresses the development of the model, as data collection and analysis moved forward.

Table 3:4 Theoretical coding

Expecting/hoping for full recovery 18	HOPING
Doubting full recovery/miracle cure 15 Hoping to improve, not recover fully 11 Impact of experience on expectation of recovery 2 Wanting to turn the clock back 1	DOUBTING
Putting on a brave face/hiding negatives 10 Trying to keep doubts at bay/hang on to hope 7 Trying to normalise feelings 4	KEEPING DOUBTS AT BAY
Despairing 5	DESPAIRING
Adjusting expectations for the future 9 Coming to acceptance 2	ADJUSTING/ACCEPTING
Taking stock – new priorities 11 Finding a meaning in life 7 Wanting to help/give back 5	TAKING STOCK/NEW MEANING

3.6.2 Analysis reliability

Ethical approval was obtained to allow a second researcher to review the analysis of the three exploratory phase texts. The reviewer was given the complete text for all three participant interviews. The text was colour coded to identify the main preliminary categories thought to apply, although it was noted that sections of text did overlap categories. In addition the reviewer had the initial line by line analysis. It was acknowledged that the categories would change as data collection continued, but it was thought important to evaluate the researcher's approach and check that the logic of her analysis was clear to others.

In total, within approximately 180 minutes of transcribed data, lack of clarity as to the rationale for allocation to a specific category was found in 15 examples. The reviewer noted overlap in 15 other sections, when text could be placed in more than one category

In considering the lack of clarity **and** overlap it was clear that, at this preliminary stage, three categories were particularly open to discussion. One category (Trusting/Doubting self and others) accounted for twelve out of the 30 examples noted by the reviewer, and two further categories together accounted for 13. When the interim stages of analysis were reviewed, in fact the overlaps had been taken into account. These early categories were modified as a result of further data collection in the main study, which seems to acknowledge the less good 'fit' of these particular concepts.

In general the questioning of clarity in 15 examples from approximately three hours of transcripts suggested the logic of the analytic method used was valid, in relation to the specific transcripts analysed.

3.7 Chapter summary

An exploratory phase allowed evaluation of the methodology and methods chosen and their appropriateness to the research question. A number of minor amendments to the process were made, but the choice of grounded theory, in its social constructivist form, was considered justified. As with any research methodology, it is important to be clear about the

claims made, and to reflect fully on the limitations of any findings. This will be addressed in a later chapter.

This chapter has described the specific methods used in the study, covering ethics, context, reflexivity, sampling/recruitment, data collection, and data analysis. In relation to recruitment, attention has been given to the needs of people with communication or cognitive impairments, both for obtaining consent and interviewing. The inclusion of this population is important if findings are to be relevant to the area of Acquired Brain Injury in general, as has been stated.

Chapter four describes the participants and the findings of the analysis.

Chapter Four - Findings

4.1 Introduction

The primary objective of the study was to increase understanding of the client's perspective, based on data from interviews. However, during the research it became apparent that, while learning more about the expectations of clients would provide information relevant to developing a model to inform service delivery, it would also be interesting to have a sense of how client expectations were related to those of clinicians in the field.

This led to an additional aim, which was to increase knowledge and awareness of the views of clinicians in the same service. It was felt that this would be useful in looking at implications for service delivery changes and recommendations. Chapter seven describes the use of a focus group to look at clinicians' views, and compares the findings with those from the study, addressed in this chapter, of client views.

4.2 Participant characteristics

In qualitative research it is accepted good practice (as was discussed in chapter two) that as much information about context as possible is included. This enables people to consider the findings in the light of the setting and participant characteristics, which in turn allows evaluation of the transferability of findings to other settings and populations. It was felt that, for this reason, information should also be provided in relation to those who chose not to take part in the study, as well as the participants.

In describing the characteristics of the sample, confidentiality is an important consideration, as the study is within a relatively small service and specified geographical area. For this reason names have been changed, and are not given for those who did not take part, and age ranges, rather than specific ages, are used. Aetiologies have been categorised as stroke, traumatic brain injury (accident or assault), and other (such as infection or sub-arachnoid haemorrhage). Some participants had unusual aetiologies that could have increased the risk that they would be identifiable.

It was decided that it may be of greater interest in describing the participants to note whether they live alone or not, rather than marital status, and for this reason classification is P – with partner, D – with other dependent, and Y – lives alone. This information was not available for those who refused to take part, and is therefore not included in Table 4:1.

Communication disorders are classified as None, Dysarthria, Dysphasia (which may co-exist with dyspraxia but this diagnosis was not always clear at this point, so the two conditions have been joined) and Cognitive-Communication Disorder (CCD). These classifications are based on the initial information on referral and the subjective opinion of the researcher at the initial visit and interview.

In total 30 people agreed to the researcher visiting to explain the research, and were given written and verbal information about the study. Time was allowed for questions and discussion, and it was explained that they would be contacted by telephone (by someone other than the researcher) within 2-3 days to ask if they did or did not choose to take part. As a result of this process, nine people refused and 21 agreed to be interviewed.

Table 4:1 Characteristics of people refusing to participate in study

Number	Male/ Female	Age	Lives alone?	Aetiology	Communication Disorder?	Reason for refusal
1	F	40-49	Y	other	No	fatigue
2	M	70+	P	stroke	Dysphasia	Wife responded
3	F	50-59	Y	stroke	No	Moved out of area
4	F	50-59	Y	other	Dysarthria/CCD	Hospital refused
5	M	70+	P	stroke	CCD	Time scale not possible
6	F	60-69	P	stroke	No	Too much to take on
7	M	60-69	P	stroke	No	Too much to take on
8	M	40-49	P	Stroke	Dysphasia	Wife responded
9	M	30-39	P	stroke	Dysarthria	Wife responded

The reasons for refusal were varied, and are listed in table 4:1. In 4 cases, all of whom had significant communication impairments, it was not possible to know whether the decision was made by the client – three were male and the decision was conveyed by their wives, and in the final case the client was female but the timescale of her first appointment necessitated the interview taking place in hospital, which was vetoed by the hospital authorities (although the client had agreed). It is outside the remit of this study, but interesting to speculate about the possibility that people with communication impairments have reduced personal decision making opportunities.

Table 4:1 includes information on age, living arrangements and aetiology in order to allow a broad comparison with the people who did agree to take part in the research. There were no discernible common characteristics between those who agreed and those who refused. Details regarding the time since onset and employment were not available prior to engaging in the process and gaining consent.

The data for the three exploratory and 18 main study participants have been combined for purposes of analysis, as there was no significant change made to the process or interview following the exploratory phase, and prospective ethical approval was obtained for the exploratory data to be part of the final analysis (Table 4:2).

There was a high incidence in this study of participants who were employed at the time of the event, but it should be noted that all four of the participants who were not in employment *per se*, were active and busy with other activities at the time of the event. Three were retired on age grounds and one as a life style choice, influenced by an existing medical condition.

While it is important to offer as much contextual information as possible in qualitative research, as has been stated, table 4:2 is quite dense and the following allows a quick reference in relation to the various parameters:

- There were ten men and eleven women.
- Eight people were aged between 40-49; seven were between 50-59; five were between 60-69; and one was over 70.
- Eleven were diagnosed as having had a stroke, four with TBI, and six with other aetiologies.
- 15 were living with a partner, four with another dependant, and two alone.

- 17 were working at the time of the ABI, and four were not in employment.
- Four people had aphasia, two dysarthria, seven cognitive-communication disorder and eight had no communication impairment.
- Time since onset was between 0-99 days for nine people; 100-199 days for eight people; 200-299 for two people; 300-399 for one person; and more than 400 for one person.

Table 4:2 Characteristics of participants

No.	Study name	M/F	Age	Living with	In work	Aetiology	Time since onset in months	Communication Disorder
1	Simon	M	40-49	P	Y	TBI	4.1	CCD
2	Mandy	F	40-49	D	Y	Other	3.0	N
3	Doug	M	50-59	P	Y	Stroke	9.3	N
4	Derek	M	60-69	P	Y	TBI	3.9	Dysarthria
5	Billie	F	60-69	P	N	Stroke	12.0	CCD
6	Kendra	F	40-49	P	Y	Other	1.1	N
7	Ben	M	60-69	P	N	Stroke	2.4	N
8	Maureen	F	50-59	P	Y	Stroke	4.4	N
9	Keith	M	50-59	P	Y	Stroke	2.7	N
10	Harry	M	50-59	P	Y	Other	13 years	CCD
11	Roy	M	50-59	D	Y	Other	4.5	N
12	Joyce	F	60-69	N	Y	Stroke	2.5	CCD
13	Annie	F	40-49	P	Y	Other	4.4	CCD
14	Sanjay	M	40-49	P	Y	TBI	2.4	CCD
15	Andrew	M	50-59	P	Y	Stroke	5.1	Dysphasia
16	Shirley	F	50-59	D	Y	TBI	3.2	N
17	Susanna	F	40-49	P	Y	Other	3.9	CCD
18	Sylvia	F	40-49	P	N	Stroke	8.6	Dysarthria
19	Susan	F	40-49	D	Y	Stroke	1.8	Dysphasia
20	John	M	60-69	P	Y	Stroke	1.5	Dysphasia
21	Trisha	F	70+	N	N	stroke	5.4	Dysphasia

4.3 Analysis: Categories and Sub-categories

Six theoretical categories were identified, and the theoretical model described later in this thesis is based upon these. The six categories are: HOPING-DESPAIRING, MAKING SENSE OF WHAT HAS HAPPENED; MOVING FORWARD; WHAT CAN I DO; TRUSTING/DOUBTING OTHERS; and ACCEPTING.

This study was based upon interviews at a single point in time, when people had been discharged from hospital and were at home, waiting to be seen by community based rehabilitation.

The core category was HOPING-DESPAIRING. As will be addressed more fully in the discussion in chapter six, participants tended to prefer the word 'hope' rather than 'expectation'. The centrality of this category was not dependent on the quantity of data, as some other categories had more examples, but throughout the modelling process described in chapter five, it was consistently HOPING-DESPAIRING that held the model together.

The period in and after hospital, up to the interview point, had been about MAKING SENSE OF WHAT HAS HAPPENED and this broad category encompassed pre-morbid and post morbid experiences and beliefs, as well as the life context in which the event occurred.

Three categories related to the perceptions and beliefs held at the point of interview: MOVING FORWARD, WHAT CAN I DO? and TRUSTING/DOUBTING OTHERS. The first of these categories may be seen as having influenced the expectations people had of recovery based on their experiences so far, while the latter – the perception that self and others have power to have an impact on progress – were factors in their expectations both of recovery and of the rehabilitation process.

The category TRUSTING/DOUBTING OTHERS is substantial, but it was considered important to represent it fully as it incorporates specific expectations and beliefs about rehabilitation, which will be picked up in the comparison with clinicians' views in chapter seven, and which are crucial to the therapeutic implications drawn in chapter eight. The central category of HOPING- DOUBTING uses the same term – doubting – and consideration was given to whether the terminology was appropriate in both instances. It was seen as justified as the terminology reflected the words used by interviewees themselves in different contexts.

The final category – ACCEPTING - was included despite very little data. It was based substantially on one ‘outlier’, a client who had been re-referred to the service many years post-onset, but it was important not to neglect a ‘negative’ case in the data, and his experiences and perceptions were clearly of as much value as other participants. It also perhaps suggests the value of further research into the impact of time on beliefs and perceptions.

It is proposed that the expectations of recovery and of rehabilitation will both determine where the individual lies on the spectrum of beliefs about recovery, from hope to despair, and the degree of engagement with rehabilitation. The resulting theoretical model will suggest that this becomes a cyclical process, so that the individual’s position on the spectrum is dynamic and changing, depending on whether expectations are met.

Table 4:3 Categories

Theoretical category	Sub-Category	Illustration
HOPING-DESPAIRING SPECTRUM	Hoping Doubting Keeping doubts at bay Despairing	<i>One hundred percent My mojo’s not coming back I’m trying to keep them at bay I just want to lie down and die</i>
MAKING SENSE OF WHAT HAS HAPPENED	Premorbid beliefs/knowledge Life context What’s going on? – Post-morbid questioning	<i>I wish I’d been more understanding You really don’t pay attention A double whammy: Brain Injury and a crap life It just came out of the blue What’s all the fuss about I was on another wavelength I’d love to know why</i>
MOVING FORWARD	Perception of progress Beginning to adapt Recognising positives	<i>I say time....time My first miracle It’s just not coming If I started to cry Making adaptations I’m over the moon</i>

WHAT CAN I DO?	<p>Being the same but not the same</p> <p>Taking stock</p> <p>Doing what I can</p>	<p><i>I'm the same person...but not the same</i> <i>I'm glad I wasn't like that</i> <i>What – no blood? – feeling judged</i> <i>I've caused so much stress</i></p> <p><i>I'd lost the meaning of life</i></p> <p><i>I am the director - taking control</i> <i>Nobody's going to do it for me</i> <i>I'm up for the challenge</i></p>
TRUSTING/DOUBTING OTHERS	<p>Early experiences</p> <p>Expectations of Family Support</p> <p>Expectations of services: expertise</p> <p>Expectations of services: Therapeutic alliance</p> <p>Expectations of services: Support for family</p>	<p><i>I just wanted to get out of there</i> <i>Rehab experiences</i> <i>A stepping stone -What is rehabilitation?</i> <i>I've been told different by the other</i></p> <p><i>Do their best</i></p> <p><i>I was expecting someone ...but....</i> <i>There's no shame in it</i> <i>Guidance is the word</i> <i>If they wanted me to...</i> <i>I wish I'd known that sooner</i> <i>I've got to trust</i></p> <p><i>She said it didn't matter</i> <i>I needed to talk to someone</i> <i>I needed someone to care</i> <i>Look I'm not stupid</i> <i>You're doing really well</i></p> <p><i>She's got it 24 hours a day</i></p>
ACCEPTING	Accepting/adjusting expectations	<i>No delusions of recovery</i>

The main categories and sub-categories are summarised in table 4:3 and each will be discussed in turn. However, it must be stated that there is overlap between the areas. It has also been acknowledged that, in qualitative research, the interpretation of the data is a co-constructed 'reality' resulting from the interplay of the data and the researcher. Attention has already been given to the characteristics of the researcher, which undoubtedly influence the following interpretation and theoretical model. However, this chapter will seek to offer

enough examples and illustrations from the data – the participants’ own words – to support this interpretation as logical and valid. A primary quality requirement of qualitative research is to provide adequate examples from the actual data.

Chapter five will describe the theoretical model that grew from the data, and will discuss this as an evolutionary process, illustrating how the model developed from an initial tentative framework, evolving through a number of incarnations as data collection and analysis continued iteratively.

4.4 HOPING-DESPAIRING SPECTRUM

As the simultaneous collection and analysis of data continued, and an interpretive model was evolving, the category HOPING-DESPAIRING was becoming central, as has already been stated, with the other categories appearing to influence where participants were on the hope-despair spectrum. Therefore the discussion will begin with this category.

The categories MAKING SENSE OF WHAT HAS HAPPENED, perceptions of MOVING FORWARD, a sense of self-efficacy (WHAT CAN I DO?) and belief and trust in rehabilitation (TRUSTING/DOUBTING OTHERS) shaped the beliefs and expectations of participants in relation to where they were on the spectrum between hope and despair. It is important, of course, to bear in mind that these interviews were at one point in the pathway, but at this stage some remained hopeful that they would recover fully, many had at least the beginnings of doubt, and some were in despair.

4.4.1 “One hundred percent” - Hoping and expecting

There was a significant group of participants who said that they expected to recover fully and were happy to use the term ‘expectation’, which implied a belief that recovery would happen. Kendra said *‘recovery wise....I expect within three months to be more or less back to my normal self’*. Sanjay was optimistic: *‘personally I view it as a temporary thing, you know I’ll go back to work eventually and that’ll be that.’* Susan expected to be where she was before *‘hundred percent’*. Susanna did not want to use the term ‘hope’: *‘I think hope – hope – is almost – I don’t think I’m even hoping actually – I think I’ve got set in my mind that it will.....it just will happen.’* Sylvia believed she had accepted the stroke, but *‘I’ve also accepted that I*

can get better....well no, I will get better....if other people can recover from stroke, so can I.'

As will be seen, however, even people who expressed these views, had emerging doubts.

For others the term 'hope' may be more appropriate than 'expectation' at this stage, and participants asked about their expectations often used the term 'hope' in their reply instead. Hoping for full recovery was mentioned by more than half of participants, but in many cases they also made comments that implied, or explicitly acknowledged, that they saw this as unlikely.

Andrew hoped to be *'right back before the stroke'*; Annie asked if she thought she would get 100% back replied *'I would hope I would'*; Ben had *'not given upum...total recovery'*; Maureen wanted to *'just carry on as if this never happened'*; John hoped for *'full recovery'*; Mandy wanted *'to get back where I am to get back to work until I'm totally as I was before'*; Keith was *'hoping there won't be any restrictions on what I can do'*; and Shirley hoped *'that I will recover completely'*. Joyce used the term 'magic fix' – *'that's what I'm looking for – I'm looking for a magic fix to sort my head out'* but recognized this as *'an unrealistic desire'*.

4.4.2 "My mojo's not coming back" – Doubting

Thus, while maintaining an overt stance of expecting to recover, doubts and questions began to creep in. Contradictory statements and questions reflected this ambivalence.

Simon illustrated this paradox, when he stated categorically when asked if he thought he would recover to his former level: *'I've never even entertained the thought otherwise – why would you'*, and *'I'd be absolutely gutted if I didn't get one hundred percent'*. He said: *'I have to get my mojo back and I have to get back to work and I have to be good at what I do.....I mean obviously people don't always get better when you bang your head but I can't consider anything else'*. However further into the interview he admitted *'the thought has glanced into my head but never....as much as it's in my head I won't consider it'*, and he clearly expressed his concerns that: *'It just started making me really scared because I'm not getting....my mojo's not coming back'; 'I'm not slipping into it as I thought I would'; and 'I'm just paranoid that it's not going to come back.'* Mandy too exemplified the ambivalence, when she said - *'I just want to get back to where I am to get to work until I'm totally as I was before'*, and yet overtly recognized she may not get back to her former work : *'Even if I didn't get back to [what I did] as long as I had a job and could provide for my children'*.

When reference is to expectation rather than hope Mandy, for instance, knew that she should: *'not expect too much but I know I do expect too much'*, suggesting that she was developing some awareness of doubt about full recovery. She said: *'me being back to how I was would be marvelous....if I could get anywhere near that.'* Even Susanna, quoted above as expecting to recover fully, later said: *'I'm expecting it because I think I need to aim for that...um....there are some doubts. If I'm very honest'* and *'Do I think that will be 100%? No I don't. But I need....I think I'll be as near as damn...'*

Despite expressing hope, some were explicit in their expectation that they would not get back fully, but did continue to expect further improvement and to be as good as possible. Trisha said *'I hope to....I'd like to do....go further'* and Maureen agreed, but *'how much....I really, really don't know.'* Andrew admitted *'I know that I most probably won't be able to get back but as much as I can I want to try.'* He did not *'think (rehab) can cure all but I think that I can (improve)'*. Annie wanted to be *'as good as I can be'*.

Derek wanted to get *'as close to normal as possible'*, but during one exchange illustrated the movement between hope and doubt: *'I know it's not going to be 100% but if I can get to 99% I'd be happy, well 99% might be a bit...even if I can get to 75% I'd be better than I was.'* John hoped for 100% recovery, but expected *'Oh...seventy....seventy'*.

Some experienced doubt related to the category MOVING FORWARD in that they saw themselves as stuck. As time went on progress slowed and people experienced frustration and felt stuck – often failing to see small improvements that may have been evident to others. Doug said: *'I just seem to have come to a bit of an impasse. I mean other people notice that I'm getting better but I don't'* and *'I feel as if I'm not getting anywhere at the moment'*. He seemed to accept that he would not recover fully and that he had to accept altered work, but at the same time he expected to make further improvement and expressed fear that this would not happen: *'the obvious fear is that you know that I don't get any better than I am'* and wondered: *'What am I going to do for the next 20 years, 30 years, whatever?'* Maureen shared this concern: *'Is this how I'm going to be for always? That's my fear'*.

This interview point seemed to be a stage at which people had conflicting beliefs and hopes/expectations – on one hand they were beginning to accept that life may not return to how it was before, while on the other hand they continued to hope that this would in fact happen. Perhaps this reflected an intellectual recognition of the situation set against

emotional denial, because of the wider implications that not fully recovering entailed. As Mandy said: *'I can't – I can't be locked up here'*.

4.4.3 *"I'm trying to keep them at bay" - Hiding the doubts*

Some participants were explicitly struggling against their emerging doubts, either by trying not to think about it or by taking a determined stand and 'not allowing' such thoughts. Maureen was crying when she said *'I just try not to think about it. I just try to forget....I just put it to the back of me head and forget about it cos I won't cope'*, but she hinted at her suicidal thinking: *'You wouldn't believe the thoughts I have'*. Joyce was trying to block her fears, although *'I'm trying not to let it rule my life....but it's always there....I'm determined not to give it room.'* Sanjay admitted *'there is doubts coming...but I'm trying to keep them at bay.'*

Annie *'didn't want to think too much because if I started to cry I didn't think I would stop, because I just felt so hurting inside that it seemed a bit overwhelming – but I kind of didn't allow myself to cry.'* She refused to be negative: *'maybe even upsetting if I allow it to – but I won't.'* Susanna said *'I need to stop worrying...so I don't'*.

4.4.4 *"I just want to lie down and die" - Despairing*

Three of the participants expressed suicidal thoughts during the interview, or immediately afterwards when the recording was completed. This seemed to be essentially attributed by them to the ABI in two cases, and to a mixture of ABI and life context in the third. Billie, who expressed overt and constant suicidal thinking, said with understatement that her life was *'a bit bleak really'*. Maureen wished *'I'd got a button I could just turn my head off....go to sleep.'* Roy explained his mood: *'I felt my life was rubbish anyway and I don't think it's improved a great deal from that.'* He admitted *'there's been moments when I just want to lie down and die, yeah definitely,'* and saw the future, once certain responsibilities had been accomplished: *'there's nothing to stop me is there?'* In his case the ABI *'might just have focused, it might be like a focusing point for everything else that's been going on – like a thunderbolt.'*

Others, while not expressing suicidal thoughts, saw themselves as surviving rather than enjoying living, unless their situation resolved further. Harry described his life: *'I try and....survive I suppose from day to day.'* Shirley said: *'I don't actually have much of a future. I've got life because the hospital gave me that, but I can't really.....unless I can improve myself and get myself back then I can only be a problem to people,'* and repeated the belief that

getting better was essential: *'Yes there are things to look forward to....as long as I can get better.'*

There was an awareness, even in the most depressed, that low mood affected thinking and could become a downward spiral, with little or no hope. Billie was aware *'I think my mood is...er...has stopped me seeing that. You know I think...yeah I think my mental capabilities are affected.'* Roy admitted *'it's probably the depression talking again isn't it?'*

4.5 MAKING SENSE OF WHAT HAS HAPPENED

Acquired brain injury usually results from a sudden and unexpected event, whether a stroke, an accident, or trauma. In cases of illness (such as encephalitis) the onset is also sudden and unexpected, even though there may be a longer period of development of symptoms. All participants set the scene by telling the story of their brain injury – how the early symptoms developed, going to hospital, being discharged home (directly or via residential care) and referral to specialist rehabilitation in the community. The interviews suggested that making sense of this experience was important to people and that they used pre-morbid beliefs and knowledge, life context and post-morbid experiences and questioning as they sought to find meaning and sense in what had happened.

4.5.1 Pre-morbid beliefs/knowledge

4.5.1.1 "I wish I'd been more understanding" Even before the brain injury, people had beliefs and prejudices about illness, disability and the efficacy of medical interventions, which informed their attempts to make sense of the experience. Simon referred to his former beliefs about people with disabilities: *'It makes me wish I'd been more understanding and patient about people who'd had similar things'*. Kendra also referred to her pre-morbid experiences when she admitted to having thought: *'if I'd end up like this do I want to be alive?'* in relation to caring for people with disabilities.

There were also pre-morbid beliefs about depression and psychological problems that emerged in the interviews – Ben was able to accept depression after his stroke, but only by attributing his mood to the impact of the brain injury. He said: *'normally people would say depression is um....being depressed unjustifiably, if you like'*.

People entered the experience with existing beliefs about the medical and other services. Simon, from a medical family, was a strong believer in seeing *'someone who's a specialist in*

that area as soon as possible’, while others had little pre-morbid experience but depended on their early hospital and rehabilitation care to form beliefs and expectations that were positive or negative.

4.5.1.2 “You really don’t pay attention” The immediate response from most participants when asked if they had previous knowledge or experience of stroke or brain injury, was negative - *‘No, no, no, no’ (Billie)*. However, it subsequently became apparent that some did have relevant pre-morbid knowledge or experience but had not linked this to their own experience.

Derek, for instance, stated he had not come across anyone who had had a brain injury – however, it then transpired that he had himself experienced *‘previous accidents before which I’ve had.....head damage or brain damage’*, but because he made speedy recoveries he didn’t *‘pay attention’*. Kendra had a history of TIAs, and worked in care homes, acknowledged she *‘knew quite a bit about strokes’* and then said *‘I never expected to have one myself’*.

This belief that strokes do not happen to young people was expressed by several participants – for example: *‘You see I thought I was too young really’ (Maureen)*; Susan’s response when asked what she believed about stroke before *‘Old. Old people’*; and Susanna’s refusal to believe it could be a stroke *‘I’m too young to have a stroke’*.

Family experiences As well as not linking personal past experiences, it was notable how often people initially did not mention family experiences. Joyce said she had no personal experience, until she suddenly announced *‘Oh....I lie....yes my step mother had a stroke’*, and went on to describe the profound impact of this on her family. Harry summed up: *‘I think we ignore...most people are...you only take notice of what affects you...which is a sad thing.’*

There were those who were aware of family or personal history, or had professional experience of ABI, which did feed into their expectations for their own recovery. For some there were positive expectations – Maureen’s father and sister had recovered quickly and almost completely, so she expected to do the same; Derek’s earlier recovery from head injury meant he thought this was the norm; and Annie’s work had been largely a positive experience. This was not always helpful, and failure to live up to the expectations in terms of their own recovery could be devastating. Other participants had a more negative perception of ABI – such as Andrew who said *‘some are not happy when they had a stroke....’* Trisha’s

family background was of severe impairments: *'I hear people say you probably won't(get better)'*.

Severity of Brain Injury The severity of brain injury seemed to have come as a shock, so past experience had not prepared people for the event or for the level of severity – Simon : *'If it hasn't happened to you or you do what you do for a living, then you can't know how profound banging your head is'*, and Mandy: *'I don't want anybody else to have this, you know, it's horrendous'*. Only one person made even an implied reference to differing severity affecting outcome – as will be seen subsequently, this was in sharp contrast to the views expressed by rehabilitation professionals.

Media knowledge There was some knowledge based on the media, and most commonly this was attributed to having seen the Stroke Association FAST advert. However, while clearly raising awareness there was also a sense that people could take the advert in a very literal, concrete way. The expectation from the advert was that a stroke would happen exactly as represented on television. This had led some people to think they were not having a stroke, as their symptoms did not 'fit' – Susanna noted that *'in the advert it happens very quickly'* and Maureen's husband did not recognise the television symptoms so assumed it was not a stroke.

Knowledge of rehabilitation Pre-morbid knowledge or experience of rehabilitation was limited, and therefore difficult to tease out from the experiences following the ABI. If people had had experience prior to that, it tended to be of physiotherapy for musculo-skeletal problems. Despite having, in most cases, had some rehabilitation after the ABI, prior to the interview, it was apparent that most would agree with Trisha: *'I don't know what can be offered because I've never had experience of it'*. The beliefs about and expectations of rehabilitation will be described later in this chapter, as they seem to be forged post-morbidly.

The intention of this study was to look at people's expectations, but it became apparent that many participants would claim to have no expectations, as they did not have the necessary knowledge or experience on which to base expectations. The above examples have illustrated some instances where expectations had been formed by pre-morbid experiences, but these were often implicit rather than recognised.

4.5.2 Life context

The brain injury does not just occur in a vacuum. General life circumstances at the time at which the brain injury occurred are relevant, and impact upon recovery, adaptation and rehabilitation. The expectations people have of recovery, of themselves, and of other people will be influenced explicitly or more subtly by the context in which the ABI occurs.

4.5.2.1 “A Double whammy” – “Brain injury and a crap life!” For at least half the participants the ABI occurred in the context of already difficult situations, compounding the impact. Simon, for example felt guilty about the impact of his injury on his wife, but this was made worse because it was not *‘long after our first attempt at IVF that this all happened and she was getting over the massive stress and let down of that being a failure’*.

In the sample of 21 interviewed for this study there were in addition to the above example, examples of cancer in the client, cancer in a partner, dementia in dependents, and other (physical and mental) illnesses in clients and/or carers. There was also recent divorce, the impact of racism, and relocation. It is not a given that the ABI assumes the greatest priority in the lives of people – Annie acknowledged the awfulness of her brain injury, but it is her cancer that concerned her most *‘hopefully I can thenget on and enjoy my life and not be thinking about whether the cancer’s there or not’*.

Sylvia had a serious long term health condition, diagnosed when she was 18, some 25 years ago, and also a subsequent diagnosis of diabetes. This context meant that she had already adjusted to some restrictions on her life style.

The health of family members was, in some cases poor before the ABI, so family life already revolved around this. Maureen described how she tried to adjust post-ABI to her husband’s ill health – *‘there’s me....only got one arm....trying to get his jumper on with his good one arm, so we just help each other out really.’* Roy cared for both his parents, and his own ABI was low down on his priority list – he asked *‘What is the brain injury and what is simply a crap life?’* Susanna described the context of her husband’s ill health and her own ABI as a *‘double whammy.’*

Life stage In a broader sense, while not negative in itself, the stage of life can have a profound effect on the rehabilitation process – having young children or being in a relatively new relationship, for instance. This may be positive or negative in terms of the impact – Doug could appreciate the impact of his previous life situation, in that he recognised that he was

getting too old and had an existing knee problem, so was not expecting to continue in his previous manual work anyway, and therefore had less distress at having to consider a change in duties.

Employment Employment featured strongly in the study, and a number of people questioned their working context as a possible factor in what has happened - Annie, Doug, Harry, Kendra, Maureen, and Roy, all allude to the stresses of work and imbalance in their lives. Annie stated: *'it doesn't surprise me that I've become so ill...I was working flat outto the extreme that it wasn't healthy'*. Maureen loved her work but wondered if she had been doing too much for her family, and that the mix was too much. Roy too, was aware that it was the combination of home pressures and work that made the context of his life so difficult even before the ABI.

The nature of work is obviously a factor. Mandy was able to acknowledge that the context in which she worked meant she would need to be performing almost back to normal in order to return : *'I work with some quite challenging boys who'd quite happily throw a ball at your head thinking Miss had had brain surgery'*.

Finances Closely related to the issue of work is that of financial security. This is a positive for some, but more often a pressure that is massively compounded by the ABI. Keith, Maureen, Simon, and Joyce all indicated fears of losing their home, as the event was in the context of an already tight financial situation. Harry *'Had my own business at the time so I was desperate to get back to work cos obviously it was losing money – couldn't afford not to....didn't want to see it all go down the pan.'* Keith noted that this also affects the ability of the family to offer support with rehabilitation – *'My wife can't afford....we can't afford for her to have a month off of work to rehabilitate me in the house, I've had to do it alone'*.

Home life Families and individuals had established their own patterns and context for home life. Some found this changed significantly, while others were able to continue much as before. Doug, rather than feeling he had had a massive impact on his wife's current life and future plans, accepted *'the best thing she's done is go back to work'* and described their lives as little changed. Mandy was a single mother and had tried to ensure her children continued to have friends round to keep a sense of normality.

External factors There were not only personal/family contexts that affected recovery and rehabilitation, but external factors – such as the economic situation. Simon worked in retail

and was able to recognize that there are pressures ‘from above’: *‘the shop is underperforming ...and a lot of this stuff started happening from above’*. The economic climate therefore placed added pressure on his work setting which in turn may well influence their ability to support his recovery.

4.5.3 What’s going on? Post-morbid questioning

The final sub-category in MAKING SENSE OF WHAT HAS HAPPENED, centres on the event itself and the questions that arose from it. By definition Acquired Brain Injury hits out of the blue without opportunity to prepare and for most – as has been seen - there is little or no acknowledged background knowledge or experience of ABI upon which to call. It is a sudden event and it is apparent that people are not prepared – even if they have experienced warning signs or have conditions or family histories that put them at risk. As a result there is sometimes a sense of not knowing what was happening at the time, and subsequently questioning, while trying to make sense of it all.

4.5.3.1 “It just came out of the blue” - Being unprepared Doug described the event in this way : *‘It just came out of the blue, just a shock’*. Andrew offered a similar statement - *‘as far as the stroke goes it hit you out of the blue – no warning, no expectation’*. Looking back on the event, some retrospectively recognized possible signs – Maureen had blurred vision and tiredness the week before, but *‘whether that was the start of it, I don’t know’*. Kendra felt as if she had flu, but on the day *‘that was the first morning that I’d actually felt fine for three or four days and of course that’s when it all happened’*. Trisha experienced several days of ‘odd’ events but had *‘no reason to guess I was having a stroke’*.

A number of participants knew they had risk factors or risky lifestyles, but either believed they were controlled or ignored them. Keith was an example of the former – *‘I’d always believed that I was healthyyou can take it for granted um....thinking we were all doing the right thing and I was taking the medication, you know, I wasn’t slipping on that and then just got hit’*. Derek continued to race cars despite several head injuries in the past, and others continued to smoke, for instance.

4.5.3.2 “What’s all the fuss about” There is overlap with pre-morbid knowledge in that many initially misattributed symptoms or signs. Ben, for example, had had a flu jab and only *‘gradually realized that er...you know it possibly wasn’t that’*. Maureen thought it might be a

panic attack, as she was *'not paralysed – just couldn't move'*. Sylvia attributed her symptoms to her pre-existing medical conditions, and Trisha's family thought she was drunk. Some were misdiagnosed by medical services – two were sent home, only to be readmitted subsequently with encephalitis and stroke respectively.

Even once diagnosed, the expectation was that it was not serious and they would recover fully and rapidly – Maureen went into hospital on Friday and said to the doctor on duty *'I hope I'm going to be ready for London on Monday. So he said I don't think you'll be going to London on Monday. So I said, Oh God'*. When asked if she wanted her family informed, Trisha replied *'No my children they won't want to know, don't bother to tell them because you know I'll be back home tomorrow'*.

Even in this very early stage people struggled to take on board what was happening, especially if they had little or no memory of the event itself – Kendra: *'They said that I was very lucky that I'd survived it...but even now, to this day, to me...um...because I...I think it's because I don't remember any of it...I just think you know what's all the fuss about'*. Similarly Roy said: *'It didn't really feel as though it was happening to me – in some ways it still doesn't...I still don't believe it happened to me'*.

Those individuals who did not get a diagnosis easily struggled with knowing what was going on. Susanna admitted : *'I think it was important to have a label in the beginning, and for everyone around me because it...if you've got something there's usually a remedy...you can fix...even cancer we have a plan. This is...there's no plan.'*

4.5.3.3 I was on another wavelength or planet It appeared to be very difficult for participants who did not have full memories of the event to make sense of what has happened. The story of their early progress was in a sense not their own – lack of awareness forced them to accept and recount others' accounts. Simon said : *'That's not what I remember – it's what I've been told'* and *'I don't remember any of this – it's just what my wife has told me'*. Mandy also commented *'All I can rely on is what people have told me'*.

Over half the participants had a blank period of time. Annie described herself as feeling *'cheated'* by this, and *'since I've been home I've been trying to piece together what actually happened because I want to know because it's very strange having stuff happen that you don't know about'*.

Harry described himself as *'on another wavelength or planet'* and there seemed to be a surreal quality about people's experiences over these early days. Kendra described it as *'dream like' and 'surreal...I knew it was me there but it wasn't my words coming out of my mouth'*. Susan felt *'disconnected'* and Susanna has memories but they are *'almost like I wasn't there if that makes sense'*.

Often family/friends provide the narrative of the event or confirm memories that are held. When others try to fill in gaps, the participants have to trust the accounts they are given. This is not always easy.

There was also doubt about the memories they did have. Mandy provided a good illustration: *'a midwife came in carrying a dead baby and I will...of all the things I can remember that is the one I would say is the one that's true but I have been guaranteed by nurses, doctors, everyone that there is no way they would have brought a dead baby into my room, but I was absolutely adamant'*. Kendra still had to remind herself that her mother was not alive, and that one of her sons was now an adult *'I can see him at four years old and then I think 'Oh God no, he's 25 now'*.

Shirley had a memory of her daughter telling her she could *'go with dad'*, and *'then I remember thinking that he must still be alive – and he's been dead nine years, but I didn't know that when I came to in the hospital'*.

Making sense of events when you do not recognize the symptoms and signs, wonder what the fuss is about in terms of severity, and have gaps in your memory is hard enough but – as Roy said *'the more you think about it...how you can make it better, but what you're thinking with is the very thing that's been injured isn't it.....so.....complicated things'*.

4.5.3.4 "I'd love to know why, so I don't get it again" Part of the process of trying to make sense of and construct a new reality from the experience, is understanding why the event occurred. The experience of many was that there was no clear answer, but they continued to question.

Wrapped up in the search for a reason is fear of another occurrence. Joyce was very clear about this: *'unless I can know the reason – what the cause was then I can't – can't take the steps to stop it happening again.'* Mandy was crying when she said: *'I'd love to know why whether it be....so I don't get it again'*. The lack of a label meant that Susanna felt *'there is a worry that whatever happened might happen again, because we don't know what it was'*.

Part of the fear of another event seemed to lie in an assumption that it would be worse. Mandy linked the fear to death: *'the thought of leaving my girls. That does worry me. Absolutely terrifies me.'*

There was, alongside the question about cause, the associated question – Why me? Kendra asked *'Why did it pick me?...and that's telling me something...but I haven't worked out yet quite what it's going...what it's telling me to do.'*

4.6 MOVING FORWARD

Following the ABI, participants developed a sense of whether they were moving forward in terms of recovery. The first sub-category within this is 'Perception of progress', including beliefs about time and speed of recovery, and whether they acknowledge improvements, 'stuckness' or deterioration. It is the perception that is important, rather than external measures. The second sub-category relates to 'Beginning to make adaptations', based on recognition of limitations; and finally the acknowledgements of any 'Positives' that have come from the experience. These factors appear to be the main determinants of belief and expectation of recovery *per se* (as opposed to the impact of rehabilitation).

4.6.1 Perception of progress

4.6.1.1 "I say time....time....." The timing and speed of recovery so far had a large impact on people's expectations of further recovery. Some experienced initial quick progress, which led them to expect this to continue and generated a hopeful approach. Annie illustrated this: *'To be honest it all – I just changed so quickly that I'm still astounded that I went from not being able to do anything to being like I am now',* and *'I feel pretty positive because I've made such rapid progress.'* Maureen was very hopeful at this point – *'I said you watch I'll be back at work by Christmas and I just in't.'*

Some remembered feeling this in the early days, but felt progress had slowed. Billie experienced this – *'I still felt that perhaps I'd get better'*. Maureen commented : *'everyone says it's going to take time – well I didn't think that took time because I done so well in hospital....things progressed so quickly in hospital, and I thought that was going to carry on, and that didn't. So that's what peed me off.'* Maureen also had the belief in rapid progress

based on her family experience, compounding the frustration, and illustrating the interwoven nature of the influences on people.

Ben's early expectations were challenged *'my walking hasn't improved like I would have thought it would.'* There is often a perception of being stuck – Doug referred to this *'It's been nine months now and I just seem to have come to a bit of an impasse'*. Alongside this experience can be the unpredictable nature of recovery – stuck at one point and then a change occurring without warning. Keith experienced this: *'yeah you could get it back and then you get a lull period and then it'll move forward again, which is actually how everything's been. You know one day I could stand and I thought right this is it, and then the next day I couldn't balance myself'*.

In some cases the progress had never appeared rapid and had been frustratingly slow. Andrew noted that he didn't notice it himself, but other people would say he was doing well. Doug accepted that *'people keep emphasising it's a slow process'* but stated *'I just feel I'm not getting anywhere at the moment'*.

Not everyone accepted other people's observations at face value – Maureen was clear *'Everyone says you've done so well for how long you've had the stroke but I don't think I have, see.....if I'd done well I'd be back at work by now.'* People had different criteria in terms of what constitutes 'doing well' and she could not understand the different view: *'they said No it can take up to a year to get better and I'm thinking well why, why would it take a year?'* Frequently in the interviews participants note that they have been told it takes time – *'People say give it' (Roy)*.

The significance of time is explicitly recognised by many. Susan noted it as the major factor in recovery: *'I say time....time'*. Having had very little rehabilitation, she noted *'before that time made everything better so...'* Derek said *'Time will tell – I'll get back to doing that sort of thing'*. John feels that *'Everything's put on hold'* suggesting that he has to wait for time to heal.

4.6.1.2 "My first miracle" "A hundred percent better" Improvements were described – but there was a flip side to improvement – while it brought hope of further recovery, it also led to greater awareness of impairments and to boredom. Simon felt he was coping, for example, until the greater demands on returning to work highlighted the remaining issues.

The perception that people have made progress is important in itself, and is attributed to a number of different aspects – or none. Derek was uncertain – *‘It just happened’*, as was Ben: *‘I had a...my first miracle was sort of still in the hospital...the first sign that you know something was coming back’*. All the participants, except John, were able to describe progress at some stage since the ABI. John was asked if he had noticed any change and emphatically replied *‘No’*. The causes given when progress was acknowledged included both personal and rehabilitation factors.

Sometimes the perception of progress was limited and reassurance was gained from comments from others. The opposite could happen too, when people believed they had improved and made progress but lacked insight. Simon had become aware of this over time : *‘My boss said to me yesterday ...that my speech has become better and I thought when I got back to work that my speech.... was already a hundred percent’*.

For a few people who noticed early improvement the picture had changed, with a sense not just of slowed or stalled progress, but of deterioration. Harry noted that *‘I feel there are certain elements that may have deteriorated slightly’* and that *‘I think everything hasgot slightly more intense...definitely worse’*. Billie was asked if she has worsened over time and states: *‘Yeah...it has....yes....definitely’*.

Roy had noticed deterioration in his memory *‘if anything it seems to have got worse’*, and Susan in her concentration *‘I could do that...no problem (when I first had the stroke). Now I can’t finish it. I can’t do....concentrate on anything’*.

4.6.2 Beginning to adapt

4.6.2.1 “It’s just not coming” Most participants were able to acknowledge improvements and limitations and were beginning to make adaptations (even if seen as short term). In the data there were examples of limitations in physical, sensory, communicative, cognitive, functional and emotional/psychological areas. Sometimes people knew something was limited but could not quite identify it, as Trisha commented *‘things wrong which are a bit strange about me’*. Kendra put this nicely – *‘I just feel as if I want to shake my head and clear out all the bad bits...and put all the good bits back in’*.

4.6.2.2 “If I started to cry I didn’t think I could stop” Participants raised emotional and psychological issues and limitations as much as other aspects. These included depression and low mood, suicidal ideation, anxiety, OCD, decreased confidence, and many other concerns.

In relation to mood antidepressants were offered to a proportion and most accepted them, but Maureen, for example, refused as she saw it as weakness, and Roy and Billie had to be persuaded over time.

Several tried hard to hide or not to allow negative feelings and thoughts, with varying success. Annie, for instance *'If I started to cry I didn't think I could stop, because I just felt so hurting inside that it just seemed a bit overwhelming – but I kind of didn't allow myself to cry and it's passing now.'* Maureen said *'I just try not to think about it. I just try to forget....sorry....'* but she was crying as she spoke. Sanjay recognised what he was doing – *'You know it's all very well to paint a rosy picture on the surface but underneath there's a lot of...um...a lot of anxiety really.'*

Roy's comment was insightful: *'I suppose the worst thing is the depression....sorting that out, and mood, because nothing else is going to do any good really until that's sorted out, I suppose'*.

4.6.2.3 Making adaptations As participants were acknowledging limitations, they also began to make adaptations, either consciously or unconsciously. There are numerous examples of such changes, which were accepted as necessary *at this point in time*. Physical limitations led to Andrew only going out with his partner, and using a wheelchair when tired. Doug knew that he needed help putting on socks and washing his back. Mandy cooked meals that did not require standing at the cooker and went upstairs on all fours.

Annie described such adaptations as 'cheats' which allowed her to retain independence and reduced the need to ask others for help: *'It's back to this thing about trying to find a way round – another way of doing the task, and to me that has become a bit of a game, because I don't want to not be able to do stuff myself. So I cheat – then I can.'*

In addition to these physical adaptations there was recognition of continuing cognitive and emotional impairments that require adaptation. Kendra recognized she was not able to remember everything so accepted she needed to rely on her husband for support in this. Mandy described problems reading: *'I would always read text messages. I now pass them to the girls to read'*. Simon, at work, accepted different duties: *'they told me just to come in in civvies and watch what was going on'*.

Acknowledging the need to adapt to the current situation did not mean participants were happy about this – Ben commented *'every time I've done something that um....copes with*

the disability, I've always had at the back of my mind that I don't really want to be coping with the disability, I want to get rid of it, you know.' Comments reflected adaptations already made – either short-term or longer-term – but began to indicate that adjustments may need to be made in relation to the future, especially in relation to working life. Doug admitted : *'I'd like to be able to get back to doing some kind of work.....possibly in the labs or the office'*, realizing he will not return to his past physical work. Simon said: *'even if I go back to pulling pints it doesn't matter as long as I can pay the mortgage'*, with a view to achieving his life plans but in a different way. At this point, however, such comments often contradicted other remarks in the same interview, suggesting people were beginning to reflect on the future, but not yet actually accepting that longer term changes would be necessary.

An interesting observation may be made in relation to looking at negative examples. One participant – Sylvia – had a pre-existing medical condition that had made her movements and walking slow and labored. After her ABI, Sylvia adapted to increased physical limitations by accepting use of a wheel chair more often – as a result she felt she was more mobile, faster and therefore less of a burden to others, and got better seats in cinemas!

4.6.3 Recognising positives

4.6.3.1 "I'm over the moon" By this stage some were able to recognise positives within the situation. The example above of Sylvia illustrates this, and other examples were giving up smoking so people feel healthier and less at risk (Kendra), no longer having headaches (Kendra and Roy), being able to support others (Andrew) and learning skills that would otherwise never have been recognised (Harry). Harry noted that learning a new skill has *'giving me something that I felt was um...positive out of the negativity that had happened before...to do something that I never would have thought of doing before I was ill.'*

Some saw positive changes in their life style, such as being more relaxed (Annie), reflective (Roy) spending time with the family (Harry) and being more understanding of others (Simon). Sanjay and Sylvia both commented on having an improved relationship with his/her partner.

The main positive for some was simply having come through the experience. They felt lucky to have improved as much as they had, and questioned 'What if the outcome had been worse?' Joyce for example said: *'each day I wake up and I've...I'm....I am intact is a bonus'*, knowing that *'it doesn't bear thinking about um....what if? What if I'd....I hadn't...I'd made it – been able to recover? And if....what if....yes....just doesn't bear thinking about.'* Kendra

simply states *'I'm happy that I've....I'm over the moon that I've actually come out the other side'*.

4.7 WHAT CAN I DO?

This category relates to people's self-efficacy and belief in their own ability to influence recovery and progress. If people trust themselves – their sense of self, their priorities and the meaning they have made of what has happened, and feel that they have some power to affect rehabilitation – they appear to be more optimistic and hopeful in their expectations. If they doubt themselves and their role, then expectations are reduced.

4.7.1 *Being the same but not the same*

4.7.1.1 *"I'm the same person - but I'm not"* Participants frequently made reference to and comparisons with their past sense of self. Negative perceptions related to the sense of self as being no longer in control, not being 'normal', being 'disabled', being dependent, needy and reliant on others, being less confident, less reasonable, less capable, more irritable, and being more demanding and perfectionist. Self is often defined by the roles people have in life, and the altered roles included not working and therefore supporting the family financially, and being unable to care for others.

Perceived physical, cognitive, communication and emotional limitations fed into this, and again depended on the qualities and abilities by which people defined themselves. Maureen saw herself as an active, busy person – *'I've never been one to be indoors for so long. I've always been out and about'*. Mandy saw herself as strong in personality and her role in the family – *'I'm so used to being the...um...I'm the strong one of the family and now it's my daughter and although she's strong enough to deal with that in any shape or form she's absolutely fantastic but it should be me and oh, it breaks my heart.'* Similarly Keith was used to being in control – *'I like to be in control of what I'm doing –always have done and because I'm not in control of it now....'*

Shirley's sense of herself was of a reasonable, capable and caring person – and her experience since her ABI had resulted in all these aspects being challenged – *'apparently I'd been difficult as well....and demanding and unreasonable apparently. I don't – don't associate that with myself because I've always been reasonable – I always feel that I've tried to be*

reasonable'. Her use of the word 'apparently' is interesting, as she was struggling between trusting her own sense of self and others' accounts.

Positive changes were in seeing self as being less driven and more relaxed – so more able to respond to family needs, and more reflective about life. Annie, for instance, commented '*I'm much more relaxed. I mean my daughter will say 'Gosh Mum' you know – because she's having a partyand she keeps saying 'Is that alright?' 'Yeah, yeah, that's fine' and I would have been wound – I was a real worrier*'.

Helpful qualities Some were able to recognize qualities that had stayed the same and identify these as positives in relation to rehabilitation – such as being a strong, dominant character, being a problem solver, having 'get up and go', having the right personality, being able to ignore others' prejudices and judgments and having a positive attitude. Determination is a quality which participants saw as useful in rehabilitation and recovery – Mandy said '*I'm quite a determined person*' and '*I don't give up – I don't give up until I get back to where I want to be*'.

Sanjay had had to cope with prejudice, and commented: '*being ridiculed and stuff like that I'm used to so I wouldn't pay any attention to anything like that at all*'. Susan acknowledged her positive attitude: '*I suppose I've um....I've kept a positive....positive...yes...yes. Cos I thought that....it could have always been worse...I only had my speech go*'.

Sometimes comparisons are put on hold, in the belief that time will determine what happens. John, asked if he thinks he has changed as a person, simply says '*I hope not. I don't know*'.

Unaltered aspects of character were also at times seen as impediments to rehabilitation – such as not being able to ask for help or say no easily, being impulsive, being too perfectionist, and being a loner. Harry saw his pre-morbid self being exaggerated – '*I was always a) perfectionist – things had to be right – I was picky but it's been magnified since the illness*'. Some mentioned specific anxieties that pre-dated the ABI, but impacted on recovery or rehabilitation, such as fear of entering new places. Shirley was nervous about engaging with rehabilitation '*I'm not very good – I never have been – at going somewhere strange...of going you know into a crowded place. I'm not very good with – I suppose I'm not, I'm just not very good with being there a first time, so I find that concerning*'.

The same individual was often able to remark on aspects that were negative and positive. Derek noted: '*I mean the way I was and the way I am now is – I wouldn't say two different*

personalities...if you mix the two up and a lot of negative would come out of it and a lot of positive would come out of it.' Simon reflected on who he was *'it's really hard...obviously I'm the same person but....I'm not.'*

Past-present self The crucial factor in terms of the impact on participants' belief in their own abilities to impact on rehabilitation and recovery seems to be how much the person perceives him or herself to differ from the pre-morbid self. It is not related to any external measures necessarily, but to the subjective and phenomenological. In illustration of this, a common comparison was against the nebulous concept of 'normality' – Mandy said *'I just don't feel normal'* and *'(I am) the person that needs help...because that is how I see myself I don't see myself as being normal any more'*.

There were some comments that suggested a long term change was acknowledged – Roy stated: *'I think I feel as though I've changed for good I think that's what happened to me I won't be the same again, I know I won't – I'll be a new....a different person.'*

There is, of course, a link with the pre-morbid life context, as the way in which individuals see themselves and their personal efficacy will be affected by, and affect, life plans and the future. If the two – 'new self' and past plans – seem irreconcilable there is concomitant increase in distress and fear. Simon feared his problems would impact on hopes for the future – having a family and owning their house. Mandy wondered about her financial situation as a single mother providing for her children. Doug, however, saw little difference and expected to fulfil his former plans of moving abroad when his wife retires : *'there's no difference living over there than it is living over here except the weather's better'*.

4.7.1.2 "I'm so glad I wasn't like that" Some participants made comparisons with others – post morbidly - which increased their trust in their own efficacy and progress. Such comparisons, in the early days, were always negative, and made about those who were more severely affected and in whom little or no progress was visible. Simon, for example, remarked *'the guys..... tend to be more ...I don't know...seem to be more affected'* and Doug *'they tried to get me to go to a group with some very badly people...and I got frustrated with it cos they worked to the slowest'*, following up by noting *'I was glad I wasn't like that'*.

Some comparisons were to do with effort and motivation, with a sense of improvement being seen as earned, that is linked to the effort put into rehabilitation. Doug described a

person in hospital who did not engage with rehabilitation: *'he got the hump when I went home cos I'd done the work'*

Comparison with others in a more positive way, appeared to help the trust and belief in recovery. Following discharge Andrew met a woman who had a 'massive stroke' and attended the rehabilitation centre to which he had been referred, and *'that did so much good – talking to someone who'd been through it. And she came out the other side.'*

4.7.1.3 "What no blood?" - Feeling judged There was a strong sense and fear in some people of being judged by others. This appeared to challenge their sense of self, and again was to do with perception rather than objective external measures.

Visible changes Visible signs of ABI do not always occur, and take two main forms when they do – functional (such as walking or other movements) or 'cosmetic' appearance (for example following a head injury there may have been a craniotomy). Those with significant visible signs may fear value judgments on appearance – Mandy said that she went *'up to my bedroom because I don't want to see people because of my hair. I do feel embarrassed,'* and *'I've booked a meal – I made myself do that...I actually sobbed my heart out when I did it – I made myself do that because I thought why should she not go out for a meal with her family because I don't like what I look like?'* Shirley thinks that *'Once I feel that I look normal, then I will be able to be treated normal...because people won't know that I'm....you know, disabled in any way.'*

Hidden changes Those who had little visible outward sign of the brain injury especially appeared to develop fears of moral judgments made by others – being seen as skiving or faking. Sanjay acknowledged this is hard for others – *'I think it's hard for my wife because I look so normal'*. In relation to moral judgment and being trusted/believed, Simon in particular expressed great concern and fear about how others perceived him: *'I feel like a fake you know and the better I get the more of a fake I feel and it's just horrible'*

This may link to former beliefs held about people with disabilities – Simon: *'I don't know if it's me being paranoid or if it's negative thoughts or expectations I've had for people in my situation in the past'*.

The link to how visible the disability is, was made explicit – Simon drew an analogy: *'It's like if you bang your hand when you're a kid and it hurts so much and you look at it and it's not even bleeding and you think 'What, no blood?''* How is it possible to have such profound

problems, and yet they cannot be seen by others? In this situation participants felt that they were seen as stupid, or as time wasters or skivers. Harry noted this too – *'If I had one leg people would accept because you know...so fine...what's your problem, so I think that is also – it's the naivety – people can deal more with what they can see than what they can't'*. There was a suspicion that they were being judged not in relation to the impact of a brain injury, but as who they really were. They wanted people to understand that it was the brain injury that caused them to behave or appear in a certain way.

Hiding problems Set against this were those who wanted to hide their problems. Harry was clear about this - he was *'trying to disguise how bad it is sometimes, and make it look a lot better than it is.'* As a result he avoided certain situations so he did not have to experience what he saw as the inevitable negative judgments, but he did recognize that it is a mix of others' reactions and his own perceptions: *'A mixture of both...partly magnified by...by...by little things that they probably say or do that probably would mean nothing really but to me it means a lot so I magnify things – I don't see things as they are and they become far greater than they probably should be so it's an element of both I think.'*

Even when other people were making positive remarks, self-judgments could be harsh in relation to the recovery made so far. Maureen felt that *'People keep saying I've done well so far but I just don't think I have – if I'd done well I'd be back at work by now.'* Harry saw himself as 'lesser' and Derek as 'disappointed'. When people express their sense of being judged it undermines their self-image and self-efficacy. If I am a lesser person, if I am stupid, if I am not normal, if I am just whinging or wasting people's time....then what?

A somewhat different aspect is when participants feel judged, but able to question this, which implies a level of self-confidence – Ben was told he was impulsive following his brain injury and disagreed *'in actual fact anybody that knows me – I'm a bit impulsive anyway, you know, I've never been convinced there was any change in that.'* Derek described being told he was negative by hospital rehabilitation staff *'I said that's not being negative. That's just my way of saying 'Oh shit they want me to do exercises again'...and then I go and do them...I was quite willing to do them'*. Sylvia felt she was patronized by people making inappropriate judgments – *'I may have had a stroke but please don't treat me as an idiot – that's what a lot of people do.'*

Being too good Being 'too good' was a judgment that caused distress to some of the participants. Joyce accepted that *'I will always have um...a problem with my*

speech....um....thatwhich will not necessarily be apparent to the casual observer.' Mandy was told by her speech and language therapist that she was *'fine'* but *'I know I'm not'*. Billie commented on the focus on the physical – *'they were very concerned with the physical things and I think when you look at me you don't think there's anything wrong.....(people) think I've recovered'*. Trisha was distressed when she was told she was too good for speech and language therapy but her previous life was all about language – *'It's what I do. It's my life.'* There is a group of people, following ABI, who are judged against standards that are not appropriate to their situation.

4.7.1.4 "I've caused so much stress to everybody" - Being a burden Guilt about the impact on family and friends was widespread among the participants in this study. Feeling a burden seemed to deplete people and impact upon sense of self and power/efficacy. Participants expressed guilt about the direct cost on families of the caring role, and on the indirect costs – changes to future life plans, financial security, not being able to fulfil former roles.

Some could accept intellectually that it was not their fault, but still felt responsible. Annie said she found it *'frustrating because I've got to put them out which I don't want to do, but there is no choice at the second,'* and recognised it *'puts more of a burden on him'*. Simon's comment that: *'I didn't do this, I did well to survive it'*, was in contrast to his statement: *'I've caused so much stress to everybody'*.

Keith felt shame at not being able to help – *'makes me sort of feel...er.....sad that I can't do that and saying sorry I can't and that sort of....well she doesn't want to hear sorry – she just wants me to get better....so yes it does, it does cause....it hasn't caused any friction – I'm just aware of how much strain it is on her at the moment.'* Shirley felt bad at relying on her daughter – *'I feel as if – you know – she's my daughter – she should be relying on me rather than the other way round'*.

Attempting to hide the problems may partly reflect a desire to minimize the burden on others. Roy was explicit about this – *'I wouldn't really want to explain to mum anyway how I was feeling or how I am feeling – you know she's got her own problems,'* and *'the family don't need to know.'*

There was also a more existential guilt at not being grateful to have survived the ABI or not to be more affected. Roy said *'It seems churlish to moan about things like this when...when your life's been saved. I mean in so many cases people don't get through it do they?'*

Sometimes there was recognition that they were difficult to care for in the early days following the ABI, when they trusted their judgment only to be proved wrong by experience. At the point of interview they had doubts about decisions they made or their awareness – Simon realized: *'I'm maybe understanding that I was a bit premature in trying...wanting to get back to work'*. Shirley was guilty about her behaviour in hospital – *'apparently I'd been difficult as well.....I feel bad about that. I do feel guilty if I behaved badly and made life difficult for people.'* Guilt and shame will impact on the responses to rehabilitation and on expectations about recovery and self-efficacy.

Interviewing so many people highlighted the danger of making assumptions about the subjective experiences of individuals. This is illustrated in this area, as while most participants clearly felt responsibility for the impact on others, one participant did not express guilt about the impact on this wife, but seemed to criticise her for not being a good enough carer.

4.7.2 Taking stock

Some had reflected on their lives as a result of the brain injury. Most commonly this was about the work-life balance that they had adopted. Annie, Kendra, Shirley and Maureen all expressed a desire to put family and health first in future. Kendra asked about her pressurized job *'Do I really need it? Do I need to be working full time?'* Annie was sure she had *'lost what was important to me.'* Shirley was clear *'There is ameaning to life and it's through my grandchildren, and my family'.....'That's what makes life worth living'.*

Despite this, some struggled to find or accept the need for an alternative or substitute meaning if work could not be resumed. The old meaning in life was lost and they could not identify something that could fill the gap in their lives. Shirley's life revolved being the person others depended upon: *'I've always been the one that people rely on and now it's opposite, so it's very difficult for me to accept that I need help'*. Sanjay, faced with the prospect of not being able to return to work, was asked if there was meaning outside work: *'Not at this stage. No. No – no there isn't at the moment.'*

Some expressed the desire to 'give back'. Derek wanted to '*make it less painful for someone else. I want to go into this sort of thing to see if I can alleviate some of it for future people.*' Keith would '*like to think I can help others as well.*'

This process of taking stock and beginning to question personal priorities is by no means universal at this stage of the pathway. The meanings and priorities people revealed illustrated to some extent the motivations that drive them – family, work, health, 'giving back' – and make them who they are.

4.7.3 Doing what I can

The participants mostly shared the expectation and belief that they should be active in the rehabilitation and recovery process. This took three main forms – taking control, being positive, and trying.

4.7.3.1 "I am the director" - Taking control The question of control was important for many clients and most expressed some degree of desire to have a measure of control within rehabilitation. Andrew, for example, said '*I set myself goals*' and hoped to continue this. Annie stated: '*I think I should be directing – and I don't mean that rudely, but I think you should be independent enough to get on with it and know what you've got to ask for help with*', although she accepted this was harder in cognitive areas which she saw as '*more nebulous actually. I don't necessarily think I can direct it but I can actually say yes I can't do this thing – can you help me with ideas of how I can think more clearly or be able to articulate more clearly.*'

Susanna used a theatrical analogy: '*If you imagine it's a play, I actually am the director? I know I've got the main part, but I'm the director and I can.....make changes....I can saythat's not working and yes.....maybe it's the producer.....I want to be the person in charge in a way.*'

It was important to feel that activities could be questioned and challenged, and people did feel this was in part their responsibility, and in part up to the therapist to explain. Doug explained: '*in the end I told her that it wasn't doing me any good. I wasn't doing it. I think she got the hump.*' Simon realized explanation could help '*having it explained to me from a perspective that I didn't understand opens up...made me understand more.*' There was a feeling that you should be able to choose. As Ben stated - '*You know you listen to what people say and then you make your mind up, you know.*' Derek felt judged by rehabilitation staff as

refusing to do things but *'I only refused to do something if I know I'm not capable of doing it'*. He commented *'You try to figure it out yourself...which is not always the right way to do it but it's the way that works best for me'*.

Taking control Sometimes people were confident enough to take control explicitly – Doug, for instance, *'this young lady trying to help me, I don't think, in fact she didn't cos I told her to bugger off – that's just me!'* Joyce was already taking control, while waiting for formal rehabilitation, and was exploring causes and making arrangements to see consultants, her employers, and sort out her driving independently. Trisha had experience of rehabilitation in the community on discharge, and took control as she did not think her needs were being met: *'Some days I....if it was too boring I just offered some other thing (to do)'*.

Other ways in which people took control was by making effort (Mandy: *I made myself*), pacing (Sanjay: *I learned my limitations so I'll take breaks regularly*), and practice (Trisha: *I kept reading and writing as far as I could...I can't think it'd do any harm*).

As in all the interviews, it is about perceptions and people's subjective interpretation of situations. Shirley illustrated this in her response to a telephone contact with a rehabilitation therapist – *'Everything I said I'd got problems with she said 'We can help' and it was like she was taking over. You know – the like 'We can help' was like taking over....saying that they can sort that out for you.'* She, as the other participants, wanted to feel in control and was concerned that she would not have the power to opt out of situations in therapy that she does not like: *'I do need to feel that I'm in charge of myself'*.

4.7.3.2 "Nobody's going to do it for me" - Being positive and motivated Attitude was seen as important in making progress, and many expected themselves to work on maintaining a positive approach. In some cases this was seen as a continuation of pre-morbid character, in others people struggled to hide their doubts and fears and – for some – this seemed impossible despite acknowledgment that it was helpful.

Annie said : *'I do think you have to think positively otherwise stuff takes over and you become negative and it's not helpful'*. Susan maintained her previous positive approach to life : *'I suppose I've um....I've kept a positive attitude'*, as did Sylvia *'always counted my blessings – if you look around there's always somebody worse off than you.'*

Ben saw *'ninety percent of this is myself you know'*, and commented *'I'm still at a stage where a ...a very positive attitude is...is sort of 98 percent advantage, but of course if I'm reaching a limit in areas then er....it's going to be a frustration...not such a positive thing'*.

Self-motivation Self-motivation was described by Doug, who accepted you *'have to just get on with it'* and *'motivate yourself'*, but appreciated this was not easy *'I've got to force myself to do it but I am doing that because I know if I leave it one day then I'll get to the next day and I'll go....you know'*. Roy accepted *'That's up to me isn't it. I've got to do something about it. If I want to and I can get motivated enough I can....I don't know what at the moment'*. Motivating factors include getting back to work, not wanting to be dependent or reliant on others, the family and resuming certain roles/plans. Joyce, for instance stated *'my day to day existence is based on me working full time so I have to get back to work which is.....which is paramount'*. Mandy said: *'At the end of the day it's all for my children'*. Another motivating factor was related to the fear of judgment described earlier – Simon wanted to prove himself – *'It just means I'm showing to my wife, my friends and my work that I'm doing everything humanly possible to get better as quickly as I possibly can....just to prove to everybody that I'm not skiving'*.

Another attitude mentioned by participants was the need to be open and honest with rehabilitation staff, even when it was difficult: *'I suppose I have to be honest and say how I am feeling and if things are too much or I can't cope with certain situations then I have to say that...so honesty probably'* (Harry).

Determination was important – John saw it as the single quality he needed to bring to rehabilitation: *'Just determination.'* Sylvia too, said *'I think determination and practice – I think that's all you need'*. This can be a response to being told something negative – Mandy admitted that she was determined because *'I don't really like being told I can't do anything, so you know'*.

Clearly the flip side of maintaining a positive approach is that this is not always something that individuals can control, and those who are depressed and low in mood struggle to see anything that can motivate or encourage, either within themselves or in the overall situation.

4.7.3.3 "I'm up for the challenge" – Trying and taking opportunities Trying and working hard was mentioned by almost all the participants. They felt that they should try anything suggested and give it a go, even if it required some pain and considerable effort. Maureen

noted *'It's only forcing myself to do these things even though sometimes it hurts and um I exhaust myself, it's the only way to do it.'* Mandy knew *'a hundred percent you've got to help yourself....I am up for the challenge'*.

There was a general sense that people would do whatever it took - Simon: 'I'll do anything I can to get better' and Susan: 'I have to do work....she can't do it for me....and if I want to speak better again I'm going to do it'. People accepted that they might not be able to do things, but 'I can only try' (Derek), 'I will have a go at anything I mightn't be able to do it but...' (Doug), and 'Is this how I'm going to be for always? That's my fear. But I shall keep trying' (Maureen).

Doug was further motivated to work as he thought that: *'they (the therapists) know if you're not working or if you, you know, just going through the motions'*. Ben remarked on his therapist knowing *'how hard...hard....perhaps too hard I was working on it'*. Sometimes people need encouragement to try – Shirley appreciated this and learnt from managing one task that trying did make a difference - *'I really do need to try'*.

There are links with taking control, as well. Joyce, for example, would take notice of any tasks in therapy she could not do and tried to work out her own approach and practice *'whatever it was I thought I couldn't do'*.

Some commented on the risks of working too hard. Ben, Derek and Maureen had all suffered the effects of doing too much physically. Derek thought that *'I've injured myself two or three times doing the exercises and had set backs through that....I tried to do every one of them and you suffer from it'*. Harry noted the impact of feeling under pressure if he pushes himself – *'anything that I do I also have this worry of pressure on me which then becomes counter-productive because then I just shut down.'*

4.8 TRUSTING/DOUBTING OTHERS

4.8.1 Early experiences

Most of the participants did not have pre-morbid experiences of hospital or rehabilitation to inform their expectations, so it is the early experiences following the brain injury that have shaped their views and beliefs. The amount and speed of recovery to date has already been discussed, and this section is concerned with the impact of early rehabilitation and hospital

experiences. Positive and negative experiences at this stage begin to impact on expectations of rehabilitation, and lead to trust and doubt in relation to those upon whom the individual depends. These experiences also shape participants' views of what rehabilitation should be.

At this stage people were placed in a position where they were forced to trust others – both those they saw as 'experts' (medical, rehabilitation and other staff) and family/friends – because they were too ill or disabled to have an active role.

4.8.1.1 "I just wanted to get out of there" – Hospital experiences The questioning of accounts of lost days/weeks, when memory and awareness impairments and disorientation were factors, has been described in relation to participants trusting their own memories. The other side of the coin is that they were forced to depend on and trust others' accounts. Personal memories were accepted or rejected perhaps only with verification from others, and intellectual if not emotional acceptance of explanations grew. Mandy needed verification of the memories she did have: *'I can remember saying that and my daughters both can confirm that I did say that'*.

Many of the participants talked about experiences while in hospital, which were in some cases deeply significant to later interventions. Annie noted her frustration when constantly disturbed by staff accessing notes *'You see things that you just think why? Why are they doing that?'* Doug was positive – *'everybody I've come across...have been excellent....everybody even down to the auxiliaries who're doing the food...nothing was too much trouble'*. However he did think *'You might as well check your dignity at the door.'* Roy found hospital not only a positive experience, but received more care and attention than he would at home because of his personal circumstances: *'you know in a sense you're made to feel important aren't you, and cared for and everything's done for you as I say I didn't feel frightened at all, I didn't um...I felt safe'*.

Several participants commented on individual members of staff – from any profession – who took it on themselves to 'go the extra mile'. This did not refer to physical care, but to those who were prepared to offer time, listen and comfort. Keith described: *'You know she was quite happy to give...give me some one-to-one and sort of if I was feeling a bit low – I didn't realize it – she...she noticed and would come and talk.'* Shirley repeatedly asked for 'someone to talk to' and did not get it, until a student provided this informal support: *'I wouldn't have survived without her'*.

Information There were numerous examples of information being conflicting or inconsistent, between clients and even in individual cases. Not all interviewees were negative – Doug was confident in what he had been told: *'They explained all that to me, everything you know'*, - but lack of information or poor communication was often distressing. Mandy was not informed she was having another operation until they came to get her: *'I was absolutely devastated there's nobody had told me, I hadn't told my family...um...I was very upset about that.'* She also told of her consultant not telling her news from her scan until she chased him down the ward, so she and her family had an unnecessarily prolonged period assuming the worst. Trisha was kept in hospital for 'tests' but not told what the tests were or given any results despite the promise *'to let me know but I haven't heard anything.'* Harry received no diagnosis or explanation of what was happening to him, even after several weeks of going backwards and forwards to hospital *'up to this point I still hadn't been told anything at that point...what it was. I just put it down to maybe some sort of viral infection'*.

When information was good, it increased confidence in expert advice. Keith was told the timings by which he should expect to hear from follow-up services, and all had been kept. He was also told about various landmarks he could achieve in hospital and these had been borne out.

Incidents reflected different views and beliefs of staff as well as family members. Some staff gave early opinions on prognosis which affected expectations, and caused varying reactions/responses from individuals. Mandy was told early on by an occupational therapist: *'She said to me in the hospital I can't see you going back to (your work) now that stays in my head. I could never understand why she said that'*. Shirley and her family were told she would not survive, and then that she would not walk – both of which she has disproved and therefore her trust in 'expert' advice was dented. The impact of this was immense : *'she said something about how long they'd been told that I was going to survive was something like six weeks, and I thought that's not six weeks yet – and I was so convinced that if I went to sleep I wouldn't wake up.'*

Predictions of recovery time The timing for recovery was an area of particular variability. Joyce was told *' where you're at after 16-17 weeks ...is possibly the extent of what you got....you can get back'*. Keith was told 6-9 months by one member of staff and years by another. Harry trusted the opinion he was given early on, that there *'was a basic 18 month recovery period and however good you were at that 18 month period....that was as good as*

it was going to get...so I knew by the time I came to you two years down the line I weren't going to get any better – damage that had been done had been done – it was a case of me learning to deal with it.' He did not question this, so by the time he received rehabilitation he had no expectation of improving, other than in how he coped.

Information about conditions Information about conditions was also variable. Ben had conflicting opinions from medical staff about whether his underlying health condition was or was not a factor in his stroke: *'the specialist said no he didn't think that was anything to do with it. My own doctor disagrees totally'*. Shirley had been told her vision would get better by one, and that it is hopeless by another person.

Not everyone felt that the information they received was knowledgeable and correct. Billie spoke of her doctor having *'a vague understanding'* and *'not being sure...um...and neither was I if I'd had a stroke or um....what's the one....(TIA).'* Harry took information on his condition to his GP as he did not know about it. Sanjay did get explanations but *'not to the depth I would have liked...not...not that I'm saying it's not available...but perhaps they thought I wasn't capable of processing the information.'*

Transfers Transfers were often traumatic points for people. Derek, for instance, was not told about his transfer: *'next thing they're packing up – what's going on? Oh you're going to rehab. What's that?'* Keith had no warning when he was taken to the next hospital, where he *'Just sat there and kept asking and they said yeah when we've got a minute and er...so that introduction wasn't too clever'*. Shirley arrived at *'about one o'clock. I didn't see a human being except for trainee nurses until afternoon the next day. I was put in a room...I was given food and medication and that's all.'* Trisha described long waits and delays in her transfer, and finally announced *'I'm going home now. I've waited long enough, I'm going to go home now.'* Anyway that moved them a bit. *They got me a taxi but they forgot to tell the taxi where we were going so I nearly...I was very tempted to go home.'*

Other patients Other patients could be disturbing, Ben for example described another patient: *'He just er...walked up and down all night, almost poking people, shouting and this sort of thingwe were all getting knackered'*. Joyce, too, felt others on her ward were distressing – *'It was a nightmare – it was an absolute nightmare'*, and could not see any commonality or reason for her placement on that particular ward.

Assumptions Ben recounted incidents of staff making assumptions – one member of staff assumed he could walk as there was no mobility aid beside the bed, and another would not listen when he was in pain: *'He basically told me I was talking rubbish....and in the end I had to – and then he did it again – really hurt me and I told him basically to bugger off'*.

Communication The situation of people with communication disorders is of particular interest. Andrew was involved in an 'incident with a hoist', of which his partner could not get a clear account, and which led him to have anxiety attacks when hoisted. Andrew looked back on this: *'Terrible. Terrible'*. John, asked about his hospital experiences, said *'Not very good. Not very good,'* but could not explain this further. Asked how important his lack of speech was while in hospital he said *'Massive'*. Susan described it, tearfully, as *'lonely....because um...couldn't speak....and they were all old'*. However, it was not only those with communication problems who felt that hospital was a lonely experience. Derek noted *'I was....I won't say left alone there but....it felt like alone'*. Shirley too *'felt kind of neglected'* and said *'it's really personal – what happened to me, happened to me. It didn't happen to anyone else so it is isolating'*.

The desire of most participants was to leave hospital and go home. However in retrospect some questioned this – experts were trusted at the time but later seen as making the wrong decision, especially in relation to discharge. Mandy admitted that she *'must have annoyed them so much I wanted to go home....all the time that's all I wanted was to go home. I mean I must have drove them crazy.'* However, at the point of the interview, she commented *'It does seem very strange to me that you're allowed to leave hospital and really you don't know what the hell's going on'*. Simon also thought: *'I shouldn't have been let out of hospital'*.

4.8.1.2 Rehabilitation experiences The experience of rehabilitation up to this point was very variable, ranging from specialist in-patient teams to none. These shaped the expectations and hopes for what rehabilitation could achieve.

Annie had such a good experience that she said: *'I think that's one of the reasons why I kind of recovered as quickly as I have considering how poorly I was.'* Ben commented: *'I could list a whole list of complaints about the hospital but not about the physios or the occupational therapists you know I thought generally that was er.....you know, really, really good....people who really understand.'*

Some found that advice was unrealistic or irrelevant. In another setting, Ben was told to walk with two members of staff to lunch, but: *'you try doing that.....you're always the last one down to lunch....you end up sitting in a corridor for ages just for someone to help'*.

Maureen had some rehabilitation in hospital, and *'they were fantastic with me. Absolutely fantastic. Can't fault them physios one little bit'*, but following her transfer *'I didn't have no rehabilitation'*. This gap in provision, whether people had been discharged home or to another facility, was a common experience. Keith received two hours a day, seven days a week in one facility and only four half hour sessions in three weeks in another. Trisha did have speech therapy arranged for a set number of weeks following discharge, but this was provided predominantly by unqualified staff: *'they were obviously being paid....simple, kind people but they didn't really help me with basic stuff....it was very iffy.'*

As with general hospital care, there was mention of individual qualities that were appreciated or not. Mandy described her physio as *'Just the sort of person I needed. She was very...um....'You will do this Mandy.'* The student who worked with Shirley *'said just try. And I did try and I managed to get up on my feet.....I felt that I had a relationship.'*

Billie knew she saw two speech therapists but *'they didn't do quite the same thing. It was all a bit of a haze what they did really.'* Shirley also had experience of speech therapists: *'three or four young girls came and asked me a variety of questions but that was all....and it was just printed on pieces of paper – they weren't using their brains – they were just reading and writing....and I don't think they were interested really.'* Susan did not have speech therapy until four weeks after her stroke, but did think *'it improved after that'* – although she questioned *'I don't know if it is because of the Speech Therapist or three weeks'*.

Being heard The importance of being taken seriously was crucial, as people struggled to trust staff who dismissed their concerns. Mandy spoke of a visit from an SLT who asked her to do various tasks, and commented : *'I couldn't even think about them and she said they didn't matter – well perhaps they didn't....'* To Mandy these difficulties **did** matter and being told they did not, denied her a voice.

The experiences did not mean that people always understood which profession they were seeing and for what reason. There was little awareness, even after hospital and/or community input, of the specific roles played by the different rehabilitation disciplines, or of the scope and extent of rehabilitation. Mandy had no sense of what each type of therapy

does: *'If there was physio obviously I separate that from, and if there's a psychological...or then...but anything else I can't get my head round any of that'*. Simon commented: *'I don't know what his job title is but he helped us'*. Harry felt the discipline was irrelevant to him – he just wanted to be helped.

The interviews seemed to suggest that the specific titles/roles of rehabilitation professionals were not understood, but that there was a pragmatic sense of accepting activities if they were seen to be helpful.

4.8.1.3 “A Stepping Stone” - What is rehabilitation? At the point of interview, participants had varying experiences of recovery/improvement, and of hospital and rehabilitation services. As may be predicted, this variability meant that people had a range of views about, and expectations of, rehabilitation and what it could achieve.

Some saw rehabilitation as being to get you back to where you were, in other words to get better. Andrew said it was about *'getting me better. That's what I think.'* John began by saying he did not know what he expected, but then said he expected it to get him to *'full recovery'*. Joyce spoke of *'efforts to be made towards getting you back to where you were before you started'*.

Roy explicitly raised the question of what getting people back to how they were means - getting people back to *'as normal a life as possible – whatever that is for that particular person. Only they can say can't they, what's...what's normal.'*

Some understood rehabilitation as a balance between getting back what you can and managing any residual problems. Ben did not want to cope with disability, but recognized this role for rehabilitation: *'probably two fold – one is to....is to get you back to...as much as possible, to how you were before the incident took place and I suppose the other side of it is...is er...managing with...with er...residual problem that you've got afterwards.'* Harry described it as *'helping you to cope with who you have become rather than who you were'*. Keith viewed it as a *'stepping stone and the help to get you out into the more real world again.'*

Not knowing what to expect However, despite having rehabilitation in hospital, a significant proportion of participants thought they had no real knowledge or expectations of the rehabilitation that awaited them in a new setting. As Trisha said *'I don't know what can be offered because I've never had experience of it'*. Keith could not answer the question as

to what he expected to happen, as *'I haven't got that bit in the middle. I've got what I'm told that they will do but I don't know the bit in the middle about how you get there.....it's an unknown'*. Roy commented *'I suppose the truthful answer is I don't really....really know what to expect at all.'*

It may be predicted that people who expect rehabilitation to lead them to full recovery will have high expectations of the rehabilitation team. Those who already realize that part of the process is about adapting, are implicitly accepting at some level that full recovery is not likely. The early experiences of rehabilitation –alongside recovery so far – have influenced these expectations, even if individuals do not think they have enough knowledge to know precisely what to expect from specialist community rehabilitation.

Information about specialist help Information about specialist rehabilitation was not always available to participants and several had been left to source it themselves, or with family help, sometimes trying other inappropriate services first – Sanjay for example attended Mind. In Sylvia's case she found out about specialist care and then her physiotherapist refused to make the referral as he did not think it would help her. Maureen feels she was not given the necessary information to allow her to make informed choices about placement after hospital discharge and that this resulted in a deeply unhappy period of time, with no rehabilitation provision. Simon's wife heard about specialist provision from someone she met in a beauty salon.

4.8.2 Experiences and expectations of family support

The support of family/friends to this point in the process was acknowledged, with an inherent assumption that this would continue. Most were appreciative, some were disappointed, and some took it for granted. Specific examples of how different families cope indicate a desire for normality – to use routines, make plans as far as possible, and value laughter – as Mandy said *'we live on humour in this house...I honestly think that's how we've got through it'*.

4.8.2.1 "To do their best. To do their best" - "It doesn't just affect one person" Most participants had support from family members, and accepted it in varying ways. Practical help, encouragement, and supportive care were all appreciated. The perceived impact on the family seems to vary. Simon described his wife's experience as worse than his own: *'she has been through hell and back'*. He said that *'this isn't something so much as happened to*

me it's happened to my wife and my friends'. Doug meanwhile reported that his wife was 'quite happy'.

Andrew was aware that his partner has been very supportive 'but if you weren't as (supportive) yeah and he was ...he....would these be so....are there some people who can't do it or won't do it?' Others appear to see it as a given. Susan appeared relaxed about leaving her mother to 'deal with that and I don't worry about it or mum'll deal with it.' Annie accepted: 'he's quite happy to do things for me and I'm quite happy to let him, and that's a bit naughty really I think.' John expected his family 'To do their best. To do their best'.

Practical help Practical help may be in the home or keeping working for financial reasons. Keith described his wife: 'really she's been my rock, the whole way, yes,' as she dealt with household chores and went to work, although this meant he had to manage his own rehabilitation. It may also include finding information and taking care of benefits and family business. Sanjay commented: 'Things you have to do by yourself so for example if I didn't have my wife to...that was on the case so to speak, then it would be difficult for me um...to find people to help.'

For some people support with personal care, activities and therapy tasks was expected from family members. Ben had considerable help from his wife 'I shout out to her 'your turn now' and she comes and does the other bits and pieces.' However, Simon for example, explains that he did not expect family/friends to do exercises with him, as he felt shame at showing his difficulties to them: 'when you're with professional people who are trained to help you in a certain way, there's no shame in it...but when you're with your wife...' Sylvia had no doubt that her husband's role was to help with therapy tasks: 'he'd need to know what exercises I'm doing so he can do them when he gets home, cos not all of them I can do on my own.'

Emotional support Encouragement includes being 'pushed'. Annie remarked that her husband: 'is very good as helping me with stuff if I need it but equally pushing me to do a bit more.' Mandy described how she was encouraged by her daughter: 'she's not just there to give you the answers to make it easy for you, she's ...um...no she's brilliant.' Sylvia saw her husband as 'the one who champions my corner – who'll fight for me. So he'll push and push and push.'

Emotional support is important. Annie appreciated this: 'he's just so strong and won't let me think negatively. He's just 'No. No. We're not going to think like that', and he constantly drove

me all the time really.' Feeling that family share in their progress was also important. Ben described his daughter realizing he could move his hand: *'she felt this squeeze for the first time, wasn't expecting it you know, tears rolling down her face and I seen it – probably mine as well.'* Not all participants were able to reveal the depth of their need or only share it with their closest family member, for example, Billie was aware that only her husband really saw the extent of her depression.

Not all experiences had been positive. Mandy's ex-husband offered a pessimistic view: *'he said to the girls that 'I think you're going to have to accept the fact that mum's not coming back' just like that, and they both looked at him and went 'I hope you're kidding, Dad, of course she is' - you know they were so absolutely determined'*. Mandy was also able to accept that *'I was upset that my mum didn't come to see me,'* but recognized that some people cannot deal with illness and disability.

Susanna acknowledged the closeness of her family, but felt that they struggled because they had always seen her as the strong one and *'do not want to worry about...that I might not get back to work...'* Derek was critical of his wife's attempts to support him: *'she's got to learn somewhere along the line that she's got to be able to give and take and slowly pull me up to it.'*

Sometimes participants were uncertain how much their families were telling them. Doug wondered: *'I sometimes get the impression she only tells me what I want to hear'*.

Expectations of the family have largely grown from the support experienced so far. There was also concern from some participants that the family needed help, and this aspect will be addressed within the section on expectations of services.

4.8.3 Expectations of services: Expertise

There are different levels of expectation of services. One level is in relation to what people expect the services to be able to achieve – that is, the efficacy of rehabilitation – can it make a difference at this stage and in what way? It has already been seen that some see rehabilitation as getting back to how they were before, while others expect only some improvement and to get help in adjusting and coping. The second level is in terms of how rehabilitation will operate, and expectations here were often shaped by the early experiences following the ABI.

In terms of the explicit expectations people have of rehabilitation, people stated clearly that they had no expectations as they *'have never been in this situation before'*, however both by statements and implication there were specific hopes and wants held in relation to engaging with rehabilitation.

4.8.3.1 "I was expecting someone the next day, but...." - Timeliness One of the most frequent criticisms of services was that help was not offered in a timely manner, and some felt this had impeded progress. Ben and Keith both thought their arm recovery would have been helped by earlier intervention. Ben said: *'I think if I'd had more arm treatment from the beginning my arm would be quite advanced now quite honestly.'*

The delay in help was especially noticed following discharge from hospital. Joyce, for example, was sent home without advice or exercises, and with no idea what she should be doing to help herself. Others were led to believe they would be contacted quickly, but were disappointed, or given time scales to which services did not adhere. Maureen described a form she needed for work which *'the doctors had for a bloody month.'*

Derek expected to get rehabilitation from the moment he arrived home *'we were really under the impression that we'd be starting there virtually immediately'*. Maureen admitted that *'I found out that everywhere takes months to get into and I didn't realize that. I was expecting you know someone to come round the next day but it don't work like that.'*

Some commented that help came too late to be of value. Susan had a visit about bath rails: *'waste of time now. I've been doing for seven weeks...but if they come the beginning I was...um...get more help from them.'*

4.8.3.2 "There's no shame in it" - Working with experts Participants' experiences over the preceding weeks/months had helped to develop a sense of what was expected from rehabilitation services, but expectations were somewhat nebulous and vague. There was still a dependency on and need to trust the 'experts'. With no knowledge of specialist rehabilitation people agreed to referral because of the opinions given by professional staff and the reputation of the centre, and a belief that everything possible should be tried. Simon wanted: *'to get help from someone who's a specialist in that area as soon as possible'* but had *'no idea....it sounds like (this centre) is where I should have been from the start'*. Doug was prepared to try it: *'I've got a completely open mind really. I really don't know anything.'*

I'd never even heard of the place, so I'm just happy for somebody else to have a look and I'll have a go'.

In terms of expectations of services there was a recognition that rehabilitation needed to be provided by people who specialised in and were expert in that field. There were some who clearly expected certain therapies, with six mentioning speech and language therapy, five physiotherapy, three counselling, two neuropsychology, two occupational therapy and one dietician. One expected a 'joined up' service and team approach: *'I feel I've been scattered slightly you know there's...this might help....I just feel a bit scattered'* (Susanna). However there was a sense that people were not always aware of possible services, as they had not been offered or experienced them previously – for instance Andrew, asked if he thought he should be offered emotional support if needed, replied *'I didn't know that (it could be).'* When mental health was perceived as a major factor by the participant, it was recognized that it was the absolute priority, with an awareness that nothing else could happen effectively until that was addressed.

Roles and responsibilities In terms of specific expert help, work was mentioned often, and specific needs identified by different participants, depending on their job. These included a number of cognitive skills, such as quickness of thinking, controlling groups of people, prioritizing, making constructive arguments, response speed and clarity, as well as physical and driving requirements. Work was a crucial area for many of the interviewees and may reflect the critical role of work on self-definition and esteem, as well as its importance financially and the desire to resume one's family role. Simon explained: *'getting back to work is primary'*.

Parenthood and/or the role of partner/spouse were also of profound importance. Mandy said: *'Now it's my daughter and although she's strong enough.....it should be me and oh it breaks my heart'* and wanted to feel her children could *'let me gradually take over and be mum again'*.

Specialist help There was variable understanding and expectations about rehabilitation as a specialist service. Ben had 'made do' with a non-specialist physiotherapist while waiting to be seen (*'I don't know how much of a specialist they actually needed to be, right or wrong....she seems to be fine, but again she's not a specialist'*), and questioned its necessity in every aspect of treatment, despite fighting to get specialist help. Others had been aware of the reputation of the specialist service and were convinced by this that it was essential for

their recovery: Susanna's physiotherapist had *'praised the...the system if you like and um....immediately she said that's what I need...that care under one roof'*.

The qualities of expertise that they expected included the belief that specialists would have a much greater knowledge of, and understanding of the impact of, the relevant aetiologies. Examples were given of people having limited understanding, because they did not have the relevant experience – Ben expected: *'people who really understand I suppose because they....that is their job to understand stroke victims you know.'* Despite his earlier questioning, he went on to say *'I expect to....to see people who are experts in the field'*. Maureen had some community physiotherapy while waiting to be assessed, and noted *'they're young girls. I've nothing against young girls – they've done their training, but they just don't understand strokes I don't think.'* Billie *'was given a list of counsellors and um...I went to one and um....I didn't think that was going to be any help...because my depression is because of my stroke... it had to be someone who knew about strokes.'*

The expectation that specialists would know what they were doing, however, did not mean people knew what they would do. Trisha said: *'I don't know what you'll do or what can be done, I really don't.'* Despite this certain expectations were apparent, often implications based on recognition of the more negative aspects of hospital and rehabilitative care received prior to the interview. These expectations relate to guidance, rationales, information, trust in experts, and aspects that could be incorporated into a broad area of the 'therapeutic alliance'. There was overlap with the expectations individuals had of themselves, and the degree of trust or doubt they had in their own efficacy impacted on the trust and doubt they had in relation to rehabilitation services.

4.8.3.3 "Guidance is the word" Participants wanted to know what to do and what not to do, to avoid harm or bad habits. Sometimes it was hard for them to define where their problems lay and what needed to be addressed: Simon described the experience: *'rehabilitationhas been an eye opener'* and *'It sort of makes you realize where you've got problems that you haven't even considered'*. Participants wanted an expert to show them what to focus on, how to cope and to have a plan: *'we've been waiting for a plan and I guess that's what (specialist rehabilitation) means, really. We'll have a plan'* (Susanna).

Ben put this nicely – *'to direct me you know not that you shouldn't be doing this – you should be doing this – have you thought about doing this sort of thing, and you've got enough back*

in this area at the moment – you want to be concentrating on here and you know, that type of thing.’ Harry wanted ‘guidance I suppose is the word. A bit of guidance.’

The need for guidance alongside reassurance was taken up also by Roy – ‘*I just needI need a reassuring guiding hand don’t I?’* Not knowing what to do and needing guidance following discharge from hospital was a common theme.

4.8.3.4 “If they wanted me to stand naked on top of the roof....I’d ask why?” - Having a rationale There was an expectation that tasks had a purpose and that these rationales for treatment approaches/tasks should be explained. When a purpose was unclear to the client, they were less engaged and motivated. Doug wanted to be ‘*doing something that I can actually feel some use of.*’ Simon commented that in his past experience ‘*they set you tasks which have seemed a bit meaningless*’. Mandy too experienced this: ‘*She kept saying you must do this with your left hand and I kept thinking why can’t I do it with my right*’. Trisha could not see the value or rationale behind being given ‘*some things out of books I think....you know photocopied things...pretty simple stuff.....I’d not be happy if they were going to keep me busy doing nothing. If they were asking me there just to pass the time*’.

Most expressed readiness to ask about the rationale behind a task if it was not clear, and accepted them if they could see the sense and reason for tasks. Mandy thought that ‘*if something I don’t knowwasn’t working for me or I didn’t understand something I think I’d happily say.....you see that’s the opportunity we didn’t get at the hospital which is such a shame.*’ Sylvia was confident she would ask: ‘*I would ask why. I always speak up for myself and so if they wanted me to stand naked on top of the roof, I’d ask why that would help me.*’

Being kept informed and understanding the theory and reason helped. Annie was happy to attempt tasks ‘*as long as I thought it made sense and was going to be helpful to me.*’

As well as the rationale, participants expected tasks to be practicable, as was seen in the discussion about their own expectation of having control. Participants expected to have choice and control, but were happy to trust the experts if the reasons were clear and tasks were seen as possible.

4.8.3.5 “I wish I’d known that a bit sooner” - Getting information Consistently mention was made of not fully understanding or knowing what had gone on or was going to happen next. There was at this point, a sense of lacking both general and specific information that would help. Simon said: ‘*when you bang your head there’s no-one to tell you about what’s*

going on' and (My wife) 'didn't know what was going on either'. Mandy felt that she needed more explanation and information - even a brief explanation offered on the telephone, about her lability, when the specialist service initially made contact resulted in her saying: 'I do wish I'd have known that a lot sooner. I really do because that's helped me cope so much more'.

There was, however, also the expectation that information would be in a suitable form, not using medical language or jargon. Maureen felt intimidated: *'I should have asked that doctor about this brain dead business'.* Sanjay commented: *'they could have done a bit better to put it in layman's terms so at least I'd know what had happened to me and how – you know – I could cope with it....certainly save a few more questions down the line.'* Jargon led people to feel unable to ask further questions. Several had tried to get information themselves from the internet, but had found it too confusing. Susanna said: *'when I try to look on the internet there's far too much to comprehend, to be fair, so I've stopped looking.'*

One piece of information many consistently wanted to know was how long they would take to improve or get better, however they often acknowledged at the same time that they knew, intellectually, that this could not be answered accurately. Mandy realized this conflict between understanding and emotional need: *'You know – I want to know now and I know there's no saying 'Oh well on 16th May you're going to....you know, I know that, but how long am I going to be like this?'* Susan also accepted this, acknowledging that she wanted to ask her consultant *'basically time and which....I know he wouldn't be able to answer.'*

Basically people wanted and expected more information and explanations about what had happened – as Trisha said: *'whenever you go into something new completely – which this is ...you know nothing, do you?'* The strong expectation was that knowing more and understanding more would be helpful – Harry *'it's just understanding and people giving you what information they can just to make it a little bit easier, if it can, just give you something to help you control from day to day.'*

4.8.3. 6 "I've got to trust"- Trusting the experts People expected to be able to trust a specialist service, in relation to the professional knowledge and skills, and information. Their past experience would impact on whether this happened, or whether people had doubts and fears about accepting what professionals said. Derek noted that *'I'll try to do everything they ask me to do....I mean they're not going to ask me to climb a wall but...um...if they think I'm capable I'll try it – I might get to the top – I might get half way, I don't know'.* He implied that he trusted the experts to know his capability, but also to choose appropriate level tasks. Doug

commented: *'I would imagine they know better than I do what's....what's going to make me better....so I'll go along....like I said I'll go along with it....'*

There were numerous examples of people being prepared to trust the experts, including the following remarks: *'my role is to do what I'm told'* (Joyce), *'Whatever they say, I'll do'* (Maureen), and *'anything (they) can throw at me and say do this because it will help, I will do'* (Mandy).'

4.8.4 Expectations of services: Therapeutic alliance

Compliments and criticisms of services received largely revolved around the relationships and personal approach of staff. There was an inherent expectation that individuals would be treated in a dignified manner and with respect for age/sex, privacy, keeping promises made and being included/informed as to what is happening. Having a voice is important, having someone to talk to, people who care, encouragement and honesty. What was apparent throughout the interviews was that the therapeutic alliance was as crucial as professional expertise.

4.8.4.1 *"She said it didn't matter" – Having a voice* Participants needed and expected to be heard by therapists. There were a number of examples where people had felt dismissed when they expressed concerns or worries, and this was especially difficult for those who had improved to a level that therapists considered within normal bounds and therefore appeared to think this should be good enough – even if below that individual's level and needs. This has been mentioned before in relation to early experiences.

In this study speech and language therapists were mentioned in this regard most often. Mandy was told she had no problems, but knew she did: *'I did see the um...um...speech and language lady just said 'Well Mandy you're absolutely spot on, you know you haven't got any worries, but I know I have because I know when I talk to my children and they burst out laughing because I've said something so ridiculous.'* Joyce described this: *'Yes I'm too good. Yeah. That my recovery has been – inverted commas – "miraculous" and because it's so miraculous, that I'm too good.....To me I'm not....not good enough. Um...it's not....it is just not good enough.'*

Some expressed the sense that the experts felt they were in charge and knew best, so their own thoughts did not matter. Shirley felt that *'they are in charge and that I've got to do whatever they want me to do and I feel as if they are in charge of me...where I've got...you know I suppose you know what I think doesn't matter'*.

4.8.4.2 "I needed to talk to someone" This could have been included under expertise, as an area of need that participants expected to be covered, but appeared to be raised by people as a general sense of someone being there, rather than a qualified psychological therapist. The expectation was that there would be people who were prepared to listen. Several specifically mentioned not having been offered any emotional support, such as Andrew who when asked if it would be helpful said: *'Yes. Cos I think maybe I should (it's been a hell of a journey).'* Harry commented that *'you don't deal with the psychological side of it'* and that *'it can also break down the feeling of it just being you...the isolation of it...um...which I think...yes....and allows you to talk about it.'*

A few had experienced individuals who had informally offered support in this way. Keith was appreciative of one therapist that *'she was quite happy to give ...give me some one to one'*, and Roy accepted that *'it was great her coming here – we could talk...it was nice to talk to somebody....that alone was brilliant to speak to someone.'*

Requests for emotional support, the chance to talk, had been ignored. Shirley still felt distress and was crying when she discussed this: *'I found it really terrifying and there's nobody to talk to – I did ask for someone to talk to and they didn't provide anyone so I...you know...I repeatedly said I needed someone ...but I didn't get it.'*

Interestingly, as an additional illustration of this need, several people volunteered their appreciation of the research interview, as having given them the first opportunity they had had to talk about their experience. Maureen said: *'This is the first time I've had anyone really to talk to'*, and Mandy: *'that was almost like I was emptying my head of it all and that I needed to empty my head of it all and it's actually nice to talk to you about it because I'm not upsetting (my children).'* She went on to say: *'I feel so much better even talking to you'*. Simon thought that he'd *'spoken to you more about this than to anyone'*.

It should be noted that not everyone wanted to talk, Trisha, for instance, did not want to *'be talking about illness'* or *'go into deep relationships with my family'*. Sanjay was uncertain and recognized that it might not be easy for him *'explaining how I feel emotionally.....I'm not a*

forthcoming person myself'. However, for those who did it want to talk it was a major theme in their personal narrative.

4.8.4.3 "I just needed someone to care" There was an expectation that staff would be genuinely interested and engaged, at a time when people felt, as Annie said, '*vulnerable*'. Those who were seen as 'just going through the motions' – perhaps, as has been quoted, following written protocols or worksheets without appearing to think about what they were doing or with whom they were speaking, were not perceived as helpful. Shirley described this approach as '*they weren't really using their brains.....I don't think they were interested really.*' Those who did not listen to people's concerns were viewed as uncaring and dismissive. As Shirley said: '*I just needed someone to care*'.

Staff who took trouble and time to talk or to respond to requests for information and meet promises were not only praised on a personal level, but also seen as inspiring a better response to rehabilitation – as Doug said '*I found most people would do anything they can to help you...and ...you return that*'.

4.8.4.4 "Look I'm not stupid" - respect and dignity The therapeutic relationship encompasses many qualities, such as respect, dignity, choice, individuality, and mutuality. A number of participants felt that their hospital experiences had lacked in some or all of these areas, and expected better. Doug commented: '*I think if anything they should....respect people's dignity a little bit more you know*'. For him part of this was being offered help by clinicians of appropriate age/sex. Doug, for instance, disliked being given personal care by a young woman: '*my boys are getting on for 30 now....and this young lady trying to help me. I don't think ...in fact she didn't cos I told her to bugger off*'.

People did expect to be treated with respect. Mandy recounted an experience in hospital when the consultant had promised to tell her test results, and she and her family were desperately waiting when she saw him walk straight past her. She had the ability to confront him but felt both her needs and her family's needs had been ignored : '*I thought – you'd walked past, why could you not - you know - just come in and say 'oh M good news, it's about...'* but I wasn't going to let him off – I was going after him'.

How people speak to participants was critical in conveying these therapeutic qualities. Some had felt patronized. Ben noted that one member of staff '*was obviously in a hurry and I thought he was possibly annoyed about something you know, something like that and he...he*

said to me I suppose I can (help you use the commode) but you know we've got to be really quick'. Sylvia perceived hospital staff as patronizing in the way they talked to her – 'I said 'Look I'm not stupid – I've just had a stroke' and noted that 'the doctors....were talking about me as if....talk to me....I'm still here, and they'd discuss it among themselves and I found that insulting actually – I didn't like that – I didn't like it at all.'

Mutual respect was valued – when the professionals, as Doug said, *'seem to learn from patients as much as patients learn from them'*.

4.8.4.5 "You're doing really well" - Encouragement and honesty Participants wanted staff to share in and show pleasure in progress made, and to say when people did well. Ben explained when *'you've got something back is tremendously exciting and you know it's absolutely vital that er....if you....An occupational therapist or physio would, would share completely your excitement.....and....talk about encouraging.'* Roy wanted *'to be told 'You know you're doing really well Roy, this was expected, just keep plugging away'.'*

Encouragement also stemmed from not being allowed to get away with things – being expected to try and take on tasks. Annie illustrated this: *'those soft skills were totally there and she was very kind, but she equally wouldn't let me get away with anything.....all the time when I would actually say 'No I can't do that - -it hurts', she would say 'Of course you can'.'*

There was an expectation of being given a realistic view of what was possible/prospects and honest feedback on performance. Sanjay was *'hoping that the experience with the rehabilitation lot will give a very realistic view of what is possible, what is not possible and then from that I will basically have to...um....deal with it.'* Susanna recognized this may not be easy to take: *'I think I'm going to be 'Well I'm quite good at that', and maybe to be told that actually you're not or 'I don't think I'm very good' at something and they say actually that's very good and we're not expecting any more improvement, so I think it's going to be tough in a lot of different ways.'*

4.8.5 Expectations of services: Support for the family

4.8.5.1 "She's got it 24 hours a day" - Expecting support for the family The hope or expectation that support would be given to the family as part of the rehabilitation process varied, perhaps depending on how much the individual perceived family life had been affected by his or her brain injury. Simon said: *'Really people, whoever looking after the person that's had the injury needs support right from the beginning'*.

The main support expected for families was information, and emotional/opportunity to talk. The assumption by most was that partners and children would be included in the offer of support, but not the extended family necessarily. Ben thought: *'the rest of the family I'd say no, everybody's not so close to it....but she's got it 24 hours a day sort of thing.'*

Simon noted: *'the people caring for the person who's been injured they need....if nothing else they need information'*. Information could help them to *'understand that any reaction that I have and things I do it's not personal to her, it's about me trying to deal with what's going on in my head'* (Harry). Sanjay expected his wife to get the same benefit as him from attending sessions with him – *'so if anything she'll get a better understanding as much as I will, cos we're the people that have to walk away from that and go back home and deal with day to day things and what not, so I'm hoping she'll gain some....positive experiences much as I expect.'*

The emotional stress caused led to the expectation that services would recognize this by offering support. Doug suggests: *'It's going to be nice for her to talk to somebody'* and Mandy hoped *'for someone to talk to my oldest one because she's took on this tough-y role now – you know, I'm the mother now and I'm the – um – I just worry about her'*. Annie too wanted her children to have *'time to talk'*.

While it was usual for participants to worry about the effect on the family, some acknowledged that not all their families would choose to take up help, and the choice must be left to them. Annie said: *'he'll make up his own mind about what he does and doesn't want to do.'* Kendra thinks that *'he likes to do things his own way.'* Billie was sure her husband would not take up offers of support – *'he's really bad about asking for help for anything.'*

4.9 ACCEPTING

4.9.1 "No delusions of recovery" - Acceptance Harry had *'no delusions of recovery'* and accepted that it was about adjustment and a different life from that which he would have predicted before his ABI. He was different from the other participants, in that his illness occurred many years before, and he had recently been re-referred to the service. He was aware of continuing problems and looking for support and advice, but he had clear expectations that both he and services could work together to improve his situation despite accepting he would not *'move forward'* in the sense of recovery: *'I knew by the time I came*

to you I weren't going to get any better – damage that had been done had been done – it was a case of me learning to deal with it'. He had made sense of his life, identified the need to find something to provide his life with meaning, and worked hard on this new pursuit – one which he would never have considered pre-morbidly. Harry admitted that he had to find something to focus on: 'if I didn't have anything then I would probably be quite depressed to be honest, so I hold onto the dream of something coming out of that.'

Some other participants were showing signs of making adjustments, such as considering the need to adapt or change their work or lifestyle. Andrew thought he might *'get back to work in another sort of way'*. Ben realized *'things are going to be different'* but expected to do his former activities *'to a limited extent'*. Doug wanted *'to get back to doing some kind of work'* but in a different capacity, as did Simon, Susanna and Mandy. Keith believed he *'will adapt to whatever happens'*. However, for all of them, at their stage in the pathway, it was theoretical. There was, in most cases, still some degree of hope – however small - that these adjustments would prove to be short term. At his later stage, Harry had adjusted his life, was clear in his expectations, and perhaps could be seen as having reached *'acceptance'*, so perhaps time is the defining factor in accepting that life has irrevocably changed. He said: *'I've probably come to a bit of an acceptance over the years that I've got these problems'*.

4.10 Chapter Summary

This chapter has described and illustrated the categories identified following analysis of the data. Illustrations are essential to demonstrate the validity of the categories and it is important to provide ample examples of raw data to support the analysis. As the simultaneous collection and analysis of data continued, a model evolved. This process is described in chapter five.

Chapter Five – Evolution of the Model

5.1 Introduction

A Grounded Theory approach was chosen because it seeks to generate a theory or model by which to understand the phenomenon being explored, without deriving constructs from existing literature. As other qualitative methods, it is iterative, and simultaneous data collection and analysis is undertaken. Constant comparison of codes and categories leads towards development of a framework. This chapter describes the evolution of the model as data collection and analysis continued, showing how further data, and subsequently theoretical sampling, developed and refined the framework to its final version.

It has already been indicated that the data and researcher interact to construct the model, and it is one possible interpretation of the data, rather than claiming to be a 'truth', in line with the epistemological and ontological philosophy underlying this research (described in chapter two).

This chapter will outline and illustrate six versions of the model which were developed from the data at different points, with the final model drawing on the final categories identified and described in chapter four. As was explained in chapter one, it seems appropriate for this chapter to be written in the first person, as it describes my personal reflections and thinking process through the course of the study.

5.2 Exploratory Phase Model

Three clients were interviewed as an exploratory study, to evaluate the methodology and methods chosen and determine their appropriateness for the main research. Figures 5:1 a and b show this model, which was in two parts. The first diagram sought to pull together the process through which clients had attempted to make sense of their experiences and the second illustrated what they expected or wanted from a rehabilitation service.

The aetiologies of the three clients were stroke, cerebral abscess, and traumatic brain injury. The data led to categories of Being unprepared, Trusting and doubting self and others, Comparing with past self, Comparing with others, and Hoping/Doubting recovery.

Figure 5:1a Exploratory phase 1

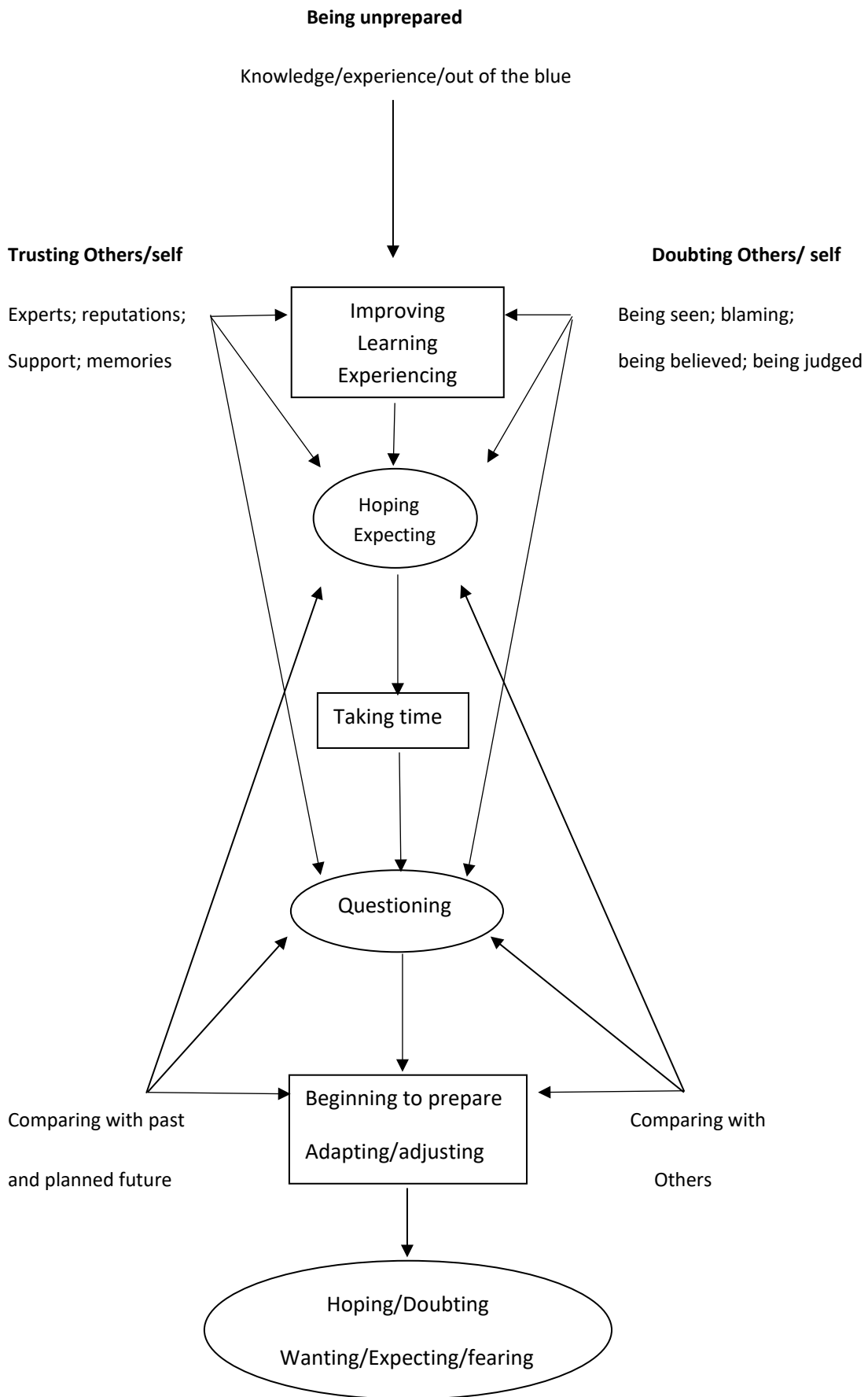
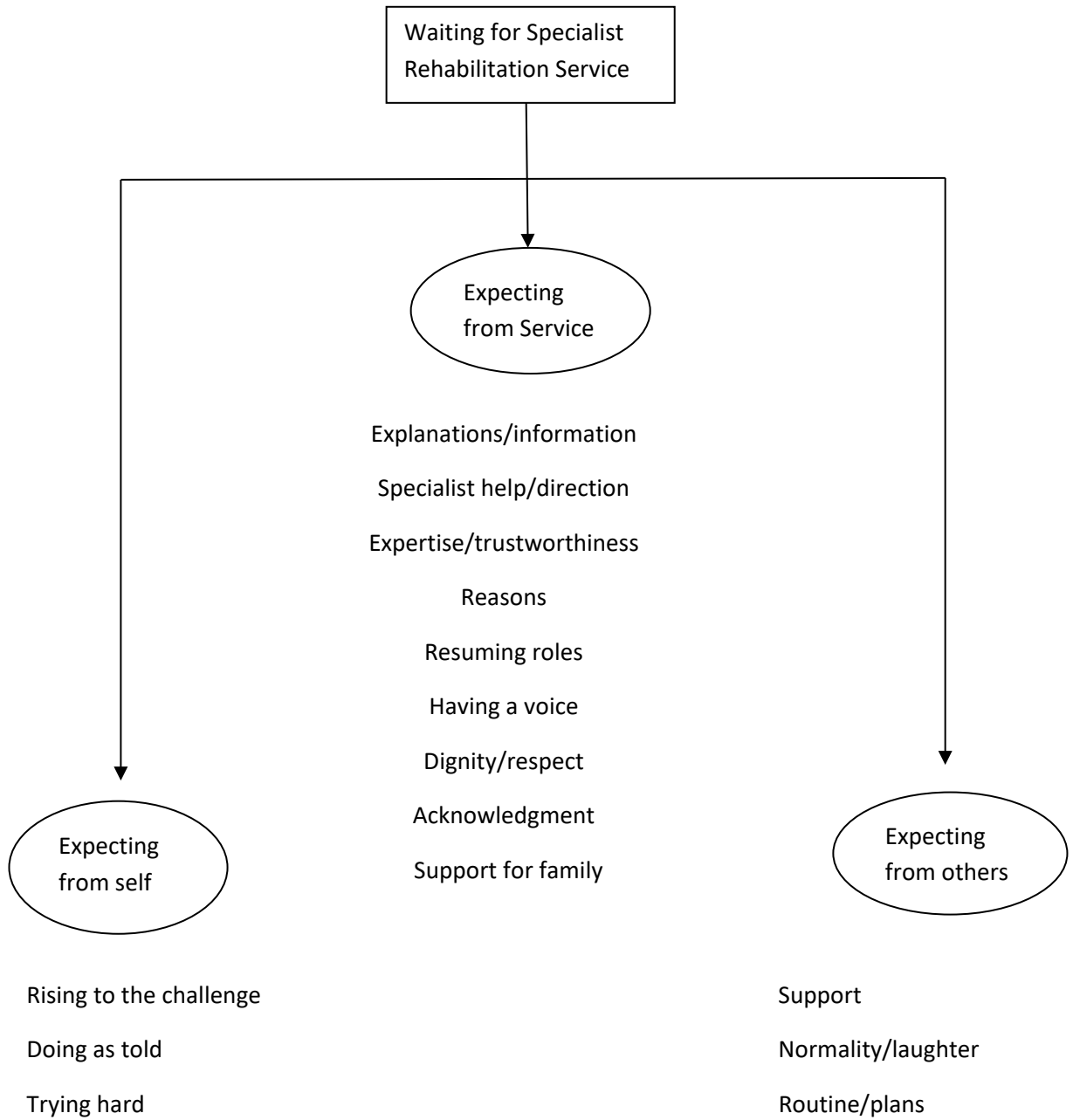


Figure 5:1b Exploratory Phase 2



Being unprepared was common to the three clients, all had seen improvements over time, and all were indicating continuing problems. However, two had significant memory gaps as a result of the brain injury which led to difficulties in trusting others' accounts of their experience and doubting their own ability to remember and cope. Memories that seemed most real were sometimes not: *'of all the things that I remember that is the one I would say is the one that's true but I have been guaranteed....there is no way.'*

Similarly there was a sense of judging themselves and being judged by others. One client had particular issues in feeling judged and guilty: *'I feel like a fake'*, as his problems were largely invisible to others as he was physically able. Against this, another of the three was scared of judgements that were based on physical appearance: *'I don't want to see people....I do feel embarrassed'*. Trust in professionals was not always present – one client, for example, was upset, knowing she had problems, and not having this acknowledged.

Hope was expressed by all, but there were implied or explicit beginnings of doubts that full recovery would be achieved. I was struck by apparently contradictory comments within the same interview, with one refusing to *'even entertain the thought'* of not getting completely better, but subsequently admitting *'the thought has glanced into my head'*, and finally *'I'm just paranoid that it's not coming back.'*

Although based on only three participants, I wanted to attempt to model their experiences, and in doing so was struck by the interlinking of Trust and Doubt both of self and others, and comparisons with their own past/future plans, and with others. Central issues were expectations and hopes, and the beginnings of doubt, about the future.

The second part of the model (5b) was a straight forward description of the expectations people had (again implied or explicit) of rehabilitation, and there seemed to be a clear sense that all three clients had expectations not just of the services, but also of themselves and of others.

At this stage I did not intend to create a model that would persist through the main body of the research, but to begin to look at how people's perceptions, expectations and beliefs linked. It was important not to attempt to create a theory too early and risk biasing the subsequent analysis, and for this reason I did not refer back to this initial model as data built up, but attempted to address the data from the first seven people in the main study

independently of the exploratory data. At that point the two data sets were compared and a further model was developed, based on ten participants.

5.3 Model based on participants 1-10

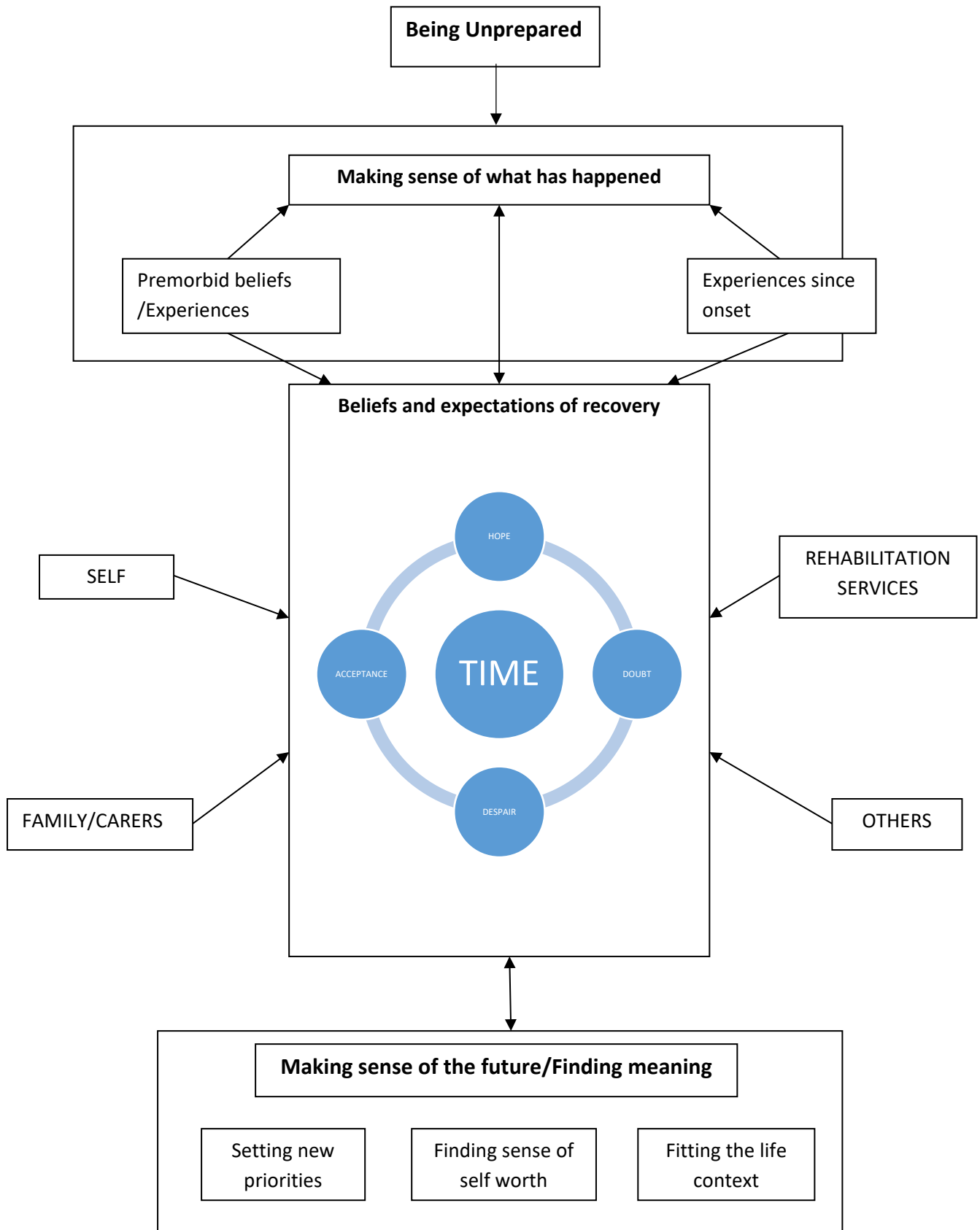
Figure 5:2 shows this model. As constant comparison of data continued it was apparent that some categories remained relevant. The category of Being Unprepared was significant in the experiences of all the participants, but seemed to lead into a process of trying to make sense of what had happened to them, which was influenced by pre-morbid beliefs and experiences, and by experiences post-onset.

The expectations of recovery coalesced in a mixture of hope, doubt, and for some despair or dawning acceptance. Time appeared to be a defining factor in the process, with all recalling the early expectation that time would improve the situation, but by the point of interview being less sure. The nature of the service means that there is some variety in the length of time post-onset before referral, and I did begin to ask questions about the relevance of time. Of the ten participants at this point, however, two were between six and twelve months post onset, and seven were less than six months post-onset. I was, of course, aware that the numbers are too small to draw firm conclusions but did look at the two people seen later in the process to determine if their degree of hope/doubt was consistent, but one remained hopeful and one was in despair.

In this model the data had introduced two aspects into consideration – two clients were in despair and actually expressed suicidal thoughts and one client was a re-referral many years after the event who clearly had a degree of acceptance – wanting help to cope but not expecting to recover. I needed to expand the initial hope/doubt concept to include this data. The other new information was related to taking stock. Two clients were explicitly beginning to question the future and attempt to find new meaning, by taking stock and setting new priorities within their existing life context.

However, including this taking stock/making sense of the future was very tentative as most clients had not found new meaning – or really indicated that they wanted to find new meaning – as there was still predominant hope in all but three that recovery would be complete. By including this step in the model, on reflection I felt I had gone beyond the data.

Figure 5:2 Main and exploratory study : participants 1-10



Beliefs and expectations to do with rehabilitation services, self, family and others were expressed, but I did not have the strong sense of trusting and doubting self and others, as much as a recognition that there was an influence from the four sources – self, family, rehabilitation services, and others. In my mind, however, I had not dismissed the concept as there were examples of people struggling with and criticising the responses of professionals, not merely accepting.

The question as to the appropriateness of the term ‘expectation’ was beginning to concern me, as clients were more likely to use the term ‘hope’, and most – as in the first exploratory sample – were showing indications of doubt, even if not always explicitly admitted. It was postulated at this point, within the model, that the hope-doubt-despair-acceptance cycle illustrated would change with time, and that people would move from hope for full recovery to doubt and either despair or acceptance. However, again, it was felt that on reflection the data was not supporting this, and I was using knowledge and experience out-with the data and making assumptions.

This model attempted to reconcile the two parts of the first model into one framework, incorporating expectations of both recovery and rehabilitation, in recognition that part of the expectation and hope of recovery were dependent upon beliefs about the efficacy of rehabilitation. The influence of self, family and others was acknowledged more centrally, but on reflection after developing this model, inclusion of the category ‘Others’ as having equal prominence did not sit comfortably with the data. With the additional seven clients’ data, fewer mentioned the influence of any parties other than their families and professional therapists, and constant comparison of the data was beginning to suggest moving away from this. I thought that families continued to be a significant factor but that the sense of self both as part of the recovery process and rehabilitation was becoming more and more powerful in the data.

I found throughout the interviews, and in the memos on individuals written immediately after interview, that certain themes and aspects came into the foreground depending on the context of their lives. I needed to be aware of the dangers of being swayed if one client’s data was especially forceful in a particular area. For example, one interview was focused almost entirely on mood issues, but I did not want to give undue prominence to this – the discipline of constant comparison was invaluable.

5.4 Participants 1-15

Figures 5:3a and b illustrate the third tentative model, based on the first 15 clients. The importance of the participants' life context was becoming more apparent, and this model brought it into prominence alongside the pre-morbid and post-morbid factors, and saw all as contributing, over time, to the expectations held about recovery and rehabilitation.

Expectations about recovery were linked to the category of Making sense, which had been viewed up till then as a process of understanding the past. I began to question whether this was actually a process of understanding or making sense of the future – that is, past experiences fed into attempts to work out whether the future could remain as previously planned, or whether they were going to have to adjust and change their thinking about the future.

The same pre-, post- and contextual factors affecting expectations of recovery were seen as affecting expectations of rehabilitation, but what seemed significant was whether the expectations were met. Participants' beliefs in rehabilitation efficacy seemed to relate to the degree to which experiences to date had fulfilled their expectations, although this was a retrospective phenomenon. One client, for example, described what she saw as exceptionally good rehabilitation as an in-patient, and expected this standard to continue. Looking back over the experiences led people to realise what was best practice in their mind. Those who had good experiences, retrospectively had a sense of expectations being met, and a greater belief in the efficacy of rehabilitation.

The hope-doubt-despair category continued to be reflected in the interview data. While not all clients fell clearly into one or other – many for example expressed hope but also admitted or implied the beginnings of doubt – there seemed to be a spectrum, and this appeared to link to the beginnings of adjustment and taking stock. I became increasingly convinced that this spectrum was central, and was important to the aims of the research – to learn about the clients' experiences and perceptions at a specific point in their care pathway. I began to question, too, whether this spectrum was significant to engagement with rehabilitation. Would a client who felt despair about recovery engage with rehabilitation? Would a client who felt only hope in recovery, expecting to be 'back to normal', engage with rehabilitation? Was it, in fact, important that clients go through a stage of experiencing doubt in order to take steps towards adjusting and moving forward, engaging both with rehabilitation and their own resources?

Figure 5:3a shows this model, and an additional attempt to ‘unpick’ the expectations of rehabilitation, self and others via a ‘triangle’ indicating the importance of meeting those expectations is shown in Figure 5:3b. In relation to the rehabilitation services, it was clear that participants valued both specialist skills and relational aspects, for which the term therapeutic alliance has been used.

The earlier reflections on the use of the term ‘other’ given equal prominence were influenced by new data – not all participants had family support, but the role of friends, other medical services and voluntary bodies was acknowledged. For this reason I decided to use the term ‘others’ in this model to encompass any influences apart from self and rehabilitation services.

This version of the model did not include acceptance within the spectrum of hope-doubt-despair, as the earlier model had done. This was because initial hints at acceptance did not seem to be supported by the data, and – while there were indications of beginning to make adaptations and talk about adjustments in the future, there was no apparent acceptance of the situation, with the one exception mentioned earlier, who was many years post-onset. I thought it was important not to lose this data, however, and my thinking in future models reflected this: I needed to consider the exceptional cases, which is an indicator of quality in qualitative analysis.

This one participant was a re-referral into the service more than ten years after his original attendance, and, bearing in mind the relevance of time in the data, his interview was of particular interest. He was ‘*under no illusion of recovery*’, and believed that he had accepted his situation would never be as it once was, but continued to hope that rehabilitation could improve certain aspects of his current life. Should the model, therefore, allow for the influence of time on adjustment and acceptance?

The importance of time seems central, and this led to consideration of taking a chronological approach to the data. Revisiting the categories from this perspective led to the formulation of model 5:4.

Figure 5:3a : Participants 1-15

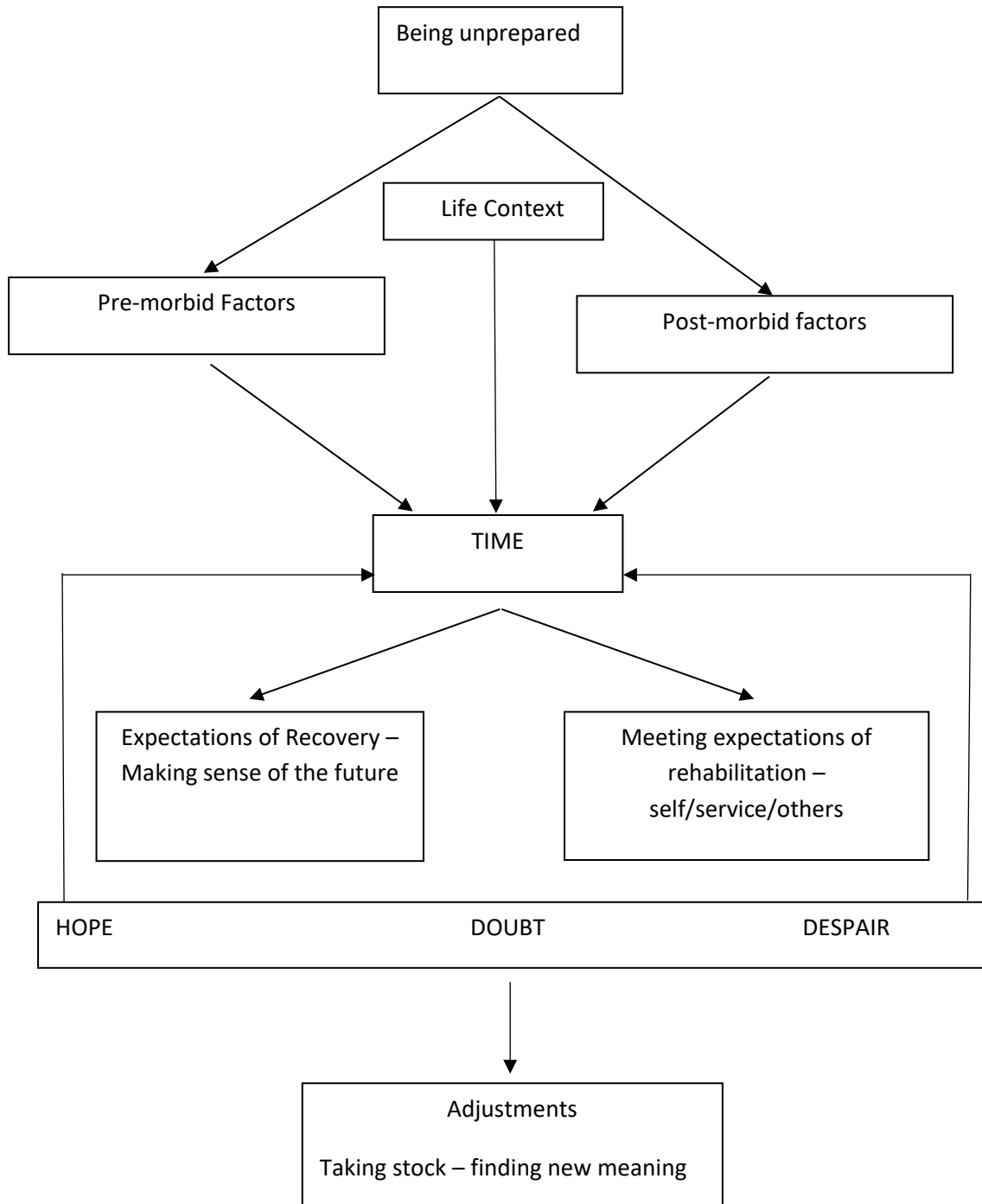
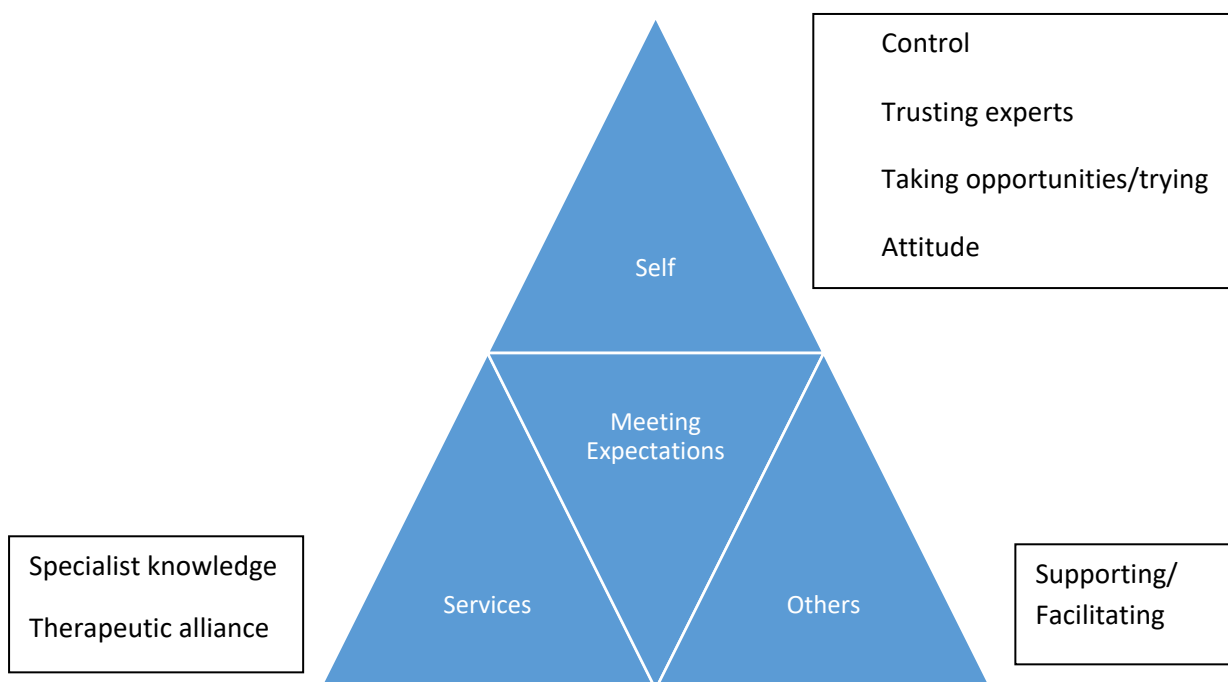


Figure 5:3b Expectations of rehabilitation/self/others



5.5 Chronological Model Participants 1-17

Model 5:4 was generated by taking the comparison back to the sub-category level, in order to see whether the data could properly be represented in this linear way. It suggests that there are pre-morbid beliefs and knowledge which, alongside life context, 'set the scene'. The event then occurs 'out of the blue' and questions are asked about the symptoms and what is happening. In the acute and early days of recovery people begin to try to make sense of experiences and information, and if necessary to fill in memory gaps.

Gradually people begin to become more aware of their limitations and improvements, but remain expecting and hopeful that recovery will be complete. Time goes on and doubts begin to develop, while improvements slow down and people feel judged and guilty about the impact of their disability on others. Despair may develop, or people may move towards acceptance as they take stock and find positives, and adjust to their new situation.

While this model had appeal as a description of the process, it did not seem to be of value in deepening understanding of the participants' perceptions and beliefs. It is descriptive rather than interpretive and, as a result, not likely to provide a framework by which service intervention can be considered. It seemed to miss the basic question about what participants believe and expect, and did not, as had previous models, include consideration of rehabilitation services, self and others. A chronological approach seemed retrospective, when the study aim was to consider prospective expectations. It also suggested a linear progression, which did not support the data. I spent some time looking at the influence of length of time post-onset for participants, but it did not clearly relate to their position in terms of hope/doubt/despair/acceptance.

While I did feel it had been a useful exercise to consider time as the central factor in this way, it did not seem to fit the data.

Figure 5:4 Chronological Model : participants 1-17

Pre-morbid	Event	Acute/early	Community	Community	Community
Wider life context Lack of knowledge of BI/stroke Lack of knowledge of rehabilitation Existing beliefs/ prejudices	Out of the blue Misinterpretations Development of symptoms	General experiences in hospital Rehabilitation experiences Information given Making sense of gaps in memory	Recognition of improvements Time/speed of recovery Time/ slowing of recovery	Recognition of limitations Perceived deterioration/stalling Why me? Comparisons with past/others Judgement/Guilt	Adjustment/adaptation Social support Finding positives Taking stock/new meaning
OBLIVIOUS	SHOCK	MAKING SENSE	EXPECTING AND HOPING	DOUBTING DESPAIRING	ACCEPTING

5.6 Efficacy Model Participants 1-17

Having decided the chronological approach was not helpful, the same data analysis was the foundation for an efficacy model, shown in figure 5:5. This used the categories of pre-morbid factors, life context and post-morbid experiences, and suggested that they feed into expectations of recovery over time, belief in self-efficacy and belief in rehabilitation efficacy.

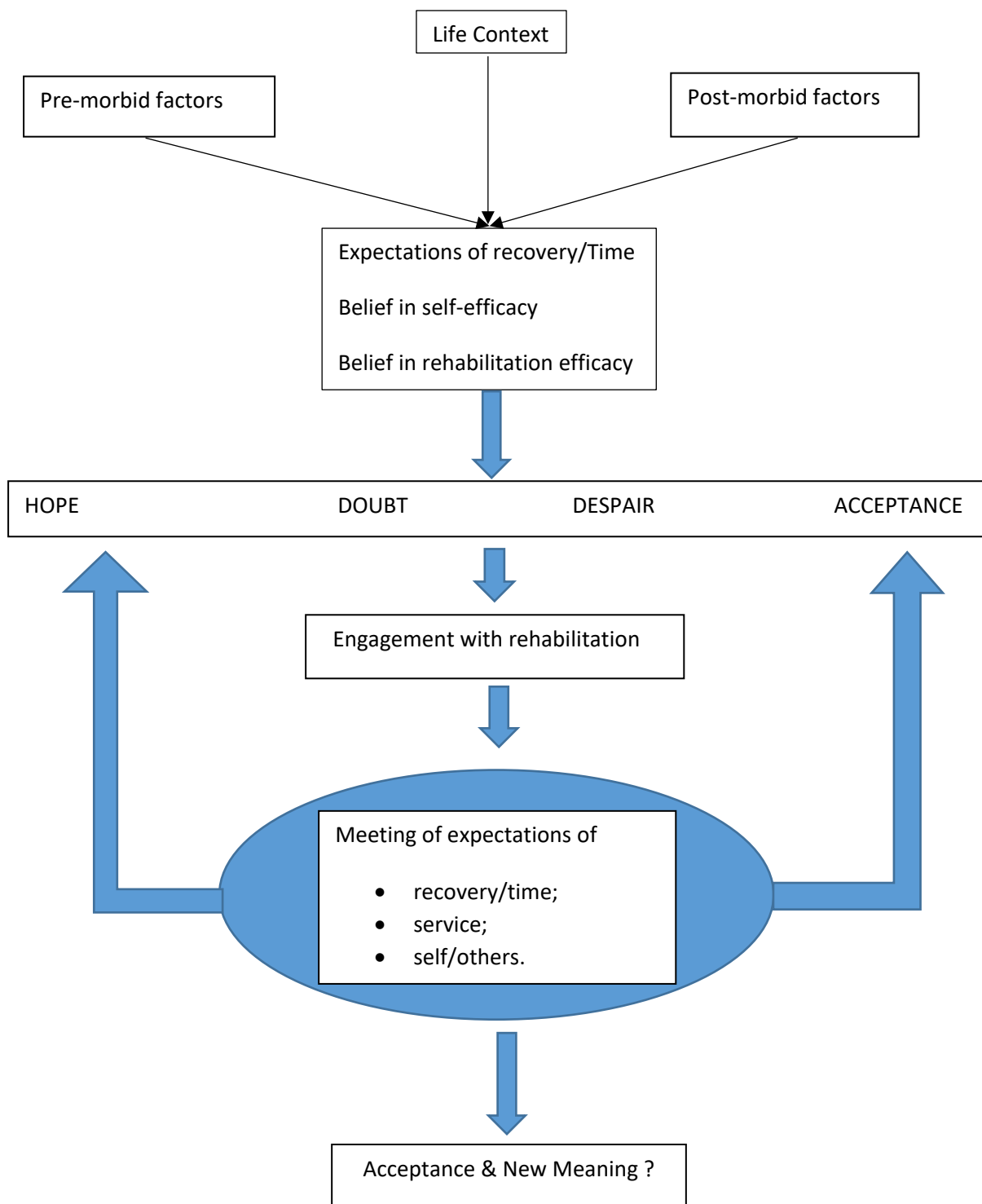
The hope-despair spectrum remains the central tenet of the model, and in this version returns to incorporating acceptance, following the inclusion of the client described earlier. The prediction from the model is that if people believe that recovery will continue, have belief in their own ability to influence this, and have belief in rehabilitation services, then they will be at the hopeful end of the spectrum, and this will facilitate engagement in rehabilitation. Past experiences have shaped this to date, and once they enter the service it is the continuing meeting of expectations that will cyclically impact on this same spectrum. It is postulated that the future holds potential for acceptance and new meaning – as in the single long term case included in this study.

This model incorporated a concept that I had been becoming more aware of throughout comparison of the data and re-reading memos – that of self-efficacy and belief in the efficacy of rehabilitation services. Earlier in the study I had given some attention to the question of how beliefs in recovery and rehabilitation interlinked, and how this may be useful to clinical practice. This efficacy model recognised that belief in self and services were important, but the data suggested that recovery was sometimes seen as independent of other factors – except for time. Efficacy was one parameter but not the full picture.

The data collection was not revealing any new categories and at the point where it was felt saturation should be considered. Efficacy seemed to be central to the developing model, as was recovery/time, but there were still questions about the inclusion of acceptance within the hope-despair spectrum as there was little data to support this. There was a barrier to acknowledging saturation, however, in relation to people with communication disorders.

Chapter four offered a summary of clients who did not take part in the research, and it was noted there that people with communication disorders were perhaps given less opportunity by families and others to make decisions about participation. Nine clients refused to take part, and of those five had communication disorders. One of the five was prepared to take

Figure 5:5 : Efficacy Model: Participants 1-17



part but was offered an earlier assessment date, making the time scale impossible. Refusals from the remaining four, however, were all given by the spouse or hospital. On reviewing the participants to this point, having already undertaken 17 interviews, I realised that people with communication disorders – specifically aphasia and dysarthria - were not well represented, despite this being one of my stated aims. I therefore used a deliberate sampling strategy at this point, to recruit people with significant communication disorders. I wanted to see if their experience differed significantly and would affect the model.

5.7 Engagement Model Participants 1-21

The final four participants included one person with significant dysarthria and three with aphasia, two of which I would classify as moderate to severe. Interestingly, however, their data did not influence the model as much as I expected. The additional data did, however, help to coalesce my ideas about the equal roles of progress, self-efficacy and belief in rehabilitation, as the constant comparison of data clarified these aspects.

I also combined the pre- and post-morbid factors with life context, in the broad category of making sense of what has happened. I thought there was a logic to the pre-morbid beliefs and life context feeding into the holistic picture. Throughout the data collection I had been struck by the importance of life context – for many of the participants other issues were more influential than the ABI itself – and examples of life events included cancer in self or family, pre-existing other serious illnesses, fertility issues, caring for dependents, and relationship problems.

The model was slightly altered and combined with a diagrammatic representation of how beliefs in recovery and rehabilitation interact, and predict the level of engagement. Both diagrams (Figure 5:6 a and b) were developed after analysis of 19 participants, and it was not felt necessary to alter this following a final two interviews. The model incorporates the categories identified in the analysis. While engagement in the specialist community service appears to be a prediction rather than grounded in data, the interviews did in fact indicate relevant information based upon the experiences participants had already had of rehabilitation. However the cyclical nature of the model (illustrated by the broader arrows) postulated, by which meeting of expectations of recovery, rehabilitation and self, feed back into the hope-despair spectrum, is an assumption.

Figure 5:6 a Engagement Model

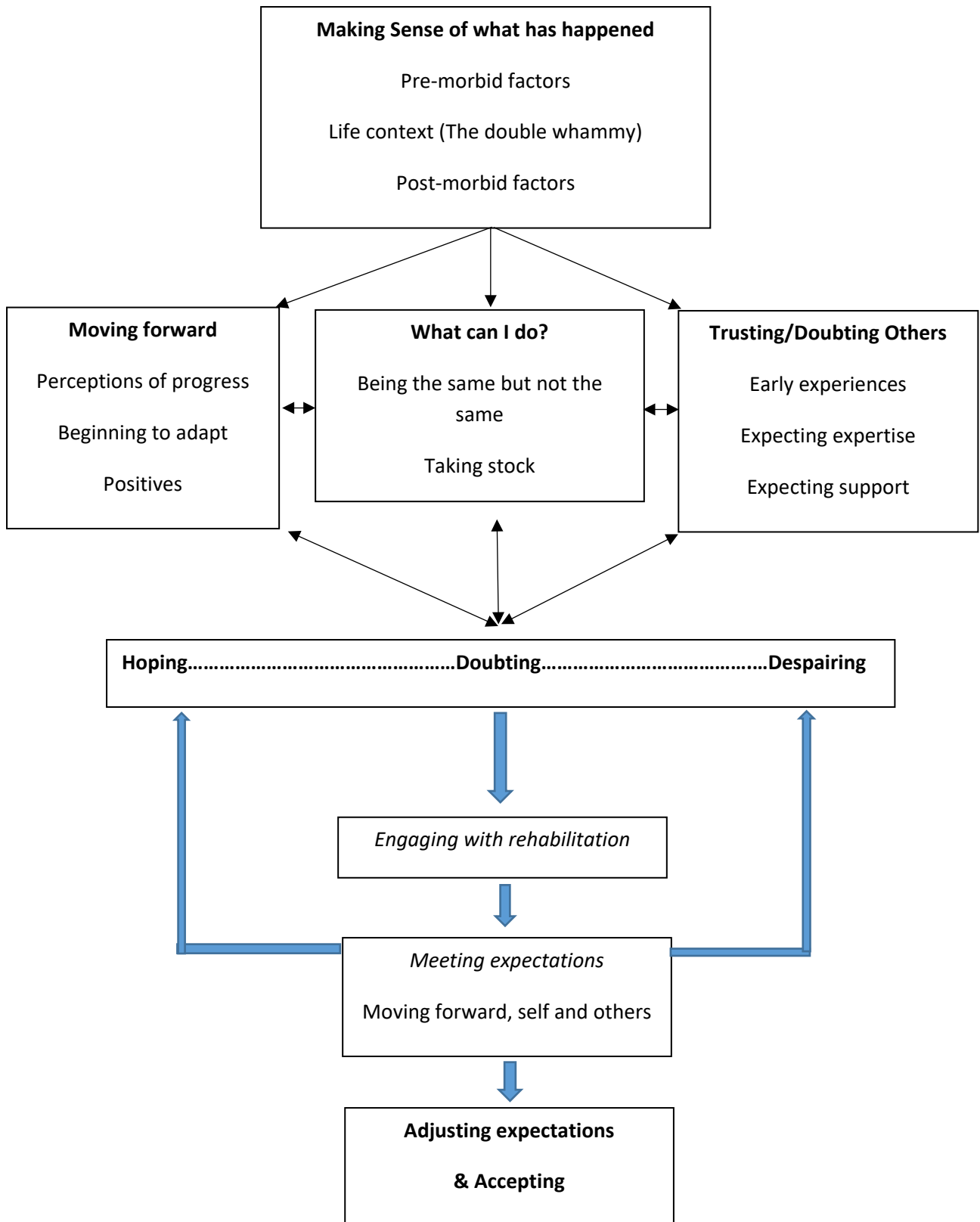


Figure 5:6b Engagement Model

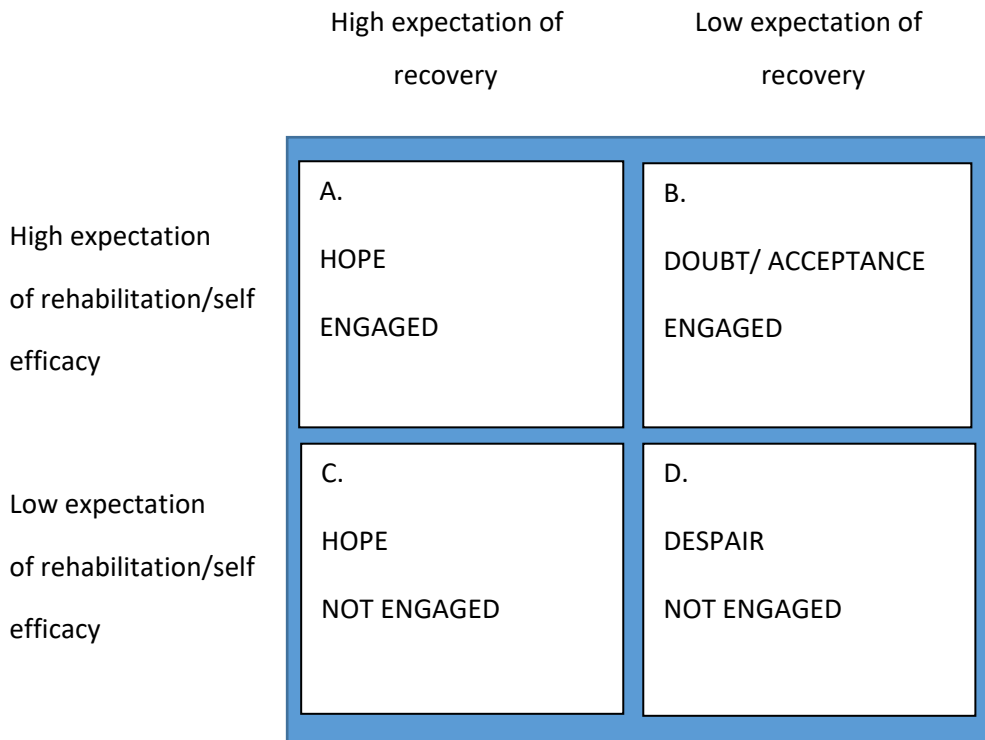


Figure 5:6a offers, therefore, a framework grounded in the data from the 21 participants interviewed. The categories have been described and illustrated in chapter four. Figure 5:6b focuses on how the expectations of recovery and of rehabilitation (including the role of self) interact to generate feelings of hope, doubt and despair, and offers a prediction as to how this interaction may impact on engagement with rehabilitation.

The inclusion of self with rehabilitation was the result of the data indicating a strong overlap between categories – for example, the belief that self should take control balanced with trust in experts, and the expectation of guidance from therapists alongside the expectation that

'no-body's going to do it for me'. At this stage in the pathway, participants are implicitly recognising that rehabilitation is a balance between self and professional responsibilities.

5.8 Implications for rehabilitation

The model has implications for rehabilitation in a number of ways. A greater understanding of the multitude of factors which influence the expectations and beliefs that people bring into the rehabilitation process may encourage therapists to challenge assumptions about engagement with rehabilitation, and about the balance between the roles of therapist and client.

If a client has high expectation of recovery, but also – perhaps as a result of good rehabilitation experiences alongside rapid recovery to date – high belief in rehabilitation efficacy and in their own role, then it is likely he or she will remain hopeful and engage in rehabilitation. Such clients will need to be monitored however, as there is a risk that hope will decrease if progress is seen to be slowed or stalled, and develop into doubt or despair over time. Appropriate educational and psychological support may be introduced while continuing with the rehabilitation plan.

If someone has low expectation of recovery, perhaps progress has stalled or they have negative pre-morbid beliefs about ABI, but high belief in the value of rehabilitation or self-efficacy, then the prediction would be that, despite being doubtful of full recovery, they will engage with the services and expect some degree of improvement as a result. This may also be the group into which people who have, over time, come to accept that they will not fully recover, but hope for some further improvement. The rehabilitation plan can be negotiated and realistic. If a client enters the service with the expectation that he or she will recover with time, regardless of any action they or others may take, then the client will feel hope but may have little motivation to engage. In this case it may be necessary to allow the client to experience controlled failure before engagement is possible. This may also explain the client who has not developed insight, and sees no value in rehabilitation because they do not appreciate their impairments.

The final category of client would enter the service with a low expectation of recovery, alongside a belief that both rehabilitation and his or her-self are powerless to make a difference. These clients feel despair, and rehabilitation will need to focus on

emotional/psychological issues before expecting other engagement with rehabilitation process. The despair – as was seen in the discussion in chapter four – may be a result of the ABI per se, the interplay of perceived progress and early experiences, or due to a combination of factors including life context. One other factor is of course the possibility of clinical depression, and the negative thinking that is part of this mood disorder. There is a higher incidence of depression in people after ABI, and there would be different implications for treatment if the despair/lack of engagement stemmed from this.

Other potential implications from the overall model developed are:

- The need for knowledge of the client’s life context and support, not exclusive focus on the ABI.
- Recognition that early experiences post-event can impact on later engagement and may need exploration, in order to offer appropriate education and information.
- Opportunity to talk via the provision of formal or informal psychological/emotional support, and recognition that the therapeutic relationship may be as important to clients as specific therapeutic activities.
- Knowledge of progress made to date, as perceived by the client, and acknowledgement that rapid early progress can lead to misleading assumptions. Education and information is important.
- It may be helpful to have an awareness of where the client is, at any time, on the hope-despair spectrum. This seems to be a dynamic phenomenon, dependent – as has been seen – on expectation of recovery, self-efficacy and belief in rehabilitation.

5.9 Chapter Summary

Grounded research encourages data from multiple sources, and chapter six will look at literature relevant to the analysis and final model outlined in this chapter. My thought process had led me firmly into seeing the hope-doubt-despair spectrum as central, so this was the area I chose to explore through existing literature.

My reflections through the process, and the evolution of the model, led to a further consideration. As the model developed I was beginning to think about the implications for rehabilitation services and this was very briefly mentioned at the end of this chapter. It became apparent as the research progressed that knowing the expectations and beliefs of

clients is only one factor in looking at therapeutic implications. It may be that clinicians, especially perhaps in a highly specialist service, are fully aware of the various factors involved, and that their expectations and beliefs are in line with those of clients. It may be that clinicians' views differ and there is lack of awareness of client beliefs. In either case additional data from the clinicians would be helpful. Chapter seven will consider recovery and rehabilitation from the clinicians' perspective, and compare their position with the clients'. The degree of difference in the perspectives will also have implications for therapy intervention, which will be revisited in the concluding chapters.

Chapter Six: Hope

6.1 Introduction

The analysis in chapter four highlights the central importance of hope, which is influenced by the need to make sense of what has happened, a sense of moving forward, trust in rehabilitation services, and self-efficacy; while chapter five suggests a model that links this to engagement. This chapter explores relevant literature, to consider alongside the data from this study.

Grounded theory, as was stated in chapter one, has generated considerable discussion about when and how to engage with the literature. Dunne (2010) suggests that not addressing the literature to some extent before data collection is 'not only disproportionate butcan distract from the overall quality of the research' (p121), but also acknowledges that it is often difficult to know the focus of literature searches at an early stage as the findings should be data led. Dunne also concludes that whatever decision is taken in terms of structuring research reports, it needs to reflect the natural development of the study. While chapter one describes the process of investigating the literature, with the specific aim of checking whether this proposed study would indeed add to the extant knowledge base, this chapter offers a review of literature in the light of the findings, focusing on hope and the beliefs that influence it.

The first part of this chapter considers the broad concept of hope – its definition and relationship to despair; its importance and how it is experienced and used by people following injury or illness; and factors that contribute to a sense of hope.

The second part of the chapter makes the link to the findings in chapters four and five more explicit, by focusing on the three beliefs identified as directly influencing where participants fall on the hope-despair spectrum: beliefs in progress/recovery, in self and in others.

6.2 Hope: The Literature

Hope is a concept which is accepted as an important consideration in health care – Eliot and Olver (2009), for example, describe it as an important psychological resource in chronic

illness. However, Bright et al., (2013, p43) comment 'there is currently little known about hope in people during the post-acute period of rehabilitation, despite this being the time when most therapy services are provided.'

6.2.1 What is hope?

Despite being a word in everyday use, hope is not easy to define. It may be a noun, verb or – in modified form – an adjective (such as hopeful); and can refer to feeling, thinking, or behaving. It can describe a constant character trait or a transient state, or can be viewed as a state or a process. It is, indeed, as Farran et al., (1995) noted, elusive and hard to define or conceptualise, but 'for the person who hopes, the boundaries of the possible are wider than they initially seem and are not bound to absolutes' (p7).

Marcel (1956, p28) writes from an existential viewpoint of the ontological mystery of hope, which is 'to hope against all hope...beyond experience of probabilities and statistics', while Farran et al., (1995) describe hope as having four ontological attributes – an experiential process, a spiritual or transcendent process, a rational thought process and a relational process.

If hope is to be the focus of health care research, there has to be an assumption that it is 'real' and can be discovered and therefore can be defined (Eliot & Olver 2002). The plethora of different views makes reviewing the literature difficult, but there are some common elements summarised in Dufault and Martocchio's (1985, p380) definition of hope, as a:

'multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving future good, which, to the hoping person, is realistically possible and personally significant'.

This definition incorporates strands evident in the literature – that hope is focused on the future, that the imagined future is better than the present, that there are cognitive and affective aspects, and that the person perceives they can realise the hope (Dorsett 2010). This latter point may appear to contradict the 'realistically possible' element of the above definition, but the critical factor is that it is perceived as such by the individual not that it is objectively accepted as realistic. Thus hope is about the perceived future, but, as Faircloth et al., (2004, p400) note, 'the future cannot be projected without a concern for the past and present.' In healthcare it may be assumed, other than in specific areas such as health

education schemes, that the present is worse than desired, and people – as in this study – will hope things will improve, fear they will not, or both.

Bright et al., (2013) discuss this interaction between past, present and future. They describe participants with aphasia who struggled to see the future from their current position, so hope fluctuated – when uncertainty dominated there was a focus on the present, day-to-day living. Past experience was seen as affecting the present – this is perhaps illustrated by the significant effect on some of the participants in this study of bad hospital experiences. Bright et al., also describe a possible disconnect between the past and possible future, when the disruption between the two is too great to manage. Lohne and Severinsson (2006) see experiences of hope as ‘continuously moving between past, present and future’ (p317).

6.2.1.1 Associated terminology

There are a number of associated concepts that crop up repeatedly in the literature on hope, and it is worth briefly acknowledging some of these.

Hope, expectation or wish? Analysis of the data in this study led to the emergence of the concept of hope, as opposed to expectation. Many participants chose to respond using the word ‘hope’ even when asked about their ‘expectations’ and this distinction is important. The difference seemed to be in relation to the degree of certainty that a desired result would be achieved. An individual may say they have 100% hope that they would recover fully, but rarely expressed this as 100% expectation, suggesting an element of doubt, even if not explicitly acknowledged. This perhaps explains the apparent paradoxical interview data described in chapter four, with 100% hope overtly claimed, alongside doubts and fears.

The terminology is not always clear - Wiles et al., (2008) commented on a lack of clarity around hope being a want or an expectation, and saw hope as expectation when there is high probability of an outcome, and hope as want if low probability. Bloch (1970) stated that one cannot have hope if the outcome is certain, as it becomes then an expectation, which implies that doubt and uncertainty are necessary for hope. According to Farran et al., (1995) wishing is different from hoping, in that it implies a more limited likelihood that a goal will be achieved, and, while positive in nature, is passive, in that it does not imply any active role in bringing it about, although others may disagree that hope necessarily implies action.

Hope or optimism? Optimism is generally used to refer to a personality trait or disposition that expects positive outcomes – the ‘cup half full’ person. Gum et al., (2006) use the term

to describe thoughts of attaining generalised positive outcomes, but without consideration of how to achieve these outcomes. Peleg et al., (2009) looked at hope, dispositional optimism and depression following TBI, in a quantitative study of 65 people. They found the degree of hope in their population was significantly below that of normal, cancer and spinal injury groups, and concluded that hope was a more important factor than optimism in predicting depression.

6.2.1.2 Models of hope

There have been numerous attempts to conceptualise or operationalise hope, and one difficulty in reviewing the literature is the lack of one consistent model or framework.

Bright et al., (2011), based on a systematic review of the literature, suggest three ways of conceptualising hope, based on how stroke survivors view it. It is a broad, constant state of being, viewed as essential for life (which aspect is unaffected by stroke, according to Bays 2011); an outcome-oriented thought process (a post-ABI example might be to return to normal); and an active process. The latter is defined by Bright et al., (2013) as 'cognitive engagement with hope alongside a process of acting on hopes' (p42), which might be illustrated by participation in rehabilitation (Arnaert et al., 2006). Wiles et al., (2008) distinguished – in a synthesis of narratives on hope, expectations and recovery from illness – between generalised hope (a state of life that protects against despair) and particularized hope (which relates to specific outcomes), which distinction was also made by Dufault and Martocchio (1985).

Other attempts to conceptualise hope include Lohne and Severinsson (2004), who discuss six dimensions that describe ontological aspects of hope – affective, cognitive, behavioural, affiliative, temporal and contextual. Duggleby et al., (2012) characterise hope as dynamic or situational, having multiple co-existing types, focused on desirable and realistic objects, future focused, and involving choice or will. Eriksson (1986) illustrated process (hoping) and substance (hope) as aspects of the overall concept.

This brief summary merely gives a flavour of the range of models that have been suggested, however Snyder's Hope Theory (2000) has been particularly influential. This is based on the definition of hope as 'the sum of perceived capabilities to produce routes to desired goals, along with perceived motivation to use those routes' (Snyder et al., 2000, p8) – that is, agency (inner resources), pathways (possible routes) and goals. The theory recognises that

hope cannot apply when a goal has either no possibility or is certain, but that it operates when there is uncertainty. Emotions are a by-product rather than a central facet, as hope is viewed primarily as a cognitive process which is followed by an emotional response depending upon the attainment or failure to attain the goal. Snyder acknowledges other theoretical approaches, perhaps most notably in relation to this study is Bandura's Social Learning Theory (1986) which is discussed later in this chapter.

6.2.1.3 Hope and despair

Often hope and despair are seen as opposites, and in this study this seems to be indicated by the data, which led to the idea of a spectrum ranging from hope, through doubt, to despair. Hope may both stem from a sense of moving forward and contribute to making progress, while despair is focused on suffering.

There is a question as to whether the term 'despair' is most appropriate. It was used mindfully within the analysis and models described earlier, as it reflected the vocabulary of interviewees and seemed appropriate for the degree of distress experienced by some. However, the opposite of hope in the literature seems to vary between the terms 'despair' and 'hopelessness'. Farran et al., (1995, p25) define this latter term:

'Hopelessness constitutes an essential experience of the human condition. It functions as a feeling of despair and discouragement; a thought process that expects nothing; and a behavioural process in which the person attempts little or takes inappropriate action.'

Hopelessness can be conceived as a personality trait or a short lived reaction to life events, as can hope. While hope can protect, hopelessness threatens well-being, according to Farran et al., (1995).

Lohne and Severinsson (2004) found in the early stage of spinal injury that despair predominated, but that every sign of improvement stimulated hope – they described these as 'turning points'. Uncertainty led to fluctuation between hope and despair and could block hope. Lohne (2008) in a synthesis of three studies on people after spinal cord injury, recognised that hope may move in and out of the foreground of experience, and suggested a model that illustrates the 'battle' between hope and suffering, with a move from despair to hope at each turning point. While the impact of moments of progress is interesting to consider, the difference between ABI and spinal injury must also be borne in mind.

Gum et al., (2006) found hopeful thinking was negatively associated with participation in more disabled participants, theorising that this may be due to setting more impossible goals rather than adjusting to limitations. They found hope to be the strongest predictor of symptoms of depression, more than levels of activity or participation and feelings of hopelessness are one of the best predictors of suicidal ideation (Beck et al., 1985, 1990). This is perhaps an appropriate point to acknowledge the overlap with depression.

Despair or depression It is outside the scope of this study to attempt to discuss depression in any depth, but it is clearly important to consider the concept as it relates to hope and hopelessness/despair. Depression is common after brain injury, and both organic and psychological factors seem to be implicated. There is a ‘chicken and egg’ debate in relation to the findings outlined in chapter four – does the hopelessness expressed by some participants stem from an underlying clinical depression or vice versa? It is not possible to answer the question from the data, and the answer is likely to be different depending on the person, but the clinical implications for individual care will be different to some extent.

The study by Peleg et al., (2009), mentioned above, of people after TBI, found a significant level of depression, associated with a pessimistic coping style. They concluded that hope was a more important factor than optimism in predicting depression, but personality was more significant in more severe depression.

Cheavens (2000) considered depression in the light of Hope Theory (Snyder et al., 2000), relating the diagnostic criteria of depression to the concepts of agency, goal seeking and pathways. Low mood is viewed as facing blocked goals with no perceived ability to find a way forward. She suggests that the importance of the goal to the person, choice of unsatisfactory goals or a generalised expectation of failure can lead to ‘blocked’ goal seeking. Agency will be affected by low confidence and low motivation, and pathways by the perceived inability to generate new options or disengage from ‘dead-end’ pathways. Cheavens goes on to suggest that hope can protect against depression, as it encompasses attributes such as setting more goals, perceiving more pathways and personal agency, expecting success and using past successes, and having goals to learn and improve (not just validation seeking).

6.2.2 The experience and importance of hope

The use of models on which to base research and make clinical decisions is both common and important. However it is also important that models or frameworks do not 'mask personal experience...(and)...widen the gap between theory and clinical practice' (Nekolaichuk et al., 1999, p430). The lived experience of hope is the foundation of any model that will be clinically relevant. Simpson (2004) notes that hope makes people vulnerable, as it always has the possibility of not being realised.

A metasynthesis of the lived experience of recovery after traumatic brain injury noted that important internal resources included the capacity for hope (Levack et al., 2010). Similarly thematic synthesis of 33 studies (Satink et al., 2013) found 'hope to continue or to adapt' as a sub-theme in 20, and concluded that hope 'seemed to be an important strategy and a major element of emotional recovery'. Maintaining hope is seen as important by many (Folden 1994).

The importance of hope in the lived experience of people with major medical difficulties has been stressed by various studies, which found hope as integral to recovery (Barker & Brauer 2005, Burton 2000, Nilsson et al., 1999). Some have specifically considered this in people following stroke (Arneart et al., 2006, Popovich et al., 2003, and Bays 2001). Cross and Schneider (2010, p487) state that hope 'is a multidimensional concept that has a sub-conscious and ongoing impact on stroke recovery. It is a silent motivator that keeps individuals fighting and maintains their spirits.' Their study took a gendered perspective, and suggested there may be a different impact of hope after stroke for men and women.

The reasons for recovery were considered by Jones et al., (2008) who identified internal and external influences in their ten participants. 'Hope and optimism for continued recovery' was a major internal factor, which they saw as 'perhaps surprising given the severe level of difficulties some were facing' (p512), and attributed to progress to date, allied to personality. The other internal influences were control and perceptions of dependence, both of which featured in this study's data. They note that maintaining optimism and hope have also been found to facilitate an individual's perception of well-being and their ability to cope and adapt. There may also be an impact on functional ability (Ostir et al., 2008) and participation level (Gum et al., 2006). Hopelessness (the expectation that desired results will not happen) was related to poor participation in cardiac rehabilitation (Dunn et al., 2009).

Kortte et al., (2012) included stroke in a longitudinal quantitative study of 174 adults, with a variety of chronic conditions. They found that hope accounted for a significant amount of variance in prediction of functional role participation at three months post discharge, but not of skill level. Increased hopefulness in rehabilitation relates to positive psychological adjustment in TBI (Peleg et al., 2009) and stroke (Tariah et al., 2006).

Positive outlook, including optimism, hope, determination and gratitude, are themes described by Grohn et al., (2012) in their study of people with aphasia. Pringle (2010), also in relation to this population, recognises hope as important in recovery, and Kortte et al., (2012) state that hope may help determination, minimise perception of magnitude of adversity, and give sense of possibility of overcoming barriers.

Bright et al., (2013) used an interpretive descriptive methodology to look at hope in five people with aphasia and identified two main forms of hope. Simply 'having hope' was seen as essential to life and largely passive. Their participants ranged from finding this unaffected by stroke and constant, to being out of reach and thus leading to despair, but in general it provided a stable base while waiting for change in an uncertain world. The second form was 'actively hoping', which involved identifying future hopes (goals) and working towards them. This study also indicated that hope is a dynamic, fluid concept, and changes in response to a variety of influences, which are discussed below. Bright et al., (2011) note, in their systematic review of studies of how survivors view hope after stroke, that, while hope can diminish as progress slows, it can coexist with uncertainty and fears and serve to lower depression.

A metasynthesis by Duggleby et al., (2012), of 20 qualitative research studies related to older people with chronic conditions, of which only one study was about stroke (Bays 2001), remarked on the difficulties associated with the use of a variety of conceptual models of hope, as studies ranged from descriptive/thematic to interpretive. Hope was seen as a positive psychological resource, impacting on sense of self, control, relationships and quality of life. Dimensions that emerged from the review were living in hope, hoping for something, hope as a light on the horizon, hope as a human-to-human relationship, hope versus hopelessness, and hope as weathering a storm.

Hope has been a focus of research in spinal injury – Lohne (2008) identified a cycle between hope and despair. Lohne and Severinsson (2006) used a phenomenological hermeneutic approach, with their main interpretation being 'the power of hope'. Sub-themes were 'will, faith and hope' and 'hoping, struggling and growing'. They state 'suffering itself has no

meaning but a person can give meaning for his/her own experience of suffering' (p316), depending on past experiences and future hopes, and refer to the influence of Frankl (1984) in this area. Dorsett (2010) also studied people after spinal cord injury, over a ten year period, and found that 73% saw hope as essential to coping, but that the focus of hope changes. His participants expressed three main foci – for full recovery, which, although strongest early on, could be maintained in tension with dawning realisation that this was unlikely; for a cure to be found; and for a better quality of life.

Another population that has been studied in relation to the experience of hope is cancer patients. Eliot and Olver (2002) looked at the use of language by patients. The word was used mostly as a noun, reflecting an independent, concrete entity, but which could vary in degree and resilience. The use of hope as a verb seemed to personalise the concept and distinguish it from medical 'objectivity' and the sense of being a victim of circumstance.

A narrative based approach was taken in looking at the experience of being HIV+ve (Ezzy 2000) and of young men after spinal cord injury (Smith and Sparkes 2005). Hope seems to vary depending on the narrative – some people were concrete, assuming a linear narrative (a controllable future which may or may not be achieved) while others had a more abstract narrative, open to the unpredictability of the future. Hope seems to be a common experience, even in the most distressing of circumstances. Verhaeghe et al., (2007) found hope the most prominent theme in the experience of the families of coma patients – although it altered with events and information, it was maintained.

6.2.2.1 Hope as a coping strategy

Linking the experience of hope after ABI to the need for hope in order to cope is a personal account by Linge (1990). A clinical psychologist who suffered a serious TBI, he stresses the importance of hope in sustaining both client and family through recovery and rehabilitation.

Hope is, according to Peleg (2009):

'considered as one of the most crucial theoretical constructs to explicate a person's way of coping with life's challenges. It is described as an inner feeling that a problem will ultimately be solved or as the person's evaluation of self-abilities to achieve goals' (p801).

In this study there was a strong sense of seeking to avoid or deny the existence of doubts, in order to hold on to the hope that recovery would be complete, or at least continue. Bright et al., (2013) described strategies in their participants, such as 'hunkering down' (taking a

day at a time), limiting engagement with hope, keeping hopes broad rather than specific, and setting limits.

Duggleby et al., (2012) discuss transcendence and positive reappraisal. The former is concerned with moving forwards and reaching both inwardly (attitude, self, spirituality) and outwardly (family, professionals) to find a meaning and purpose. Frankl (1984) in his seminal work on man's search for meaning addresses this. Positive reappraisal is to do with re-evaluating within a new situation, to find positive aspects and new hopes, even if there is the loss of some past hopes. This was seen in the participants in this study, with their emphasis on self and the influence of others, alongside taking stock of their pre-morbid lifestyle.

Hope is seen as an important coping mechanism, and – as Wiles et al., (2008) suggest – it may be 'more psychologically damaging to destroy it than leaving individuals to adapt to the 'reality' of their situation in their own time' (p569). Clients and professionals have a different view of what is realistic, and the client's view may not be an irrational response so much as a different perspective (e.g. Verhaeghe et al., 2007, Thorne et al., 2006, Eliot & Olver 2002)

6.2.3 What contributes to hope and despair?

Having discussed the concept of hope, as described in the literature, the main influences found in this study relate to the beliefs held by individuals in three main areas: belief in progress and recovery; belief in their own ability to affect the outcome (self-efficacy); and trust that others (including rehabilitation therapists) can have an impact. Relevant literature for each of these will be discussed in more detail later in this chapter, but in summary there seems to be agreement that hope is influenced by a mix of internal and external factors.

In their systematic review of hope in people with stroke, Bright et al., (2011), acknowledge both internal (personal attitude, progress made, stroke severity) and external (social connectedness, spirituality, health care) factors in development and maintenance of levels of hope. Cross and Schneider (2010) also identify factors that influence levels of hope, in the long term. They separate internal (determination, positive attitude and spirituality) and personal factors (progress made, goal setting, being active, awareness and information), alongside their category of external influences, which encompasses medical-rehabilitative factors, other survivors and support networks. These factors were summarised in Bright et

al.,’s paper (2011) as support, self-belief and belief in progress, which mirror the main aspects of the model formulated in chapter five of this study.

While stroke severity and spirituality were not factors for participants in this study, the other areas were all evident in the data. The model in chapter five suggests that personal factors (what can I do, and making sense of what has happened), belief in recovery (moving forward) and rehabilitation factors and social support (trusting/doubting others) all influence levels of hope and despair. There seems, therefore, to be agreement that there are certain common themes – internal factors, progress, and external influences.

While this chapter will look in more depth at belief in progress/recovery, rehabilitation and self-efficacy, a brief mention of personality, meaning/sense of self, and psychological factors seems valid, as they feature prominently in the hope literature.

6.2.3.1 Personality

Rodriguez-Hanley and Snyder (2000) differentiate high hope people from low hope. Using the Hope Theory described earlier, they describe people with high hope as able to adjust to difficult experiences, seeing barriers as challenges to be overcome rather than blocks to progress. Snyder (2000) relates this to developmental factors stemming from a supportive environment that allows hopeful thinking to grow.

Experience of success is used by high hope people as evidence that they can overcome difficulties, which links to the concept of self-efficacy, which will be discussed in more depth later in this chapter, and they can identify more appropriate and a greater number of pathways to a goal. Greater self-efficacy leads to increased hope and greater self-confidence (Dorsett 2010, Carifo & Rhodes 2002). Michael (2000) notes that self-efficacy, while related to hope, is distinct from it. Hope is ‘a unique predictor of general well-being above and beyond self-efficacy’ (Margaletta & Oliver 1999).

Cheavens and Gum (2000) see high hope people as able to change or adapt goals and pathways to suit new circumstances. Lohne and Severinsson (2006) describe a personal inner strength, which enables people to keep going regardless of their situation, and willpower providing energy. Higher dispositional hope, according to Gum and Snyder (2002), is related to psychological well-being, better social functioning, more adaptive physical outcomes, preventative health behaviours, and better adjustment to chronic illness and pain.

6.2.3.2 Meaning and Self

Nocchi (1998a, p873) sees 'one strategy against the loss of self by comparison (with past/present/future) is to keep the hope of recovery'. The existential reestablishment of self involves having a hopeful outlook, according to Lamb et al., (2008), who see hope as a positive anticipation of recovery. Bright et al., (2013) see the importance of identifying hopes/goals that are broad and have meaning to the person's sense of self.

Hope theory (Snyder 2000) also considers the emotional salience of goals. Goals need to have meaning for the individual: 'Without a goal that is perceived as meaningful, there is really no need for either agentic determination or generation of effective strategies....Hope declines, distress follows' (Simpson & Qualls Elder 2000, p174-5). Cheavens and Gum (2000) suggest that older people may learn to conserve their energy for the most important goals and be more able to fit coping strategies to the situation than younger less experienced people.

6.2.3.3 Psychological factors

Depression has already been mentioned in relation to hope, in a theoretical way, but is a personal factor that can have a profound influence on hope. Perhaps less often acknowledged is the impact of anxiety (Michael 2000), which can also affect the way in which a situation is viewed and lead to cognitive distortions (Beck 1995), perceptions of low self-efficacy and inability to find a way forward. Some degree of anxiety can facilitate agency, and high hope people react to increased levels of arousal by trying hard in the expectation of attaining the goal.

6.3 Beliefs and hope

As has been stated above, the current study identified three specific areas that seem to impact on hope, and these in some ways may appear to encompass both internal and external aspects. However, the critical factor seems to be the beliefs that are held, rather than objective measures *per se*. The remainder of this chapter, in order to explore whether the existing literature supports the importance attributed to them in the current research, will focus on these three beliefs – belief in progress/recovery; belief in self-efficacy; and belief in others. The latter will primarily consider rehabilitation, as most relevant to this

discussion, but this is not intended to downplay the broader social context and its importance. The model of engagement offered in chapter five links the latter beliefs – in self and others – and a search of literature in the field of education found an interesting model – the tripartite efficacy model – which makes this link explicit and seems to hold potential in the field of ABI rehabilitation. The chapter will conclude with a brief description of this model.

6.3.1 Belief in progress/recovery

Belief in progress and recovery will mean different things to different people – one may hope for a return to ‘normal’ life, while another may have adapted and hope for some degree of improvement or have adjusted their life goals. Factors that are influential in the belief are perceived progress, time, the stage in the pathway and information/knowledge.

6.3.1.1 Perceived progress

The need to make visible progress seems crucial, and is apparent in the data provided in chapter four. Hafsteindottir and Grypdonck (1997) note that it is forward movement that leads to confidence in recovery potential, and hope is crucial as this can be such a slow progression. They comment that the process of recovery and ensuring forward progress, ‘included preserving energy, increasing control over recovery, and maintaining hope’ (p583). The slowing or stalling of recovery was believed by Salter et al., (2008) and O’Connell et al., (2001) to diminish initial optimism, and Burton (2000) notes that hope is important in the early days after stroke, with rapid improvement at that stage helping to suggest that full recovery is possible.

Dolittle (1992) notes the reduction in apparent benefit from ‘effortful striving’ and discouragement as recovery plateaued, and the impact of unexpected achievements on increasing hope. As long as people believe they are progressing they feel secure in their ability to cope, according to Jones et al., (2008), Folden (1994) and others.

6.3.1.2 Time

Time is seen as a major factor, with some researchers suggesting a linear pattern from early hopes for a full recovery to realisation that this will not happen as time goes on. The data in this study seem to suggest it is the perception of progress that is crucial, although clearly this is linked to time. Dowswell et al., (2000) found that a year after stroke, people struggled to

accept that recovery may not be complete, and three of the 30 participants expressed suicidal thoughts. Nilsson et al., (1997) also note the decrease in hope over time in some people after stroke, with depressive signs, while others kept 'unrealistic hopes'. They described much of the despair as gaining insight that they must submit to the inevitable. In contrast, in their study of spinal injury, Lohne and Severinsson (2006) saw the *focus* of hope change over time, rather than necessarily decreasing, from recovery or improvement to 'feeling fine'. Nilsson et al.,'s later study (1999), from an existential perspective, saw a theme of trying to 'grasp the severity of the situation and still preserve hope' (p263), with realisation dawning, leading to 'a wavering between hope and despair' (p264). People may face a dilemma in whether to adapt or wait for further improvement (Wallenbert & Jonsson 2005).

6.3.1.3 Stage in the care pathway

Discharge, rather than time per se, was seen as a factor in decreased hope by Satink et al., (2013), as people realise that normal life will not resume, and experience a decrease in rehabilitation efforts. Wade et al., (1985) suggested that realisation usually accompanies discharge from active therapy or from hospital, and that involves a loss of belief that recovery will continue, leading to grief. Alaszewski et al., (2004) consider Holbrook's stages of adjustment to stroke (1982) – crisis, treatment, realisation and adjustment. In the treatment stage they postulate that high expectations of recovery go alongside denial of permanent disability. Alaszewski's study indicated that some people become stuck in a stage with a false sense of optimism and continue to believe they will fully recover.

Graven et al., (2013) considered patient and carer perspectives of recovery. Their participants felt there were essential elements in recovery: return to normality, improvement, acceptance and social networks. Returning home was an important stage, with disappointment as the situation did not get easier. The focus in relation to the rehabilitation environment was on satisfaction, access and their own role. They argue that awareness of client perspectives of recovery will assist in developing appropriate programmes.

6.3.14 Information

Numerous researchers suggest that time leads to reduced belief in recovery, from the starting point in acute care when belief is high. The influence of perceived rapid improvement is one factor – moving forward – but there is also likely to be an influence from

professional involvement. Wiles et al., (2008) discuss the reluctance of professionals to provide information as to the extent of probable recovery.

In 2002, Wiles et al., studied the information exchanged between patients and physiotherapists about recovery, and acknowledge the impact of the information given on patient expectations of recovery. While their participants accepted the reluctance to provide timescales, most still believed that therapists expected them to make a good recovery, and 'assumed that therapists knew what their hopes and expectations were' (p847). Patients were disappointed with their recovery at discharge, which is not surprising as there was an expectation at three interview points (from in-patient care to the community) that there would be a full recovery if they did as told by the therapist, were determined and positive. Stein et al., (2003) also reported that expectations for recovery exceeded actual recovery, and people had limited knowledge of stroke.

Interestingly therapist views on timescales for recovery varied quite markedly – from three months to two years in Wiles et al.,'s study (2002), so it is not surprising that patients are confused about timescales. Wiles et al., found that the therapists did not directly encourage over-optimism through their information provision, but by avoiding discussion of likely recovery allowed patients to maintain high expectations throughout the process.

6.3.2 Self-efficacy

Research supports the need to consider beliefs and expectations (e.g. Rath et al., 2011, Rath et al., 2003, Cicerone et al., 2004) and a highly influential theory in this area has been Bandura's Human Agency in Social Cognitive Theory (1986) which states that people contribute to their motivation and action, in interaction with environmental factors. The central tenet is that the beliefs that a person holds about their ability to exercise control over events – that is, self-efficacy beliefs - are important determinants of action, mediated through motivational, emotional and cognitive processes. Relevant sources of information include experiences of mastering situations/tasks, social influences, persuasion, comparing with others and physiological state. It is, however, important to remember that Bandura does not discount environmental influences.

Bandura relates higher self-efficacy to setting higher goals, firmer commitment, greater effort, and ability to deal with stress. Self-doubt, on the other hand, limits performance, leads

to visualising failure, increased subjective distress and arousal. Difficulties, he argues, will cause self-doubt but it is the resiliency of self-efficacy that is important – how soon the person recovers from set-backs. Optimistic appraisals, if not too disparate from what is possible are advantageous as they encourage efforts to be made. Depression is the result of perceived lack of self-efficacy to fulfil goals that have personal value. Selection of environments that people feel they can control and manage will promote certain abilities but will also limit other abilities.

Prior to taking action people will anticipate certain outcomes, then set goals and make adjustments as feedback occurs. Those with high self-belief will respond to challenge by increased effort, while low self-belief will lead to giving up. This resonates with the research into hope described earlier, where high-hoppers are more able to set goals and adjust.

A qualitative study by Dixon et al., (2007) looked at self-efficacy in neuro-rehabilitation, and identified three domains that impacted on self-belief: self, others and process. In relation to self, clients cited self-reliance, determination, independence, recognition of improvements and pushing self. Others facilitated belief through reassurance, comparisons and working *with* professionals. Process factors were setting goals, getting information and allowing time for rehabilitation. They go on to suggest these themes as a useful basis for measurement of self-efficacy.

Perceived self-efficacy is seen as domain-specific (Lequerica and Kortte 2010) so relates to specific actions in context. Jones et al., (2008) sum this up: 'Proponents of self-efficacy theory state that individuals must believe that they are capable of performing specific skills in a specific situation in order to reach a desired goal.' (p249). For example, Hellstrom et al., (2003) looked at a specific 'task' in their study of falls in older people, and found high self-efficacy people had better motor function and balance, and difference between them and low self-efficacy people increased over time.

The recent interest in self-efficacy research has suggested it is important in the first six months (Robinson-Smith et al., 2000), long term management (Marks et al., 2005, Jones 2006), quality of life (LeBrasseur et al., 2006, Moore & Stambrook 1995) and mood (Thomas & Lincoln 2006). Korpershoek et al., (2011) did a systematic review of 17 articles from a nursing perspective and interventions did seem promising in improving outcomes.

Various associated concepts have been mentioned – such as autonomy, which Proot et al., (2000, 1999) found to consist of self-determination, independence, and self-care, in the view of professionals. Confidence is another associated construct – Jones et al., (2008) see their Stroke Self-Efficacy Questionnaire as a valid measure of confidence.

There is a tension between having a sense of control and influence on recovery and rehabilitation, and feeling passive and controlled by professionals. Horton et al., (2011) describe this as a balance between institutional control and autonomous self-governance, but recognise this needs to be a gradual process. In the post-acute stage explored in this study, this was apparent with both elements seeming to be equally important. Horton et al., offer examples of over-controlling speech and language therapy, suggesting that patients were more fully engaged in occupational and physical therapy activities as they were more meaningful.

6.3.3 Belief in others

The analysis in chapter four highlights the importance of being able to trust others in the development of hope, specifically rehabilitation staff. There seem to be a number of factors that influence this, but this section will focus on two – the attitudes and beliefs of clinicians and the therapeutic alliance. In the literature considerable attention is given to the attitudes and beliefs of clinicians, and to the clinically controversial concept of ‘false hope’. The approach of clinicians influences the client’s subjective belief that rehabilitation can have an impact – ‘other-efficacy’. The therapeutic relationship or alliance features in the literature in a variety of areas of study (e.g. health, education, rehabilitation of offenders) and the participants in the current study endorse its importance. It should not be forgotten, however, that the influence of social connectedness is important within, as well as without, the rehabilitation setting, but it is outside the scope of this thesis to address this in detail.

6.3.3.1 The attitudes and beliefs of Therapists

Hope may be influenced by ‘hopeful’ language used by support networks and health care professionals (Hopper & Edey 2007). Pound et al., (1994) speak of hope in relation to rehabilitation – specifically physiotherapy – suggesting that patients are uncertain, so invest too much in the potential of therapy. They comment that maintaining hope is important, but that there is a danger of unconscious promotion of an extended belief in recovery by

therapists and that a balance is needed. Relationships between clients and professionals often reflect the tension between hope and realism, and managing this can be difficult (e.g. Hersh et al., 2012). Worrall et al., (2009) suggest that removing hope may be devastating for people with aphasia.

The hope of the clinician will have a profound influence on the client (Snyder & Taylor 2000). Eliot and Olver (2002) point out that hope can mean many different things at different times, and that clients may find hope in consultations, when not intended by the clinician. They note that having therapy itself implies hope, and state 'the chameleon-like nature of hope in everyday speech ensures that medical staff can neither wisely nor ethically assume a shared and enduring meaning of hope, as some patients may hold that "there is no hope" yet conclude that "one can always hope" ' (p191). Bright et al., (2011), in their systematic review of 19 papers, summarise and highlight the influence of staff – 'Health providers both developed and destroyed hope' (p495).

Smith and Sparkes (2005) postulate that able bodied people, including clinicians, encourage certain hopes in people with disabilities and discourage other hopes, because it helps the clinicians manage emotionally difficult situations. They suggest that people learn what is acceptable and which hopes to express in order to maintain relationships with professionals and others. Therapists construct narratives that enable themselves to cope with lack of hope and despair. In a similar vein, Elliott and Kurylo (2000) state that staff lack awareness of what can be a healthy coping strategy, and may pathologise hope as false and inappropriate. They question whether what is sometimes seen as denial of *problems* is actually more about clients rejecting the attempts (overt or implied) by staff to remove hope.

This links to the question of what is 'good' hope and the tendency for professionals to make judgements, albeit not consciously. Hope was studied on a stroke unit by Tutton et al., (2011) who identified themes of suffering, struggling with no hope/despair, hope for recovery and realistic hopefulness. They included staff and patients, and found them not always in agreement, and that staff reframe longer term hopes into what they see as balanced and realistic - to 'keep hope real.'

There is some degree of tension, or even conflict, in rehabilitation, in balancing the idea that clients need to have personally meaningful goals, but professionals may see those goals as unrealistic, and how to manage the impact of such conflict on hope. Professionals need to

remember that hope serves an important psychological purpose (Wiles et al., 2008) and question the objectivity of deciding for clients which goals are 'realistic' or 'acceptable'.

False Hope Managing so-called 'false hope' is seen as important by many rehabilitation professionals, and 'unrealistic hopes' are often mentioned both in literature and in clinical practice. There are references to the preference of staff for hopeful clients, and that this may affect interactions, encouraging what some might call false hope (The et al., 2000, Hoffman 1974). Others have asked whether there is actually evidence that it is counter-productive.

Snyder et al., (2002) criticise the concept in three ways. Firstly, false hopes are seen as unrealistic, but may reflect a bias to positive thinking rather than a lack of reality judgement, and positive thinking provides a sense of control (which is lacking in depression). They note that people with high hope can often find meaning in difficult circumstances. Secondly is the claim that false hopes are built on inappropriate and unattainable goals, so people will be depressed when they are not achieved, but set against this are so-called 'heroic' achievements attributed to greater effort and motivation from high goals. The third criticism is of the idea that false hopes reflect poor planning, but Snyder et al., found high hopes went with adaptive strategies to reach goals – although Kwon (2002) did not support this.

Dorsett (2010 p84) explicitly challenges the idea that hope is a form of denial, and poses questions about whether encouraging clients' hopes does in fact impede long term adjustment. If hope actually is a positive adaptive response, enabling people to cope, then clinicians need to be considering how best to support hope and how to facilitate developing hope in those who have none.

The concept of 'unrealistic hope' is also questioned by Eliot and Olver (2002) who suggest that it stems from an assumption that there is one shared reality in the clinical situation. Hope, they note, cannot be known to be false until death, and therefore there may be no point in seeking to destroy it. The different perspectives of staff and clients will be discussed further in chapter seven, but it is interesting to consider whether the apparent mismatch is not about clients failing to have a good reason for their beliefs or not understanding information, but about a basic difference in the way hope is viewed.

Clients do not seem to distinguish realistic and unrealistic hope in the same way as professionals. Providing information, in trying to make a hope 'realistic', may replace the more valuable process of listening to and seeking to understand the client's

phenomenological position. Folden (1994) notes that if clients disagree with professional predictions of recovery, they will often seek different sources of support and continue to hope. Gum and Snyder (2002) do not feel that 'false hope' is a concept supported by evidence and stress the importance of goals that are chosen by the individual. What may seem like an unrealistic hope may be the expression of a 'want' rather than an expectation, and the client may be fully aware of the actual possibilities (Wiles et al., 2008). In his personal account of recovery from a serious TBI, the psychologist Linge (1990, p126) states:

'I have heard other colleagues hesitate, saying they are 'afraid of raising false hopes that are doomed to disappointment' but I have never regretted instilling hope in a family nor have I been reproached for it by one.....I will not destroy hope. I will not tell anyone 'This is the end of your journey', for I have seen many miracles.'

6.3.3.2 The therapeutic relationship

Social connectedness can apply to existing family and other relationships, or to post-ABI relationships. In this study, as in many others, the support of family was important, but perhaps even more striking was the degree of importance placed on the therapeutic relationship with professionals. In the proposed model in chapter five, this is an influence within the category of trusting/doubting others, and is also mentioned by Bright et al., (2013). The starting point should be a relationship with therapists that is trusting, non-judgemental, accepting, respectful and open. Sympson and Qualls Elder (2000) describe the therapeutic alliance as the 'sine qua non of all therapeutic relationships' (p175) and literature supports the idea that rehabilitation staff can influence hope in clients, either positively or negatively (Cross & Schneider 2010, Elliott & Kurylo 2000), as has been described in the previous section on Therapists' beliefs and attitudes.

The therapeutic alliance is conceptualised by Bordin (1979) as dependent on agreement of goals, assignment of tasks, and development of bonds. Ackerman and Hilsenroth (2003) saw therapist variables in terms of personal characteristics and application of technique. It is not enough to have certain characteristics, however, such as empathy, consistency and confidence, but they must be perceived by the client. If a therapeutic environment is created it will communicate 'a sense of hope for patients to achieve their goals' (p7). They suggest that if the therapist starts the process with a positive expectation it may influence the actual experience. Bachelor (1995) identified three types of perceived alliance – nurturant, insight-

oriented, and collaborative, which – respectively – facilitated attitudes, self-awareness, and involvement.

Snyder and Stukas (1999) undertook an analytic review of interpersonal processes, and how interactions are affected by expectations, which develop from past experience, group generalisations and personality factors. Consequences are both perceptual, in the mind of the perceiver, and behavioural in the actions of the other – so the perceiver holds certain beliefs/expectations about the other, which may lead the other to behave in certain ways (self-fulfilling prophesies). Snyder and Stukas considered power differential, and suggest behavioural confirmation is more likely if the perceiver is deemed to be more powerful. This is relevant in this study, as therapists are seen as more powerful, and, while they acknowledge both have expectations of the other, they suggest that there will be a greater impact from therapist to client than vice versa. It may be that meeting therapist expectations (behaving ‘appropriately’) leads to social inclusion, and this further confirms expectations.

The need to have support from rehabilitation/health care providers is seen by Simpson (2004) as a determining factor in maintaining hope, as she suggests that hope cannot be sustained in isolation. It may be, of course, that other sources of support and/or a sense of progress can offset the need for rehabilitation to assume this central role in maintaining hope.

While the therapeutic relationship is crucial in developing trust in rehabilitation, and has been the focus of considerable research, it is important also not to lose sight of the relevance of the skill and expertise of clinicians, and it is the balance of both that fosters hope in people, as seen in the data presented in chapter four. This trust may be based on the assumption that professionals know what they are doing or on evidence gathered through earlier experience.

6.3.3.3 Relationships outside rehabilitation

Outside the rehabilitation setting, social influences on hope are also important. The initial literature review in chapter one highlighted how central social connectedness is to the experience of ABI. Gum and Snyder (2000) acknowledge one of the pathways used by high hope people is communication and asking for support, and agency is increased by developing social opportunities. Green and Waks (2008) found that people with aphasia could develop hope through meaningful activities and relationships and accepting limitations. Other people

may be both a source of hope and a risk – for example by making comparisons with other people, and perhaps with the progress made by other ABI survivors (Bright et al., 2013). The support of families and other significant people is evidenced in the literature (Bright et al., 2011, Cross & Schneider 2010, Gum & Snyder 2002, Farran et al., 1995).

The relevance of cultural expectations of ‘progress, productivity and instant cure’ (Dolittle 1992, p123), and of judgements and fears of there being a ‘big difference between being a temporary burden....and becoming a permanent burden’ (Dowswell et al., 2000, p513) are additional factors affecting level of hope.

6.3.4 Combining Belief in Self and Others: The Tripartite Efficacy model

The beliefs that both self and others can have an impact on progress and contribute to hope have been described, but Lent and Lopez (2002) further developed Bandura’s (1989) concept to encompass relational aspects. In the current study, there was considerable overlap between the expectations people had of self and of rehabilitation services – at times seeming to be one concept viewed from different perspectives, so it seemed appropriate to consider in more detail a model that combined the two.

Lent and Lopez (2002) developed a tripartite model of efficacy beliefs in growth promoting relationships. While acknowledging the importance of Bandura’s concept of self-efficacy, they recognised the complexity of social interaction and suggested ‘a conceptual scaffold to facilitate the extension of self-efficacy to interpersonal contexts’ (p257). They – as did Bandura – saw the four informational sources that contribute to the development of self-efficacy, as being personal performance, vicarious experiences, social persuasion, and psycho-affective states. In the course of a relationship the efficacy of the other person is appraised, which may or may not be in tune with their actual abilities, and the authors suggest that this can lead to self-fulfilling prophecies. If, for example, a clinician holds negative expectations about a person’s abilities to improve, this may affect the behaviour towards that person and, in turn, influence the beliefs or behaviours of that person.

In addition to beliefs about self-efficacy and the efficacy of the other, however, is a third efficacy belief – relation inferred self-efficacy (RISE). While the other person’s expectations may be conveyed, they are not necessarily introjected, and RISE beliefs act as a cognitive filter. If an individual perceives others as genuinely believing in them, their self-efficacy may

be enhanced, but people may discount behaviours if the perception is that behaviours are not genuine – “He’s saying that, but doesn’t really mean it.”

The paper suggests that RISE effects are greatest in certain contexts, such as when sources of self-efficacy information are limited, when there is a power imbalance, different knowledge levels, and limited access to valued resources or reinforcers. Lent and Lopez claim that the relationship and the individual will be affected depending on the degree of congruence between the three efficacy beliefs. Engagement will be discussed in chapter eight, but it is worth mentioning that the authors link the concepts: if a person sees themselves as able but believes the other does not, they will disengage physically or psychologically, or will attempt to manipulate information in order to convince the other. Similarly, if a person has low self-efficacy they may discount positive information as it contradicts their self-image.

In relation to hope, they suggest that it will not be sufficient ‘simply to express hope-mobilising messages. Rather, it may also be important to explore how clients are processing the helper’s efficacy-relevant messages, such as positive feedback’ (p281).

The tripartite efficacy model, in combining belief in self and others offers further support to the final engagement model outlined in chapter five.

6.4 Chapter summary

This discussion of relevant literature on hope and the beliefs influencing its development and maintenance has reinforced the interview data collected and analysed prior to this phase of the literature search. Existing knowledge supports the importance of perceived improvement/recovery, self-efficacy, and belief in others/rehabilitation, as having an impact on hope.

The model suggested in chapter five links these three influential beliefs not only to hope, but also to the level of engagement. Clearly an overt link to engagement cannot be made, based purely on the client interviews as data collection preceded actual involvement with community rehabilitation. However, it is hypothesised that the same beliefs that generate hope will also influence engagement with rehabilitation. This will be discussed in chapter eight, following a description of the final stage of data collection, that is, the additional aim

of exploring clinician beliefs, as yet another data source towards drawing final conclusions and considering clinical implications.

Chapter Seven – The Views of Clinicians

7.1 Introduction

An additional aim was introduced during the course of the study, as alluded to in earlier chapters. The rationale for this was that the overall objective of this research is to improve clinical practice, by gaining a greater knowledge of the perspective of people who have had ABI, and whether there are common expectations and beliefs that affect engagement with and response to rehabilitation. Therefore it seemed logical also to gain an understanding of the perspective of clinicians, in order to evaluate whether the expectations of staff and clients did indeed differ, and if so in what way. A greater understanding of the differences in expectations may enable service developments that contribute to improving engagement and outcomes.

7.1.1 Ethics

Ethical approval for this amendment to the original research design was obtained through the University of Sheffield Research Ethics Committee procedures.

7.1.2 Context

The rehabilitation service has been described in chapter one, but it may be helpful to provide additional information about the clinical team at this point. There is a service manager, whose background is in physiotherapy; and two rehabilitation team coordinators, both of whom are occupational therapists, responsible for clinical service management.

Speech and language therapy, physiotherapy, occupational therapy, neuropsychology (including counselling) and social work are represented, and each department has a senior Head, who is in all cases the most experienced member of the discipline. In addition there are two rehabilitation assistants, who have a generic role, and who have considerable experience in the service.

The highly specialised nature of the service means that all professional members of staff are experienced in the field of ABI – newly or recently qualified Therapists, or those without relevant experience, would not be recruited.

7.2 Review of Literature/Different perspectives

There is considerable evidence of differences between the perspectives of professionals and clients in the literature. Brown et al., (2010), specifically addressing the needs of people with aphasia, stress that professionals should look at their own value systems in order to identify discrepancies between themselves and clients, and suggest that this will enable more relevant service provision. This is the underlying assumption that led to the additional goal of exploring the views of the professional team in this research.

Many researchers stress the importance of staff understanding the perspective of individuals and acknowledge that discrepancies between staff and clients' views may influence the ability of the latter to have an active role in rehabilitation (e.g. Satink et al., 2013; Olofsson et al., 2005; Snead and Davis 2002). Although outside the scope of this discussion, it is worth noting that the perspectives of clients also differ from those of care-givers (e.g. Ferguson et al., 2010, Lynch et al., 2008).

It has already been noted that clients and staff may see recovery differently and Dolittle (1992) makes reference to the different frames of reference held. Hafsteindottir and Grypdonck (1997) and Bendz (2003) among others, illustrate this when they note that clients see recovery as a return to how they were before the stroke, while professionals focused on discrete recovery of certain abilities or functions. Another example is in clients' reticence to use some assistive devices to avoid judgements and stigma, but which may be seen as non-compliance (Gitlin et al., 1998). Becker and Kaufman (1995) see professionals as having a much more limited view of what is possible to achieve, and take into account assumptions related to age and costs. Mold et al., (2003) found inequalities in the conceptualisation of stroke illness based on age.

7.2.1 Philosophical differences

It may be that the professional rehabilitation staff have a different philosophical starting point. Alaszewski et al., (2004, p1073) suggest, for example, that the bereavement model

frequently used by Therapists is not shared by clients – in their study no stroke survivors mentioned bereavement or grieving. They describe professionals as ‘experts who are expected to draw on collective professional knowledge developed by generalising from individual cases to general underlying and abstract processes...(which) involves a process of decontextualisation’. This, however, risks ignoring aspects that are deeply relevant and meaningful to a specific individual. They advise against using psychological models to try to understand individuals, and focusing instead on discovering how each makes sense of their own reality.

7.2.2 Judgements and motivation

A judgemental aspect within the therapeutic relationship is alluded to by various researchers. McKeivitt et al., (2004) suggest that motivation and continuance in rehabilitation is often judged by the compliance of the individual. Bendz (2000) puts it strongly, describing the patient’s position as ‘subordinate’ to that of the professionals. Patients being assessed for rehabilitation are required to demonstrate motivation, and Gold (1983) argues this entails conforming to the expectations of the professionals.

Certainly there seems to be a wide consensus that clients at least initially have higher expectations and hopes for recovery, while professionals are cautious in their outlook (McKeivitt et al., 2004, Dowswell et al., 2000, Dolittle 1991). There is a risk that clients who want to hold onto goals which the professionals deem unrealistic are seen as ‘stuck’ or ‘non-accepting’, and the therapeutic relationship can become strained (Rosewilliam et al., 2011). This links to the discussion in chapter six about hope.

Nochi (1998a) comments that some clients with TBI believe that staff normalise changes in mental health in order to avoid addressing such changes - calling something normal implies it is inherent in the person’s personality rather than ascribable to the injury. In 2000 the same author suggests:

Rehabilitation professionals tend to pay more attention to individuals who have problems managing their new lives...yet individuals who seem to succeed in coping...should be examined too.’ (p1795).

7.2.3 Goal setting

In 2011, Rosewilliam et al., undertook a systematic review of both qualitative and quantitative research into the differences between clients and staff in relation to goal

setting. While professional staff thought that they were patient centred, clients did not feel they had control over their own goals. Often the client's needs were not explicitly addressed in goals set by professionals. In general clients would choose goals that increased participation, while staff focused on interventions at the impairment or activity level.

Bendz (2003) stressed the need for goals to be relevant to the individual, noting that professionals often ignored factors that were of concern to patients, such as having control, fatigue and fear of a further event/relapse. She found that clients' goals were more nebulous and non-specific, to do with being 'normal' again. She acknowledged (Bendz 2000) the difficulties and the fine balance involved for rehabilitation staff working within a predominantly medical model of care: 'The combination of a biomedical discourse and the subordinate roles of stroke survivors does not provide enough space for either the stroke survivors or the health care providers to focus on any other needs than the biomedical ones' (p721).

Clearly there are differences between professionals. Alaszewski et al., (2004) found that some stressed clinical aspects more and others focused on the more personal and social aspects of clients' lives. Mold et al., (2003) describe a difference between positive and negative staff, suggesting that giving a client a negative label (such as being uncooperative) in turn affects the care given.

7.2.4 Pressures on staff

Staff feel pressure to improve the situation of their clients. Fordyce and Rouche (1986, p227) suggest that 'recognising that not everyone is an ideal candidate for such rehabilitation activities may relieve some of the feelings of failure on the part of staff'. They found that views were better aligned after rehabilitation than before, unless therapy was focused on insight issues.

There is also a risk taking aspect to provision of care, perhaps more so as a result of an increasingly litigious world. Alaszewski et al., (2006, p14) looked at risk: 'much professional practice is based on prevention and on protecting vulnerable individuals from dangers. In the case of stroke survivors there was little evidence that this approach contributed to reported strategies for either reconstructing life or re-establishing identity.' They emphasize the importance of learning how to negotiate risks and challenges, in order to feel a sense of agency.

Another factor influencing the therapeutic relationship may be clients' reticence to share beliefs and fears, because of what they may be told. Jones, Mandy and Partridge (2008) see this as detrimental to developing self-efficacy and resilience, as honesty and openness are essential to an effective interaction.

7.2.5 Hope

Ferguson et al., (2010, p694) described tensions between the roles of client and professionals as a result of differing perspectives, and the 'tensions between hopeful and accepting outlooks for the future'.

Hill (1999, p842) in a personal narrative complained of the negativity shown by professionals, who made 'gloomy predictions' without good evidence:

'Fortunately I did not believe them, but others in a similar position might have and allowed these predictions to be self-fulfilling.....resisting the gloomy forecasts was extraordinarily difficult, because I was interpreted as flouting the established order and authority that 'knew better''

The question of hope has been addressed in more detail in chapter six.

7.2.6 Summary

This brief review of the literature reinforces the importance of clinician beliefs on the process of rehabilitation, and endorses the value of including clinicians' views in the current research. The methodology by which clinicians' views were explored, and the findings, are described in the next part of this chapter.

7.3 Methodology and Method

Chapter two describes the epistemological and ontological underpinnings of the research design, and these equally apply to this additional element of the research. The methodology of grounded theory is appropriate, but individual interviews with clinicians were not practical, because of the time required and the impact on clinical responsibilities. The idea of a focus group seemed to have potential, and was considered in more detail.

7.3.1 Focus Groups: Background

Focus groups, while in existence for a long time, have only latterly become popular outside the social sciences, but this approach is now valued within health education, promotion and in general health research. Willig (2008) defines the focus group as 'a group interview that uses the interaction among participants as a source of data', with the researcher as a moderator, who steers the discussion and sets certain limits (p30). Wilkinson (2008) states that it is an approach 'demonstrably more suited to some kinds of research questions than others' (p188), and sees it as useful when eliciting understanding, opinions and views. Interestingly in the light of its late addition in this research, Janesick (2000) describes using a focus group to develop her ideas as 'something I could not have planned in the first days of the study' (p211). Fontana and Frey (2000) discuss how they can 'provide another level of data gathering or a perspective....not available through individual interviews' (p364).

Discussion in focus groups is focused, but interaction between members is an important part of the process. Wilkinson suggests that 'it can involve as few as two, or as many as a dozen or so participants', however Willig (2008) recommends no more than six participants, in order to allow active involvement and to facilitate transcription, which is notoriously laborious and time-consuming. She notes that this will not be 'the equivalent of six individual interviews' because of the influence of group dynamics, supporting Fontana and Frey's comments above (p32). Although written a long time ago, Merton et al., (1956) offer a nice description of the advantages – 'data rich, inexpensive, flexible, stimulating, aiding recall, and cumulative, over and above individual responses' (p365).

Wilkinson (2008) views the main difference as in the technique of data collection, rather than in analysis methods, but stresses that 'ideally... there should also be an analysis of group interaction'.

Willig describes (2008) differences in membership, depending on the research question; for instance, a group may be formed of people who have a shared experience or interest, or not. It may consist of an existing circle or have a newly constituted membership, formed for the purpose of the group. Finally she suggests members may be concerned with the issue or naïve.

There are important considerations in running a focus group, not least of which is the role of the moderator, who must not only listen to the content but be aware of and respond to the

group dynamics. Wilkinson offers a useful guide to the practicalities of focus group work (2008) including basics of design: time, number of members/groups, type of participants, recruitment, recording, transcription and analysis method. Researcher skills, questions and materials need careful preparation.

This background information on the nature of focus group work suggested it was an appropriate method to elicit views of clinicians. An opportunity arose within the existing staff educational programme to organise and run a focus group addressing questions of value both to the service and this research.

7.3.2 Sampling and recruitment

The focus group was a convenience sample, as the service was undertaking a review of strategy and process, and members of staff were addressing issues of their own beliefs about recovery and rehabilitation. This opportunity to make use of an existing staff focus group addressing similar questions, which the researcher was invited to lead as part of a broader service development initiative, was invaluable, as it minimised the demands on clinicians.

Recruitment for this group consisted of verbal and e-mailed invitations, with all clinicians in the service being sent an information sheet and consent form, which are included in the appendices. If clinicians were unable to attend the group, but wanted to contribute they were invited to send in written responses to the questions, or to meet the researcher to give their views on the same questions discussed in the focus group. Signed consent was obtained from each member of staff who took part. It was made clear regarding comments made in the focus group that individuals could choose not to have their contributions included in this research, and in that event their comments would be redacted prior to analysis.

The group was held as part of the existing education programme, in the meeting room at the rehabilitation centre. Members of the clinical team are used to, and comfortable with, this location and form of discussion. The objectives in relation to service development were to understand and explore clinicians' own attitudes and beliefs about rehabilitation and recovery, and also to consider discharge. People were encouraged to do this within a non-judgemental culture, as the intention was to understand the range of views in the clinical team.

7.3.3 Data collection and analysis

The group addressed three questions relating to beliefs and expectations of recovery following brain injury, rehabilitation provision, and discharge from the service, which are presented below. Prompts were provided for the first two questions, that could be used if necessary, and these are given in brackets.

1. What are your beliefs regarding recovery after ABI? (What factors are most relevant? What do you think affects clients' expectations of recovery?)
2. What expectations do you hold in relation to rehabilitation? (What do you expect of clients/yourself/others? What do you think clients prioritise from rehabilitation services?)
3. When do you believe it is the right time to discharge clients from our service?

Data collection was through audio-recording of the group discussion, which was transcribed and analysed, following the same grounded theory protocol as for the individual interviews. Additional contributions were then analysed and incorporated into the focus group findings. These methods have been described in chapter three.

It has already been stated that involving clinicians was a later addition to the research design. The focus group was held at a point when approximately 18 of the final 21 participants had been interviewed. The timing of this, as has been noted, was opportunistic and therefore not deliberately planned.

7.3.4 Reflexivity

In relation to the focus group of clinicians, it is also important to reflect on my role in the data collection. I am one of only three members of staff who have been in the service since it opened, in 1997. I am the most experienced member of staff in brain injury rehabilitation, and am line manager/appraiser of Speech and Language Therapists. In my role as Counsellor, I am line-managed by the senior neuropsychologist.

In the focus group, as a result of holidays, no other SLTs were present, but two did contribute feedback in written form. This may have been influenced by my managerial role, if either felt

there was a risk of being judged on responses made. Similarly my age and experience may intimidate younger members of staff. However, although there is a hierarchy the staff group only consists of experienced, specialist professionals (with the exception of the rehabilitation assistants) and therefore it is thought that such concerns are minimised.

In facilitating the group, I took the role of introducing the questions and occasionally asked for clarification of points. A colleague supported the group process by monitoring and ensuring all group members who indicated that they wanted to make a contribution could do so. A member of the administrative team also supported the group by keeping a record, to facilitate the transcription process.

7.4 Participant characteristics

This section of the chapter will describe the participants in more detail, and provide information on the relative contributions by role and profession.

In total 18 members of staff contributed to the study. The focus group consisted of 14 people, which is larger than the ideal size for such a group, but group membership was outside the researcher's control, as the primary purpose was service not research led.

7.4.1 Staff focus group

The clinicians involved were from six professions, and – although all were at a senior and experienced level in their profession – there were some in managerial roles and others who are fully clinical. Rehabilitation assistants were included as it is usual practice to include them in team discussions and decisions. It was felt useful to include both a breakdown of professional background and of current roles, to enable understanding of the context of this research. Tables 7:1 and 7:2 give the numbers of staff by role and by professional background, with the total number of comments and proportion of time taken in the group. It is notable that managers and heads of department appeared to dominate the discussion, although it is difficult to draw conclusions based on the staff roles or professions, as there was a significant difference both in the number of contributions made, and the percentage of group time taken, by different individuals. One person made 33 comments, taking up 20% of the total time, while another made two comments, taking 0.5% time.

Table 7:1 Focus group by role

Role	Number of comments	Percentage of time
Managers (3)	64	39.73
Heads of Dept (3)	69	31
Clinicians (8)	61	19.34

Table 7:2 Focus group by professional background

Profession (number)	Number of comments	Percentage of time
Occupational Therapy (6)	98	54.6
Physiotherapy (3)	46	21.78
Psychology (3)	46	11.85
Social Work/ Rehabilitation Assistant (2)	4	1.84

Nb Percentage time does not total 100 as presentation of questions and clarifying questions are not included.

7.4.2 Additional comments

There were four staff who were unable to attend the focus group and responded to the invitation to provide their own comments (representing three disciplines), all of whom were fully clinical in their role. Table 7:3 summarises these contributions.

Table 7:3 Additional comments by discipline

Discipline	No of comments
SLT (2)	25 (12.5)
Physio (1)	21
RA (1)	18

7.4.3 Overall: Characteristics of participants included in analysis

Overall contributions were included as shown in tables 7:4 and 7:5.

Table 7:4 Overall No comments by discipline:

Discipline	No. respondents	No. comments	Average/respondent
PT	4	67	17
OT	6	98	16
Psychology	3	46	15
SLT	2	25	12.5
RA	2	19	9.5
SW	1	2	2

Table 7:5 Overall No. comments by role:

Role	No respondents	No. comments	Average/respondent
Manager	3	64	21
Head of Dept	3	69	23
Clinician	12	125	10.5

7.5 Findings

The transcripts of the focus group and additional comments were analysed in the same way as the individual client interviews, that is, line-by-line coding leading to more focused codes and categories. Three main categories were identified: FACTORS AFFECTING RECOVERY, EXPECTATIONS IN REHABILITATION, and BELIEFS ABOUT DISCHARGE. These are summarised, with sub-categories, in table 7:6.

Table 7:6 Categories

Main category	Sub-categories
FACTORS AFFECTING RECOVERY	Brain injury factors Pre-morbid factors Client's personal resources Beliefs about rehabilitation efficacy
EXPECTATIONS IN REHABILITATION	Expectations of rehabilitation services Expectations of clients Expectations of others
BELIEFS ABOUT DISCHARGE	Reasons not to discharge Long term care questions

7.5.1 FACTORS AFFECTING RECOVERY

7.5.1.1 *Brain injury factors*

These factors were the first mentioned within the focus group and there was a general consensus both in the group and in additional comments that this was the primary determinant of recovery. The main factors identified were the nature of the brain injury, the level of resulting disability and/or complexity, and the time since the injury – comments made include, for example:

- *'the degree of brain injury';*
- *'where the brain injury occurs';*
- *'their prognosis or their ability to move on and adjust is really significantly reduced I think by the type of injury';*
- *'it depends on the severity'.*

However, despite this general agreement, there was one questioning voice: *'I'm not sure I entirely agree because I think actually people come to us with exactly the same impairment but have a completely different outcome in their recovery, so I think it's potentially a relevant factor but it isn't always the most important.'*

Cognitive ability was viewed as an important factor, as illustrated in these contributions:

- *'your cognitive ability determines whether you have a realistic perspective on that responsibility because if you don't have any insight.....we want them to have less responsibility, to have more external support rather than them doing....it depends on their ability to understand where their strengths and weaknesses are.'*
- *'is very dependent on your frontal lobe skills, and if you don't have them it doesn't matter how good your therapist is or what the quality of your information is, that person will often need support either from the therapist or from the people around them'.*

7.5.1.2 *Pre-morbid factors*

Clinicians highlighted co-morbidities, age and educational background, and pre-morbid life context and choices as relevant to recovery. Observations included:

- *'other medical conditions I mean that's huge....so many people with cardiac problems that really limits their output and diabetes and other medical conditions,'*
- *'those clients that are abusing alcohol particularly so they're very chaotic as well and all that comes together to mean that it doesn't matter how specialist you are, some of these clients just can't profit from rehab.'*

7.5.1.3 Client's Personal resources

The personal resources of clients felt to impact recovery included being motivated/determined, having a positive self-image, having coping strategies, and pre-morbid beliefs.

Determination and taking responsibility for recovery was seen as critical and illustrated by a number of comments, such as the following:

- *'Whether they see it as their responsibility to do their rehab or have it done to them';*
- *'Almost it's too hard but they're having to keep going and going and going....seem to make gains that other clients just don't';*
- *'Persistent at working on their problems;'*
- *'Determination, motivation – it's all that but above and beyond the normal.'*

The motivational force of having valued roles and responsibilities to resume was recognised: *'Whether they have roles and responsibilities on which to attach the rehabilitation in order to promote their recovery'.*

Pre-morbid characteristics were also seen as relevant to recovery: *'the way you think pre-morbidly and what you believe in and how you manage stress – your coping style, your coping strategies I think impact a lot on how you then cope with this very traumatic....'*

Having a supportive social situation – or not – was also felt to be a factor influencing recovery:

- *'social support networks are quite important – whether they've got them, haven't got them, what types they are;'*
- *'socio-economic stressors so when people lose their employment and can't get back to work....lose their house etc.'*

7.5.1.4 Beliefs about rehabilitation efficacy

The term 'rehabilitation efficacy' has been used both in this context and in the discussion of the client's responses and developing models, and refers to the subjective belief that rehabilitation can be effective in bringing about change. The nature of the change is less important per se than the degree of importance placed on it by the individual. Clinicians made a basic assumption that clients would not recover fully, and the expectation that rehabilitation would be effective therefore implied improvement but not full recovery. The consensus was that clinicians thought that the clients would have an expectation of greater recovery than would the clinicians, although Therapists' experiences varied and led to some differences in what it was thought rehabilitation could achieve.

- *'I don't expect the client to make a full recovery. I am hoping they'll get to a position where they can keep making progress on their own, which could happen over years, but I think the client often comes with the expectation that they will almost be back to normal.'*
- *'that we are not expecting a full recovery?'.....'I thought that was a given, do you know what I mean, so we didn't state the obvious.'*
- *'the expectation of rehab I think for us and our clients is always to get a degree of improvement.'*
- *'there'd probably be a range but I suspect they would put different emphasis on prioritisation – they might come up with similar points but there'd be different emphases.'*

It was noted how often Clients were heard to use the term 'normal' and this was accepted as a subjective term: *'they use that language but if you were to actually question about that, do they actually mean – what is normal to them'*

Expectations and beliefs held by clinicians as to what rehabilitation could achieve were seen as time-dependent to a significant degree: *'I think there's a difference in recovery in terms....as time goes on, so the very early stages it's about physiological change and as time goes on it's more about adjustment and compensation and I think the emotional side of things has a big impact.'*

It was felt that clients would change their expectations as time went on: *'It'll be dependent on where they are in their journey. I think if you asked that question at the beginning of their*

rehabilitation journey, I think that they'd put up very different things to us, when they're towards the end of their rehabilitation journey I'd be surprised if they differed as much.'

Another observation was that: *'I'd hazard a guess that most people early on would put a very high priority on severity of injury.'*

The reputation of specialist services was seen as leading clients to have greater expectations of what could be attained through rehabilitation: *'Is that because clients have been told up to the time they come here 'Oh wait until you go (there) they'll be able to tell you' – so the expectation's been built up by community or hospital professionals?'*

7.5.2 EXPECTATIONS IN REHABILITATION

7.5.2.1 Expectations of rehabilitation services

Aspects identified by clinicians as significant were timeliness, quantity, quality/specialism, an holistic philosophy, team working, and information giving.

Timeliness There was a sense that timing was important, but was not just about seeing people quickly. Comments included: *'for some people early intervention might suit them, for some people they need a...a period possibly of settling down and getting back into the community before they begin their rehab;'*

Quality and quantity The consensus was that quantity should not be confused with quality, and that the priority was very much to provide a quality, highly specialist service. Illustrations of this sub-category included: *'the quantity of input and the quality of the input;'* and *'it is more about the quality....the team approach and the specialist nature and the ability for us to understand the client's problems it's easier for us....to address the actual needs and in a timely way to promote further change.'*

Another observation was *'seeing the whole picture and understanding not just the client's physical impairment and the cognitive but the interplay around the emotions and the fatigue – it was the whole picture – the holistic impact.'*

Bespoke services Rehabilitation services should be bespoke and individualised, adapting to the client, and should provide emotional and psychological support as an intrinsic part of the service: *'the bespoke nature of it and that comes into the timeliness, the location,....who*

it's done by, how often it's done, so it's not having packages that people fit into, it's being creative for the individual.'

Therapeutic relationship The therapeutic relationship was valued by all: *'the relationship.....between the therapist and the client is very, very powerful.'* It seemed to be accepted that therapists should be expected to take responsibility for the relationship or therapeutic alliance:

'I kind of have the expectation that I'm the best person for that particular person just because they randomly showed up into my assessment slot.....if we aren't gelling it's my fault I need to look at a way of making this gel rather than 'Here I'm not gelling with this person – you work with them and see how it is.'

'In my training I was definitely developed with the expectation that I would change myself and who I am dependent upon that client's needs, and I have the expectation that I can adapt to work with any different type of client....I might be wrong.'

Expertise/specialism The relationship was seen as linked to expertise: *'If you have trust in expertise then that will help you in the rapport too.'* This area too was seen as the therapist's responsibility: *'as a specialist in rehab our job is to dip into the toolbox of many, many different methods and keep trying until we find something that the client can work with.'* It was felt that therapy tasks should be realistic and achievable by clients, and enable future self-management wherever possible.

Information provision Information should be provided, to help clients to understand what has happened: *'the biggest gains I've seen is in clients that you give them a little bit of information so they understand the deficit and they just make recovery without me even necessarily seeing them for a couple of weeks – they come back and they're in a different position.'*

Information was also to enable them to make informed choices: *'they need to have a range of options...or information and options and then they would need to go away and try and experience and decide what works for them,'* and *'it's about choice – it's about information.'*

However, this should not be at the expense of hope, as it was felt important to keep hope alive: *'offer them as much factual evidence as where possible but at the same time to not*

steal away their hope by saying it's never going to get better than this or that...being categorical doesn't help.'

The differences between disciplines was discussed, and questions raised as to whether different disciplines have different expectations both of their own and other professions. For instance: *'What are our expectations of physio, of psychology you know – is it that we are hoping that they'll turn everything round and the person will be going home happy?'* and *'what I'm learning today is that it is probably different for different specialities.'*

7.5.2.2 Expectations of clients

As has been stated, there was a consensus that the cognitive level of the client would be the primary determining factor in terms of what could be expected from the client. Assuming an appropriate level, clients were expected to prioritise rehabilitation, to take responsibility, to engage with rehabilitation, to trust therapists, to expect answers, to be honest and to try hard and face challenges.

Comments such as *'Rehabilitation should be empowering. It should help people to take some responsibility for their future,'* and *'it's not passive, it's active,'* illustrate the expectation that clients should be fully engaged and involved. However, it was recognised that *'engagement in its own right is a high level cognitive skill and not all of our clients have high level cognitive skills – I think the dynamic has to change dependent on client.'*

While expecting honesty from clients – to say if therapy is working for them or not – it was acknowledged that this is not easy: *'If you're feeling vulnerable anyway you're under stress, this is your treatment team, it takes a powerful person to be able to express (any sort of criticism).'*

Expectations are not always met: *'I have an expectation that clients will be committed and actually prioritise their rehabilitation and that sometimes I find disappointing.'* This seems to cut to the very point of this research – why are some clients committed and engaged and others not?

7.5.2.3 Expectations of others

Clinicians expected to involve the client's family: *'it's an interactive process between our clients, their families and ourselves, and if you don't get that interaction....'*

The other expectations were of other services and there was an expectation that other service providers would share the priorities of the rehabilitation team, and that confidence levels in other services was a factor in rehabilitation provision - *'I have the expectation that other services think that the client that I work with is just as important in their life to them as it is to me and that isn't always the case.'*

7.5.3 BELIEFS ABOUT DISCHARGE

7.5.3.1 Reasons not to discharge

It was felt that therapy should continue while there was a perceived therapy effect, and that there may also be value in maintenance therapy in some cases. Different needs and cognitive levels were recognised.

While one aim of rehabilitation was seen as *'For them to have the skills to continue their progress themselves'*, individual differences made it difficult to be categorical: *'It's dependent on therapy for improvement so that's the question isn't it? How much of improvement is self-management and how much of it is therapist involvement.'*

Some clients may need to be discharged: *'for some clients it is about end of rehab now means they've now made a recovery and they need to get on with their life, and they need that cut off point.'* Other therapists felt: *'I don't think we should discharge our clients. This is a chronic condition and there's no-one else out there that's better to deal with them in the long run than us.'*

Against this the point was made that *'the downside of saying it's a chronic condition we're the people best here, is that you never – well the danger is that you – you don't allow the client to think I can manage this on my own.'*

Availability of other services to pick up the ABI client's needs was another factor: *'when we discharge clients is how confident we are about other services around us and what can be offered and whether that's....an appropriate service for the client, the carer, whatever, because if there isn't that confidence as a therapist or whatever there is a reticence I think to move people.'*

The possibility that discharge was sometimes delayed for the Therapist's sake rather than the client's was raised: *'I hear more of the individual therapist view – that they want to be there at the end of that journey, I'm not sure the client necessarily needs them to be there to the end'*.

7.5.3.2 Long Term Care

Clinicians agreed that working towards self-management should be a transparent aim, but there was discussion about continuing to provide services against risking dependency. Chronic long term needs of the ABI population need to be acknowledged, but there was debate about who could and should provide this care and how much choice could and should be available to clients. Differences of opinion between clinicians are illustrated in the following two quotations: *'I think we've got to be very careful about the dependency issue, that you know we're not a service that we want our clients to become dependent on, however we're a service that we want to be available for our clients when they need us so there's a very difficult balance.'* The second quotation is: *'I don't think they're dependent on us. They use us but I don't think they're dependent.'*

7.6 Comparison of staff and client beliefs/expectations

It is important to begin by acknowledging the difficulties in making a direct comparison between clinicians' and clients' expectations. Clinicians and clients were not asked the same questions, and do not share the same vocabulary, so some of the comparisons are based on implication. Clients were interviewed at a single point in time, after referral but before being seen in the service, whereas clinicians obviously interact with clients across a broad time scale and cannot limit expectations to one point. However, despite these limitations it is possible to gain a greater awareness of any significant differences between the two groups, which could potentially impact on rehabilitation.

Qualitative research is data led, and in the broader less structured interviews with clients, data was less constrained than in the specific questions asked of staff. For this reason, the comparison has taken the categories identified in relation to recovery and rehabilitation in the staff group, and then considered any overlap with client responses. The comparison is summarised in table 7:7a and b. Discharge beliefs have not been included in the comparison as it was not relevant to the client interviews at this stage in their pathway.

7.6.1 Factors affecting recovery

The implied definition of recovery seemed to be different between the two groups – clinicians had no expectation of full recovery, but used the term to mean some degree of improvement, ideally to potential. Clients, however, defined recovery as being back to ‘normal’, that is how he or she was before the ABI, and there was a range of expectations from full recovery to no expectation of improvement, resulting in the hope-despair spectrum described in chapters four and five.

Clinicians stressed the brain injury related factors such as the nature, severity and site of the injury, and the comment quoted above suggested an assumption that clients too would have this view : *‘I’d hazard a guess that most people early on would put a very high priority on severity of injury.’* However, no client mentioned these factors, and for clients there did not seem to be an obvious link between severity of impairment and expectation of recovery.

Table 7:7a Comparison of clinician/client expectations about recovery

Category	Staff	Client
Understanding of the term	Improvement	Back to ‘Normal’
Degree of recovery expected	Full recovery not possible	Range from full to none
Brain Injury factors	nature/site/severity comorbidities Time	x X Time
Premorbid factors	Life context Social support	Life context Social support
Personal resources	Roles and responsibilities Past self/self-image Motivation/determination x	Roles and responsibilities Past self/self-image Motivation/determination Judgment/Guilt
Rehabilitation efficacy beliefs	Will improve situation	Range of expectation

Both groups did agree that time is a factor, which the clients related to the speed of improvement and the degree of perceived improvement or deterioration. Comorbidities were seen as important factors in recovery by clinicians, whereas some clients linked this to rehabilitation (such as knee problems making physiotherapy more complicated) but not explicitly to recovery.

Life context was highlighted by both groups, including the importance of social support from family and others.

Personal factors were acknowledged by both groups. Clinicians identified roles/responsibilities explicitly, which clients implied through numerous responses. Both groups also recognised self-image (and comparison with past self) and motivation/determination. However clinicians did not refer to the question of judgement and guilt, which came up frequently in client interviews, and seemed to have an implied relationship to expectation of recovery.

Rehabilitation was seen as a factor in recovery by both groups.

7.6.2 Expectations in rehabilitation

Again the basic premise seemed to be different. Clinicians had an assumption that rehabilitation would be effective in leading to improvements (which were not fully defined), while clients generally stated that they had no real expectations or knowledge. Some explicitly stated that they would have to wait and see what happened. However, there were implied expectations within the client data.

Both groups made reference to the influence of acute/early care in and immediately post-hospital discharge, and to the expectation of and importance of timeliness in service provision. In terms of the professional role, both groups agreed on the need for specialist, quality rehabilitation, but while there was reference to it, neither stressed the importance of quantity. Only one client mentioned the value of a team approach ('joined up services') and another the need for individualised care, both of which were major factors for the staff group. The expectation of information was there for both, as was realistic, practicable

Table 7:7b Comparison of clinician/client expectations about rehabilitation

Category	Staff	Client
Stated expectation overall	To offer appropriate intervention to effect improvement	No explicit expectations of rehabilitation
Expectations of rehab : Professional factors	Acute/early stage care Timeliness Team/holistic Expertise/specialism Bespoke/individual Information Realistic/practicable x Family support	Acute/early stage care Timeliness x Expertise/specialism x Information Realistic/practicable Rationale/guidance Family support
Expectations of rehab: Relational factors	Therapy relationship Psychological support Keeping hope alive	Therapy relationship Someone to talk to/have a voice/respect Encouragement/honesty
Expectations of clients	Be responsible/self-manage Trust therapists Engage and try hard Prioritise rehabilitation X Be honest	Have control/direct rehab Trust therapists/ choose which advice to follow Engage and try hard X Be positive Be honest

therapy. The client group did, however, stress the need for clear rationales for treatment, which was not mentioned by staff. The therapeutic relationship featured highly in both groups, albeit with different terminology. Clients spoke of being heard (having a voice), having someone to talk to, respect and dignity, encouragement and honesty. Clinicians used terms such as psychological support, adapting to the individual and '*keeping hope alive.*'

Both acknowledged the need for family to be involved and to have support.

Interestingly the two groups also seemed to be in agreement, but using different language, about the client's own role. Therapists spoke of 'self-management' and 'taking responsibility', alongside trusting the experts. Clients also expected to have control and direct their own rehabilitation (albeit to varying degrees) and to balance trusting the experts against choosing which advice to follow.

Both staff and clients expected the client to work and try hard, to be motivated and determined, and to be honest. Staff mentioned the expectation that clients should prioritise rehabilitation, which was not mentioned in client interviews. Clients expected to maintain – if at all possible, and if not the importance was still acknowledged - a positive attitude.

7.7 Discussion and Therapeutic Implications

Many of the expectations about recovery and rehabilitation are shared, however, there are areas in which different understandings and beliefs could impact negatively on engagement with rehabilitation. A brief outline of some of the relevant literature was given at the beginning of this chapter, and the findings from the focus group endorse the general acceptance that there are discrepancies between professionals and clients, commented on by Satink et al., (2013), Brown (2010), Ferguson (2010) and many others.

7.7.1 Recovery

In relation to recovery there is an essential difference in expectations, as therapists do not expect clients to recover fully while most clients – at least at this point in their pathway – still **hope** for full recovery. Some still **expect** full recovery, although there is a range of expectation. Dolittle (1992) discusses the different interpretations of the term 'recovery',

which result in different frames of reference by which improvements and achievements are evaluated. Dowsell et al., (2000) note that clients see recovery in total, not as individual parts, making it hard to feel positive perhaps when professionals applaud small steps. Professionals' views, however, are dominated by the belief that the potential to influence the illness trajectory is very limited (Becker & Kaufman 1995).

Different professionals or professional groups may have different levels of positivity about the possibility of improvement – Pound and Ebrahim (1997), for example, found that speech and language therapists believed they could influence quality of life by aiming for improvement within the restrictions of the disability rather than for full recovery. The findings in this study suggest clients may not agree. Jones, Mandy and Partridge (2008) raise the question of how open clients feel able to be about their beliefs, suggesting they may not admit their hopes as they fear professionals will give a more negative view, and reduce their hope.

Hill (1999) offers a personal view about the way in which professionals can take away hope by giving gloomy predictions: 'Fortunately I did not believe them, but others in a similar position might have allowed those predictions to become self-fulfillingresisting the gloomy forecasts was extraordinarily difficult, because I was interpreted as flouting the established order and authority that 'know better'.'

Perhaps one of the major influences on this difference is in relation to the beliefs about the brain injury itself, which is the primary determinant of progress for clinicians and is not mentioned by clients. There may be implications in terms of education in the early stage of the rehabilitation process, which might be welcomed as information is seen as significant by both groups. If people have no conscious knowledge of ABI, they have no reason to think that it cannot 'get better'. Bonds-Shapiro (2011) highlights the importance of what information is given, suggesting that people use it to 'reconstruct a narrative' and create expectations. Clinicians may benefit from education as well, in relation to the impact on clients of perceived judgement and guilt about being a burden on others and in not making assumptions about clients having knowledge about brain injury per se.

7.7.2 Rehabilitation

In relation to rehabilitation, while therapists are clear about their expectations and what therapy can provide and achieve, most clients at this stage feel that they do not have the knowledge and experience to have any clear expectations. Clinicians expect an holistic, bespoke, team approach to be valuable, and the fact that clients do not mention this to any great extent may well be due to the lack of general knowledge about rehabilitation. The main area that perhaps has implications for clinical staff is the emphasis placed in the interview data on being given clear rationales, and it may be a useful aspect of rehabilitation provision for reflective practice.

The need for clear rationales also links to the need for clients to perceive goals as personally relevant and valuable, not just 'allocated'. Therapists expect clients, in the current study, to trust them, while clients expect to trust the therapists but choose which advice to follow. This seems to be a critical difference. Brown et al., (2010) stress the need for speech and language therapists (although the point could apply to any professional) to examine their own beliefs and values in order to discover how they align with clients, and identify congruences and discrepancies. There is a danger, as Alaszewski et al., (2004) found, that if their goals are seen as unrealistic by staff, clients are deemed 'stuck', 'uncooperative' or 'not accepting'. Furthermore, even when professionals explicitly adopt a client-centred approach, clients perceive goals as professionally determined (Rosewilliam et al., 2011). Mismatched goals will, according to Niemi and Johansson (2013) lead to ineffective rehabilitation; and affect clients' ability to take part in their own rehabilitation (Olofsson et al., 2005).

The therapeutic relationship is an expectation of both groups and is valued by both, as is the role of the client. At this point there was a sense that clients want to have control and responsibility in the rehabilitation process, and balance trusting and accepting advice against the ability to make choices. It would be interesting to look at whether the process facilitates this expectation being met, or if clients lose 'power'. Wiles et al., (2002) and Alaszewski et al., (2006) comment on a tendency for professionals to err on the side of caution and prevent risk taking, although negotiating risks can increase people's sense of agency.

Clearly this study has looked at a very specific clinical team, made up of experienced and specialist staff, and it might be thought that such a team is more likely to have knowledge and awareness of the specific needs of the ABI population, and therefore be more in tune with the expectations and beliefs of the population. It would be interesting to undertake a

similar exercise with staff groups who do not specialise or have less experience. It was apparent from the sample characteristics that the more experienced, senior staff made proportionally more contributions and comments, which may also have affected the data. However, the literature above raises the question of whether there is a difference between explicit stated beliefs and approaches, and actual practice, which needs to be borne in mind.

It must also be acknowledged that the client's views have been simplified for the purpose of this comparison, and not all would share every expectation, so it should be borne in mind that clients are individuals and their expectations and beliefs will be the result of a complex interplay of factors. It is hoped the description of findings in chapter four and the model in chapter five give an indication of the complexity of influences involved.

7.8 Chapter Summary

In summary there are many shared expectations, but a need is highlighted by the comparison for education of both groups in order to bring the expectations even closer. Reflective practice and an open culture for discussion and debate within clinical teams, while not an explicit finding from the focus group, is an approach that can facilitate this, so that assumptions are recognised as such and not taken as fact.

This chapter has contributed to the research objective which was to consider clinical practice changes that may increase engagement and improve outcomes for clients. With this comparison in mind, alongside the model suggested in chapter five, the next stage is to discuss how the findings of this research link to the concept of engagement, drawing the threads from the qualitative research and the literature together, and returning to the original research question – what influences engagement with rehabilitation following ABI?

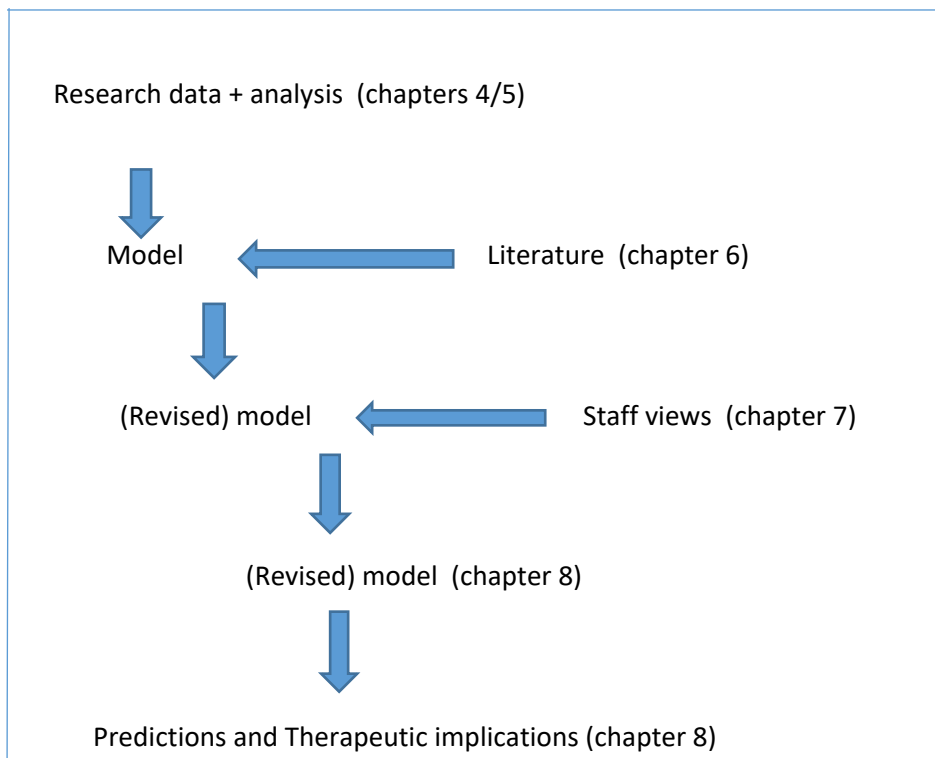
Chapter Eight : Discussion

8.1 Introduction

The purpose of this chapter is to draw together the research findings into a coherent model, and discuss its relevance and value in relation to the explicit objective of this research, which is to use the theoretical framework as a basis for improving clinical practice. It is outside the scope of this study to evaluate the practice changes suggested, and it would be necessary to do this before advocating widespread changes, but the therapeutic implications drawn follow logically from the model.

Figure 8:1 illustrates the development of the study, with initial analysis of the data obtained from the client interviews, followed by consideration of relevant literature, and final data from the staff focus group. The evolution of the model throughout the initial data gathering and analysis has been described in chapter five, but this chapter will consider whether revision of the model is justified in the light of the additional literature and focus group data.

Figure 8:1 Data collection stages



Engagement was the starting point of this research, and it is hypothesised that the same beliefs that affect hope are critical in engagement, so there will be reference to the literature on engagement. The model will be revisited, and illustrative case studies will be presented to test and illustrate the final version of the model. Finally there will be detailed consideration of the implications of the model for clinical services.

8.2 Revisiting the models: Interview data

Two models were outlined in chapter five, based on the final interview data. The first sought to summarise the data, while the second linked the main concept of that first model – hope – to engagement, in effect making an explicit link between the two concepts. Both models are re-illustrated here to facilitate discussion.

Figure 8:2 seeks to clarify the links between the categories that emerged from the interview data. In summary, the process of clients trying to make sense of what has happened is ongoing and interacts with the other categories, having an indirect influence on the hope-despair spectrum. The three categories – MOVING FORWARD, WHAT CAN I DO?, and TRUSTING/DOUBTING OTHERS – seem to have a more direct influence on hope. The prediction from the model is that people feel hope if they perceive that they are making progress, have a sense of self-efficacy and believe that rehabilitation can make a difference, and that this affects engagement. Neither hope nor engagement are constant states, clients will continue to make sense of what is happening by evaluating progress and the benefits of their own efforts and of rehabilitation. If expectations are met, hope will continue, clients will engage, adjustments be made and – it is proposed – clients will be able to come to an acceptance of their new situation.

As this first model is essentially a summary of the data, it is not appropriate to change it in the light of other sources of data, and it can stand alone as one possible interpretation of the perceptions and subjective experience of the interviewees. It must, of course, be remembered that this is based in a very specific context and at a single point in the ABI trajectory – between acute and community rehabilitation. However, in comparing the model against the literature as reviewed in chapter six, there seems to be considerable evidence that perceived progress, self-efficacy and belief in services are important factors in developing hope.

Figure 8:2 Engagement Model



The second model of engagement (which is illustrated later in this chapter in figure 8:3) presents the data in a more theoretical, interpretive way. It illustrates the interactions between belief in recovery and belief in the ability of self/others to influence that recovery, and predicts that the interaction will determine whether people have hope, and whether they will engage. It also postulates that the two concepts are distinct – it would be possible to have hope for recovery without engaging, if there is no belief that self/rehabilitation services can have an impact, for example. In order to explore the issue of engagement, a brief discussion of the literature is necessary, before revisiting this second model.

8.3 Engagement

8.3.1 What is engagement?

The question of engagement has been a subject of considerable interest in the fields of health and education, where studies have looked at cognitive, behavioural and affective engagement. Fredricks et al., (2004) reviewed literature on engagement in education and found these three aspects interact so that engagement is best seen as a meta-construct. Galla et al., (2014) recognised this, stating that it is generally accepted that engagement with learning requires ‘coordination of behaviours, emotions and cognition’ (p296). Behaviour has been studied through conduct, participation and active involvement, and they noted that engaged behaviour needs the ability to self-regulate in order to meet goals. Engagement, they indicated, involves self-efficacy and effort, and affects achievement, although the mechanism of this is not clear.

Engagement may be seen as a spectrum or continuum, ranging from enthusiastic interest to apathy and passivity (Matthews et al., 2002). It is seen as a crucial factor in rehabilitation, and various definitions have been offered, including that of Lequerica (2010, p416) – ‘the act of beginning and carrying on of an activity with a sense of emotional involvement or commitment and the deliberate application of effort.’ In practice, in rehabilitation, this would mean a client was invested in working actively towards therapy goals. It includes attitudes about treatment, bonding with providers and active participation (Cunningham 2009), and lack of engagement is seen as limiting gains, adjustment and quality of life (Medley & Powell 2010). Danzl et al., (2012, p35) stated: ‘Interventions cannot merely be applied to a patient; rather the individual needs to be engaged in the rehabilitation process’.

They claimed that applying principles of engagement can yield neuroplastic changes and improve functional outcomes.

Bains et al., (2007) considered whether engagement in ABI rehabilitation could be predicted by Johnston's 1997 interpretation of Ajzen's theory of planned behaviour (1988), which considered how cognitive processes underpin attitudes that influence health behaviours. Intention is the critical concept, which the model sees as due to attitude, beliefs about what is normal/acceptable, and the perception of how much control there is over behaviour. They states that 'no studies have investigated patients' expectations of ABI rehabilitation' up to that point, and questioned whether there is a link between beliefs about rehabilitation and engagement (p177). They also hypothesised that if the family believe in rehabilitation, the client will engage better, because of the need to meet the expectations of significant others.

Acknowledging that the clients were already in rehabilitation programmes at the time of the study, they stated 'future work needs to focus on predicting engagement in people who are new to rehabilitation' (p185). The study involved clinicians rating clients on a five point Likert scale, and admitted that this was not truly objective, as clinicians had formed and shared views about clients, and a single rating did not allow for variability between tasks and disciplines. However, therapy outcome belief was the only significant individual predictor of engagement, and Johnson's theory was not adequate to bridge the potential divide between intention and behaviour.

Lequerica and Kortte (2010) considered what leads people to engage with and benefit from rehabilitation. They see it as different from participation, which can be passive, and cite an educational psychology definition by Frydenberg et al., (2005), describing it as 'a multidimensional concept containing cognitive (striving to achieve), emotional (enjoyment of school activities) and behavioural (attendance) aspects' (Lequerica and Kortte 2010, p416). Based on this, they suggested a cognitive model of engagement, which linked perceived need (awareness of deficits and benefits of therapy) and perceived self-efficacy (awareness of ability and demands of therapy) to outcome expectancies. According to their model, if the outcome is seen as likely and valuable, and the person is willing to comply in order to achieve goals, there will be an intention to engage. Engagement is then maintained by analysing experiences and reassessing the beliefs.

8.3.2 Associated concepts

8.3.2.1 Engagement and motivation

A concept often related to engagement is motivation, which is also a complex construct, which seems to involve both internal and external determinants. The internal determinants include personality traits, the effects of the brain injury, and psychological adjustment; and the external would encompass rehabilitation environment, social support and the cultural context (Lequerica et al., 2006). Maclean and Pound (2000)'s critical review of the literature on motivation and physical rehabilitation found three approaches – viewing it as an internal personality trait, as a quality affected by social factors, and as a combination of the two. Lequerica and Kortte (2010, p417), again in line with Frydenberg et al., (2005,) described motivation as 'energy directed in a particular way, whereas engagement is that energy put into action' – that is, it is effortful.

In effect motivation is a pre-requisite for engagement but not sufficient. Motivation involves the desire to take action in order to achieve something and the person's own belief that the outcome is attainable (Chervinsky et al., 1998). However, engagement is by definition enacted, whereas motivation is the desire to take action. There is in the literature some confusion as to how the two terms are employed, and at times a lack of clarity about this distinction.

8.3.2.2 Readiness to engage

While readiness to engage has only recently been considered after ABI, it is a concept that has been studied in other areas, notably education and rehabilitation of offenders. In 2012, O'Callaghan et al., looked at insight and readiness affecting engagement after TBI, but acknowledged this was a new concept in brain injury research, despite being considered in chronic illness studies (e.g. Charmaz 1997). McMurran and Ward (2010) considered engagement of offenders in correctional contexts, and their work has interest in relation to ABI. Their starting point was the recognition that many offenders do not engage with psychotherapy, and the need to look at the factors that already exist and may predict engagement. They broadly define the construct of 'readiness to engage' as:

'the presence of characteristics (states or dispositions) within either the client or the therapeutic situation, which are likely to facilitate engagement in therapy.....to be ready for treatment implies that the person desires to alleviate their suffering, is able to respond appropriately to interventions, finds the treatment strategies offered

both relevant and meaningful (ie. can engage) and possesses the capabilities (ie. is able) to successfully enter the treatment programme.’ (p78).

Their Multifactor Offender Readiness Model (Ward et al., 2004) considers person factors (cognitive, affective, volitional, behavioural and identity) and contextual factors (circumstances, location, opportunities, resources, interpersonal supports and programme characteristics). It postulates that certain personal qualities and a supportive environment are prerequisites for people to be ready to change and engage with therapy. Similar factors have been listed in relation to hope and engagement after ABI, for example, Van den Broek (2005) suggested that the term ‘motivational readiness’ is considered prior to active rehabilitation and O’Callaghan et al., (2012) felt that clients who were aware and ready, were quick to engage with strategies and ideas. There is a ‘need to be mindful of making assumptions about an individual’s readiness for self-responsibility and insight into their problems’ (Jones 2006, p846).

A model intended to illustrate the use of motivational interviewing to promote engagement was suggested by Medley and Powell (2012), and of interest in relation to readiness for engagement is its explicit link to the influential change model of Prochaska and DiClemente (1982). Medley and Powell suggest the starting point is the therapeutic alliance, but the next stage is addressing issues relevant to the Pre-contemplation/Contemplation stage of change, which seems to be the same as ‘readiness’ and is used to develop self-awareness and prepare for action. It is only after this stage that goals are considered and engagement can occur.

Polaschek and Ross (2010) stated: ‘for many, a good therapeutic alliance with a client who is not yet ready to begin changing problematic behaviour is an oxymoron’ (p108) but went on to suggest that conflict will be inevitable if a therapist wants immediate engagement and the client is not ready. They suggested that goals and tasks can be specific to developing readiness, and that, as the alliance develops, the client can move from contemplation to preparation (Prochaska & DiClemente 1994).

8.3.3 Barriers to engagement

While lack of engagement is often seen after ABI (Lequerica et al., 2006, Chervinsky et al., 1998) and is cited as a reason for poorer functional outcomes and long term adjustment (Dixon et al., 2007, Ownsworth & McKenna 2004), and descriptions of the issues are

numerous, there is a relative paucity of research that addresses the question of engagement beyond mere description of the problem. The possible sequelae of brain injury include cognitive and neuro-behavioural impairments that can disrupt the ability to engage, which are both organic and psychological in nature.

Perhaps the most obvious such factor is lack of insight or self-awareness: if an individual has limited or no insight into the existence of a problem, there would be no inherent reason for that person to engage with therapeutic interventions (Medley & Powell 2010, Lequerica et al., 2006, Toglia & Kirk 2000). Studies showing that poor self-awareness also leads to poorer outcomes include Schonberger et al., (2006) and O'Callaghan (2006). O'Callaghan et al., (2012) note that 'being ready differs from being aware and being aware of impairments does not necessarily equate to being ready for therapy' (p1600).

Executive control function, metacognitive processes, and subjective beliefs are implicated in low insight (Medley & Powell 2010). It is difficult for clinicians to distinguish the influence of psychological denial (Ownsworth et al., 2002, Prigatano & Klonoff 1998) from organic impairments such as anosognosia (Kortte et al., 2003). Medley and Powell (2010) differentiate the therapeutic approaches to be taken if the primary cause is seen as neurological or psychological.

Apathy may also be a barrier. Mayo et al., (2009) found some degree of apathy was persistent and prevalent after stroke, and, while related to depression, is a distinct construct (Levy & Dubois 2006, van Reekum et al., 2005).

Lewandowski et al., (2011) considered engagement with psychotherapy, acknowledging both affective and cognitive aspects, and specifically addressed the way in which cognitive appraisal operates. When people presented with distorted beliefs – such as magnifying negatives and making global assumptions – unhelpful coping strategies resulted (e.g. oppositional styles, submissiveness) and influenced the level of involvement or engagement in therapy.

8.3.4 What contributes to engagement?

In the current study it is postulated that engagement, like hope, is affected by belief in recovery, belief in self-efficacy, and belief in others/rehabilitation. This model has been

described in chapter five. Huyser et al., (1997) lists factors thought to be relevant to adherence to a rehabilitation programme in fibromyalgia, as self-efficacy, outcome expectancies, depression/helplessness, therapy regimen characteristics, disease characteristics, and demographic variables. Choi and Twamley (2013) suggest that neural (compromised brain systems) and psychological factors (such as defeatist beliefs and hopelessness) both directly and indirectly (via multiply determined factors such as depression and denial) impact on adherence and engagement. The discussion that follows will focus on the beliefs that emerged from the interviews, but it is important to acknowledge the underlying effects of both neurological and psychological factors.

8.3.4.1 *Belief in recovery*

Belief in recovery, which may decline over time anyway, is not enough to ensure engagement. Maclean (2000) indicates that some people are not actively motivated as they believe that recovery is merely a matter of waiting. In order to engage people also need to believe that the actions of self and rehabilitation can help progress.

Approaching the question from a narrative stance, Bonds-Shapiro (2011, p20) states that the client's internal narrative is crucial – if their 'story' is that rehabilitation can help and recovery can continue, there is incentive fully to engage with the process: 'recovery is an engaged process' (p20). They emphasize that rehabilitation is hard work and requires a high level of motivation, an observation borne out by Linge's personal account (1990).

8.3.4.2 *Belief in Self/Personal factors*

Self-efficacy has been discussed, but there are other individual beliefs that impact on the process of engaging in rehabilitation, and influence behaviour, affect and cognition. It is seen as essential that the individual is the centre of intervention, and that the subjective meaning he or she attaches to activities and tasks is evaluated. Douglas (2010) goes so far as to claim that all intervention will fail if there is no meaningful engagement in chosen life activities, following Ylvisaker's work on identity mapping (2008). Plans need to take into account the client's level of cognitive and communicative ability – Silverman, for example, suggests an individualised (re-) engagement plan for people with aphasia (2011). Data in this study highlighted the desire for clear rationales for intervention. Horton et al., (2011) pick up this thread, suggesting strategies for promoting understanding of rationales, explaining and linking them to personal goals.

The level of participation and engagement in rehabilitation is difficult to define, as it is not as simple as mere attendance, but it may be possible to manipulate personal attitudes, emotional factors, understanding and motivation (Kortte et al., 2007). Kortte et al., (2009) looked at avoidance in relation to medical rehabilitation, noting that this can be a coping mechanism in adjusting to long term chronic conditions, but leads to poor outcomes. It can be manifest through active behaviours (such as self-harm, substance abuse, and avoidance of certain contexts) or passive, by dissociation or distraction.

Joe et al., (1998, 1999) considered engagement in drug abuse treatment, recognising that attendance, while a useful indicator (Fiorentine & Anglin 1997, Simpson et al., 1997) is only one aspect, and subjective cognitive involvement is also essential. They list the components of cognitive engagement as motivation, rapport/alliance, and efficacy. Treatment readiness was significantly related to both attendance (retention) and relational measures. In their model (Joe et al., 1999) treatment session attributes, such as frequency and topic content, interact with the cognitive components to determine engagement/retention. Interestingly, in the light of data in this study, they also indicate the role of background factors, including with demographic and psychological functioning, the impact of previous treatment: 'events very early in treatment have some effect on later outcomes' (p122).

The attitudes and beliefs people have on a deeper level may also affect how individuals approach tasks. Although this aspect seems to feature in educational research rather than in rehabilitation, there may be relevance to both fields. Dweck (1986) suggested a social-cognitive theory of motivation which postulated that underlying theories about intelligence as fixed or controllable determine how people approach learning and the nature of the goals that are adopted. Combined with effort and persistence, this determines achievement. In this model there are performance goals, which focus on external outcomes (such as grades or comparison with others) and mastery goals, which are about mastering a task and personal improvement. If people have the belief that intelligence is fixed, it is more likely that they will have performance goals, give up easily and avoid difficult tasks. At the other end of the continuum, believing that intelligence is incremental, people will adopt mastery goals, seek challenges and persist. Dupeyrat and Marine (2005) developed the theory and did indeed find that mastery goals were related to active engagement manifested in effort. They also suggested that intelligence is only part of broader epistemological beliefs about the nature of knowledge.

This was picked up by DeBacker and Crowson (2006), who considered the influence on cognitive engagement of epistemological beliefs and the need for closure. They felt that the former may create tendencies towards certain types of goals, so if a person believes that knowledge is simple, certain and fixed they are likely to have goals which are related to a specific performance task, rather than more general 'mastery' goals, and a high need for closure – to have an answer rather than ambiguity. The suggestion is that meaningful cognitive engagement is more likely if people have a lower need for predictability and order, seeing knowledge as complex, tentative and malleable. Interestingly for ABI rehabilitation, they stress that the need for closure can be increased when the cognitive load is increased.

8.3.4.3 Belief in Others/Rehabilitation factors

Clients need to believe that rehabilitation can help and the discussions on self-efficacy and hope indicate that the environment is important in fostering both. The rehabilitation environment, in its broad sense, interacts with internal resources in shaping a person's readiness to engage. Rath et al., (2011, p321) note the growing consensus that rehabilitation must 'address both objective cognitive deficits and subjective attitudinal, motivational and emotional factors (e.g. self-efficacy, confidence, self-esteem) in tandem'. McMillan (2013) argues for the importance of holistic rehabilitation to improve community re-integration and self-efficacy.

Danzl et al., (2012) describe the therapeutic relationship as important in engaging a client. They see optimal outcomes as stemming from a relationship in which both the client and clinician are invested in the process. In ABI rehabilitation the perceived need for therapy will depend on the degree of cognitive ability and insight. The quality of interactions with staff may work in a dynamic way, as Maclean et al., (2000) describe clients who are motivated as perceiving staff as encouraging and trustworthy, but lack of motivation is linked to feelings of being dominated. Adherence to treatment in general is common in health care, and multifactorial in nature, but there is a consistent sense that the characteristics of the treatment provider are important in terms of speciality/expertise, but also empathy, consistency and relational qualities (Clay & Hopps 2003).

The importance of the therapeutic relationship is apparent in a variety of contexts and settings, including forensic and educational. Polaschek and Ross (2010) found that it was the gradual development of the alliance over time that led to greater engagement and most change in violent psychopathic prisoners. In educational settings students who demonstrate

that they are trying are more likely to have positive relationships with teachers, than those who feel disengaged (Jennings & Greenburg 2008, Muller 2001). Van Uden et al., (2014) found that perceived teacher behaviour was the best predictor of student engagement on cognitive, behavioural and affective measures, and that teachers who behaved in a cooperative way but demonstrated authority enhanced engagement.

Labelling clients as not engaged can be counter-productive and influence interactions. Maclean et al., (2000, 2002) noted that patients classified as highly motivated were those who shared the professionals' aims and methods, and Pound and Ebrahim (1997) that decision making was influenced by the label given. The personality of both client and clinician will influence the interactions in therapy, and can bias judgements made by clinicians, but Lequerica et al., (2006) stress the need to separate likeability and engagement. Labelling a client as motivated or not can imply that the individual is responsible for outcomes, and lead to moralising by staff, who reward the right behaviour based on their own assumptions about what is appropriate (Maclean & Pound 2000, Kaufman & Becker 1986).

The relationship between the clinician and client may, by fostering compliance, be a barrier to enabling the client to be more reflective. Jones et al., (2013) suggest that over focusing on 'realistic SMART goals' may not encourage self-discovery.

Motivation is generally seen as important by rehabilitation staff (Maclean et al., 2002) but their views centred on two qualities – the patient's demeanour ('appropriate' behaviour) and patterns of compliance. Staff expected people to be proactive – but only in certain ways – a proactive refusal to perform a task was seen as a lack of motivation. Similarly compliance was desired, but being over-compliant was seen as a lack of intrinsic motivation. Sugavanam et al., (2013) did a systematic review of goal setting after stroke, with the explicit aim of recommending best practice. They state that professionals see goals as increasing motivation, but recognise a variety of barriers – most significantly communication or cognitive impairment.

The tripartite efficacy theory (Lent & Lopez 2002) described in chapter six, stresses relational aspects, and as such seems to have relevance in this study, and potential value in rehabilitation. It has been supported in sport, exercise and educational research (Dunlop et al., 2011, Jackson et al., 2007), but has not been considered specifically in brain injury rehabilitation. Jackson et al., (2012a) did consider the implications for engagement in physical rehabilitation, looking at adherence to physiotherapy exercises. They studied the

interplay and mutual influence of both participants in an interaction, and found links between a positive appraisal of the relationship and perceptions of the efficacy of self and other, and ratings of engagement. Jackson et al., (2012b) also studied school Physical Education, supporting the inter-relationship of the tripartite efficacy beliefs, and found them predictive of various behaviour outcomes, including engagement.

The engagement of staff may be as relevant as the engagement of clients in some instances, as the interaction has been seen to be hugely influential in developing hope and encouraging engagement. Pryor and Buzio (2010) found a significant improvement in the engagement of patients, when nursing staff felt engaged fully in a practice development project. Anderson and Marlett (2004) stress the importance of how staff communicate with clients, not just what they communicate, so that a problem centred focus is avoided, and a positive approach taken, to build hope and facilitate engagement.

Self-determination theory (Ryan & Deci 2000) suggests that people function best if their needs for autonomy, relatedness and competence are met. Klassen et al., (2012) looked at this in the teaching profession, and found that meeting these needs led to greater intrinsic motivation, mastery goals and engagement. The relatedness to students was more significant than to colleagues in determining engagement levels.

The expectations people have of rehabilitation may not be achieved, but both intervention and time may allow a gradual adjustment. Pouliquen et al., (2013) looked retrospectively at the initial records of people after TBI, and found more than half of these early expectations had no correspondence to eventual outcome. It may well be that disappointment with rehabilitation and recovery are significant factors in psychosocial difficulties (Gainotti & Marra 2002).

8.4 Linking Hope and engagement

The review of the literature on engagement has much in common with the research into the concept of hope in rehabilitation. Table 8:1 summarises this, by listing the factors identified in the literature that are thought to influence both concepts, taken from the preceding literature reviews.

As can be seen in the table, both constructs feature the three main areas identified in this study – self-efficacy, trust in rehabilitation, and belief in a desired outcome – that is, progress and/or recovery. This underlines the links between the two, although the constructs are considered distinct: hope in recovery can exist for example, without engaging with services.

It is apparent in this table that, in addition to the main categories, a number of the sub-categories discussed with the findings in chapter four are also represented, such as attitude, determination, information and social support. The literature highlights the importance within the field of acquired brain injury of cognitive abilities, particularly in relation to insight/self-awareness. It also suggests that hope (as opposed to state optimism) and engagement are context specific – as indeed is the constituent factor of self-efficacy, according to Bandura (1986), on whose work the concept is based.

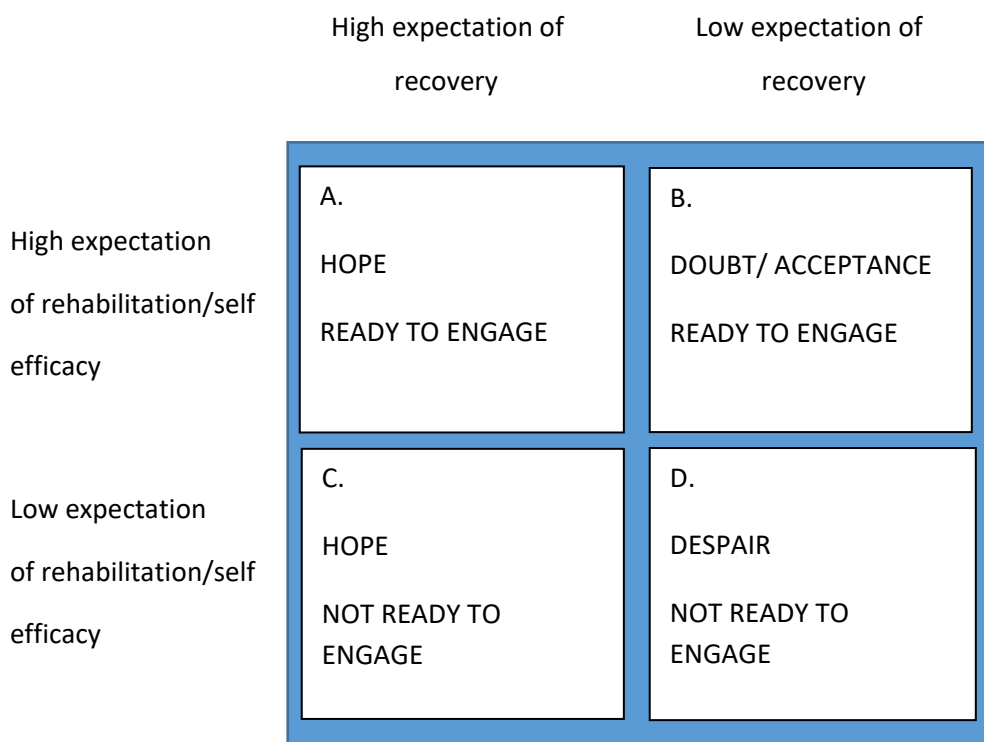
Table 8:1 Shared factors influencing hope and engagement

Factor categories	Factors affecting Hope and Engagement
Internal	<ul style="list-style-type: none"> • Self-efficacy • Personality • Attitude/determination • Cognitive abilities/insight • Being active • Goal setting/personal meaning
External	<ul style="list-style-type: none"> • Rehab/intervention & perceived benefits • Social connectedness • Information • Support networks
Desired outcome	<ul style="list-style-type: none"> • Belief in progress/recovery

8.5 Revisiting the model: Incorporating the literature

Taking into consideration the literature outlined in chapter six, and the research into engagement and this discussion on the similarities between the concepts in terms of underlying influences, the model seems to be well supported. However, the literature review did introduce a concept that may be a better 'fit' to the data, which is that of readiness to engage as opposed to engagement *per se*. The data was collected at a single point, as has been stated, which precedes actual involvement with the community rehabilitation service. It is therefore not perhaps justified to draw conclusions about engagement – although it would be perfectly possible to continue with the original model and undertake further research to see if it can predict engagement. It seems more helpful within the spirit of grounded theory to adjust the model to 'readiness to engage'. The two, as has been stated in the literature section, share common influences. Figure 8:4 therefore incorporates this revision.

Figure 8:3 Revised Engagement Model (2)



A further benefit of this adaptation is in relation to the implications for therapy, as it moves the focus to that of preparing the client whereas the term 'not engaged' has perhaps a more negative implication.

The findings of the staff focus group did not suggest changes to the models, but are highly relevant to the therapeutic implications. Similarly, while neither model attempts to illustrate the additional issues that may exist in this population that impact on rehabilitation – such as lack of insight/self-awareness - it is of course essential to consider these in interventions.

8.5.1 Implications of the Revised Engagement Model

The model implies that the expectations and beliefs that people hold about recovery, self-efficacy and other-efficacy (rehabilitation) will influence both the degree of hope people have and their readiness to engage in rehabilitation. If people have high expectations of recovery and also believe that self and rehabilitation can impact on that recovery, they will be ready to engage with rehabilitation. If they believe in recovery but not that self/rehabilitation can help, they will be hopeful but not ready to engage.

If there is low belief in potential for recovery, allied with a high belief that self/rehabilitation can still play a role, people may doubt full recovery or even accept that full recovery will not happen, but will still be ready to engage as they recognise improvement is possible. For those who believe that they will not recover and nothing they or others do will help, there will be despair and lack of readiness to engage.

It may be helpful to return to the original interviews to consider the revised model, shown in figure 8:4, and see if, in addition to explicating the combined data, it is useful in relation to individuals. To this end five case studies will be offered, using quotations from interviews to illustrate the four groups within the model. Group B will be illustrated by two clients – one who seems to doubt that he will fully recover and one who is accepting that he will never fully recover.

8.5.2 Case Studies

8.5.2.1 Group A: *Hoping and ready to engage (Simon)*

Simon is a married man in his 40s, who was in a road traffic accident and sustained a traumatic brain injury. He was in hospital for four days and then discharged into his wife's care at home, despite not being 'able to walk or talk properly'. Once at home he was not offered any support or rehabilitation, but he and his wife managed to access some support through Headway.

He is aware now that he has limitations, but recognises that his insight has been a problem and he has tried to return to activities too quickly, in the belief that he would have no difficulties. He has found the input from Headway useful as it has opened his eyes to his limitations and he has realised that recovery is slower than he thought.

Simon felt hopeful, at interview, that the rehabilitation centre is the right place to help him:

'It sounds like (it) is where I should have been from the start'

He desperately wants to prove to others that he is not 'skiving' but trying as hard as he can to recover, so going to rehabilitation means:

'I'm showing to my wife, my friends and my work that I'm doing everything humanly possible to get better as quick as I possibly can.'

He also feels that having professional rehabilitation is acceptable, and he does not feel shame as he does if he is doing exercises with his wife or friends.

In relation to his future expectations, Simon expects to return to how he was before, and to work, have a family, pay the mortgage and recover to his former level:

'I've never even entertained the thought otherwise 'cos why would you?'

'I'd be absolutely gutted if I didn't get one hundred percent better.'

'The thought's glanced in my head but never....I won't even consider it.'

Simon sees both value in rehabilitation and believes it can help, and also is clear that he wants to work hard – both to improve and also to prove to others that he is doing his best.

He continues to hope for a full recovery, and is determined not to consider any other option. He therefore seems to fit into the hoping and ready to engage group on the model.

8.5.2.2 Group B: Doubting but ready to engage (Andrew)

Andrew is in his 50s and lives with his partner. He had a stroke and following a lengthy period in hospital, then attended a residential centre before being discharged home. He has significant physical disabilities and aphasia, and for the latter reason his partner was present throughout the interview. He was motivated and was able to use a mixture of verbal and non-verbal behaviours to convey his message, with support from the interviewer and his partner, although occasionally some factual information was provided by his partner.

Andrew is able to recognise his limitations, and admits he expected to have made more progress by now, but also acknowledges some slow improvements. He attributes his ability to cope so far in part to his partner's support and to the fact that:

'I set myself goals and there's if I've got a...yeah that's...my....'

He sees himself as having a role in the process:

'I get myself better.....that's my role'

In relation to rehabilitation he sees it as:

'I'm thinking of the like – get you better as...you can and I can see my getting back to work as I have been at work and ...mean my life with what I can....you know drive the car...' 'it's getting me to walk forward that I...yeah getting me better.'

'I know that I most probably won't be able to get back but as much as I can I want to try.'

Asked directly if his approach to having rehabilitation was about hope, he replied:

'Yep it is. Yeah. Yep.'

Andrew seems to have hope that he will continue to recover but doubts that he will fully return to his former level of abilities and roles. He is prepared, for example, to adjust what work he does. He believes that rehabilitation can help him, and his experience is that he has made gradual if slow improvement through the process in residential care and hospital. He also has a sense of self-efficacy and sees himself as having a role in his own recovery. He seems to fit into the doubting but ready to engage group on the model.

8.5.2.3 Group B: Accepting and ready to engage (Harry)

Harry had encephalitis more than ten years ago. He ran his own business until then, but has been unable to work since as a result of cognitive impairments, fatigue, pain and personality change. He has low mood and anxiety, manifesting in increasingly severe OCD. He attended community rehabilitation ten years ago, and requested re-referral. He accepts that he will always be different:

'anybody who has a brain injury whatever may have caused it....them as a person are going to change afterwards.....you're the same but you're not the same.'

Harry's narrative of the progression of his initial illness, repeated testing and hospitalisations with little information or support reflects his sense of isolation at that time. He has a clear sense of his current limitations and difficulties. Since being discharged from rehabilitation, and as a result of intervention he received at the time, he has published an e-book and written poetry.

He acknowledges the support his wife has provided, especially in relation to his profound sense that other people are judging him. He also has adjusted his life to match his abilities and comfort level – for instance only going into known environments.

Harry is able to acknowledge the importance of finding an activity that has given him a sense of self-worth and the enormous effort it takes to continue with the activity:

'It doesn't matter if it takes you ten, twenty years...just try to do it.'

Support and encouragement from others was crucial, but he tries to write as if he was at a job, starting at eight or nine in the morning and writing all day.

'attempted to write a book which I did finish after years of doing it because I probably do about a page a week.'

He believes rehabilitation can help, but is clear that he doesn't expect it to 'cure' him:

'I see rehab as actually coping – helping to cope with who you've become rather than who you were. That would be my perception.'

'I had no delusions of recovery, I just wanted to function better'

'I don't expect a miracle cure but...guidance I suppose is the word.'

'It can make a difference because it can teach you to survive on a day to day basis but apart from that it can also give you an understanding....and it can break down the feeling of it just being you....the isolation of it...'

Harry expects to play a part in rehabilitation, but his words suggest he sees himself as a more passive recipient:

'my role is to take whatever I can from it that'll make my life a little bit better at the end of it.....to take out of it what I can.'

However he goes on to say:

'I suppose I have to be honest and say how I'm feeling and if things are too much or I can't cope with situations then I have to say that....so honesty probably.'

Some positives are apparent to Harry – as well as his achievement writing, he believes he has a closer bond with his children because he has been at home with them rather than working all the time.

Asked how he views the future, he replies:

'I have a little bit of hope, because I hope something will come of the writing....have some recognition for it, because that then gives a little bit of self-worth.'

Harry accepts what has happened to him and that he will not recover or ever be the person he was before. Even though he sees his role in rehabilitation as a recipient, his descriptions of his activities and efforts, especially in writing his book, suggest that he has self-efficacy, to the extent that he has overcome not only the impact of his brain injury but also pre-morbid dyslexia, and persisted despite the lengthy effort required. Indeed he is able to recognise that he would never have attempted a book if he had not become ill:

'I never would have thought of doing before I was ill'.

In addition he requested re-referral so was active in wanting to engage with the process. He believes that rehabilitation can help. In summary he appears to have self-efficacy and believe rehabilitation can help, and – while not expecting to fully recover – he does believe he can be helped to cope better.

Harry seems to fit into the Doubt/Accept, but ready to engage with rehabilitation group.

8.5.2.4 Group C: Hoping but not ready to engage (Shirley)

Shirley is a woman in her 50s, who worked in health care. She was involved in a road traffic accident, in which she received multiple physical injuries in addition to a traumatic brain injury. She has no memory of the accident and was extremely confused when in hospital and remembers this period with great distress and fear. While in a coma she was aware of her children saying goodbye to her, having been told she would not survive, and felt that if she slept she would not wake up. She felt neglected and uninformed. Despite repeatedly asking if she could talk to a counsellor, this was not provided.

Shirley has worked very hard on her own recovery, both physically and in relation to her memory and communication. To recover her reading ability, for example, she is using her granddaughter's school books and is improving her speech. She has double vision and is carefully following exercises recommended by her doctor. However she feels that her children should not need to look after her, and that she should still be caring for them. She expresses hope in relation to her own efforts:

'I would hope to be able to improve my physical ability. I would hope to be able to improve my memory...and just....hope to improve my life.'

Her experience of rehabilitation in hospital was mixed. She was grateful to a physiotherapy student who had given her time and information, but she felt that the SLTs were just following a form:

'young girls came and asked me a variety of questions but that was all...and it was just printed on pieces of paper – they weren't really using their brains – they were just reading and writing...and I don't think they were interested at all.'

In relation to rehabilitation subsequently, she sees it as getting back to normal, but says:

'I don't think I actually need that. I think I'm fairly normal you know. I understand what I need to do.'

When contacted by the rehabilitation service, she was fearful that they would take over and it would not be her decision to stay or leave, even though she accepted that people were positive about the service.

'I feel as if they are in charge and I've got to do whatever they want me to do....what I think doesn't matter'.

She explicitly links her bad experiences in hospital to her current fears and concerns about being controlled and abandoned, without the ability to escape from the situation.

Asked about the future, she has mixed feelings:

'Well I don't actually have very much of a future. I've got life because the hospital gave me that, but I can't really...unless I can improve myself and get myself back then I can only be a problem to people.'....'there are things to look forward to – as long as I can get better.'

'there is a meaning to life and it's through my grandchildren and my family.'

'I hope that I will recover completely.'

Shirley seems to have a strong sense of self-efficacy – she believes that she can improve through her own efforts – but does not feel she needs rehabilitation. She hopes for full recovery, but seems to place the responsibility for this upon herself, and there is an implication that her future depends on continued progress. In relation to the model, Shirley seems to be hopeful in that recovery will continue, but, while she believes she can work hard to help herself, she does not believe that rehabilitation is essential to this. Her fears from the hospital experiences may be a factor, as she explicitly acknowledges that she is frightened to attend further institutions as she believes she will lose control of her life again. She seems to fit into the hoping but not being ready to engage group.

8.5.2.5 Group D: Despairing and not ready to engage (Billie)

Billie was an active woman in her 60s when she had a stroke, a year ago. Since retiring she had kept busy with voluntary and cultural activities. She had had no rehabilitation or support since leaving hospital after only three days. Having agreed to be interviewed, she became tearful within minutes, and was unable to respond to questions about what had happened to her. She indicated she wanted me to continue when I offered to switch off the recorder, but immediately following the interview she said that she had suicidal thoughts. All her energies had been put into trying to disguise these feelings, even from her family, and she appeared exhausted. She wanted to let me know how high functioning she had been prior to her stroke, and how deeply her confidence had been affected by the stroke. She focused on her mood throughout the interview, and made comparisons with how she had been

before. She felt that others judged her as having no difficulties because she looks fine physically.

She had no knowledge of stroke before this.

Billie could see that she had recovered well physically, and felt that her need was mostly in relation to psychological help – what she called mental health. She acknowledged that her cognitive capabilities had been affected but that the extent was hidden by her depression. She thought that SLT might be useful but did not identify any other additional needs. Initially she had assumed that she would just get better:

'I still felt that perhaps I'd get better'.....'And well I haven't so.....'

At first she did not recognise her mood, but it has gradually worsened over time, despite taking a low dose of anti-depressants. It seemed important to her that the depression was seen as due to the stroke and not to an innate weakness, and therefore she did not feel that counsellors who did not understand stroke would be able to help. She seemed to feel guilty that she was affecting her husband:

'I feel very sorry for my husband. I think I'm a lot quieter than I used to be...oh dear....'

Her only use of the term hope in any form was:

'there're psychologists so ...um....hopefully people who could help me (cries)'

She expressed doubts that she would recover her confidence:

'I think my husband probably thinks that it's a confidence thing really....and I don't...I don't know....well....I don't know if I'll get that back.'

When asked if she wanted to get involved with activities again, her response was:

'Well I haven't got the ability.....haven't got the ability.'

Asked directly if she had any expectation that rehabilitation could help she replied:

'I haven't given it much thought...haven't given that much thought.'

Asked how she saw the future, she replied:

'I'm a bit bleak really.'.....'I don't know if I'll get that back. I don't know.....a bit bleak really.'

Billie expressed no indication that she felt she could play any active role in her own recovery, said she had not thought about whether rehabilitation could help and her sense of the future was bleak. Other than one suggestion that psychology might be able to help, she appeared to have no hope. This was reinforced by her expression, after the recorder was turned off, of suicidal ideation. Interestingly she also appeared to think that there was no point in raising the dose of anti-depressants, confirming the sense that she did not believe that any intervention could really be of benefit.

Billie seemed to be on the despairing end of the spectrum, with no belief that she or rehabilitation could have an impact, or that she would improve. This places her in the despair and not ready to engage with rehabilitation group.

8.5.2.6 Summary of case studies

Returning to the original data is a valuable exercise in itself, as it serves as a check that individuals have not been lost in the analysis process. The quotations given seem to evidence the appropriateness of the model. As the interviews were prior to the rehabilitation service being involved, the model appears to offer a prediction as to whether each person was or was not ready to engage at that point. It would be interesting to test the predictions against their actual engagement in the service in future research.

8.5 Revisiting the model: staff views

8.6.1 Expectations within rehabilitation

The hypothesis is that the model presented in figure 8:4 could be useful in predicting readiness to engage with rehabilitation, prior to the process beginning, based on the individual's beliefs and perceptions about recovery, their own efficacy and the value of rehabilitation, mediated through hope.

If this is so then the obvious question is whether clinical interventions might be helpful specifically for those who are not ready to engage. Clinical interventions depend not only on the client, however, but also on the Therapists and the environment. This section of the discussion will consider the specific expectations within rehabilitation that clients expressed in their interviews and clinicians in their focus group.

Despite often claiming at first that they had no expectations in relation to services, clients, as has been seen in chapter four, expect both expertise and a good therapeutic relationship. The former is illustrated by the desire for timeliness of intervention, guidance, a clear rationale and information provision. In relation to the relationship, they want to feel the Therapists are trustworthy, listen to/allow the client a voice, show respect and caring, encourage and are honest. They also see a role in supporting their families and care-givers.

In chapter seven the responses of Therapists, (bearing in mind the focus group involved specialist staff), did not differ markedly, even if terminology differed. They too made reference both to the expertise and the relational aspects of rehabilitation. In the former timeliness was again mentioned, as was information giving, and a high quality, bespoke therapeutic programme. The relationship was given high priority, and 'keeping hope alive' was important. Family support was seen as an important aspect of care.

Clients and Therapists had expectations of the client's own role that again corresponded well. Both groups acknowledged the importance of taking some responsibility (termed self-managing by staff and having control by clients). Both expected that Therapists should be honest and that they should be trusted, although clients wanted choice as to which advice to follow rather than blind acceptance. Trying hard and engaging with rehabilitation was highlighted by both, with Therapists noting that they expected clients to prioritise rehabilitation. Clients wanted a positive approach from rehabilitation providers, and this reflects the literature on balancing positivity to encourage hope.

This comparison has already been made in chapter seven, but is important as it suggests that there is a basic shared sense of what ideal rehabilitation should be like, in a general way. There were differences in specifics, due at least in part to levels of knowledge, such as the roles of individual disciplines.

Combining the level of agreement about what **should** happen with the impact of early experiences in hospital is pertinent. Clients who had these expectations met – that is, that they received timely and expert care, and experienced good therapeutic relationships – are perhaps more likely to be ready to engage fully with community rehabilitation after discharge from the acute sector. Those clients whose expectations were not met, which seemed to happen more in terms of the therapeutic alliance, were less motivated to engage. The case studies presented illustrate this – Shirley is negative about her early experiences and seems negative about engaging, while Harry, with good experience in the past, is ready

to engage even though his expectations for improvement are limited. This links to the review of literature described in chapter six, which consistently returns to the importance of the therapeutic alliance. In the focus group, staff expressed the belief that it was their responsibility to ensure the relationship fostered rehabilitation efforts.

8.6.2 Expectations of recovery

The comparison of client and therapist views about recovery suggests less agreement. Most clients at this stage in their trajectory still had some degree of hope that they would get 'back to normal', while staff expected improvement but not full recovery. While both groups saw time as crucial, staff had a significant focus on the nature of the brain injury, its site and severity, to which clients rarely alluded.

However, both groups talked about pre-morbid factors, such as life context and social support, and about the personal resources needed by the client. Those mentioned by both were the person's past sense of self, determination and motivation, and their roles and responsibilities. These seem to relate to the literature on self-efficacy discussed in chapter six. Clients, but not therapists, often referred to the idea of being a burden and being judged both by self and by others.

Beliefs as to the efficacy and value of rehabilitation varied. In the focus group there was a sense that staff believed that rehabilitation could make a difference, but with the implication that this would depend ultimately on the brain injury – there would be people who, for example, would not recover enough cognitively to manage without support – and, sometimes, on co-morbidities, either psychological (such as substance abuse) or physical. Staff also acknowledged the importance of the social situation and support, again implying that these may limit the ability of rehabilitation to be effective.

Interestingly in relation to the literature and potential for staff to make assumptions or be judgemental about clients, there was a strong sense that it was important that clients were determined and motivated, took some personal responsibility, tried hard and trusted the therapists. Such 'ideal clients', almost by definition, will be engaged, but there will be other clients perhaps who – as the model suggests – are not ready to engage. Staff did acknowledge the central importance of cognition in this, and recognised that some clients cannot respond to rehabilitation in this ideal way.

If clients and therapists, prior to rehabilitation beginning, are broadly in agreement about what rehabilitation should look like in practice, based on verbal opinions, the question remains as to whether this is borne out in actions. The issue of whether what is said in interview does reflect actual behaviour is a difficult area to address, as is recognised frequently in qualitative research literature.

8.7 Implications for clinical practice

The objective of this study was to develop a framework or model, upon which changes to practice could be based. As has already been stated, such changes would need to be evaluated prior to recommending widespread adoption, but this section will offer suggestions that are logical in the light of this model, and – by implication – reflect the subjective perceptions of clients, the views of staff, and the literature. It will support and develop the suggestions by considering relevant literature.

Before summarising the implications for practice drawn from the current research, it is worth briefly considering relevant literature, with reference to the findings. The implications for practice will be discussed in two broad areas of general relevance - philosophical issues and therapy factors (the relationship and specialist knowledge and skills). This will be followed by more specific suggestions in relation to raising hope and developing readiness to engage.

Finally a summary draws together the threads from the research and the literature. It is important to be able to justify clinical practice through having a clear philosophy of care, and a model or framework for intervention, and the summary will be based on the revised model of engagement illustrated in figure 8:3, and discussed earlier in this chapter.

8.7.1 The philosophy of rehabilitation

There has been a tension between the traditional medical model and the social model within rehabilitation over recent years. The literature cited in this chapter suggests that there is still a tendency for professionals to assume they know best in practice. The starting point for change in practice is reflection at both individual and service levels, not just in terms of specific techniques and evidence based interventions, but in considering the meaning of these to the client. This means reflecting on whether paternalistic (or ‘benign dictator’)

assumptions are being made that professionals know best, and accepting the potential tensions and lack of comfort that will follow if staff genuinely move towards 'reluctant democracy' (Norris & Kilbride 2014).

The clients in this study seem, with few exceptions, willing to share responsibility, both acknowledging their own role and being prepared to trust and work with the rehabilitation team. The challenge is to maintain this balance through the underlying philosophy that the client's subjective experience is paramount, and not implicitly or explicitly fostering the sense that the 'staff know best'. One way in which this is manifest often is in the long-standing debate between so-called 'realistic' and 'unrealistic' hope – terms employed exclusively by professionals.

Faircloth et al., (2004) suggest 'presenting an outlook for a patient's future in ways that the patient anchors everyday life may produce better outcomes than the reliance on professional rhetoric' (p410), and Bluvol and Ford-Gilboe (2004) urge clinicians to focus on strengths and achievements in order to foster hope. Wiles et al., (2008) warn that there are many views on what is realistic, and question whether professionals have the expert knowledge to make such judgements, and Elliott and Olver (2002) also question the objectivity of such judgements. Clinical practice changes are not easy to instigate, especially in relation to an area such as engagement which is difficult to measure and monitor. It requires the whole service to buy into the necessary beliefs and re-prioritise – for example devoting time specifically to the therapeutic relationship, rather than seeing it as something that 'just happens'. In the study referenced above, Norris and Kilbride (2014) interviewed stroke therapists, and found normal practice to be a 'benign dictatorship' in which therapists were most comfortable when in control despite having some concerns about power imbalance. The move to a 'reluctant democracy' was accompanied by fears of losing control, doing nothing, and taking risks, causing tension in balancing professional judgements and clients' wishes. Clinical change requires readiness to engage in both clients and professionals.

8.7.2 Therapy Factors

The client interviews, literature review and professional focus group findings all stress the importance of the therapeutic alliance or relationship. In the interviews, there are several examples of situations in which participants felt that they had been denied a voice or been

the subject of unthinking application of protocols or techniques. These illustrate how important it is to pay attention to the relational aspects of care. The relational aspects have been discussed in relation to hope and engagement.

However, of equal importance is the need to demonstrate professional specialist knowledge and skill. There is an expectation, from clients and professionals, that staff will know about the specific issues arising from ABI. While specific techniques and approaches are outside the scope of this chapter, it may be that specific interventions are required that address the individual's underlying cognitive issues in order to allow a broader engagement with rehabilitation, such as focusing on insight or apathy. Clearly engagement is affected by insight and the literature covers a range of interventions that seek to address this, via individualised work based on the particular combination of neurological and psychological factors (Medley & Powell 2010, Fleming & Ownsworth 2006, Lucas & Fleming 2005). Biderman et al., (2006) emphasize the need to consider reconstitution of self-identity and meaning alongside improved insight. Mayo et al., (2009) suggest that it may not be necessary fully to disentangle the psychological and neurological routes of fatigue, mood, and apathy, but to focus on emotional resources.

In addition to the therapeutic techniques, the importance of providing information in a way that has meaning to the client is highlighted throughout the study, which means considering not just what information is given but how, and evaluating its impact on the individual client.

8.7.3 Clinical implications/Hope

The assessment of hope is difficult both because of the complexity of hope as a construct, but also because of the specific characteristics of acquired brain injury, which may, for example, include fatigue, limited attention, low self-awareness/insight, and communication impairment. Farran et al., (1995) note the importance of the therapeutic relationship, and the need to encourage the person to tell his or her story. Observation, interview and a variety of scales may be used (e.g. Lopez et al., 2000) but there is no generally accepted measure, in part because of the diverse models upon which scales may be based.

Farran et al., (1995) states: 'When persons present symptoms of non-hope or hopelessness...we are challenged to intervene in ways not demanded when hope is present.' (p24). The attributes of hope identified by Farran et al., (1995) are the basis for their clinical

interventions – experiential (identifying and sustaining the areas of hope in the person’s life); relational (the importance of connectedness); spiritual (providing time and opportunity to reflect and find purpose); and rational. This last attribute looks at goals, resources, action, control and time.

Snyder et al., (2002), offer a comprehensive approach based in Hope Theory, with suggestions relating to goals, pathways, and agency. In relation to goal setting:

- Consider whether goals are congruent with values, although Snyder and Rand (2000) point out the danger of judging others’ goals without knowing their subjective beliefs.
- Help clients establish goals that match skills.
- Determine whether goals are central to self-concept.
- Assess attainability against effort required and past experiences.
- Consider goals in different areas to spread the chance of success.
- Consider priorities and incompatibilities between goals.
- Have concrete and specific goals, even if only in the sub-steps required, as abstracts can be difficult to monitor

In addition they consider the pathways or means of attaining the goals:

- Ensure the means and methods are congruent with values and quality of life.
- Match the means to skills.
- Think about how long goals will take – people with high hope will often set an alternative, while low hope people become stuck and ruminate.
- Consider allowing the client to follow a path that professionals may feel is doomed to failure, as trial and error can be a way to raise hope through self-correction and feedback.

They believe agency can be helped through psychological intervention, including listening and caring, social support networks and relationships, guidance on understanding goals and skills, and increasing activities that promote positive thinking and hope, such as physical exercise. Gum and Snyder (2002) add to these suggestions in a subsequent paper based upon working with terminally ill patients.

Snyder's approach acknowledges self-efficacy ideas, and Dorsett (2010) also stresses the need to develop this clinically, as well as considering meaning, self-esteem, problem solving and management of physical issues. Acknowledging the clinical tension in relation to realistic or unrealistic hope, he suggests that if a client asks if there is hope, the clinician should enquire 'For what are you hoping?' and be led by the client. Svendsen and Teasdale (2006) looked at the benefits of neuropsychological rehabilitation after ABI, and found that rehabilitation did increase self-efficacy, as well as lowering symptoms of anxiety and depression.

The findings of this study described in chapter four were that hope plays a central role and is a critical factor at the point of interview – that is, as clients prepare for rehabilitation, and – based on the literature - probably at all stages in the rehabilitation process.

8.7.4 Clinical implications/Readiness to engage

The work with offenders undertaken by McMurrin and Ward (2010) led them to argue the need for theoretical and empirical models, robust assessment tools for readiness and engagement, development of pre-therapy preparation interventions to promote engagement, and strategies to address barriers to engagement. Intervention is three stranded – modifying the environment, the programme and the offender/client. This broad model appears to have much to offer for work with people following ABI.

There have been attempts to develop measures of engagement, using observational, self report and single item scales, such as the Occupational Therapy Task Observation Scale (Margolis et al., 1996), the Motivation for TBI Rehabilitation Questionnaire (Chevinsky et al., 1998) and the Pittsburg Rehabilitation Participation Scale (Lenze et al., 2004) respectively. The Rehabilitation Engagement Scale (RTES) (Lequerica et al., 2006) was an attempt to quantify engagement based on ratings by professionals (OTs and Physiotherapists).

Bains et al., (2007) suggest that labelling clients as unmotivated or not engaged may affect staff attitudes and behaviour, and stress the need for a theoretical model to formulate lack of engagement. It may be necessary for rehabilitation to incorporate a motivational phase in which attitudes and intentions can be addressed, followed by the volitional phase of active rehabilitation. Preparatory information on the purpose and philosophy of rehabilitation and opportunity to explore the meaning each client attaches to the ABI, may be helpful in

'altering patients' perspectives and beliefs'. Mixed messages and conflicting information – described by participants in this study – had a negative effect on motivation.

Also linking the concepts of motivation and engagement is the work of Medley and Powell (2012) who make a strong case for the value of motivational interviewing, acknowledging the importance of the therapeutic relationship in engagement and participation. Developing the therapeutic relationship may help engagement, so time needs to be invested in building rapport and trust, communication and motivational interviewing, client education and understanding, and empowerment (Danzl et al., 2012). Motivational interviewing has been found to have value in relation to alcohol and substance abuse after ABI (Bombardier & Rimmel 1999), quality of life (Bell et al., 2005) and mood (Watkins et al., 2007).

The model proposed by Medley and Powell (2010) was described earlier, but is worth mentioning here, as it makes explicit the process from therapeutic alliance, to preparation/development of self-awareness, to active rehabilitation (e.g. goal setting) which is when engagement is possible and self-efficacy grows.

Cognitive Behavioural Therapy has been used to address 'cognitive distortions' in a variety of client groups, including people who have early Alzheimer's Disease and Schizophrenia, to address defeatist attitudes and hopelessness (Choi & Twamley 2013, Choi et al., 2010). Kortte et al., (2007) suggest a number of interventions that might target rehabilitation engagement levels, including supporting attendance, prompting, positive attitude, acknowledging benefits of rehabilitation, and active participation. In the 2010 paper, written with Lequerica, they suggest designing interventions to address cognitive issues that affect motivation and engagement, such as starting with simple tasks to help low self-efficacy and modification of the environment to support distractible clients. Lewandowski et al., (2011) discuss the value of learning more about how cognitive appraisal affects engagement, with the implication that cognitive therapies could be useful in facilitating the process.

If an individual is not ready to engage, it may be that the timing of intervention needs to be considered. This has obvious cost implications, and may not fit the established modes of service provision. Either techniques are needed that facilitate earlier intervention, or it may be that a break from formal rehabilitation is used, with appropriate supports in place, to determine if insight develops (O'Callaghan et al., 2012). There may also be occasions when a different service or one discipline within a team adopts the primary role, for example in the

case of severe depression, when medication or specific psychotherapeutic interventions are required before other aspects of rehabilitation can be considered.

Specific therapeutic focus on self-efficacy is also recommended by an increasing number of practitioners and researchers, and is seen as important in relation to effective self-management (Jones et al., 2008). Self-management has been the focus of considerable interest as it could have personal, service and economic benefits (Boger et al., 2013, Harwood et al., 2012). Jones and Riazi (2011) undertook a systematic review of papers addressing self-efficacy and self-management after stroke, noting the four main sources – in line with Bandura (1989) - as mastery experiences, vicarious experience, verbal persuasion and physiological feedback. However, self-management is not synonymous with self-efficacy, and – while it becomes increasingly important as rehabilitation progresses - at this post-acute stage of community rehabilitation it is not the primary consideration. The relevance here is that building self-efficacy at this stage, will potentially have a long term benefit.

Lent and Lopez (2002) suggest exploring the ‘value of helpers intentionally conveying positive yet realistic efficacy-related messages to clients’ (p280) as people often enter treatment feeling de-moralised and unable to assume control. This extends, they argue, outside therapy settings, and they advise considering the relation-inferred self-efficacy beliefs (RISE) perceptions with significant others.

8.7.5 Applying the research findings: a summary of therapeutic implications

The objective of this study was to develop a framework from which therapeutic implications could be made, to improve engagement with rehabilitation after ABI. The resultant model has been described, and relevant literature in the areas of the therapeutic relationship, therapy factors, developing hope and increasing readiness to engage have been discussed. How, then, can this broad discussion link to actual practice?

Firstly, there is a need for services to reflect on their philosophy of rehabilitation, and specifically to consider whether the stated philosophy is seen in practice. Alongside this is the need to place as high an emphasis on the therapeutic relationship, as on clinical techniques. This is not presented as an easy process, as it is recognised that there will be differing views in many aspects of rehabilitation between individuals and between

professional groups. An example might be the question of ‘false hope’ which is likely to remain a controversial area within the rehabilitation world. Another area of reflection is in considering, in supervision or another reflective forum, what beliefs are held by individual clinicians and how these may be transmitted to clients inadvertently. Other aspects are looking at the assumptions made about shared understanding of terminology, and listening to the meaning goals hold for clients.

In applying the model illustrated in figure 8:4 it is interesting to consider whether a similar construct could apply to staff. If, for example, a therapist (or team) views a client as insightful, motivated and positive, with no critical organic barrier to improvement; believes in the ability of rehabilitation to effect change in that client; **and** expects them to improve, will the therapist/team be more hopeful and more engaged, and manifest different interaction behaviours that perpetuate in turn the client’s hope/engagement. Certainly some of the literature in the field of education, and specifically the tripartite efficacy model described earlier, might indicate this is an area worthy of further study.

Secondly, on initial assessment, when a client comes into a service, his or her subjective beliefs should be sought, specifically on what they expect in terms of recovery, their own role and efficacy, and the efficacy of the rehabilitation service. It is outside the scope of this study to offer in any detail the method by which this might be achieved, but it may be possible to employ a simple rating scale. If the model is valid, the prediction is that this process will indicate which clients are ready to engage. The dynamic nature of the beliefs must be considered throughout the process of engagement, so it is important to monitor over time. For example, if a person perceives their progress has stalled or slowed, their belief in ultimate recovery may change, affecting their engagement at any point in the process.

Depending on the interplay of the three beliefs some clients will be ready to engage with normal evidence based practice within rehabilitation. Those clients who are not ready to engage would be offered appropriate intervention – within the context of a good therapeutic relationship – to raise their sense of self-efficacy, or address their beliefs about recovery and rehabilitation. The effect of this would be, according to the model, not only to prepare people to engage, but also to raise hope.

Approaches and techniques may include psycho-education (acknowledging the lack of knowledge people have prior to their brain injury); pacing of intervention (clients who are despairing or who lack insight may need time to adjust); and psychological therapies such as

Cognitive-Behavioural Therapy and Motivational Interviewing. Hope may be specifically targeted in line with Snyder's (2000) theory, considering goals, pathways and agency, which in practice seem very much related to the development of self-efficacy and the need for clinicians to consider the subjective meaning of goals for clients. It is predicted that raising hope will raise engagement potential, as well as vice versa.

8.8 Chapter Summary

This chapter has revisited the model developed from interview data, in the light of relevant literature, case studies and staff focus group views. The revised model provides a framework for considering appropriate interventions at the point of entering community rehabilitation. It is recommended that clinicians and services reflect on their underlying philosophy of care, and specifically upon the balance of power. The therapeutic relationship is critical to any intervention, and needs to be given appropriate focus.

Evaluation of clients' expectations of recovery, self, and rehabilitation will indicate where clients are on the hope-despair continuum, and determine the need for hope-building interventions. The same considerations apply to the question of readiness to engage, and whether time needs to be spent on addressing this prior to more traditional rehabilitation.

If those clients who lack hope and/or are not ready to engage can be enabled and prepared for rehabilitation, the evidence suggests that better outcomes will follow. Chapter nine will consider the limitations of the current study and consider the quality of the research, in order to evaluate whether the findings and conclusions drawn have merit, and will suggest future avenues of research.

Chapter Nine: Conclusion

9.1 Introduction

The original study objectives and aims were to gain greater understanding of the client's perspective and expectations of rehabilitation prior to engaging in community rehabilitation, and to develop a framework or model upon which to justify clinical decisions and interventions, and improve service delivery. Subsequently an additional aim was introduced, as it was recognised that the views of clinicians also need to be taken into account, rather than making assumptions about their beliefs and expectations.

In this final concluding chapter it will be argued that the aims have been met, and that logical and coherent suggestions have been made for clinical practice. It is outside the scope of this research to evaluate these suggestions, but this would be the necessary next step. In order to illustrate the clinical implications the revised model in chapter eight will be used to discuss what therapeutic interventions may be appropriate.

The limitations of this research and an appraisal of quality issues will be discussed and future research avenues considered.

9.2 Clinical implications

It is apparent that not all the recommendations made are new or innovative – it has long been recognised that the therapeutic relationship is crucial, for example, and goal setting practice is often in line with the hope building suggestions of Snyder et al., (2002). What this study does offer, however, is a coherent model upon which to base recommendations and practice, enabling a clear rationale. It introduces the element of preparing people for rehabilitation as a distinct stage in the process, rather than dismissing those clients who do not engage as unable to benefit from rehabilitation. Central to the recommendations is the need to consider the clinician's beliefs alongside those of the client, and the importance of these beliefs to the experience of hope.

In chapter eight, the model was illustrated in relation to five case studies taken from the data. Relevant literature was discussed in considering what clinical and therapeutic

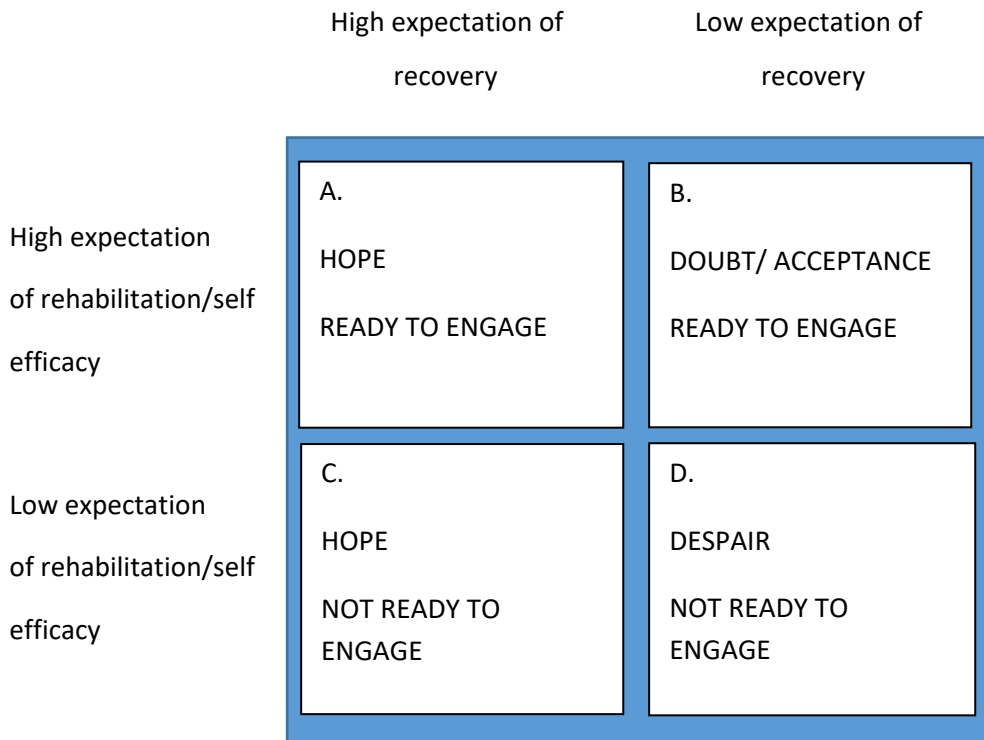
implications may be appropriate. In order to address this further, clinical interventions that may benefit the four combinations of belief in recovery and in self/others efficacy/impact potential will be described. The model is shown again in figure 9:1 to facilitate the discussion.

It is important to acknowledge that this study focuses on participants at a single point in time, but that hope and engagement – as has been seen in the literature review – are not static qualities, and therefore clients may move between groups as rehabilitation progresses. It is postulated that this will depend on a mix of internal and external factors, and critically upon the meeting of expectations over time.

The first group (A) is of people who have a high expectation of recovery and of self/other efficacy, and as a result demonstrate high hope and readiness to engage. The implication is that this group is able to engage straight away with the rehabilitation programme. The importance of developing a therapeutic alliance and considering the balance of power between client and clinician is still critical. The implied risk in this group is that the expectation of full recovery will change over time, potentially leading to adjustment of expectations in which case there would be a move to group B, or to a loss of confidence and hope, leading to despair. The clinical imperative in this group is to maintain hope and engagement, but support adjustment via ensuring goals have meaning for the client. It is this group and group C, that are the focus of the controversial clinical debate discussed in chapter six, as to what is 'realistic hope', and the literature suggests that clinicians need to reflect on their own philosophy and belief systems in making judgements. It may be better to accept the client's hopes but work, as Snyder et al., suggest (2002) on gradual steps, and not to take the paternalist view that clinicians know what is or is not appropriate.

In group B people have a high expectation that the mix of rehabilitation and their own efforts will have an impact, but are either accepting that recovery will be limited or at least doubting that full recovery will result. The belief in self/others will mean that there is readiness to engage. This is the group with which clinicians may well feel most comfortable, as they are able to engage and willing to work hard, but also accept that they will not fully recover, fitting the clinicians' own beliefs about recovery. There is still some degree of hope, but it is for improvement rather than full recovery.

Figure 9:1 Revised Engagement Model (2)



The third group (C) retain hope that they will recover fully, but do not believe that this will happen as a result of their own or others' efforts, but will be an inevitable process over time. As there is no sense that effort is required, there is unlikely to be engagement in traditional rehabilitation programmes. This may be a result of lack of insight and a failure to appreciate their impairments and limitations, but can also occur with insight. If the issue is lack of insight, the implication from the discussion in chapter eight is that this group may benefit from intervention specifically aimed at preparation to engage, either by working on insight directly or by allowing 'safe failure', to develop insight by learning from experience. If people have insight into their limitations, but believe that time is all that is necessary to recover, there may be value in psycho-education and other approaches to develop readiness to

engage. As has been stated, the issue of ‘false hope’ or ‘realistic hope’ is relevant in this group.

The final group D has no hope of recovery, and sees no value in any intervention or personal effort. The implication is that the despair needs to be addressed before expecting engagement in formal rehabilitation. This may – if there is a clinical depression or mental health issue – take the form of medication or psychotherapy/counselling. Depression itself alters thinking patterns and leads to cognitive appraisals that are distorted and negative, further impeding engagement. However, this may not be due to depression per se, but to a rational understanding that recovery cannot be expected. The value of psycho-education, cognitive behavioural therapy and motivational interviewing has been discussed in chapter eight, and can be used to address thought patterns. Hope therapy, as suggested by Snyder, can be used to encourage positive appraisals and increase self-efficacy.

Clinicians and clients, as has been seen in the findings of the interviews and focus group, share many beliefs, but not all. Most significantly there is a difference in what ‘recovery’ means, and a tendency for clinicians to evaluate clients’ beliefs not from the client’s perspective and the meaning they have for that individual, but from a ‘benign dictator’ viewpoint (Norris & Kilbride 2014). Taylor and White (2000) draw attention to the importance of considering the tacit assumptions made in clinical practice, and not simply the way in which tasks are performed. Chapter eight argues the need for open and reflective debate about therapists’ philosophical and epistemological beliefs, in order to align more with the beliefs of clients and their families.

9.3 Limitations of the study

It is essential to acknowledge the limitations of this study. The context is a single location, with particular geographical, demographic and clinical characteristics. Notably there is little ethnic diversity in the population studied. Although it is accepted that qualitative research ‘does not produce findings that are necessarily generalizable’ (Wiles et al., 2002, p849), it is important to consider the context in relation to the transferability of findings.

The recruitment procedure depended upon the Rehabilitation Team Coordinators, who acted as gate-keepers, and invited people at screening to participate in the research. It is not known if all potential candidates were approached or how many (and for what reasons)

refused to take part at this stage in the process. The main exclusion criterion was that people could not be approached if there was any doubt as to mental capacity, which could have excluded those with very severe cognitive limitations.

As recruitment was based upon meeting referral criteria for the service, there was no attempt to differentiate the experiences of people with different types of ABI, or based on severity or demographic factors (such as age or gender). It may be that the experience of ABI and expectations vary as a result of such factors. In addition the service is highly specialist and one of the criteria for acceptance is that people have a level of complexity in their presentation and needs.

The focus group used to explore the views of clinicians, was also service based and, as such, only included clinicians who were experienced and specialist in the field of ABI. It could be postulated that less experienced therapists, or those outside the field of ABI, would have different beliefs and expectations.

The dual role of the researcher has been discussed and made explicit, but could be considered a point of potential bias or influence. Apart from a second researcher being invited to comment on the logic and appropriateness of the exploratory phase analysis, there were practical issues in this research (funding, timescales) that did not allow the involvement of additional researchers in data collection, analysis and interpretation.

9.4 Quality Evaluation

The Critical Appraisal Skills Programme (CASP) exists to encourage effective evaluation of the quality and trustworthiness of published research, and has been used to evaluate the quality of articles, in systematic reviews (e.g. Satink et al., 2013, Duggleby et al., 2012, Wiles et al., 2002). Indeed Wiles et al., (2002) comment that the 'CASP tool is a high benchmark' for quality evaluation (p566). The approach consists of three steps, asking if the study is valid, what the results are, and if the results are useful. In relation to qualitative research ten questions are suggested, which have been designed to enable explicit, systematic evaluation. These questions will be considered here, in relation to this study, in order to appraise the quality of the research.

9.4.1 Was there a clear statement of the aims of the research? The aims and goals of the research were introduced in chapter one, and have been referenced throughout. The relevance and importance of the study to clinical practice has been highlighted.

9.4.2 Is a qualitative methodology appropriate? Chapters two and three discuss in detail the decisions and rationale for choosing a qualitative approach. The focus is on the subjective experiences of research participants, and the stated aim is to increase understanding of their experiences and perceptions. The reasons for the methodological decisions taken were logically described in the sequence in which they were addressed – from ontological and epistemological considerations, to the choice of a qualitative approach and specifically grounded theory. The epistemology, methodology and method are internally consistent (Carter & Little 2007).

9.4.3 Was the research design appropriate to address the aims of the research? The specific decisions taken in designing the research have been described and explained in detail – the underlying theoretical basis for decisions was introduced in chapter two and the specific design in chapter three.

9.4.4 Was the recruitment strategy appropriate to the aims of the research? The sampling and recruitment strategies were clearly explained, with rationales, and the process of selection described fully. The participants were the most suitable to provide access to the information and knowledge sought, as they had all experienced an acquired brain injury and were at the appropriate stage in the care pathway – that is, between discharge from the acute service but prior to starting community based therapy. People with communication and cognitive impairments were accepted, as long as they had mental capacity, to ensure that their views were represented. The decision to include people with communicative and cognitive impairments was discussed and a clear rationale provided. While many studies exclude people who cannot easily take part in a verbal interview, strategies were put in place to ensure their views could be communicated. The reasons why some people did not choose to take part, after information was provided, were discussed in chapter four, and illustrated in tabular form.

9.4.5 Was the data collected in a way that addressed the research issue? Decisions regarding the approach that would be taken in data collection were explained, and the adoption of grounded theory principles suited the research issue – namely to gain greater understanding of people's perceptions and expectations, and to develop a model upon which

to base clinical suggestions. The setting for data collection was described and justified, and it is clear how data at each stage was collected. The process was summarised in diagrammatic form in chapter eight, with the interviews, literature searches and focus group explained at appropriate points. The methods chosen were justified and made explicit in the descriptions in chapters two and three – for example, the use of semi-structured interviews – and topic/questions guides are offered in the appendix. Methods were checked and tested in an exploratory phase, and any amendments and modifications have been explained and discussed. The form of data – audio recordings, transcriptions and field notes – has been described, and saturation of the data discussed.

9.4.6 *Has the relationship between researcher and participants been adequately considered?* Willig (2008) differentiates between personal and epistemological reflexivity, and both have been addressed in this study. Chapter two explains from a theoretical perspective that reflexivity is critical in contributing to the quality of qualitative research, influencing, for example, transferability, and recognising that findings are co-constructed (Jootun et al., 2009, Yardley 2008). Chapter three describes the personal characteristics and beliefs of the researcher, paying particular attention to areas of potential conflict, influence or bias, such as the dual role of researcher and clinician. Considerable attention has been paid to the question of the researcher/participant relationship, and to illustrate this reflections of early interviews have been included in the appendices. It is clear that the research questions were formulated as a result of the researcher's clinical role and that this had potential to impact on the participants, and that the researcher's personal characteristics and experience needed to be considered carefully.

9.4.7 *Have ethical issues been taken into consideration?* Clearly the research was approved by the necessary ethical committees, and there is within the text detailed explanation of how the research was presented to participants, recognising the special ethical issues in research involving people who have had brain injuries. Information was available in standard and adapted format, in order to meet the needs of people who had communicative or cognitive impairments, and these are in the appendices. In addition, as a second check, a questionnaire was presented to ensure that the participants had fully understood the information, which is also in the appendices. The question of informed consent prior to the interviews or participation in the focus group, was explicitly discussed, but in addition the researcher responded when issues were raised through the process of

interviewing. In illustration the researcher's actions when a client expressed suicidal ideation and when clients asked clinically relevant questions were described.

9.4.8 Was the data analysis sufficiently rigorous? Qualitative research must be rigorous, and this necessitates a clear, transparent and systematic design (Meyrick 2006, Pope & Mays 2000). Validity is supported by detailed description of method, reflexivity and attention to negative cases. Reliability is based in a clear audit trail. Chapter two offers a discussion of broad quality issues and summarises various criteria for evaluating qualitative research, which seem to have in common that they recognise the need for explicit methods, contextual information, attention to contradictory cases, reflexivity and enough original data in the report to justify the interpretation offered (Collingridge & Gantt 2008, Kuper et al., 2008, Jootun et al., 1999).

The analysis process was described and examples provided in chapter three, and – as outlined in the text - a second researcher was invited to evaluate the process after the exploratory phase interviews, in order to judge the appropriateness and logic of the analysis. It is acknowledged that chapter four is lengthy, but this was a deliberate decision so that the choice of categories (and subsequent modelling) could be illustrated with direct quotations from participants. The importance of presenting enough data in each category cannot be overstated. There were examples of contradictory data, and categories and models evolved to take such information into account – chapter five describes the evolution of the model as data emerged. The sampling decision not to exclude people referred to the service (other than on mental capacity for ethical reasons) meant that one re-referral was included. This single case appeared to be an exception, and led to the 'Acceptance' category being incorporated into the final model. Throughout the analysis care was taken to consider the researcher's interaction with the data, in order to minimise bias.

9.4.9 Is there a clear statement of findings? The findings are made explicit in tabular form, prior to the detailed explanations and illustrations, in chapter four and in chapter seven. The literature – in line with qualitative methodology – has been explored after the initial analysis and modelling, in order to minimise the risk of prejudicing the analytic process, but the discussion of the literature offered evidence in relation to the researcher's arguments. While there are practical difficulties in establishing the credibility of findings inherent in a PhD project that limit the feasibility of having additional researchers involved to consider the raw data or to separate the data collection and analysis, the use of a second researcher to assess

the analysis of the exploratory phase, and the drawing in of evidence from a variety of sources – interview, literature and clinicians’ focus group – do contribute to the credibility of the study. The findings are discussed in relation to the original research question.

9.4.10 How valuable is the research? There was, from the original conception of this study, a desire to contribute to improving clinical practice with this population, based on better understanding of the client’s perspective and the findings have been discussed in relation to the implications for clinical practice. The suggestions for clinical interventions fit logically with the model presented in chapter eight and earlier in this chapter, but it is made clear that there needs to be further evaluation in order to assess the value of such an approach in practice. The description of the context of this research enables readers to consider the transferability of the findings, and the limitations of the study have been discussed in relation to the specificity of the population researched. Notably, for example, the participants do not exemplify the ethnic mix found in many clinical services, and it would be necessary to consider the applicability of the model in other populations within Acquired Brain Injury services. Furthermore, the grounded theory approach seeks to generate models of wide applicability, and it is believed that further study may indicate that the model has broad relevance in looking at engagement in other areas of health care.

9.5 Future Research

The research has generated numerous areas for future consideration. Some of these link to the limitations of the study discussed earlier, and extending transferability; some to the applicability of the model more widely; and some to the evaluation of recommendations made. In addition, the single participant interviewed some years post-onset suggests the importance of time in longer term recovery. A final critical area for study is in relation to the expectations of carers and families.

9.5.1 Transferability

It would be interesting to consider the expectations and perceptions of people with ABI from a more diverse ethnic mix or in a more urban environment, and to explore whether there is variability of expectations resulting from factors such as type of injury, severity and social-demographic aspects.

In relation to training and development of staff, it would be valuable to consider the views of clinicians who are not experienced or specialist in this area, and undertake comparisons both with the staff group in this study and client views.

9.5.2 Evaluation of the model

The single interview is not seen as a limitation of the study as it was a necessary element of the design, as expectations prior to assessment were sought, and expectations would have been altered had clients been interviewed later. However, it would have been interesting to be able to return to the participants at the completion of the programme, in order to see if the model was supported.

Research in other locations in which ABI rehabilitation is undertaken could evaluate the applicability of the model further, but the model holds promise in other areas as well as ABI. In line with the original precepts of grounded theory, this model is suggested as a formative one, needing research to consider if it fits widely enough to develop into a substantive model of engagement.

One possible approach, if evaluation of the model was within the service described in this thesis, would be to develop a mixed method study. Simple rating scales for each of the three factors identified in the model – belief in recovery, belief in self and belief in rehabilitation – could be developed, which clients could be asked to complete as part of the existing assessment process in the service. A three monthly review process already operates, so these measures could be repeated at regular intervals and at discharge from the service. This would allow predictions of engagement level to be made using the model. Ratings of engagement, made by both client and clinician, could be taken and compared to the predictions. It would be important to ensure that the clinicians involved with individual clients were blinded to the belief ratings made, and that the research is not conducted by a member of the clinical team. Quantitative, statistical analysis would establish whether the predictions were associated with the engagement ratings. Qualitative data would be a valuable aspect of such a study, and could include information about the clinical practices employed with people who fall into each of the four groups in the model.

9.5.3 Evaluation of clinical recommendations/implications

In chapter eight, and earlier in this chapter, various recommendations for clinical practice have been made. Those specifically related to and derived from the model need to be

evaluated, to assess whether clients can be better supported to engage with rehabilitation and whether, as a result, outcomes improve. In the evidence based and financially motivated world of health care in which services operate, evaluation of the benefits in cost terms would be important.

9.5.4 Time in Long Term Recovery

The participants in this study were interviewed at a single time point, as has been described, and for the purpose of this study that was a valid methodology to employ. However, the inclusion of a re-referred client some years post-onset, does raise the question of how time *per se* affects people's perceptions and expectations. It would be interesting to undertake a longitudinal study to learn more about how expectations change, and what factors, including time, influence the development of acceptance.

9.5.5 Expectations of carers/families

This study initially focused on the expectations of clients, and subsequently also considered the expectations of clinicians, recognising their importance in the process of engaging clients in rehabilitation. However, there is a third group that have a crucial role in this process – the carers and families. Throughout this study, although not the focus of it, reference has been made to the importance of social support and the influence of others outside rehabilitation. Research into the expectations and hopes of this group would also be important. Matching client, carer and clinician expectations may be an unachievable goal, but bringing them together as much as possible for each individual case is crucial, and depends on increased knowledge of carers' perspectives.

9.6 Summary

This thesis began with Mary, the client who acted as the catalyst for this research. It seems appropriate to conclude with her, as a representative of the ABI population. Mary had little hope for recovery or that her own or others' efforts could help her situation, and was not engaging with the rehabilitation process. According to the model developed in this study she would have fallen into the despairing group.

The recommendation from the model would be to address her expectations and explore her beliefs, in order to understand her perspective, and then to employ a specific approach and techniques to increase her sense of self-efficacy and other-efficacy, instil hope and prepare her for engagement with the more formal rehabilitation programme. The effectiveness of the approach would depend on clinicians' readiness to question and reflect on their practice and assumptions, the development of effective therapeutic relationships, and appropriate assessment and intervention to move towards engagement. Support at service level is also needed to give the necessary time and attention to this preparatory stage.

It is hoped that this research has contributed to a deeper understanding of clients' perspectives and beliefs, provided a useful and relevant model upon which to base intervention, and that it will ultimately improve the quality of life of people who have experienced the profound trauma of acquired brain injury.

References

- Ackerman, S.J., & Hilsenroth, M.J. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review*. 23, 1-33.
- Ajzen, I. (1988). *Attitudes, Personality and Behaviour*. Chicago: Dorsey Press.
- Alaszewski, A., Alaszewski, H., & Potter, J. (2004). The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation*. 26(18), 1067-1078.
- Alaszewski, A., Alaszewski, H., & Potter, J. (2006). Risk, uncertainty and life threatening trauma: analysing stroke survivors' accounts of life after stroke. *Forum Qualitative Social Research*. 7(1).
- Aleligay, A., Worrall, L. E., & Rose, T. A. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*. 22(4), 383-407.
- Anderson, R. (1993). *The aftermath of stroke: the experience of patients and their families*. Cambridge: Cambridge University Press.
- Anderson, S., Marlett, N.J. (2004). The language of recovery: How effective communication of information is crucial to restructuring post-stroke life. *Topics Stroke Rehabilitation*. 11(4), 55-67.
- Andersson, S., & Fridlund, B. (2002). The aphasic person's views of the encounter with other people: a grounded theory analysis. *Journal Psychiatric and Mental Health Nursing*. 9, 285-292.
- Appelbaum, P. S. & Grisso, T. (1988). Assessing patients' capacities to consent to treatment. *New England Journal of Medicine*. 319, 1635-1637.
- Arendell, T. (1997). Reflections on the researcher – researched relationship: a woman interviewing men. *Qualitative sociology*. 20, 341-368.

Arnaert,A., Filteau, N., & Sourial, R. (2006). Stroke patients in the acute care phase: role of hope in self-healing. *Holistic Nursing Practice*. 20, 137-146.

Ashworth, P. (2008). Conceptual foundations of qualitative research. In J.A.Smith (Ed). *Qualitative Psychology: a Practical Guide to Research Methods*. Pp 4-25.

Australian Dept of Human services and Health. (1994). *The National Policy on services for people with ABI*. ADHSH.

Bachelor, A. (1995). Clients' Perception of the Therapeutic Alliance: a qualitative analysis. *Journal of Counselling Psychology*. 42(3), 323-337.

Bains, B., Powell, T., & Lorenc, L. (2007). An exploratory study of mental representations for rehabilitation based upon the Theory of Planned Behaviour. *Neuropsychological Rehabilitation*. 17(2), 174-191.

Bandura, A. (1986). *Social foundations of thought and action: a social cognitive theory*. Englewood Cliffs NJ: Prentice hall

Bandura, A. (1989). Human Agency in Social Cognitive Theory. *American Psychologist*. 44(9), Sept, 1175-1184.

Barker, R.N., & Brauer, S.G. (2005). Upper Limb recovery after stroke: the stroke survivors' perspective. *Disability and Rehabilitation*. 27, 1213-1223.

Barry, J.R., Dunteman, G.H., & Webb, M.W. (1968). Personality and motivation in rehabilitation *Journal of Counselling Psychology*. 15(3), 237-244.

Bays, C.L. (2001). Older adults' descriptions of hope after a stroke. *Rehabilitation Nursing*. 26(1), 18-27.

Beck, A.T., Steer, R.A., Kovacs, M., & Garrison, B. (1985). Hopelessness and eventual suicide: a ten year prospective study of patients hospitalised with suicidal ideation. *American Journal Psychiatry*. 142, 559-563.

Beck, A.T., Brown, G., Berchick, R.J., Stewart, B.L., & Steer, R.A. (1990). Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *American Journal Psychiatry*. 147(2), 190-195.

Beck, J.S. (1995). *Cognitive Therapy: Basics and Beyond*. NY: Guilford Press.

- Becker, G., & Kaufman, S. (1995). Managing an uncertain illness trajectory after stroke: Patients and physicians views of stroke. *Medical Anthropology Quarterly*. 9, 165-187.
- Bell, K.R., Temkin, N.R., Essleman, P.C., Doctor, J.N., Bombardier, C.H., Fraser, R.T., et al.,. (2005). The effect of a scheduled telephone intervention on outcome after moderate to severe TBI: a randomised trial. *Archives Physical Medicine Rehabilitation*. 86, 851-856.
- Bendz, M. (2000). Rules of relevance after a stroke. *Social Science and Medicine*. 51, 713-723.
- Bendz, M. (2003). The first year of rehabilitation after a stroke – from two perspectives. *Scandinavian Journal Caring Sciences*. 17, 215-111.
- Biderman, D., Daniels-Zide, E., Reyes, A., & Marks, B. (2006). Ego-identity – can it be reconstituted after a brain injury? *International Journal Psychology*. 41(5), 355-361.
- Bloch, E. (1970). Man as possibility. In W.H. Capps (Ed). *The future of hope – essays by Bloch, Fackenheim, Moltman, Metz and Capps*. Ch2. Fortress Press: Philadelphia.
- Bluvol, A., & Ford-Gilboe, M. (2004). Hope, health work and quality of life in families of stroke survivors. *Journal Advanced Nursing*. 48(4), 322-332.
- Boger, E.J., Demain, S., & Latter, S. (2013). Self-management: a systematic review of outcome measures adopted in self-management interventions for stroke. *Disability and Rehabilitation*. 35(16-17), 1415-1428.
- Bombardier, C.H., & Rimmel, C.T. (1999). Motivational interviewing to prevent alcohol abuse after TBI: a case series. *Rehabilitation Psychology*. 44(1), 52-67.
- Bonds Shapiro, A. (2011). A story to create: Stroke survivors' narratives. *Topics Stroke Rehabilitation*. 18(1), 18-23.
- Bordin, E.S. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research and Practice*. 16(3), 252-260.
- Brady-Wagner, L. C. (2003). Clinical ethics in the context of Language and Cognitive Impairment: Rights and Protections. *Seminars in Speech and Language*. 24 (4), 275-284.

Brands, I.M.H., Wade, D.T., Stapert, S.Z., & van Heugten, C.M. (2012.) The adaptation process following acute onset disability: an interactive two-dimensional approach to acquired brain injury. *Clinical Rehabilitation*. 26(9), 840-852.

Braunack-Mayer, A. & Hersh, D. (2001). An Ethical Voice in the Silence of Aphasia: Judging Understanding and Consent in People with Aphasia. *The Journal of Clinical Ethics*. 12(4), Winter, 388-396.

Brennan, A. D., Worrall, L. E., & McKenna, K. T. (2005). The relationship between specific features of aphasia friendly material and comprehension of written material for people with aphasia: an exploratory study. *Aphasiology*. 19(8), 693-711.

Bright, F.A.S., Kayes, N.M., McCann, C.M., & McPherson, K.M. (2013). Hope in people with aphasia. *Aphasiology*. 27(1), 41-58.

Bright, F.A.S., Kayes, N.M., McCann, C.M., & McPherson, K.M. (2011). Understanding hope after stroke: a systematic review of the literature using concept analysis. *Topics Stroke Rehabilitation*. 18(5), 490-508.

Britten, N. (2006). Qualitative interviews. In C. Pope & N. Mays (Eds). *Qualitative research in Health Care*. London: BMJ Books/Blackwell. pp. 12-20.

Britten, N. & Fisher, B. (1993). Qualitative Research and General Practice: editorial. *British Journal of General Practice*. 43, 270-271.

Bronstein, K.S. (1991). Psychosocial components in stroke – implications for adaptation. *Nursing clinics of North America*. 26, 1007-1017.

Brown, C., & Lloyd, K. (2001). Qualitative methods in psychiatric research. *Advances in Psychiatric Treatment*. 7, 350-356.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success – an insider perspective on living successfully with aphasia. *Aphasiology*. 24, 1267-1295.

Bryman, A. (1988). *Quantity and Quality in Social Research*. NY: Routledge.

Bryman, A. & Burgess, R. G. (1994). Reflections on Qualitative Data Analysis. In A. Bryman & R. G. Burgess (Eds). *Analysing Qualitative Data*. NY: Routledge. Pp 216-226.

- Burton, C. (2000). Living with stroke: a phenomenological study. *Journal of Advanced Nursing*. 32(2), 301-309.
- Cant, R. (1997). Rehabilitation following a stroke: a participant perspective. *Disability and Rehabilitation*. 19(7), 297-304.
- Carifo, J., & Rhodes, L. (2002). Construct validities and empirical relationships between optimism, hope, self-efficacy and locus of control. *Work*. 19, 12-136.
- Carlsson, G.E., Moller, A., & Blomstrand, C. (2004.) A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in persons over 75 years. *Disability and Rehabilitation*. 26(23), 1373-1380.
- Carlsson, G.E., Moller, A., & Blomstrand, C. (2009). Managing an everyday life of uncertainty – a qualitative study of coping in persons with mild stroke. *Disability and Rehabilitation*. 31(10), 773-782.
- Carroll, L.J., Cassidy, J.D., Holm, L., Kraus, J., & Coronado, V.G. (2004). Methodological issues and research recommendations for mild traumatic brain injury: the WHO Collaborating Task Force on Mild TBI. *Journal Rehabilitation Medicine*. 43, Suppl, 113-125.
- Carter, B.S., Buckley, D., Ferraro, R., Rordorf, G., & Ogilvy, C.S. (2000). Factors associated with reintegration to normal living after sub-arachnoid haemorrhage. *Neurosurgery*. 46(6), 1326-1334.
- Carter, S. M. & Little, M. (2007). Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qualitative Health Research*. 17(10), 1316-1328.
- Charmaz, K. (1990). 'Discovering' Chronic Illness: Using Grounded Theory. *Social science and Medicine*. 30(11), 1161-72.
- Charmaz, K. (1991). Translating graduate qualitative methods into undergraduate teaching: Intensive interviewing as a case example. *Teaching Sociology*. 19, 384-395.
- Charmaz, K. (1995). Grounded Theory. In J. A. Smith, R. Harre, L. Van Langerhove (Eds). *Rethinking methods in Psychology*. London: Sage. 27-49.

Charmaz, K. (1997). *Good days, bad days: the self in chronic illness and time*. New Brunswick NJ: Rutgers University Press.

Charmaz, K. (2000). Grounded Theory: Objectivist and Constructivist Methods. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp. 509-535.

Charmaz, K. (2004). Premises, Principles & Practices in Qualitative Research: Revisiting the Foundations. *Qualitative Health Research*. 14(7), 976-993.

Charmaz K (2006) *Constructing Grounded Theory : a practical guide through qualitative analysis* London: Sage

Cheavens, J. (2000). Hope and depression: light through the shadows. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 321-339.

Cheavens, J., & Gum, A. (2000). Gray power: hope for the ages. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. pp 201-220.

Chervinsky, A.B., Ommaya, A.K., deJonge, M., Spector, J., Schwab, K., & Salazar, A.M. (1998). Motivation for traumatic brain injury rehabilitation questionnaire (MOT-Q): Reliability, Factor analysis, and relationship to MMPI-2 variables. *Archives of Clinical Neuropsychology*. 13(5), 433-446.

Chiovitti, R.F., & Piran, N. (2003). Rigour and grounded theory research. *Journal Advanced Nursing*. 44(4), 427-435.

Choi, J., Fiszdon, J.M., & Medelia, A. (2010). Expectancy value theory in persistence of learning effects in schizophrenia: role of task value and perceived competency. *Schizophrenia Bulletin*. 36, 957-965.

Choi, J., & Twamley, E.W. (2013). Cognitive rehabilitation therapies for Alzheimer's Disease: A review of methods to improve treatment engagement and self-efficacy. *Neuropsychological Review*. 23, 48-62.

- Cicerone, K.D., Mott, T., Azulay, J.A., & Friel, J. (2004). Community integration and satisfaction with functioning after intensive cognitive rehabilitation for TBI. *Archives Physical Medicine Rehabilitation*. 85, 1643-1650.
- Clark, P. (2003). Towards a greater understanding of the experience of stroke: Integrating quantitative and qualitative methods. *Journal of Aging Studies*. 17, 171-187.
- Clarke, A. (2005). *Situational Analysis : Grounded Theory after the Post-Modern turn*. Thousand Oaks, CA: Sage.
- Clarke, P., & Black, S.E. (2005). Quality of life following stroke: negotiating disability, identity and resources. *Journal of Applied Gerontology*. 24(4), 319-336.
- Clay, D.L., & Hopps, J.A. (2003). Treatment adherence in rehabilitation: The role of Treatment Accommodation. *Rehabilitation Psychology*, 48(3), 215-219.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: complimentary research strategies*. Thousand Oaks CA: Sage Pub.
- Collingridge, D. S. & Gantt, E. E. (2008). The quality of Qualitative Research. *American Journal of Medical Quality*. 23(5), 389-395.
- Conneeley, A.L. (2003). Quality of life and traumatic brain injury: a one-year longitudinal qualitative study. *British Journal Occupational therapy*. 66(10), 440-446.
- Coyne, I. T. (1997). Sampling in qualitative research: purposeful and theoretical sampling, merging or clear boundaries? *Journal of Advanced Nursing*. 26, 623-630.
- Crisp, R. (1993). Personal responses to traumatic brain injury: a qualitative study. *Disability, Handicap and Society*. 8(4), 393-404.
- Critical Appraisal Skills Programme (CASP). (1998). Ten questions to help you make sense of qualitative research. <http://www.casp-uk.net/index.aspx?o=1152> . downloaded Sept 2014.
- Cross, A., & Schnieder, M. (2010.) A preliminary qualitative analysis of the impact of hope on stroke recovery in women. *Topics Stroke Rehabilitation*. 17(6), 484-495.
- Cruice, M., Hill, R., Worrall, L., & Hickson, L. (2010). Conceptualising quality of life for older people with aphasia. *Aphasiology*. 24(3), 327-347.

Cunningham, W., Duffee, D., & Huang, Y. (2009). On the meaning and the measurement of engagement in youth residential treatment centres. *Research Social Work Practice*. 19(1), 63-77.

Dalemans, R. J. P., Wade, D., Van den Heuvel, W., & De Witte, L. (2009). Facilitating the participation of people with aphasia in research: a description of strategies. *Clinical Rehab*. 23, 948-959.

Dalemans, R.J.P., de Witte, L., Wade, D., & van den Heuvel, W. (2010). Social participation through the eyes of people with aphasia. *International Journal Language and Communication Disorders*. 45(5), 537-550.

Dale Stone, S. (2005). Reactions to invisible disability: The experience of young women survivors of haemorrhagic stroke. *Disability and Rehabilitation*. 27(6), 293-304.

Daly, J., MacDonald, I., Willis, E., & Silverman, D. (1992). Applying the qualitative research method to clinical care. In J. Daly, I. MacDonald, E. Willis (Eds). *Researching Health Care: designs, dilemmas, disciplines*. London: Tavistock/Routledge. Pp 176-188.

Danzl, M.M., Etter, N.M., Andreatta, R.D., & Kitzman, P.H. (2012). Facilitating neurorehabilitation through principles of engagement. *Journal Allied Health*. 41(1), 35-40.

Darragh, A.R., Sample, P.L., & Kreiger, S.R. (2001). "Tears in my eyes 'cause someone finally understood": Client perceptions of practitioners following brain injury. *American Journal of Occupational Therapy*. 55(2), 191-199.

DeBacker, T.K., & Crowson, H.M, (2006). Influences on cognitive engagement: Epistemological beliefs and need for closure. *British Journal of educational Psychology*. 76, 535-551.

Denzin, N. K. & Lincoln, Y. S. (2000). Introduction : the discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 1-29.

Department of Health. (2010). *The NHS Constitution*. UK:Crown

Department of Health. (2007). *National Stroke Strategy*. DoH Pub.

- Dey, I. (1999). *Grounding Grounded Theory: Guidelines for Qualitative Inquiry*. San Diego CA: Academic Press.
- Dixon, G., Thornton, E., & Young, C.A. (2007). *Perceptions of self-efficacy and rehabilitation among neurologically disabled adults*. *Clinical rehabilitation*. 21, 230-240.
- Dixon Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Qual. Saf. Health Care*. 13, 223-225.
- Dolittle, N.D. (1992). The experience of recovery following lacunar stroke. *Rehabilitation Nursing*. 17(3), 122-125.
- Dombovy, M.L. (2004). Understanding stroke recovery and rehabilitation: Current and emerging approaches. *Current Neurology and Neurosurgery Reports*. 4, 31-35.
- Dorsett, P. (2010). The importance of hope in coping with severe acquired disability. *Australian Social Work*. 63(1), 83-102.
- Douglas, J. (2010). Placing brain injury rehabilitation in the context of the self and meaningful engagement. *Seminars in Speech and Language*. 31, 197-204.
- Dowswell, G., Dowswell, T., Lawler, J., Green, J., & Young, J. (2002). Patients' and Caregivers' expectations and experiences of a physiotherapy intervention one year following stroke: a qualitative study. *Journal of Evaluation in Clinical Practice*. 8(3), 361-365.
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*. 9, 507-515.
- Draucker, C. B.; Martsof, D. S. ; Ross, R., & Rusk, T. B. (2007). Theoretical sampling and category development in grounded theory. *Qualitative Health Research*. 17(8), 1137-1148.
- Dufault, K., & Martocchio, B.C. (1985). Hope: its spheres and dimensions. *Nursing Clinics of North America*. 20, 379-391.
- Duggleby, W., Hicks, D., Nikolaichuk, C., Holtslander, L., Williams, A., Chambers, T., & Eby, J. (2012). Hope, older adults and chronic illness: a metasynthesis of qualitative research. *Journal of Advanced Nursing*. 68(6), 1211-1223.
- Duncan, G. J. (2008). When to promote, and when to avoid, a population perspective. *Demography*. 45(4), 763-784.

Dunlop, W.L., Beatty, D.L., & Beauchamp, M.R. (2011). Examining the influence of other-efficacy and self-efficacy in personal performance. *Journal Sport and Exercise Psychology*. 33, 586-593.

Dunn, S.L., Stommel, M., Corser, W.D., & Holmes-Rovner, M. (2009.) Hopelessness and its effect on cardiac rehabilitation exercise participation following hospitalisation for acute coronary syndrome. *Journal Cardiopulmonary Rehabilitation & Prevention*. 29, 32-39.

Dunne, C. (2010). The place of the literature review in grounded theory research. *International Journal Social Research Methodology*. 14(2), 111-124.

Dupeyrat, C., & Marine, C. (2005). Implicit theories of intelligence, goal orientation, cognitive engagement, and achievement: A test of Dweck's model with returning to school adults. *Contemporary Educational Psychology*. 30, 43-59.

Dweck, C.S. (1986). Motivational Processes affecting learning. *American Psychologist*. 41, 1040-1048.

Eaves, Y. D. (2001). A synthesis technique for Grounded Theory data analysis. *Journal of Advanced Nursing*. 35(5), 654-663.

Eliot, J., & Olver, I. (2002). The discursive properties of "hope": a qualitative analysis of cancer patients' speech. *Qualitative Health Research*. 12(2), 173-193.

Elliott, R., Fischer, C. T. & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*. 38, 215-229.

Elliott, T.R., & Kurylo, M. (2000). Hope over acquired disability: Lessons of a young woman's triumph. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 373-385.

Ellis-Hill, C.S., Payne, S., & Ward, C. (2000). Self-body split: issues of identity in physical recovery following a stroke. *Disability and Rehabilitation*. 22(16), 725-733.

Erikson, A., Park, M., & Tham, K. (2010). Belonging: a qualitative, longitudinal study of what matters for persons after stroke during one year of rehabilitation. *Journal of Rehabilitation Medicine*, 42, 831-838.

- Estabrooks, C. A. (2001). Research utilization and qualitative research. In J. M. Morse, J. M. Swanson & A. J. Kuzel (Eds). *The Nature of Qualitative Evidence*. Thousand Oaks CA: Sage. Pp 275-298.
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social science and medicine*. 50, 605-617.
- Fadan, R. R. & Beauchamp. T. L. (1986). *A History and Theory of informed Consent*. NY: Oxford University Press. 302.
- Faircloth, C.A., Rittman, M., Boylstein, C., Young, M.E., & Van Puymbroeck, A. (2004). Energising the ordinary: Biographical work and the future in stroke recovery narratives. *Journal of Aging Studies*. 18, 399-413.
- Farran, C.J., Herth, K.A., & Popovich, J.M. (1995). *Hope and Hopelessness: Critical Clinical Constructs*. London: Sage Pub.
- Fenton, A., Markkanen, S. & Monk, S. (2011). *Hidden Needs: hidden deprivation and community need in Suffolk*. The Suffolk Foundation.
- Ferguson, A., Worrall, L., Davidson, B., Hersh, D., Howe, T., & Sherratt, S. (2010). Describing the experience of aphasia rehabilitation through metaphor. *Aphasiology*. 24(6-8), 685-696.
- Field, P. A. & Morse, J. M. (1989). *Nursing research: the application of qualitative approaches*. London: Chapman & Hall.
- Fiorentine, R., & Anglin, M.D. (1997.) Does increasing the opportunity for counselling increase the effectiveness of outpatient drug treatment? *American Journal Drug Alcohol Abuse*. 23, 369-382.
- Fleming, J.M., & Ownsworth, T. (2006). A review of awareness interventions in Brain Injury rehabilitation. *Neuropsychology Rehabilitation*. 16(4), 474-500.
- Flory, J. & Emanuel, E. (2004). Interventions to improve Research Participants' Understanding in Informed Consent for Research: a systematic review. *Journal of the American Medical Association*. 292(13), 1593-1600.

Folden, S. (1994). Managing the effects of a stroke: The first months. *Rehabilitation Nursing Research*. 3(3), 79- 85.

Fontana, A. & Frey, J. H. (2000). The Interview: from structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. pp 645-672.

Fordyce, D.J., & Roueche, J.R. (1986). Changes in perspectives of disability among patients, staff and relatives during rehabilitation of brain injury. *Rehabilitation Psychology*. 31(4), 217- 229.

Fortune, N., & Wen, X. (1999). The definition, incidence and prevalence of acquired brain injury in Australia. *Australian Institute of health and Welfare*.

Fraas, M. (2011). Enhancing quality of life for survivors of stroke through phenomenology. *Topics Stroke Rehabilitation*. 18(1), 40-46.

Frankl, V.E. (1984). *Man's search for meaning*. Washington Square Press: London.

Fredricks, J.A., Blumenfeld, P.C., & Paris, A.H. (2004). School engagement: potential of positive concept, state of the evidence. *Review of Educational Research*. 74, 59-109.

Frydenburg, E., Ainley, M., & Russell, V.J. (2005). Student motivation and engagement. *Dept Education, Science and Training/Schooling Issues Digest*. 16.

Gainotti, G., & Marra, C. (2002). Determinants and consequences of post-stroke depression. *Current Opinions in Neurology*. 15, 85-89.

Galla, B.M., Wood, J.J., Tsukayama, E., Har, K., Chiu, A.W., & Langer, D.A. (2014). A longitudinal multi-level model analysis of the within person and between person effect of effortful engagement and academic self-efficacy on academic performance. *Journal of School Psychology*. 52, 295-308.

Gibbs, L., Kealy, M., Willis, K., Green, J., Welch, N., & Daly, J. (2007). What have sampling and data collection got to do with good qualitative research? *Australian & New Zealand Journal of Public Health*. 31(6), 540-544.

Gillen, G. (2006). Coping during in-patient stroke rehabilitation: an exploratory study. *American journal Of Occupational Therapy*. 60, 136-145.

- Giorgi, A. & Giorgi, B. (2008). Phenomenology. In J. A. Smith (Ed). *Qualitative Psychology: a practical guide to research methods: second edition*. Pp 26-52.
- Gitlin, L.N., Luborsky, M.R., & Schemm, R.L. (1998). Emerging concerns of older stroke patients about assistive device use. *Gerontologist*. 38, 169-180.
- Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley CA: The Sociology Press.
- Glaser, B. G. & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Gold, S.J. (1983). Getting well: impression management as stroke rehabilitation. *Qualitative Sociology*. 6, 238-254.
- Graven, C., Brock, K., Hill, K., Ames, D., Cotton, S., & Joubert, L. (2011). From rehabilitation to recovery: protocol for a randomised controlled trial evaluating a goal-based intervention to reduce depression and facilitate participation post-stroke. *Neurology*. 11, 73.
- Graven, C., Sansonetti, D., Moloczij, N., Cadilhac, D., & Joubert, L. (2013). Stroke survivor and carer perspectives of the concept of recovery: a qualitative study. *Disability and Rehabilitation*. 35(7), 578-585.
- Grbich, C. (1999). *Qualitative Research in Health: An Introduction*. Thousand Oaks: Sage Pub.
- Green, T., Gandhi, S., Kleissen, T., Simon, J., Raffin-Bouchal, S., & Ryckborst, K. (2014). Advance care planning in stroke: influence of time on engagement in the process. *Patient Preference and Adherence*. 8, 119-126.
- Green, C., & Waks, L. (2008). A second chance: recovering language with aphasia. *International Journal of Speech-Language Pathology*. 10(3), 127-131.
- Grohn, B., Worrall, L.E., Simmons-Mackie, N., & Brown, K. (2012). The first three months post-stroke: What facilitates successfully living with aphasia? *International Journal of Speech-Language Pathology*. 14(4), 390-400.
- Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. London: Sage.
- Gubrium, J. F. & Holstein, J. A. (2000). Analysing Interpretive Practice. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 487-508.

- Guidetti, S., Asaba, E., & Tham, K. (2007). The lived-experience of recapturing self-care. *American Journal of Occupational Therapy*. 61, 303-310.
- Gum, A., & Snyder, C.R. (2002). Coping with terminal illness: the role of hopeful thinking. *Journal of Palliative Medicine*. 5(6), 883- 894.
- Gum, A., Snyder, C.R., & Duncan, P.W. (2006). Hopeful thinking, participation, and depressive symptoms three months after stroke. *Psychology and Health*. 21(3), 319-334.
- Gustafsson, L., & McKenna, K. (2010). Is there a role for meaningful activity in stroke rehabilitation? *Topics Stroke Rehabilitation*. 17(2), 1080118.
- Hafsteindottir, T.B., & Grypdonck, M. (1997). Being a stroke patient: a review of the literature. *Journal of Advanced Nursing*. 26, 580-588.
- Haggstrom, T., Axelsson, K., & Norberg, A. (1994). The experience of living with stroke sequelae illuminated by means of stories and metaphors. *Qualitative Health Research*. 4(3), 321-337.
- Haggstrom, A., & Larsson Lund, M. (2008). The complexity of participation in daily life: a qualitative study of the experiences of persons with acquired brain injury. *Journal Rehabilitative Medicine*. 40, 89-95.
- Hagner, D. C. & Helm, D. T. (1994). Qualitative methods in Rehabilitation Research. *Rehabilitation Counseling Bulletin*. 37(4), 290-303.
- Harding, S. (1987). Introduction: Is there a feminist method? In S. Harding (Ed). *Feminism and Methodology: Social Science Issues*. Bloomington: Indiana UP. Pp 1-14.
- Harwood, M., Weatherall, M., Talemaitoga, A., Barber, P.A., Gommans, J., Taylor, W., et al.,. (2011). Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life – a randomised controlled trial. *Clinical Rehabilitation*. 26(6), 493—501.
- Hasenbein, U., Kuss, O., Baumer, M., Schert, C., Schneider, H., & Wallesch, C.W. (2002). Physicians' preferences and expectations in stroke rehabilitation – results of a case based questionnaire survey. *Disability and rehabilitation*. 24(18), 954-960.

- Hasenbein, U., Kuss, O., Baumer, M., Schert, C., Schneider, H., & Wallesch, C.W. (2003). Physicians preferences and expectations in traumatic brain injury rehabilitation – results of a case based questionnaire survey. *Disability and rehabilitation*. 25(3), 136-142.
- Hellstrom, K., Lindmark, B., Wahlberg, B., & Fugl-Meyer, A.R. (2003). Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: A prospective investigation. *Journal Rehabilitative Med.* 35, 202-207.
- Henwood, K., & Pidgeon, N. (1992). Qualitative research and psychological theorizing. *British Journal Psychology*. 83, 97-111.
- Hersh, D., Worrall, L., Howe, T., Sherratt, S., & Davidson, B. (2012), SMARTER goal setting in aphasia rehabilitation. *Aphasiology*. 26, 220-233.
- Higgingbottom, G. M. A. (2004). Sampling issues in qualitative research. *Nurse Researcher*. 12(1), 7-19.
- Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R.D., Chataway, J., & Ames, D. (2010). Psychological distress after stroke and aphasia: the first six months. *Clinical rehabilitation*. 24, 181-190.
- Hill, H. (1999). Traumatic brain injury: a view from the inside. *Brain Injury*. 13(11), 839-844.
- Hilton, E. (2002). The meaning of stroke in elderly women. *Journal of Gerontological Nursing*. 28(7), 19-26.
- Hinckley, J. (2006). Finding messages in bottles: living successfully with stroke and aphasia. *Topics in Stroke Rehab*. 13, 25-36.
- Hoffman, J. (1974). Nothing can be done: social dimensions of the treatment of stroke patients in a general hospital. *Urban Life and Culture*. 3, 50-70.
- Holbrook, M. (1982). Stroke: social and emotional outcome. *Journal Royal College Physicians London*. 16, 100-104.
- Holstein, J. A. & Gulbriun, J. F. (1995). *The active Interview*. Thousand Oaks CA: Sage Pub.
- Hopper, T., & Edey, W. (2007). *An exploration of hope and aphasia*. Paper presented at The Clinical Aphasiology Conference, Scottsdale, Arizona.

Horton, S., Howell, A., Humby, K., & Ross, A. (2011). Engagement and learning: an exploratory study of situated practice in multi-disciplinary stroke rehabilitation. *Disability and Rehabilitation*. 33(3), 270-279.

Howe, T., Worrall, L., & Hickson, L.M.H. (2008). Interviews with people with aphasia: environmental factors that influence their community participation. *Aphasiology*. 22(10), 1092-1120.

Howes, H., Benton, D., & Edwards, S. (2005). Women's experience of brain injury: an interpretative phenomenological analysis. *Psychology and Health*. 20(1), 129-142.

Hunter, K. F. & Jensen, L. (2003). Obtaining informed consent for participation from cognitively impaired adults. *JWOCN*. 30, 241-244.

Huyser, B., Buckelew, S.P., Hewett, J.E., & Johnson, J.C. (1997). Factors affecting adherence to rehabilitation interventions for individuals with Fibromyalgia. *Rehabilitation Psychology*. 42(2), 75- 91.

Jackson, B., Beauchamp, M.R., & Knapp, P. (2007). Relational efficacy beliefs in athlete dyads: an investigation using actor-partner interdependence models. *Journal of Sport and Exercise Psychology*. 29, 170-189.

Jackson, B., Dimmock, J.A., Taylor, I.M., & Hagger, M.S. (2012a). The tri-partite efficacy framework in client-therapist rehabilitation interactions: Implications for relationship quality and client engagement. *Rehabilitation Psychology*. 57(4), 308-319.

Jackson, B., Whipp, P.R., Chua, K.L.P., Pengelley, R., & Beauchamp, M.R. (2012b). Assessment of tripartite efficacy beliefs within school-based physical education: Instrument development and reliability and validity evidence. *Psychology of Sport and Exercise*. 13, 108-117.

Janesick, V. (2000). The Choreography of Qualitative Research Design: minuets, improvisations and crystallization. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 379-400.

Jennings, P.A., & Greenburg, M.T. (2008). The prosocial classroom: teacher social and emotional competence in relation to student and classroom outcomes. *Review Educational research*. 79, 491-525.

Joe, G.W., Simpson, D.D., & Broome, K.M. (1998). Effects of readiness for drug abuse treatment on client retention and assessment of process. *Addiction*. 93, 1177-1190.

Joe, G.W., Simpson, D.D., & Broome, K.M. (1999). Retention and patient engagement models for different treatment modalities in DATOS. *Drug and Alcohol Dependence*. 57, 113-125.

Johnston, M. (1997). Representations of disability. In K.J. Petrie & J.A. Weinman (Eds). *Perceptions of Health and Illness*. London: Harwood Academic Press.

Jones, F. (2006). Strategies to enhance chronic disease self-management; How can we apply this to stroke? *Disability and Rehabilitation*. 28(13-14), 841-847.

Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: a perspective based on personal experience. *Disability and Rehabilitation*. 30(7), 507-516.

Jones, F., Partridge, C., & Reid, F. (2008). The Stroke Efficacy Questionnaire: measuring individual confidence in functional performance after stroke. *Journal of Nursing and Healthcare of Chronic Illness*. 17(7b), 244-252.

Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disability and Rehabilitation*. 33(10), 797-810.

Jones, F., Riazi, A., & Norris, M. (2013). Self-management after stroke: time for some more questions? *Disability and Rehabilitation*. 35(3), 257-264.

Jones, F., Waters, C., Benson, L., Jones, C., Hammond, J., & Bailey, N. (2012). Evaluation of a shared approach to inter-professional learning about stroke self-management. *Journal of Inter-professional Care*. 26, 514-516.

Jones, R. (1995). Why do qualitative research?: Editorial. *BMJ*. 311:2.

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*. 23(23), 42-46.

Kagan, A. (1995) Revealing the competence of aphasic adults through conversation: a challenge to health professionals. *Topics in Stroke Rehabilitation*. 2, 15-28.

Kagan, A., & Kimelman, M. D. Z. (1995). Informed Consent in Aphasia Research: Myth or Reality? *Clinical Aphasiology*. 23, 65-75.

Kaufman, S. (1988). Illness, biography and the interpretation of self following a stroke. *Journal of Aging Studies*. 2(3), 217-227.

Kaufman, S., & Becker, G. (1986). Stroke: health care on the periphery. *Social science and Medicine*. 22, 983-989.

Kautz, D. (2008). Inspiring hope in our rehabilitation patients, their families, and ourselves. *Rehabilitation Nursing*. 33(4), 148-153/177.

Kearney, M. H. (2007). Going deeper versus wider in qualitative sampling. *Journal of Obstetric, Gynecologic and Neonatal Nursing*. 36(4), 299.

Keeble, S. (2011). *Diversity profile for NHS Suffolk*. NHS Suffolk Pub.

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Sciences and Medicine*. 64, 735-746.

Kendrick, D., Silverberg, N.D., Barlow, S., Miller, W.C., & Moffat, J. (2012). Acquired Brain Injury self-management programme: A pilot study. *Brain Injury*. 26(10), 1243-1249.

Kennedy, T. J. T. & Lingard, L. A. (2006). Making sense of Grounded Theory in Medical Education. *Medical Education*. 40, 101-108.

Kessler, D., Dubouloz, C-J., Urbanowski, R., & Egan, M. (2009). Meaning perspective transformation following stroke: the process of change. *Disability and Rehabilitation*. 31(13), 1056-1065.

Kim, S. Y., Karlawish, J. H., & Caine, E. D. (2002). Current state of research and decision making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry*. 10, 151-165.

Klassen, R.M., Perry, N.E., & Frenzel, A.C. (2012.) Teachers' relatedness with students: An underemphasized component of teachers' basic psychological needs. *Journal of Educational Psychology*. 104(1), 150-165.

Korpershoek, C., van der Bijl, J., & Hafsteindottir, T.B. (2011). Self-efficacy and its influence on recovery of patients with stroke: a systematic review. *Journal of Advanced Nursing*. 67(9) 1876-1894.

- Kortte, K.B., Falk, L.D., Castillo, R.C., Johnson-Greene, D., & Wegener, S.T. (2007). The Hopkins Rehabilitation Engagement Rating Scale: development and psychometric properties. *Archives Physical Medicine Rehabilitation*. 88, 877-884.
- Kortte, K.B., Stevenson, J.E., Hosey, M.M., Castillo, R., & Wegener, S.T. (2012). Hope predicts positive functional role outcomes in acute rehabilitation populations. *Rehabilitation Psychology*. 57(3), 248-255.
- Kortte, K.B., Veiel, L., Batten, S.V., & Wegener, S.T. (2009). Measuring avoidance in medical rehabilitation. *Rehabilitation Psychology*. 54(1), 91-98.
- Kortte, K.B., Wegener, S.T., & Chwalisz, K. (2003). Anosognosia and denial: their relationship to coping and depression in ABI. *Rehabilitation Psychology*. 48(3), 131-136.
- Kovacs-Burns, K., Bellows, M., Eigenseher, C., & Gallivan, J. (2014). 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. *Health Services Research*. 49, 175-190.
- Kuluski, K., Dow, C., Locock, L., Lyons, R.F., & Lasserson, D. (2014). Life interrupted and life regained? Coping with stroke at a younger age. *International Journal of Qualitative Studies on Health and Well-being*. 9, 22252
- Kuper, A., Lingard, L., & Levinson, W. (2008). Critically appraising qualitative research. *British Medical Journal*. 337, 687-689.
- Kvale, S. (1994). Ten Standard Objections to Qualitative Research Interviews. *Journal of Phenomenological Psychology*. 25(2), 147-175.
- Kvigne, K., Gjengedal, E., & Kirkevold, M. (2002). Gaining access to the life world of women suffering from stroke: methodological issues in empirical phenomenological studies. *Journal of Advanced Nursing*. 40(1), 61-68.
- Kvigne, K., & Kirkevold, M. (2003). Living with bodily strangeness: Women's experiences of their changing and unpredictable body following a stroke. *Qualitative Health Research*. 13(9), 1291-1310.
- Kvigne, K., Kirkevold, M., & Gjengedal, E. (2004). Fighting back – struggling to continue life and preserve the self following a stroke. *Health Care for Women International*. 25, 370-387.

Kwon, P. (2002). Hope, defence mechanisms and adjustment: implications for false hope and defensive hopelessness. *Journal of Personality*. 70, 207-231.

Lamb, M., Buchanan, D., Godfrey, C.M., Harrison, M.B., & Oakley, P. (2008). The psychosocial spiritual experience of elderly individuals recovering from stroke: a systematic review. *International Journal of Evidence Based Health Care*. 6, 173-205.

Lawrence, M. (2010). Young adults experience of stroke: a qualitative review of the literature. *British Journal Nursing*. 19(4), 241-248.

LeBrasseur, N., Sayers, S., Oullette, M., & Fielding, R. (2006) Muscle impairment and behavioural factors mediate functional limitations and disability following stroke. *Physical Therapy*. 86, 1342-1350.

Lennon, S., McKenna, S., & Jones, F. (2013). Self-management programmes for people post stroke: a systematic review. *Clinical Rehabilitation*. 27(10), 867-878.

Lent, R.W., & Lopez, F.G. (2002). Cognitive ties that bind: A tripartite view of efficacy beliefs in growth-promoting relationships. *Journal of Social and Clinical Psychology*. 21(3), 256-286.

Lenze, E.J., Munin, M.C., & Quear, T. (2004). The Pittsburg Rehabilitation Participation Scale: reliability and validity of a clinician rated measure of participation in acute rehabilitation. *Archives Physical Medical Rehabilitation*. 85, 380-384.

Lequerica, A.H., & Kortte, K. (2010). Therapeutic Engagement: a proposed model of engagement in medical rehabilitation. *American Journal Physical Medical Rehabilitation*. 89, 415-422.

Lequerica, A.H., Rapport, L.J., Whitman, R.D., Millis, S.R., Vangel, S.J., Hanks, R.A., & Axelrod, B.N. (2006). Psychometric properties of the rehabilitation therapy engagement scale when used among individuals with acquired brain injury. *Rehabilitation Psychology*. 51(4), 331-337.

Levack, W.M.M., Kayes, N.M., & Fadyl, J.K. (2010). Experience of recovery and outcome following traumatic brain injury: a meta-synthesis of qualitative research. *Disability and Rehabilitation*. 32(12), 986-999.

- Levy, R., & DuBois, B. (2006). Apathy and the functional anatomy of the prefrontal cortex-based ganglia circuits. *Cerebral Cortex*. 16, 916-928.
- Lewandowski, M., D'Iuso, D., Blake, E., Fitzpatrick, M., & Drapeau, M. (2011). The relationship between therapeutic engagement, cognitive errors, and coping action patterns: an exploratory study. *Counselling and Psychotherapy Research*. 11(4), 284-290.
- Lewinter, M., & Mikkelsen, S. (1995a). Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation*. 17(1), 3-9.
- Lewinter, M., & Mikkelsen, S. (1995b). Therapists and the rehabilitation process after stroke. *Disability and Rehabilitation*. 17(5), 211-216.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. Bev. Hills, Ca.: Sage Pub.
- Lincoln, Y. S. & Guba, E. G. (2000). Paradigmatic controversies, contradictions and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 163-188.
- Linge, F.R. (1990). Faith, Hope, and Love: Non-traditional therapy in recovery from serious head injury, a personal account. *Canadian Journal of Psychology*. 44(2), 116-129.
- Lofland, J. & Lofland, L. H. (1995). *Analyzing Social Settings: second edition*. Belmont CA: Wadsworth.
- Lohne, V. (2008). The battle between hope and suffering; a conceptual model of hope within a context of spinal cord injury. *Advances in Nursing Science*. 31(3), 237-248.
- Lohne, V., & Severinsson, E. (2004). Hope and despair: the awakening of hope following acute spinal cord injury – an interpretive study. *International Journal Nursing Studies*. 41, 881-890.
- Lohne, V., & Severinsson, E. (2006). The power of hope: patients' experiences of hope a year after acute spinal cord injury. *Journal of Clinical Nursing*. 15, 315-323.
- Lopez, S.J., Bouwkamp, J., Edwards, L.M., & Teramoto Pedriotti, J. (2000). Making hope happen via tried interventions. *Paper presented at 2nd Positive Psychology summit. Washington DC.*

Lucas, S.E., & Fleming, J.M. (2005). Interventions for improving self-awareness following ABI. *Australian OT Journal*. 52, 160-170.

Luta, B.J., Young, M.E., Cox, K.J., Martz, C., & Creasy, K.R. (2011). *Topics Stroke Rehabilitation*. 18(6), 786-797.

Lynch, E.B., Butt, Z., Heinemann, A., Victorson, D., Nowonski, C.J., Perez, L., & Cella, D. (2008). A qualitative study of quality of life after stroke: the importance of social relationships. *Journal Rehabilitation Medicine*. 40, 518-523.

Maclean, N., & Pound, P. (2000). A critical review of the concept of patient motivation in the literature on physical rehabilitation. *Social Science and Medicine*. 50, 495-506.

Maclean, N., Pound, P., Wolfe, C., & Rudd, A. (2000). Qualitative analysis of stroke patients' motivation for rehabilitation. *British Medical Journal*. 321, 1051-1054.

Maclean, N., Pound, P., Wolfe, C., & Rudd, A. (2002). The concept of patient motivation: a qualitative analysis of stroke professionals' attitudes. *Stroke*. 33, 444-448.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*. 91, 1-20.

Marcel, G. (1956). *The philosophy of existentialism*. Citadel Press Kensington Pub Co: NY.

Marcus, G.E. (1994). What comes (just) after "Post"? The case of ethnography. In N.K. Denzin & Y.S. Lincoln (Eds). *Handbook of Qualitative Research*. London: Sage. pp 563-574.

Margaletta, P.R., & Oliver, J.M. (1999). The hope construct, will and ways: their relations with self-efficacy, optimism and general well-being. *Journal Clinical Psychology*. 55(5), 539-551.

Margolis, R.L., Harrison, S.A., Robinson, H.J., & Jayaram, G. (1996). Occupational Therapy Task Observation Scale (OTTOS): a rapid method for rating task group function of psychiatric patients. *American Journal Occupational Therapy*. 50(5), 380-385.

Marks, R., Allegrante, J.P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy enhancing interventions for reducing chronic disability implications for health education practice (part 11). *Health Promotion Practice*. 6, 148-156.

- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*. 13(6), 522-525.
- Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and SLTs' explanatory models of language development, language delay and intervention. *International Journal Language and Communication Disorders*. 42(5), 533-555.
- Martin, C., Dellatolas, G., Viguier, D., Willadino-Braga, L., & Deloche, G. (2002). Subjective experience after stroke. *Applied Neuropsychology*. 9(3), 148-158.
- Mason, J. (1996). *Qualitative Researching*. London: Sage.
- Matthews, G., Campbell, S.E., Falconer, S., Joyner, L.A., Higgins, J., Gilliland, K. et al., (2002). Fundamental dimensions of subjective state in performance settings: task engagement, distress and worry. *Emotion*. 2(4), 315-340.
- Maykut, P. & Morehouse, R. (1994). *Beginning Qualitative Research: A Philosophic and Practical Guide*. London: Falmer Press.
- Mayo, N.E., Fellows, L.K., Scott, S.C., Cameron, J., & Wood-Dauphinee, S. (2009). A longitudinal view of apathy and its impact after stroke. *Stroke*. 40, 3299-3307.
- Mays, N. & Pope, C. (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal*. 311, 42-45.
- Mays, N. & Pope, C. (1995). Qualitative Research: Rigour and Qualitative Research. *British Medical Journal*. 311: 109.
- Mays, N. & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*. 320, 50-52.
- Mays N, & Pope C (2006). Quality in qualitative health research IN Pope & N Mays *Qualitative Research in health Care : 3rd edition* pp 82-101.
- McCormack, B. (2002). The person of the voice: narrative identities in informed consent. *Nursing philosophy*. 3, 114-119.
- Mckevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke. *Stroke*. 35, 1499-1505.

- McMillan, T.M. (2013). Outcome of rehabilitation for neurobehavioural disorders. *Neurorehabilitation*. 32, 791-801.
- McMurrin, M., & Ward, T. (2010). Treatment Readiness, treatment engagement and behaviour change. *Criminal Behaviour and Mental health*. 20, 75-85.
- Medley, A.R., & Powell, T. (2010). Motivational Interviewing to promote self-awareness and engagement in rehabilitation following acquired brain injury: a conceptual review. *Neuropsychological rehabilitation*. 20(4), 481-508.
- Merton, R.K. (1956). *The focused interview*. Free Press: Glencoe IL.
- Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal Health Psychology*. 11(5), 799-808.
- Michael, S.T. (2000). Hope conquers fear: overcoming anxiety and panic attacks. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 301-318.
- Mintz, R. (2010). *Introduction to conducting qualitative research: Information Sheet*. Lutterworth: BACP.
- Mold, F., McKeivitt, C., & Wolfe, C. (2003). A review and commentary of the social factors which influence stroke care issues of inequality in qualitative literature. *Health and Social Care in the Community*. 11(5), 405-414.
- Moore, A.D., & Stambrook, M. (1995). Cognitive moderators of outcome following traumatic brain injury: a conceptual model and implications for rehabilitation. *Brain Injury*. 9(2), 109-130.
- Morse, J. M. (1991). Strategies for sampling in J. M. Morse (Ed). *Qualitative Nursing Research: a contemporary dialogue*. Newbury Park, Ca.: Sage Pub.
- Muller, C. (2001). The role of caring in the teacher-student relationship for at-risk students. *Sociological Inquiry*. 71(2), 241-255.
- Murphy, E., & Dingwall, R. (2003). *Qualitative methods and health policy research*. NY: Aldine de Gruyter.

- Murray, C.D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disability and Rehabilitation*. 26(13), 808-816.
- National Health Service Health and Social Care Information Centre. (2012). *Hospital Episode Statistics 2011-2012*. NSCIC: UK Gov.
- Nekolaichuk, C.L., Jevne, R.F., & Maguire, T.O. (1999). Structuring the meaning of hope in health and illness. *Social Science and Medicine*. 48, 591-605.
- Nelson-Marten, P. & Rich, B. (1999). A Historical Perspective of informed consent in clinical practice and research. *Seminars in Oncology Nursing*. 15(8), 1-88.
- Niemi, T., & Johansson, U. (2013). The lived experience of engaging in everyday occupations in persons with mild to moderate aphasia. *Disability and Rehabilitation*. 35(21), 1828-1834.
- Nightingale, D., & Cromby, J. (1999). *Social Constructivist Psychology: a critical analysis of theory and practice*. Buckingham: OU Press.
- Nilsson, I., Jansson, L., & Norberg, A. (1997). To meet with a stroke: patients' experiences and aspects seen through a screen of crisis. *Journal advanced Nursing*. 25, 953-963.
- Nilsson, I., Jansson, L., & Norberg, A. (1999). Crisis phenomena after stroke reflected in an existential perspective. *International Journal Aging and Human development*. 49(4), 259-277.
- Nochi, M. (1997). Dealing with the 'void': traumatic brain injury as a story. *Disability and Society*. 12(4), 533-555.
- Nochi, M. (1998a). "Loss of self" in the narratives of people with traumatic brain injuries: a qualitative analysis. *Social Science Medicine*. 46(7), 869-878.
- Nochi, M. (1998b). Struggling with the labelled self: people with traumatic brain injuries in social settings. *Qualitative Health Research*. 8(5), 665-681.
- Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science and Medicine*. 51, 1795-1804.
- Norris, M., & Kilbride, C. (2014). From dictatorship to a reluctant democracy: stroke therapists talking about self-management. *Disability and Rehabilitation*. 36(1), 32-38.

O'Callaghan, C., Powell, T., & Oyebode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a TBI. *Neurological Rehabilitation*. 16(5), 579-593.

O'Callaghan, A., Macallister, L., & Wilson, L. (2012). Insight vs readiness: Factors affecting engagement in therapy from the perspectives of adults with TBI and their significant others. *Brain Injury*. 26(13014), 1599-1610.

O'Connell, B., Hanna, B., Penney, W., Pearce, J., Owen, M., & Warelow, P. (2001) Recovery after stroke: a qualitative perspective. *Journal Qualitative Clinical Practice*. 21, 120-125.

O'Connell, D.C., & Kowal, S. (1994.) Some current transcription systems for spoken discourse: a critical analysis. *Pragmatics*. 4(1), 81-107.

O'Connell, D. C. & Kowal, S. (1995). Basic Principles of Transcription. In J. A. Smith, R. Harre & L. Van Langenhove (Eds). *Rethinking methods in psychology*. London: Sage. pp 93-105.

O'Flaherty, C.A., & Douglas, J.M. (1997). Living with cognitive-communication difficulties following traumatic brain injury: using a model of interpersonal communication to characterise the subjective experience. *Aphasiology*. 11(9), 889-911.

Olesen, V.L. (2000). Feminisms and qualitative research at and into the millennium. In N.K.Denzin & Y.S.Lincoln (Eds). *Handbook of Qualitative Research 2nd edition*. pp 215-155.

Olofsson, A., Andersson, S-O., & Carlberg, B. (2005). 'If only I manage to get home, I'll get better' – Interviews with stroke patients after emergency stays in hospital on their experiences and needs. *Clinical rehabilitation*. 19, 433-440.

Oppermann, J.D. (2004.) Interpreting the meaning individuals ascribe to returning to work after traumatic brain injury: a qualitative approach. *Brain Injury*. 18(9), 941-955.

Ostir, G.V., Berges, I.M., Ottenbacher, M.E., Chow, A., & Ottenbacher, K.J. (2008) .Associations between positive emotion and recovery of functional status following stroke. *Psychosomatic Medicine*. 70, 404-409.

Owensworth, T., & McKenna, K. (2004), Investigations of factors related to employment outcome following TBI: a critical review and conceptual model. *Disability and Rehabilitation*. 26(13), 765-784.

Owensworth, T.L., McFarland, K., & Young, R.McD. (2002). The investigation of factors underlying deficits in self-awareness and self-regulation. *Brain Injury*. 16, 291-309.

Palmer, R. & Paterson, G. (2011). One size does not fit all: obtaining informed consent from people with aphasia. *Advances in Clinical Neuroscience and Rehabilitation*. 11(2), 30-31

Park, C.L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*. 136(2), 257-301.

Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: living with loss of language after stroke*. Buckingham, England: OUP.

Patton, M. Q. (1987). *How to use qualitative methods in evaluation*. London: Sage Pub.

Patton, M. Q. (1990). *Qualitative evaluation and research methods: 2nd edition*. Newbury Park, Ca.: Sage Pub.

Peleg, G., Barak, O., Harel, Y., Rochberg, J., & Hoofien, D. (2009). Hope, dispositional optimism and severity of depression following traumatic brain injury. *Brain Injury*. 23(1), 800-808.

Polaschek, D.L.L., & Ross, E.C. (2010). Do early therapeutic alliance, motivation, and stages of change predict therapy change for high-risk, psychopathic violent prisoners? *Criminal behaviour and Mental health*. 20, 100-111.

Pope, C., & Mays, N. (1995). Qualitative research: Reaching the parts other methods cannot reach. *British Medical Journal*. 311, 42-45.

Pope, C., van Royen, P. & Baker, R. (2002). Qualitative methods in research on healthcare quality. *Qual Saf Health Care*. 11, 148-152.

Popovich, J., Fox, P., & Burns, K.R. (2003). "Hope" in the recovery from stroke in the US. *Int Journal Psychiatric Nursing Research*. 8(2), 905-920.

Possil, J., & von Cramon, D.Y. (1996). Clients' view of neuropsychological rehabilitation. *Brain Injury*. 10 (2), 125-132.

Pouliquen, U., Etcharry-Bouyx, F., Pinon, K., Patureau, F., Petit, A., Lambert, A., & Richard, I. (2013). Post-acute assessment programme for patients with traumatic brain injury:

measuring the gap between patients' expectations on entering and end of programme recommendations. *Brain Injury*. 27(7-8), 789-792.

Pound, C., Parr, S., Lindsay, J., & Woolf, C., (2001). *Beyond Aphasia: Therapies for Living with Communication Disability*. Bicester UK: Speechmark.

Pound, P., Bury, M., Gompertz, P., & Ebrahim, S. (1994). Views of survivors of stroke on benefits of physiotherapy. *Quality in Health Care*. 3, 69-74.

Pound, P., & Ebrahim, S. (1997). Redefining 'doing something': Health professionals' views on their role in the care of stroke patients. *Physiotherapy Research International*. 2(2), 12-28.

Pound, P., Gompertz, P., & Ebrahim, S. (1998). A patient-centred study of the consequences of stroke. *Clinical Rehabilitation*. 12, 255-264.

Prigatano, G.P. (2011). The importance of the patients' subjective experience in stroke rehabilitation. *Topics Stroke Rehabilitation*. 18(1), 30-34.

Prigatano, G.P., & Klonoff, P.S. (1998). A clinician rating scale for evaluating impaired self-awareness and denial of disability after BI. *Clinical Neuropsychologist*. 12(1), 56-67.

Pringle, J., Hendry, C., McLafferty, E., & Drummond, J. (2010). Stroke survivors with aphasia: personal experiences of coming home. *British Journal of Community Nursing*. 15(5), 241-247.

Prochaska, J.O., & DiClemente, C.C. (1982). Transtheoretical therapy: toward a more integrative model of change. *Journal of Consulting and Clinical Psychology*. 51, 390-395.

Proot, I.M., Abu-Saad, H.H., de Esch-Janssen, W.P., Crebolder, H.F.J.M., & ter Meulen, R.H.J. (2000a) Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. *International Journal Nursing Studies*. 37, 267-276.

Proot, I.M., Crebolder, H.F.J.M., Abu-Saad, H.H., Macor, T.H.G.M., & ter Meulen, R.H.J. (2000b). Facilitating and constraining factors on autonomy. *Clinical Nursing Research*. 9(4), 460-478.

Pryor, J., Buzio, A. (2010). Enhancing inpatient rehabilitation through the engagement of patients and nurses. *Journal of Advanced Nursing*. 66(5), 978-987.

- Rath, J.F., Hradil, A.L., Litke, D.R., & Diller, L. (2011). Clinical applications of problem-solving research in neuropsychological rehabilitation: Addressing the subjective experience of cognitive deficits in out-patients with acquired brain injury. *Rehabilitation Psychology*. 56(4), 320-328.
- Renshaw, K.D., McKnight, P., Caska, C.M., & Blais, R.K. (2010). The utility of the relationship assessment scale in multiple types of relationship. *Journal of Social and Personal Relationships*. 28(4), 435-447.
- Richards, H. M., & Schwartz, L. J. (2001). Ethics of qualitative research: are there special issues for health services research? *Family Practice*. 19(2), 135-139.
- Robinson-Smith, G. (2002). Prayer after stroke: its relationship to quality of life. *Journal Holistic Nursing*. 20(4), 352-366.
- Robinson-Smith, G., Johnston, M.V., & Allen, J. (2000). Self-care, self-efficacy, quality of life, and depression after stroke. *Archives Physical Medical Rehabilitation*. 81, April, 460-464.
- Roding, J., Lindstrom, B., Malm, J., & Ohman, A. (2003). Frustrated and invisible: younger stroke patients' experiences of the rehabilitation process. *Disability and Rehabilitation*. 25(15), 867-874.
- Rodriguez-Hanley, A., & Snyder, C.R. (2000). The demise of hope: on losing positive thinking. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 39-53.
- Roozenbeek, B., Maas, A., & Menon, D. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*. 9, 231-236.
- Rose, T.A., Worrall, L. E., Hickson, L. M., & Hoffman, T. C. (2011). Aphasia Friendly written health information: content and design characteristics. *International Journal of Speech-Language Pathology*. 13(4), 335-347.
- Rosewilliam, S., Roskell, C.A., & Pandyan, A.D. (2011). A systematic review and synthesis of the qualitative and quantitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation*. 25(6), 01-514.
- Royal College of Physicians Intercollegiate Stroke Working Party. (2012). *National Clinical Guidelines for Stroke 4th edition*. London: RCP. p4.

- Rubenstein, R. (1994). Proposal writing. In J. Gubrium & A. Sankar (Eds). *Qualitative methods in aging research*. London: Sage Pub.
- Rutherford, N.A., & Wood, R.L. (2006). Evaluating a theory of stress and adjustment when predicting long-term psychological outcome after brain injury. *Journal International Neuropsychological society*. 12, 359-367.
- Ryan, R.M., & Deci, E.L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist*. 55(1), 68-78.
- Sachs, G. A. & Cassel, C. K. (1990). Biomedical research involving older human subjects. *Law, Medicine and Health Care*. 18(3), 234-243.
- Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal Rehabilitative Med*. 40, 595-602.
- Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in nursing and health*. 18, 179-183.
- Sandelowski, M. (2004). Using qualitative research. *Qual. Health Res*. 14(10), 1366-1386.
- Sandelowski, M. & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*. 13(7), 905-923.
- Satink, T., Cup, E.H., Iloft, I., Prins, J., de Swart, B.J., & Nijhuis-van der Sanden, M.W. (2013). Patients' views on the impact of stroke on their roles and self: A thematic synthesis of Qualitative Studies. *Archives of Physical Medicine and Rehabilitation*. 94, 1171-1183.
- Sbordone, R.J., Seyranian, G.D., & Ruff, R.M. (1998). Are the subjective complaints of traumatically brain injured patients reliable? *Brain Injury*. 12(6), 505-515.
- Scheper-Hughes, N. (1992). *Death without weeping*. Berkeley: University of California Press.
- Schonberger, M., Humle, F., & Teasdale, T.W. (2006). The development of the therapeutic working alliance, patients' awareness and their compliance during the process of brain injury rehabilitation. *Brain Injury*. 20(4), 445-454.
- Schwandt, T. A. (2001). *Dictionary of Qualitative Inquiry: second edition*. Thousand Oaks, CA: Sage.

- Schwandt, T. A. (2000). Three Epistemological Stances for qualitative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 189-214.
- Selikoff, I. J. (1991). Statistical Compassion. *Journal Clinical epidemiology*. 44, 1415-1485.
- Sherer, M., Davis, L.C., Sander, A.M., Caroselli, J.S., Clark, A.N., & Pastorek, N.J. (2014). Prognostic importance of self-reported traits/problems/strengths and environmental barriers/facilitators for predicting participation outcomes in persons with Traumatic Brain Injury: a systematic review. *Archives Physical Medical Rehabilitation*. 95, 1162-1173.
- Silverman, D. (2011). *Interpreting qualitative data: 4th edition*. London: Sage.
- Silverman, D. (2000). Analyzing Talk and Text. In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 821-834.
- Silverman, M.E. (2011). Community: The key to building and extending engagement for individuals with aphasia. *Seminars in Speech and Language*. 32, 256-267.
- Simpson, C. (2004). When hope makes us vulnerable: a discussion of patient-healthcare provider interactions in the context of hope. *Bioethics*. 18(5), 428-447.
- Slaughter, S., Cole, D., Jennings, E. & Reimer, M. (2007). Consent and Assent to Participate in Research from people with Dementia. *Nursing Ethics*. 14 (1), 27-40.
- Smith, J. K. & Deemer, D. K. (2000) The problem of criteria in the age of relativism In N. K. Denzin & Y. S. Lincoln (Eds). *Handbook of Qualitative Research: second edition*. Pp 877-896.
- Smith, J. A. & Osborn. M. (2008). Interpretative Phenomenological Analysis. In J.A.Smith (Ed). *Qualitative Psychology: a practical guide to research methods: Second edition*. London: Sage. Pp 53-80.
- Smith, B., & Sparkes, A.C. (2005). Men, sport, spinal cord injury and narratives of hope. *Social Science and Medicine*. 61, 1095-1105.
- Snead, S.L., & Davis, J.R. (2002). Attitudes of individuals with acquired brain injury towards disability. *Brain Injury*. 16(11), 947-953.
- Snyder, C.R. (2000). Hypothesis: There is hope. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. pp 3-20.

Snyder, C.R., Rand, K.L., King, E.A., Feldman, D.B., & Woodward, J.T. (2002). "False Hope". *Journal Clinical Psychology*. 58(9), 1003-1022.

Snyder, C.R., & Taylor, J.D. (2000). Hope as a common factor across psychotherapy approaches: A lesson from the Dodo's verdict. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 89-108.

Snyder, M., & Stukas, A.A. (1999). Interpersonal processes: The interplay of cognitive, motivational, and behavioural activities in social interaction. *Annual review of Psychology*. 50, 273-303.

Sofaer, S. (2002.) Qualitative research methods. *International Journal for quality in health care*. 14(4), 329-336.

Spradley, J. P. (1979). *The ethnographic Interview*. NY: Holt, Rinehart & Winston.

Starks, H. & Brown Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and Grounded Theory. *Qualitative Health Research*. 17(10), 1372-1380.

Staub, F., & Bogousslavsky, J. (2001). Fatigue after stroke: a major but neglected issue. *Cerebrovascular Disease*. 12, 75-81.

Stein, J., & Brady-Wagner, L .C. (2006). Is informed consent a 'Yes or No' response? Enhancing the shared decision making process for persons with aphasia. *Topics in Stroke Rehabilitation*. 13(4), 42-46.

Stein, S., Shafqat, S., Doherty, D., Frates, E.P., & Furie, K.L. (2003). Patient knowledge and expectations for functional recovery after stroke. *American journal Physical Medicine and Rehabilitation*. 82, 591-596.

Stewart, K., Gill, P., Chadwick, B., & Treasure, E. (2004). Qualitative research in dentistry. *British Dental Journal*. 204(5), 235-238.

Stineman, M. G., & Musick, D. W. (2001). Protection of human subjects with disability: Guidelines for research. *Archives Physical Medicine Rehabilitation*. 28, (suppl 2), S9-S14.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded Theory, Procedures and Techniques*. London: Sage Pub.

- Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for developing Grounded Theory: second edition*. Thousand Oaks CA: Sage.
- Sugavanam, T., Mead, G., Bulley, C., Donaghy, M., & van Wijck, A. (2013). The effects and experiences of goal setting in stroke rehabilitation – a systematic review. *Disability and Rehabilitation*. 35(3), 177-190,
- Svendsen, H.A., & Teasdale, T.W. (2006). The influence of neuropsychological rehabilitation on symptomatology and quality of life following brain injury: A controlled long-term follow-up. *Brain Injury*. 20(12), 1295-1306.
- Sympson, S.C., & Qualls Elder, M. (2000). Feminist Therapy as empowering hope. In C. R. Snyder (Ed). *Handbook of Hope: Theory, Measures and Applications*. London: Academic Press. Pp 167-182.
- Tagliaferri, F., Compagnone, C., Korsic, M., Servadei, F., & Krauss, J. (2006). A systematic review of brain injury epidemiology in Europe. *Acta Neurochir*. 148, 2355-2368.
- Tariah, H.A., Hersh, G., & Ostwald, S.K. (2006). Factors associated with quality of life: perspectives of stroke survivors. *Physical and Occupational Therapy in Geriatrics*. 25, 33-50.
- Taylor, S. J. & Bogdan, R. (1984). *Introduction to qualitative research methods: The search for meanings: second edition*. Chichester: John Wiley & Sons.
- Taylor, C., & White, S. (2000). *Practicing reflexivity in health and welfare: making knowledge*. OUP: Buckingham.
- Teasdale, T.W., & Engberg, A.W. (2005). Subjective well-being and quality of life following traumatic brain injury in adults: a long term population based follow-up. *Brain Injury*. 19(12), 1041-1048.
- The, A.M., Hak, T., Koeter, G., & van den Wal, G. (2000). Collusion in doctor-patient communication about imminent death: an ethnographic study. *British Medical Journal*. 321(7273), 1376-1381.
- Thomas, S.A., & Lincoln, N.B. (2006). Factors relating to depression after stroke. *British Journal Clinical Psychology*. 45, 49-61.

- Thomas, W. I. & Thomas, D. S. (1928). *The Child in America*. NY: Alfred A Knopf.
- Thompson, C. (1999). Pearls, pith and provocation. Qualitative research into nurse decision making: factors for consideration in theoretical sampling. *Qualitative Health Research*. 9(6), 815-828.
- Thorne, S., Hislop, T., Kuo, M., & Armstrong, E-A. (2006). Hope and probability: patient perspectives of the meaning of numerical information in cancer communication. *Qualitative Health Research*. 16(3), 318-336.
- Tistad, M., von Koch, L., Sjostrand, C., Tham, K., & Ytterburg, C. (2013). *Health Expectations*. 16, e24-e35.
- Toglia, J., & Kirk, U. (2000). Understanding awareness deficits following brain injury. *Neurorehabilitation*. 15, 57-70.
- Townend, E., Brady, M., & McLaughlan, K. (2007). Exclusion and Inclusion criteria for people with aphasia in studies of depression after stroke: a systematic review and future recommendations. *Neuroepidemiology*. 29, 1-17.
- Townsend, N., Wickremasinghe, K., Bhatnagar, P., Dmolina, K., Nichols, M., Leal, J., et al.,. (2012). *Coronary Heart Disease statistics 2012 edition*. British Heart Foundation: London.
- Tuckett, A. G. (2004). Qualitative research sampling: the very real complexities. *Nurse Researcher*. 12(1), 47-63.
- Tuckett, A. G. (2005). Part 2. Rigour in qualitative research: Complexities and solutions. *Nurse researcher*. 13(1), 29-42.
- Tutton, E., Seers, K., Langstaff, D., & Westwood, M. (2012). Staff and patient views of the concept of hope on a stroke unit: a qualitative study. *Journal of Advanced Nursing*. 68(9), 2061-2069.
- Van den Broek, M.D. (2005). Why does neuro-rehabilitation fail? *Journal Head Trauma Rehabilitation*. 20(5), 464-473.
- Van Reekum, R., Stuss, D.T., & Ostrander, L. (2005). Apathy – why care? *Journal Neuropsychiatry Clinical Neuroscience*. 17, 7-19.

- Van Uden, J.M., Ritzen, H., & Pieters, J.M. (2014.) Engaging students: The role of teacher beliefs and interpersonal teacher education in fostering student engagement in vocation education. *Teaching and Teacher Education*. 37, 21-32.
- Verhaeghe, S.T.L., van Zuuren, F.J., Defloor, T., Duijnste, M.S.H., & Grypdonck, M.H.F. (2007). The process and the meaning of hope for family members of traumatic coma patients in intensive care. *Qualitative Health Research*. 17(6), 730-743.
- Vivar, C., McQueen, A., Whyte, D. , & Armayar, N. (2007). Getting started with qualitative research: developing a research proposal. *Nurse researcher*. 14(3), 60-73.
- Wade, D. (1996). Goal planning in stroke rehabilitation: How? *Topics in Stroke Rehabilitation*. 6(2), 16-36.
- Wade, D., Leigh-Smith, J., & Langton Hewer, R. (1985). Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *International Rehabilitation Medicine*. 7, 176-181.
- Wallenbert, I., & Jonsson, H. (2005). Waiting to get better: a dilemma regarding habits in daily occupations after stroke. *American Journal of Occupational Therapy*. 59, 218-224.
- Ward, T., Day, A., Howells, K., & Birgden, A. (2004). The multifactor offender readiness model. *Aggression and Violent Behaviour*. 9, 645-673.
- Warren, J.W., Sobal, J., Tenney, J.H., Damron, D., Levenson, S., & DeForge, B.R. (1986). Informed consent by proxy: an issue in research with elderly patients. *New England Journal Medicine*. 315, 1124-1128.
- Watkins, C.L., Auton, M.F., Deans, C.F., Dickinson, H.A., Jack, C.I.A., Lightbody, E., et al.,. (2007). Motivational Interviewing early after acute stroke: a randomised controlled trial. *Stroke*. 38, 1004-1009.
- Wear, S. (1993). *Informed Consent: Patient Autonomy and Physician Beneficence within Clinical Medicine*. Dordrecht, The Netherlands: Kluwer Academic.
- Wellington, J. (2000). *Educational Research: contemporary issues and practical approaches*. London: Continuum.

Western, H. (2007). Altered living: coping, hope and quality of life after stroke. *British Journal of Nursing*. 16(20), 1266-1270.

Whyte, W. E. (1982). Interviewing in Field Research in R. G. Burgess (Ed). *Field Research: a sourcebook and field manual*. London: George Allen & Unwin. Pp 111-122.

Wiles, R., Ashburn, A., Payne, S., & Murphy, C. (2002). Patients' expectations of recovery following stroke: a qualitative study. *Disability and Rehabilitation*. 24(16), 841-850.

Wiles, R., Cott, C., & Gibson, B.E. (2008). Hope, expectations and recovery from illness: a narrative synthesis of qualitative research. *Journal Advanced Nursing*. 64(6), 564-573.

Wiles, R., Pain, H., Buckland, S., & McLellan, L. (1998,) Providing appropriate information to patients and carers following a stroke. *Journal Advanced Nursing*. 28(4), 794-801.

Wilkinson, S. (2008). Focus Groups. In J.A.Smith (Ed). *Qualitative Psychology: a Practical Guide to research Methods*. Pp 186-206.

Williams, L.S., Weinberger, M., Harris, L.E., & Biller, J. (1999). Measuring quality of life in a way that is meaningful to stroke patients. *Neurology*. 53(3), 1839-1843.

Willig, C. (2008). *Introducing Qualitative research in Psychology: second edition*. Maidenhead: OUP.

Wirshing, D. A., Wirshing, W. C., Marder, S. R., Liberman, R. P. & Mintz, J. (1998). Informed consent: assessment of comprehension. *American Journal Psychiatry*. 155(11), November, 1508-1511.

Wohlin Wottrich, A., Astrom, K., & Lofgren, M. (2013). On parallel tracks: newly home from hospital – people with stroke describe their expectations. *Disability and Rehabilitation*. 34(14), 1218-1224.

Wood, J.P., Connelly, D.M., & Maly, M.R. (2010). 'Getting back to real living': a qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation*. 24, 1045-1056.

World Health Organisation Monica Project Investigators. (1988). The WHO MONICA Project (monitoring trends and determinants in cardiovascular disease). *Journal Clinical Epidemiology*. 41, 105-114.

World Medical Organisation. (1964). World Medical Organisation: Declaration of Helsinki. *British Medical Journal*. 313 (7070), 1448-9.

Worrall, L., Davidson, B., Hersch, D., Howe, T., & Sherratt, S. (2009). *What do people with aphasia and their families want? Introducing the goals in aphasia protocol*. Paper presented at Speech Pathology Australia National Conference, Adelaide.

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersch, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: their goals according to the ICF. *Aphasiology*. 25(3,) 309-322.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed). *Qualitative Psychology: a Practical Guide to Research Methods*. Pp 235-250.

Young, C.A., Manmathan, G.P., & Ward, J.C.R. (2008). Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. *Journal Rehabilitation Medicine*. 40, 190-194.

Young, D. R., Hooker, D. T., & Freeburg, F. E. (1990). Informed consent documents: Increasing comprehension by reducing reading level. *IRB*. 12(3), 1-5.

Young, J., & Forster. A. (2007). Rehabilitation after stroke. *British Medical Journal*. 334, 86-90.

Ylvisaker, M., McPerson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping: facilitating goal setting and engagement in rehabilitation after TBI. *Neuropsychological Rehabilitation*. 18(5-6), 713-741.

List of Appendices

Appendix 1 – Ethical Approval Documents

Appendix 2 – Information sheets, questionnaires and consent forms

A2.1 Standard information sheet

A2.2 Standard Questionnaire

A2.3 Standard Consent Form

A2.4 Adapted information sheet

A2.5 Adapted Questionnaire

A2.6 Adapted Consent Form

Appendix 3 – Interview

A3.1 Interview schedule

A3.2 Exploratory Phase Interview reflections

Appendix 4 – Sample research diary pages

Appendix 5 – Transcript and analysis example

A5.1 Sample Line by line analysis (Shirley)

A5.2 Categories (Shirley)

Appendix 6 – Comparison analysis example

Appendix 7 – Sample Memos

A7:1 Memo: Shirley

A7:2 Memo: Expectations of Recovery

A7:3 Memo: Expectations of Rehabilitation

Appendix 8 – Focus Group information sheet and consent forms

A8.1 Information sheet

A8.2 Consent Form

Appendix 9 – Focus Group Questions

Appendix 1: Ethical Approval Documents



Department of Human Communication Sciences
31 Claremont Crescent
Sheffield S10 2TA UK

Head of Department
Professor Joy Stackhouse, PhD., F.R.C.S.L.T., C.Psychol., A.F.B.Ps.S

Telephone: +44 (0) 114 222 2418/ 2402/ 2405
International: +44 (0) 114 222 2418
Fax: +44 (0) 114 273 0547
Email: hcs-support@sheffield.ac.uk
<http://www.shef.ac.uk/hcs>

12th January 2012

Dear Rosemary

Title: Expectations of rehabilitation in the post-acute stage of brain injury

Thank you for your submission to the HCS Research Ethics Committee. The committee has reviewed your submission and supporting documents and grants you approval to commence the research.

We hope your project proceeds smoothly

Yours sincerely



Prof R Varley
Chair of HCS Ethics Committee

ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Names of Ethics Reviewers:	Dr Tom Muskett
2. Research Project Title:	Expectations of recovery and rehabilitation in the post-acute stage after brain injury: pilot study amendment
3. Principal Investigator (or Supervisor):	Rosemary Gravell (Prof Brumfit/Dr Body)
4. Academic Department / School:	Human Communication Sciences
5. I confirm that I do not have a conflict of interest with the project application	

6. I confirm that, in my judgment, the application should:			
Be approved:	Be approved with <i>suggested</i> amendments in '7' below:	and/or	Be approved providing <i>requirements</i> specified in '8' below are met:
X			<u>NOT</u> be approved for the reason(s) given in '9' below:

7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):

8. Approved providing the following, compulsory requirements are met (ethics reviewers <u>need to see the required changes, which should be highlighted in the resubmitted form</u>):
--

9. Not approved for the following reason(s):


10. Date of Ethics Review: 11 September 2012
Signature of reviewer: 

ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Names of Ethics Reviewers:	Prof P E Cowell Dr Tom Muskett Dr Catherine Tattersall
2. Research Project Title:	Expectations of recovery and rehabilitation in the post-acute stage after brain injury
3. Principal Investigator (or Supervisor):	Rosemary Gravell (Prof Brumfit/Dr Body)
4. Academic Department / School:	Human Communication Sciences
5. I confirm that I do not have a conflict of interest with the project application	

6. I confirm that, in my judgment, the application should:			
Be approved:	Be approved with <i>suggested</i> amendments in '7' below:	and/or	Be approved providing <i>requirements</i> specified in '8' below are met.
X			NOT be approved for the reason(s) given in '9' below:


7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):
•
8. Approved providing the following, compulsory requirements are met (ethics reviewers need to see the required changes, which should be highlighted in the resubmitted form):
9. Not approved for the following reason(s):
10. Date of Ethics Review: 15 November 2012
Signature of reviewer: 

ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Names of Ethics Reviewers:	Dr Tom Muskett
2. Research Project Title:	Expectations of recovery and rehabilitation in the post-acute stage after brain injury: Supplementary Study (Focus Group)
3. Principal Investigator (or Supervisor):	Rosemary Gravell (Prof Brumfit/Dr Body)
4. Academic Department / School:	Human Communication Sciences
5. I confirm that I do not have a conflict of interest with the project application	

6. I confirm that, in my judgment, the application should:			
Be approved:	Be approved with <i>suggested</i> amendments in '7' below:	and/or	Be approved providing <i>requirements</i> specified in '8' below are met:
X			NOT be approved for the reason(s) given in '9' below:

7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):
8. Approved providing the following, compulsory requirements are met (ethics reviewers <u>need to see the required changes, which should be highlighted in the resubmitted form</u>):
9. Not approved for the following reason(s):
10. Date of Ethics Review: 17 September 2013
Signature of reviewer: 

Appendix 2:1 Standard Information sheet

Expectations of Rehabilitation after stroke or brain injury :

Information sheet November 2012

Invitation

You have been asked to consider taking part in a research project. It is important that you understand why the research is being done and what it will involve for you **before** you decide to take part.

Please read this information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you need more information. Take time to decide whether or not you want to take part.

What is the project about?

We want to improve our service. We will do this by interviewing clients and asking them for their views. In the interview you will be asked about what you expect from having rehabilitation at the Rehabilitation centre.

Why have I been chosen?

You have been chosen because you are over 18, have had a brain injury/stroke and have been referred, but have not yet been assessed. Taking part in this study and being assessed at the rehabilitation centre are not connected.

Do I have to take part?

No. It is entirely up to you whether you take part or not. If you do agree you will be asked to sign a consent form, but you can withdraw at any time, without giving a reason.

Taking part will not affect your treatment.

Saying no will not affect your treatment in any way.

What would I have to do?

Before you are assessed, I would visit you at your home and talk to you about your views and expectations of rehabilitation. This will take about an hour.

You may complete this in one visit or over two visits. If two visits are needed, the second will take place within one week of the first

It would be audio-recorded.

Once you attend for assessment, no further interviews will be requested.

Your assessment timing will not be influenced in any way by the research project.

I would contact you by telephone to arrange a convenient time for you, within the hours of 9am and 4pm, from Monday to Friday.

Are there any possible problems or risks?

I am aware that you have been through a traumatic experience and that talking about it may be upsetting or distressing. If you are worried about this, it may be best to decide not to take part. You may find the interview makes you tired – if so, you can always ask for a break or to stop.

Are there benefits?

There are no immediate benefits to the people taking part in the project, but it is hoped that the information gathered will help to improve the service for people in the future, and may also be of value to other services working with people who have had brain injuries.

What if something goes wrong?

If you are unhappy about any aspect of the research and how it affects you, you can either talk to me or to the project supervisors, whose address is at the end of this sheet.

Will this information be kept confidential?

All information about you will be kept strictly confidential within the project. You will not be identified in any reports or publications. When the project has been fully reported, all personal information and recordings will be destroyed in line with the rehabilitation centre's confidential waste disposal practice

The audio-recordings of the interviews may be used in academic reports and in conference presentations/lectures, but your name will not be included in or alongside these recordings.

No-one outside the project will have access to the original recordings. Your name and personal details will be kept separately from the recordings and other data.

I will also have access to the clinical notes held for all clients, which are securely held and confidential to the service, in order to obtain information (such as age and diagnosis) that I will need for my report. The notes will not be removed from the centre.

If you say something that suggests there is a significant risk to yourself or others, I may not be able to keep it confidential. In this event I will talk to you about what to do. This will be in line with existing service policy.

What will happen to the findings?

The research findings will form a PhD thesis for The University of Sheffield. There may be additional reports published from the research. The findings may be shared via professional conferences and academic lectures. However, you will not be identified personally.

Who is behind the research?

There is no funding for this research. It is part of a University Research Degree, and has been approved by the Department of Human Communication Sciences Research Ethics Review Panel, in accordance with procedures at the University of Sheffield.

It is undertaken with the agreement of the rehabilitation centre.

You can get more information by contacting:-

Rosemary Gravell, Lead Researcher

Or

Prof. Shelagh Brumfitt / Dr Richard Body, Project Supervisors

Dept Human Communication Sciences, University of Sheffield,

Claremont Crescent, Sheffield, Yorks S10 2TA

0114 222 2406

s.m.brumfitt@sheffield.ac.uk

Complaints

We hope that taking part in this research will not present any problems for you. However, if you have concerns that you do not feel can be addressed by me, then you can use the University's standard complaints procedure by contacting the following.

1. The project supervisors: Professor Brumfitt and Dr Body (as above)

2. Professor Patricia Cowell

HCS Director of Research

Dept Human Communication Sciences, University of Sheffield,

Claremont Crescent, Sheffield, Yorks S10 2TA

0114 222 2406

p.cowell@sheffield.ac.uk

3. The Registrar & Secretary

The University of Sheffield

Firth Court, Western Bank, Sheffield S10 2TN

0114 222 1100

registrar@sheffield.ac.uk

Appendix 2:2 Standard Questionnaire

Have you understood what you are being asked to do?

	YES	NO
Is this project about finding out what people expect from rehabilitation?	<input type="checkbox"/>	<input type="checkbox"/>
Do I have to take part?	<input type="checkbox"/>	<input type="checkbox"/>
Does taking part mean I will definitely have rehabilitation at the centre?	<input type="checkbox"/>	<input type="checkbox"/>
Will refusing affect my treatment in any way?	<input type="checkbox"/>	<input type="checkbox"/>
Will the interview be recorded?	<input type="checkbox"/>	<input type="checkbox"/>

Can I stop at any time?

Will I personally benefit from it?

Will I be identified by name?

Is this research through the NHS?

Participant Consent Form

Title of Research Project: Expectations of rehabilitation in the post-acute stage after brain injury.

Name of Researcher: Rosemary Gravell

Participant Identification Number for this project **Please initial box**

1. I confirm that I have read and understand the information sheet dated November 2012 explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I give permission for my interview to be audio-recorded.

4. I give my permission for parts of the recording to be used at academic Conferences/for educational purposes.

5. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

6. I agree to take part in the above research project.

Name of Participant
(or legal representative)

Date

Signature

Lead Researcher

Date

Signature

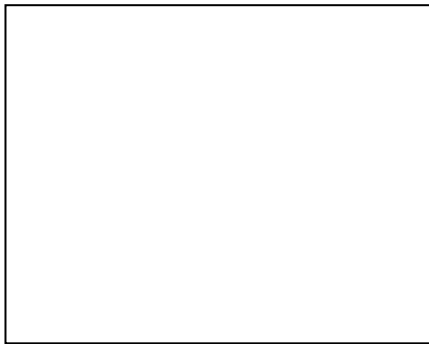
To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Research : Rehabilitation after brain injury

You have been invited to talk about your **brain injury**.



Rosemary Gravell

I am a Speech Therapist
and Counsellor.

I am also a research
student with
Sheffield University.



I want to talk to you
about what **you expect** at the
rehabilitation centre.

We want to make the service **better**.

Why have I asked you?

I am talking to people who have been **referred** to the centre.

You need to **understand** about the research.



You can ask **questions**



You can have **someone with you.**

You do not **have to** take part.

You can say **NO now** or **later**.

It will **NOT** affect your therapy.

What will I do?



Before you come to the centre.
I will visit you **at home**.

You choose the day and time.

It will take about **1 hour**.



You can **rest** or **stop whenever** you want.



It will be **recorded**

I may ask to **visit again**.

I may look at your **medical Records**, to get information such as age and diagnosis.

Benefits?

It will **help the rehabilitation centre**.

It may **help other people** with brain injury in the future.

It will **NOT** help you get better.

It does **NOT** mean you will go to the centre.



What you say is **private**.

Your name will not be used.

Tapes will be kept **secure**.

The only people who hear the complete tapes are:



Me
My supervisors
Other researchers involved

I may use parts of the tapes in presentations.
Your name will not be used.

Possible **problems?**

You **may** feel **upset**.

You **may** get **tired**.

What happens with the research?



I will **talk** at conferences
and **write about it**.

I will **NOT** use your
name or details.

It is **NOT NHS** research.

No-one is paying for this research.

It is part of a University Research Degree.

It has been approved by a University of Sheffield
Ethics panel.

The rehabilitation centre supports the research.

Questions or complaints?



You can contact me:

Rosemary Gravell

My supervisors:

Prof. Shelagh Brumfitt & Dr. Richard Body

Dept. Human Communication Sciences

University of Sheffield,

Claremont Crescent

Sheffield S10 2TA

The Director of Research: Prof. P Cowell

Dept. Human Communication Sciences

University of Sheffield,

Claremont Crescent

Sheffield S10 2TA

The university :

The Registrar and Secretary, University of Sheffield

Western Bank, Sheffield S10 2TN



Have You Understood?

	YES	NO
It is about what you expect from rehabilitation	<input type="checkbox"/>	<input type="checkbox"/>
Do I have to take part?	<input type="checkbox"/>	<input type="checkbox"/>
If I say YES, does it affect my therapy at the centre?	<input type="checkbox"/>	<input type="checkbox"/>
If I say NO, does it affect my therapy at the centre?	<input type="checkbox"/>	<input type="checkbox"/>
Will I be recorded ?	<input type="checkbox"/>	<input type="checkbox"/>

Can I **stop** at **any time**?

Will it **help me**?

Will my **name** be used?

Is this **NHS** research?

Appendix 2:6

Adapted Consent Form

University of Sheffield

CONSENT FORM



I understand it is research
Into **brain injury**



I can ask **questions**



I can **stop** at **any time**



I will be **recorded**



Parts of the tape can be used for **education/academic purposes**



What I say will be kept **confidential**



I **agree** to take part

Name:

Date:

Signature:

Researcher Name:

Date:

Signature:

Appendix 3 Interview schedule

Expectations of rehabilitation in the post-acute stage after brain injury

Introduction

- Repeat information re consent; purpose; confidentiality; right to stop/withdraw; no effect on relationship with the service; does not mean you will be accepted on a programme.
- Get written consent.

Background/Context

- Can you tell me about your stroke/brain injury from when it happened until now?
- Tell me about how you are getting on day-to-day.
Prompt : successes/achievements; problems
- Did you have any knowledge of stroke/brain injury before this happened to you?
Prompt : people you know/family/professional role

Understanding of Rehabilitation

- What is your understanding of 'Rehabilitation'? What do you think 'Rehabilitation' is all about/means?
- Tell me what experience you have already had of rehabilitation.
Prompt : Self (home/hospital; different disciplines) and Others
- How did you come to be referred to the centre?

Expectations

- What does going to the centre mean to you?
- I am interested in learning about what you expect if you do go to the centre for rehabilitation. Tell me your thoughts about it.
Prompts : Hopes; Fears/concerns; potential problems; practicalities; physical/mental/emotional/communicative aspects
- What part do you expect to play in your rehabilitation?
- How do you view the future?

Closing

- Are there any other thoughts you have about rehabilitation that have not been covered today?
- Do you want to make any comments or ask any questions before we finish?
- Get consent for possible further visit & Thanks.

Appendix 3:2 Reflections on Exploratory Phase Interviews

The specified questions are perhaps used too inflexibly and risk biasing the intention of gaining knowledge of the clients' own experience. The structure follows the guidance/advice in terms of starting and ending with less sensitive areas. I did have the schedule with me for the interviews and referred to it at times, but less in subsequent interviews. It did help to stop me worrying about what to ask next.

The schedule was considered in the light of Smith and Osborn (2008) and Whyte (1982). In the transcripts there is evidence of all the behaviours noted by Whyte. The introduction of new topics is related directly to the interview schedule questions. Most comments and follow up questions related to the most recent remark from the client, but there were occasions when I returned to earlier points.

The transcripts do show this general advice was followed. There are examples of following up client's comments; pulling back when too emotive/sensitive; checking understanding; validating experience; responding to client's words/language; and not rushing.

Common pitfalls

Field and Morse (1989) offer a list of eleven common pitfalls in interviewing. In relation to this project there were four that had particular relevance. There were interruptions from outside – in one case a telephone call (not taken by the client) and in one case a dog – but neither event seemed to interrupt the flow significantly.

The other three concerns were related to the interviewer's behaviour. One issue is the danger of counselling rather than interviewing, a great temptation to a qualified Counsellor, by summarising too quickly and thus interrupting the flow. This did perhaps occur on a couple of occasions, and is something to be aware of in future interviews. There is also the risk of presenting one's own perspective and risking biasing the interview. In interviewing client one, asking a question about his expectations of recovery led to a response that referred to the question – 'if you asked that you must mean I might not recover'. On reflection the question was too directive and could have been worded more neutrally.

The other relevant pitfall is jumping between subjects. The schedule sought to ensure that questions followed in a logical order, and therefore could lead in to the next area.

Another issue that Britten mentions (2006) is that of being asked questions – as he states 'the problem with this is that in answering questions, clinical researchers may undo earlier efforts not to impose their own concepts on the interview' (p16). He suggests one possible, albeit not ideal, method is to promise to return to the question/issue at the end of the interview.

In the interviews this approach was taken with client 3, who became distressed, as a way to ensure her concerns were not dismissed but that the interview did not turn into a counselling or information giving session, which would have affected the data adversely.

Reflections on individual interviews

Client 1

In line with principles suggested in the literature, opening questions were factual and designed to allow the client to tell their story at their own pace. Subsequent questions followed the pre-formulated schedule. It is clear when the questions identified on the schedule are asked, although not followed word-for-word, and when the interviewer is following up on comments/narrative from the client. This is largely through prompts and specific, but open questions. Often the suggested prompts from the interview schedule are used. Sometimes yes/no questions are used, but this seems to be acceptable in relation to establishing certain types of experience and ensuring certain aspects are considered – such as checking the different disciplines against the client's knowledge/experience.

Paraphrasing is used to clarify understanding and check accuracy. Validation of the client's difficulties is used to draw out points further and to establish rapport via conveying the intention is to understand his perspective.

This client had to request repetition of the question on a number of occasions, as a result of his cognitive impairment. At times I became evasive and wordy as I struggled to remember the exact question asked, and he wanted to have the actual question repeated in his desire to do the interview 'properly'.

At times questions or comments needed to be reworded to clarify. One example was in asking about the client's role in the rehab process, and another when asking whether he expected full recovery– in both cases my phrasing may have been leading.

On two occasions I picked up on specific words used as they seemed to be indicative of particular significance to him – 'skiving' and 'shame'.

I did return to issues raised earlier in the interview on two occasions. One was to clarify and extend understanding, but the second example was when I was trying to move him off topic as he was asking for information about the likelihood of recovery and had read into my question a suggestion that he may not recover. My discomfort also led to a wordy response to attempt to reassure. I moved the subject to a more factual area thinking it would reduce the emotional tension.

I went outside the schedule in asking a question about feeling he was the same person, which was sparked by his comments. I also added another new question about whether he had an image that summed up his experience. I am not sure that

this contributed to the interview goals, but was more about my own interest in clients' representations of experience through metaphor.

I did challenge an apparent contradiction at one point, but I think this was at an acceptable level and seen by the client as checking out understanding, and could not have been interpreted as 'catching out'.

Closing the interview was done by offering a couple of opportunities to generate any areas of significance that had not been covered.

My perception was that we had established a rapport. He commented that he had not talked about many of the issues covered before or been able to open up in this way.

Client 2

The same schedule was used. Prompts and questions were needed to facilitate the narrative at times, and elicit more information. This client seemed more 'factual' in responses rather than introducing more emotional areas. Occasionally I felt that my attempts to elicit more depth of information were received a little irritably as he felt he had already answered the question. I deliberately made comments without emotional content to keep him at ease (such as acknowledging his interest in holidays) and did not feel probing into feelings was appropriate.

When he did introduce areas of more significance I did follow up (e.g. Feeling his recovery had reached an impasse and his fears of boredom/stagnation).

In relation to his views about the centre's role, I asked some directive questions because of areas introduced by the first client – that is, work and family. I do not think I led in that a particular answer was expected, but undoubtedly I was the one who introduced the topics, so I introduced some bias to the data – neither area may have been significant enough to him to raise spontaneously. I also found more prompts and questions were necessary with this client to elicit information – I tried to gather knowledge about what he wanted from rehabilitation by asking about his experience to date and what could have been improved.

I also raised the question of seeing the point of therapy tasks, which came out of the first interview, and returned to my added question about an image/metaphor of what had happened.

I found this interview harder work, and felt it did not manage to gain a deeper understanding of his experience. However, on analysis there was more implied and 'hidden' meaning than I appreciated at the time.

I felt uncertain about the level of rapport achieved. At times I felt he was irritated by the questions, and perhaps my attempts to probe more deeply gave the impression I had not listened to his responses the first time.

Client 3

The same schedule was followed. This client was the only woman interviewed. The nature of her difficulties and concerns made this the most emotional interview and she wanted to explore and understand her experience as much as I did.

As in the other interviews I used prompts, questions and occasional challenge to clarify and understand her experience.

She became emotional on a number of occasions, and I chose to respond to these moments by offering reassurance that we would come back to the issues at the end of the interview, which I did. I did not feel the issues could be dismissed for reasons of humanity or, more prosaically, for purposes of developing rapport. At these points I changed the subject or asked more specific questions to draw back into less emotive areas.

I did attempt to paraphrase/summarise the issue raised about being heard by the SLT who told her she had no concerns. I was concerned that I had over-stressed this for my own reasons, but was reassured at the close when she mentioned that as one of the areas she had wanted to talk about. However it did raise my awareness of the risk of putting words into the interviewee's mouths.

She asked for reassurance to which I responded with normalising statements, trying to avoid explanation or counselling. However I was quite wordy and hesitant in my responses, indicating my own doubt about the appropriate response to make.

Following up on areas she introduced, as with the others, meant that each interview covered certain common ground but also individual issues – for example, in her case her seizures, the value of humour and early hallucinations - that the others had not raised. This highlights the individuality of the experience of brain injury, and the need to remember this even while exploring the possibility of a unifying model/theory.

I stayed with the question about an image that summarised the experience, and need to consider whether this is appropriate to retain. I also asked the question about being asked to do tasks, which was a leading question based on what earlier interviewees had said. Again I need to reflect on the appropriateness of this – I may well be putting words into the client's mouths.

The rapport with this client seemed good. She commented on how much better she felt having talked to me, and perhaps opened up more because she began to view the process almost like a counselling session.

Overall reflections/concerns on interviews

- Leading and directing too much
- Summarising/clarifying too soon or in my words, rather than their own.

- Wordiness and hesitancy when asking follow up questions or responding in the moment.
- Is it appropriate to change the focus/topic if the emotional tension seems too high, or am I falsely affecting the flow of the client's experience?
- My voice seems lacking in expression apart from a couple of instances, and I speak very slowly and deliberately. In working with brain injured clients the rate may be beneficial, but the tone may be off putting or be calming and helpful.
- I think I gave adequate time for clients to respond and raise issues, and did not feel the interview was rushed at all.
- The interview schedule questions seem appropriate, but probably make the interview semi-structured. Is there debate over the appropriateness of this to a grounded analysis? Is this schedule/guidance for the interview at a suitable level to allow a grounded analysis? Am I using it too inflexibly?

Appendix 4: Sample Research Diary pages

	<u>Reflections</u> <u>10/5/13</u>
	Issues to consider
1.	— What people do <u>not</u> disclose & why (depression? marital issues? fears re future?) especially when additional info available. — choices re disclosing or not disclosing.
2.	Learning from experience — variety of hospital/post-acute impact on expectations?
3.	Identify constructed actions/processes <u>NOT</u> topics eg. ? memories of early stages not just factual topic ?
4.	Can the model apply to newcomers into service?
5.	Possible considerations motivating factors Self determination / trust in self vs. trust in experts Pre-morbid beliefs
6.	Need to diagram/chart causes & conditions of phenomena.
7.	Difference between what rehab "should do" and "can do" in belief constructs

Sampling is done not to generalize but to illuminate and understand the topic. Once a model is developing, sampling develops this by selective data collection. Range of possible relevant perspectives / negative cases may help develop theory.

- Should categories change from topic →
- Remembering / making sense of what happened
 - Being Unprepared ✓
 - Motivating aspects
 - life context
 - stage of life
 - taking stock / ^{finding} meaning
 - Changing expectations
 - hope
 - doubt
 - despair
 - acceptance
 - Trusting & Doubting {

{	expens / services	}	pre/post event?
	self		
	others		
 - Finding self worth / making sense of the future
 - judgement
 - blame / shame
 - +ves

Questions to ask of model :

- If have prior knowledge/experience what is the impact?
- ~~How~~ does early awareness / memory of event make a difference?

Appendix 5:1 Sample Line by Line Analysis (Shirley)

<p>Accepting what told Having no memory</p> <p>Trusting others' accounts</p> <p>Not remembering the day</p> <p>Having no memory</p> <p>Coming to in hospital Being aware of pain Having individual memories</p> <p>Being told she couldn't walk Being stopped from walking</p> <p>Knowing she was in hospital but not remembering</p> <p>Being told she was difficult to cope with Having no memory</p> <p>Memory gradually improving Being terrible with faces/names Remembering isolated incidents Remembering doctor talking to her Feeling panicked Not knowing where she was Thinking things had been moved Being distressed Fearing others had had accidents Panicking if people were late Being very distressed Being kept in the dark (eyesight and information)</p>	<p><i>Just put this on.</i> Yes that's fine. <i>Brilliant. And I always start Shirley by just asking you to tell me as much as you can about what happened to you.</i> I can only tell you what I've been told because I have no memory of it. I was driving along the road on my scooter and a car pulled across in front of me and knocked me off the scooter and sent me over the roof, into the road and all sorts of things happened to me but I have no memory of it. <i>OK. Where do you remember up to before that?</i> I don't even remember much of the day. If I'd been asked to be specific I would have been able to tell them who I'd been visiting but I honestly can't really remember. I don't have any memory of the day. <i>No. And so when's your first memory after it?</i> After it, when I came to in the hospital I woke up and I felt pain in my knees, and that's my first memory. I don't remember beinganywhere else other than ... just individual memories. I have a memory of being stopped from trying to walk...and being told....being pushed back into the bed. My legs being lifted up and put back into the bed...and I was told that I couldn't walk, so I mustn't try because I would break a bone if I fell. And that's my...my first memory. I have no memory of being at the hospital before that, because I was in hospital – I can't remember the name of it...but it was a ...it's a famous hospital. <i>Somewhere local?</i> Yeah but I was taken there from the first hospital because they couldn't cope with me, but I have no memory of being there. <i>And then – so you then sort of got a first memory, and from there has it gradually...?</i> It's gradually improved. I'm...I'm terrible with faces and names – I get them confused but I can remember what happened. You know the doctor came and he gave me medication and spoke to me about certain things – I can remember all of that –that we discussed my medical health. But I can't...I can't tell you – I can remember feeling panicked because I didn't know where I was, and I felt I'd been moved – things weren't where I expected them to be, and I really did get distressed about them and I can remember feeling panicked because my daughter hadn't turned up when I thought she'd said she was going to come and I immediately thought she'd had a traffic accident because I had had one, you know, and everybody that was late I thought had had a traffic accident....because I thought that would happen. <i>It sounds like confusing and scary.</i> Oh very distressing. I was finding that things were being moved and because of my eyesight I wasn't being told about them being moved, and then I was coming to and realising I was – they'd been moved</p>	<p>00:30</p> <p>01:00</p> <p>01:30</p> <p>02:00</p> <p>02:30</p> <p>03:00</p> <p>03:30</p>
--	--	--

<p>Not being told what was happening</p>	<p>and I felt as if I was in a different place, and the nurses were telling me that I hadn't been moved and that they'd only moved certain things but I found that distressing.</p>	
<p>Not being reassured by what people said</p>	<p><i>Sure - absolutely, and the – sort of the things you do now know about what happened, who's sort of – who's filled in those gaps for you?</i></p>	04:00
<p>Not believing what people said</p>	<p>My daughter has told me. My mum has also told me certain things on the telephone when I've spoken to her, because she spent a couple of weeks here, when I was in hospital cos I was in a coma, for three weeks, and they were told I was going to die. My daughter was told to say goodbye to me twice...so she found that distressing, and my mum was told and my brothers and sisters were told that I was not going to survive. I've proved them wrong. (<u>Laughs</u>).</p>	04:30
<p>Trusting daughter's accounts</p>	<p><i>Big time.</i></p>	
<p>Trusting mother's account</p>	<p>Absolutely. (<u>Laughs</u>)</p>	
<p>Being in a coma for three weeks</p>	<p><i>So they filled in the gaps – do you feel you've made sense of it now in your own head or is it still difficult?</i></p>	
<p>Knowing family were told she would die</p>	<p>Not entirely – I mean I understand what happened, I understand that I've had brain damage but I don't feel as if I've had brain damage, you know I feel as if my brain's working OK– it's just my memory's at fault. And my speech was at fault....but I think I've managed to correct that. I can make myself understood by most people, so I think I've managed to sort that out. And the children didn't seem to know me but that's sorted itself out once I came home. I did insist on coming home and my daughter felt that I was being a bit unreasonable but I knew I'd be better off here and I just felt that I was not going to be helped in the hospital because I just felt kind of neglected.</p>	05:00
<p>Knowing daughter told to say goodbye</p>	<p><i>Right.</i></p>	
<p>Knowing daughter distressed</p>	<p>And I did kind of say something to my daughter about that and she got quite cross and you know she asked was I being neglected andthe thing was that I felt I'd been left without explanation.</p>	05:30
<p>Knowing family were told she would die</p>	<p><i>Right –so I guess that links up to finding it difficult to make sense of what happened to you?</i></p>	06:00
<p>Proving them wrong by surviving</p>	<p>Yes. I couldn't make sense of it because I was being left for hours on my own and that was quite distressing. You know because you can't just...you can't tell your mind what to think...and I must admit because something my mum said, and she said something about how long they'd been told that I was going to survive was something like six weeks, and I thought that's not six weeks yet – and I was so convinced that if I went to sleep I wouldn't wake up.</p>	06:30
<p>Understanding facts of what happened</p>	<p><i>That's terrifying.</i></p>	
<p>Not feeling brain damaged</p>	<p>Yeah and I found it really terrifying and there's nobody to talk to – I did ask for someone to talk to and they didn't provide anyone, so I – you know – I repeatedly said I needed someone for counselling (<u>crying</u>) but I didn't get it.</p>	07:00
<p>Knowing memory is 'at fault'</p>	<p><i>Yeah. Yeah.</i></p>	
<p>Correcting poor speech</p>	<p>And I knew what I needed, and I kept asking and I did ask three or four people.</p>	
<p>Sorting out her speech</p>		
<p>Making herself understood</p>		
<p>Not being the same for grandchildren</p>		
<p>Improving at home</p>		
<p>Insisting on coming home</p>		
<p>Being thought to be unreasonable about coming home</p>		
<p>Knowing she would be better at home.</p>		
<p>Feeling neglected in hospital</p>		
<p>Telling her daughter she felt neglected</p>		
<p>Feeling alone/left without explanation</p>		
<p>Not making sense of what was happening</p>		
<p>Being left alone and distressed</p>		
<p>Not being able to control her thoughts/feelings</p>		
<p>Being aware that family told she only had six weeks to live</p>		
<p>Being convinced she would die if she slept</p>		
<p>Having no-one to talk to</p>		
<p>Repeatedly asking to talk to someone</p>		
<p>Not being given someone to talk to</p>		
<p>Knowing she needed to talk about it</p>		
<p>Not having opportunity to talk</p>		

<p>Asking several people and getting nothing</p> <p>Having one excellent student</p> <p>Being helped by student</p> <p>Writing to commend student</p> <p>Needing to tell student she would not have survived without her help</p>	<p><i>Was there anyone that you could at that stage get a sort of ...any sort of relationship with to talk?</i></p> <p>There was. Once I came back to this hospital there was an excellent girl – she was in physiotherapy ...her name was S and she was doing what you’re doing – a university degree.</p> <p><i>Oh OK.</i></p> <p>But she was doing this as work experience and she really did help me (she really was excellent).</p> <p><i>(Right. Excellent)</i></p> <p>I wrote a letter – I wrote a note for her teacher because I felt that she needed that, you know that I needed to tell her that I wouldn’t have survived without her.</p>	<p>07:30</p>
<p>Student’s help meaning a lot</p> <p>Feeling there was no point trying</p> <p>Having fixed idea in head because told she couldn’t walk</p> <p>Being encouraged to try</p> <p>Being heard</p> <p>Getting response to requests</p> <p>Finding information out for her</p> <p>Being helped to understand</p> <p>Feeling someone took time and trouble</p> <p>Praising student</p> <p>Appreciating student taking extra care</p> <p>Knowing she needed someone to care</p> <p>Being encouraged if she felt she couldn’t do something</p> <p>Trying</p> <p>Managing to do tasks with encouragement</p> <p>Believing she had a relationship with someone</p>	<p><i>That would mean a lot.</i></p> <p>She...It really did mean a lot to me. That she – when I said that I couldn’t walk because I’d been told I couldn’t walk and I’d got that firmly fixed in my head that there was no point in trying, but I did need to try. And the things that I asked her for she provided and she went to the trouble of when I said things she thought she didn’t understand and she went on the internet and then came back and told me what she’d found out. You know with the brain damage and the bleeding on the brain and the things I didn’t understand she was able to clear up for me and she took the time and the trouble to do that...so she was really good. She even came to see me in the residential home, so you know because that was her last day in work experience she popped over to say goodbye to me, and went back to college, so you know I really did appreciate what she did.</p> <p><i>And you knew that was what you needed?</i></p> <p>I knew that I needed that and she also stopped me when I said I couldn’t do it, and she said just try. And I did try and I managed to get up on my feet and walk with a parallel bars...you know that really did help me. The physiotherapist was there and she was you know sort of encouraging me too, but I felt that I had a relationship with S..with...with...</p> <p><i>With the student yeah.</i></p> <p>With the student.</p> <p><i>And how – after all that – how are you now coping back at home on (a day to day basis?)</i></p>	<p>08:00</p> <p>08:30</p> <p>09:00</p> <p>09:30</p>
<p>Coping fine at home</p> <p>Having carers for washing/dressing</p> <p>Being looked after by daughter</p> <p>Relying on daughter</p> <p>Feeling bad about relying on daughter</p> <p>Hating role reversal</p> <p>Wanting to be helping daughter</p> <p>Describing role with daughter before accident</p> <p>Combining work and child care for daughter</p>	<p>(Oh very well) actually I’m coping fine. I have carers come in in the morning and they help me get washed and dressed, after that I mean my daughter helps me all day. She has to go to work but I’m on my own a few hours and I manage to get up and go to the toilet and she always leaves me lunch ready for me and tablets ready for me so I can take those when I need to – so I manage OK on my own, but I do rely on her and I do feel bad about that. Well I feel as if – you know – she’s my daughter – she should be relying on me rather than the other way round. That’s how it used to be because when – before the accident I used to look after the children when she went to work. I used to come home from...I lived here...I’d lived here for just over a year because they’d asked me to come and live here, and I’ve got ...this is my sitting room and I’ve got my bedroom upstairs.</p>	<p>10:00</p> <p>10:30</p>

Living with daughter before accident	But they...you know, I came to live here and I looked after the children. I came home from work, she went to work, she came home and I went back to work...and it worked like that. It was OK. But	11:00
Being experienced looking after children Being foster parent/child minder Being trusted by daughter to look after children Feeling strange about being looked after Comparing with past as carer of others Being hard to accept she needs help Feeling better physically Feeling more in control mentally	because I'd spent a lot of time looking after children in a previous – you know, a previous time, I'd child-minded and I'd fostered children, so she was aware of all that you know –she had brothers and sisters and sharing things so she knew that I was experienced, so I looked after the children.	11:30
Remembering distant past	<i>So it's a strange role for you to be in now?</i> It is – a very strange role for me to be reliant on someone. I've always been the one that people rely on....and now it's opposite, so it's very difficult for me to accept that I need help. <i>Do you still feel things are moving forward and progressing?</i> I do feel as if I'm... I'm getting better. Physically I feel better. Mentally I feel as if I'm in more control....with my brain (Laughs) I don't feel as if I...I can remember things from the past – I can remember you know things that my mum says that happened when I was a child, I can still remember them. I can remember my dad – he's been dead a few years. I did find difficulty when I first....I can remember – I answered your question wrong. I do have a different memory.	12:00 12:30
SECTION REDACTED TO MAINTAIN CONFIDENTIALITY		
Remembering more now	<i>And now you remember much, much more?</i> I remember much more, yes.	15:00
Remembering daily life	<i>And day to day – how's your memory?</i> That is OK – I can remember things that happened today and yesterday and tomorrow and what's expected of me. That's OK. <i>And what about other um...things – your speech you felt was(...got better)</i>	15:30
Knowing there were records of her bad speech Being told by doctor that her speech had been bad Being told her speech is now OK Being told she was difficult/ demanding in hospital	(I felt that my speech) was very bad at first and it's been recorded that my speech was bad...because when my – I came home, I was worried about my medication so I phoned...my daughter phoned my doctor and he came and spoke to me, and he said that it was recorded that my..my...my speech had been bad, but that it was OK now, so it must have been recorded that – you know he was reading from notes– that my speech had been bad. But apparently I'd been difficult as well...and demanding and unreasonable apparently. I don't – don't associate that with myself because I'm always reasonable – I always feel that I've tried to be reasonable...and I feel bad about that. I do feel guilty if I behaved badly and made life difficult for people.	16:00
Not being able to associate being difficult with self view Seeing herself as reasonable Feeling guilty/bad about being unreasonable Hating that she made life hard for people Seeing herself as calm/reasonable Feeling anger justified if she knew what had happened	<i>Can you make sense of that– you know when you were acting...?</i> No I just don't understand how I could do that because I've always been reasonable – you know I've never been angry – I can understand how I could get angry if I'd known what had happened but I didn't know what had happened...so that doesn't make sense. I've just always been so reasonable. (laughs) <i>So that's hard for you to ...</i>	16:30

<p>Not being able to make sense of her behaviour Struggling to accept her reported behaviour</p>	<p>That is hard for me to understand. <i>And is that about – do you feel people were judging you based on that?</i></p>	<p>17:00</p>
<p>Thinking medics judged her by her behaviour Thinking medics not truthful with her because of her behaviour Seeing medics as avoiding confronting her with truth for fear of upset</p>	<p>Yes probably – that’s one of the things that I felt that maybe that the nurses and the doctors weren’t as truthful as they could have been with me because they were expecting me to be unreasonable. <i>OK...Right so... so it had sort of set up an expectation?</i> Yes and that maybe they were avoiding upsetting me by not – you know – that’s how they worked it out, you know – they didn’t want to upset me so they didn’t confront me, when I could have been confronted.</p>	<p>17:30</p>
<p>Feeling she could have been told truth Acknowledging medics could not know she was reasonable</p>	<p><i>So that would have been the better...(better approach?)</i> (That would have been) better for me, but you know they didn’t know that I was going to be reasonable (<u>laughs</u>) <i>Before all this happened to you, did you have any knowledge of brain injury or stroke?</i></p>	<p>18:00</p>
<p>Knowing about stroke Being a carer for people after stroke</p>	<p>No. Stroke yes – because I’ve been a carer. For seven years I was a carer and some of the people I’ve worked with had strokes – one in particular I can distinctly remember being associated with her because we dealt with her when she first came out of hospital...and we sort of kind of set her up and for a few years I was helping her – not regularly but every so often I went to see her so I could tell the difference – you know the improvements or the lack of progress.</p>	<p>18:30</p>
<p>Seeing improvements and lack of progress in clients</p>	<p><i>Do you see any similarity with what’s happened to you and a stroke?</i> No. No.</p>	<p>19:00</p>
<p>Not connecting stroke/BI</p>	<p><i>So what did you know about brain injury?</i> Nothing. Nothing. <i>Nothing at all?</i></p>	<p>19:30</p>
<p>Knowing nothing about BI Lacking knowledge of how BI affected people after accidents</p>	<p>No. I had never come across anyone with a brain injury from an accident you know, that was... <i>So all very weird?</i></p>	<p>20:00</p>
<p>Feeling BI alien Feeling it happened to another person Not linking BI and self</p>	<p>Yes. And just very alien. You know it’s like it must have happened to someone else. It can’t possibly have been me. <i>And it still feels like that?</i></p>	<p>20:30</p>
<p>Knowing about injuries from physical evidence</p>	<p>It does still feel like that. I know I’ve had injuries because my jaw was broken and it’s – I can feel all the scars in my mouth. I had teeth and my teeth were removed because they’d been smashed and the hospital have left me with no teeth at all, so....they had to remove those because I can feel all the scars, I can feel the inside of my mouth is scarred so I know that happened. My mum has told me that I’m held together with metal (<u>laughs</u>) and my hand is – I’ve had plastic surgery on my fingers (<u>removes wrist/hand support</u>) I wear this...um...only because it aches sometimes but it’s because I went up to the shower I put that on in case – you know – walking up the stairs hurts sometimes and I wear that but I don’t wear it all the time, but I know that the bones in here were broken (<u>indicates hand/arm</u>) .</p>	<p>20:00</p>
<p>Feeling scars and lack of teeth</p>	<p><i>So it’s like you know in your head that all this happened – but it hasn’t quite got as far as your heart yet (-emotionally)</i></p>	<p>20:30</p>
<p>Being told she is held together by metal Having surgery on hand</p>	<p></p>	<p></p>
<p>Using support as hand aches</p>	<p></p>	<p></p>
<p>Knowing bones were broken</p>	<p></p>	<p></p>

<p>Having no memory of pain</p> <p>Praising hospital for pain control</p> <p>Knowing what happened must have caused pain</p>	<p>(No it hasn't.) because I had never in my life broken a bone. I have no memory of the pain. The hospital I was in must have been really excellent, because I have no memory of the pain except when I woke up in the hospital and my knees hurt. I have no memory of waking up with any kind of pain...and I must have been in bad pain because I'd got broken bones all over the place. You know – this must have hurt – having my teeth removed must have hurt – but I don't honestly remember any kind of pain...so they have to be applauded for that.</p> <p><i>So they controlled that well.</i></p> <p>They did control it well.</p>	21:00
<p>Seeing rehab as teaching you to be as normal as possible</p> <p>Having to come to grips with normality</p> <p>Questioning if she needs rehab as she feels normal</p> <p>Understanding she cannot work</p> <p>Feeling frustrated by not being able to work</p> <p>Knowing her eyesight is damaged</p> <p>Being told to practice opening eye</p> <p>Being told sight may correct itself</p> <p>Being told sight was hopeless</p> <p>Getting second opinion from specialist</p> <p>Being given time scale for eye/ one year</p> <p>Exercising eye as told</p> <p>Finding vision confusing</p>	<p><i>So coming on to sort of rehabilitation Shirley, what's your understanding of what rehabilitation is?</i></p> <p>Well rehabilitation is supposed to teach you how to live your life as normal as possible and I think that's what it's for. You have to come to grips with normality. And if you can't manage then you have to learn to be normal, but I don't think I actually need that. I think I'm fairly normal you know. I understand what I need to do I understand that I won't be able to work and I find that frustrating. I mean I understand that I can't see from both my eyes, but I can open it – can you see it's open?</p> <p><i>Yeah, yeah , yeah.</i></p> <p>When it's open I've got double vision but I can open it because my GP told me to keep practicing opening it, because the sight may correct itself. I saw a doctor at the hospital and he told me it was hopeless but then I saw another doctor because I insisted on seeing a specialist and he told me that if I was patient it would correct itself in time – maybe a year – but at the end of the year if it wasn't corrected it wouldn't work. So I've been exercising my eyelids and I can open it, but it does give me double vision, so if it accidentally opens I find it confusing .</p>	21:30
<p>Having physio in hospital</p> <p>Being asked questions in hospital</p> <p>Feeling like an examination</p>	<p><i>Did you have any rehabilitation in hospital?</i></p> <p>Only physiotherapy that's all I had. I did have questions – they came with sheets and asked me questions – went through lots of sheets like it was an examination (<i>laughs</i>) "Could I read this, could I understand this, could I tell them the opposite to this was I able to describe something, could I understand the difference between a sheep and a cow, or whatever?" you know – different – just general knowledge.</p>	22:00
<p>Being asked general knowledge questions</p>	<p><i>How was that for you?</i></p> <p>That was OK. I felt like I was under an examination, but I managed it really well.</p>	22:30
<p>Feeling she was being examined but managed well</p>	<p><i>Did you see the point of it?</i></p> <p>I could see the point of not being able to answer the questions - that would show them what I couldn't do. I couldn't read, and I must admit I found it difficult to read lots of words, but I've managed that now. I've managed to – I've been practising with my granddaughter's reading books because the print is big...</p>	23:00
<p>Acknowledging failing questions would have given useful info</p> <p>Finding reading difficult</p> <p>Reading better</p> <p>Practising reading on granddaughter's books</p>	<p><i>That's a good idea</i></p>	23:30
<p>Reading books at right level</p>		24:00
<p>Having physio in hospital</p>		

<p>Being asked questions by SLTs Seeing several different young SLTs/girls</p>	<p>And it's not too much of it – I've got some books in the drawer which I can read. <i>So...but the only rehab that you had in hospital was physio?</i> Yes it was just physiotherapy. <i>So no Speech Therapist?</i></p>	<p>24:30</p>
<p>SLTs following paper tasks – not thinking about what they were doing Thinking SLTs not interested really</p>	<p>They came and... <i>Apart from the questions?</i> ..made questions and did I understand this, could I understand sentences even, and that did...there was three or four young girls came and asked me a variety of questions but that was all...and it</p>	<p>25:00</p>
<p>Seeing SLTs as just doing what they 'had to do' Needing someone to care</p>	<p>was just printed on pieces of paper – they weren't really using their brains – they were just reading and writing....and I don't think they were interested really. <i>That's interesting – so you got a sense it was just like....</i> Something they had to do.</p>	
<p>Finding physio student did care Having evidence of caring by doing more than necessary</p>	<p><i>It's not what you want is it?</i> No it wasn't. I needed....I don't know, I just needed someone to care. <i>Yeah.</i></p>	<p>25:30</p>
<p>Being helped by caring person</p>	<p>And I did have that with the physiotherapy – she did care. And she showed – you know she showed me she cared because when I said things she didn't understand she went and found out, only she wouldn't have done that if she didn't care. <i>Absolutely. Yeah.</i> So she helped.</p>	
<p>Asking to see a psychologist Needing to talk to someone</p>	<p><i>And the OT – did you see any occupational therapists?</i> No. <i>And no psychologists?</i> No Just the questions and physio?</p>	<p>26:00</p>
<p>Having evidence of caring from student putting herself out</p>	<p>Yes. I mean I asked to see a psychologist because I felt that that's what I needed at the time. <i>Yeah – that was when you were feeling distressed?</i></p>	
<p>Having student provide what she needed</p>	<p>I was – when I was feeling – I needed someone to talk to. And it was only the physiotherapy that really wanted to talk to me. She was actually interested you know, she even came and put herself out, she came in the daytime and she took me for a shower. You know and I hadn't had a shower at all in the weeks I'd been there and I said something to her about not having had a shower and she said I'll come, and she came in the morning, she put herself out – she came early, you know she really did care, and I appreciated that I must admit.</p>	<p>26:30</p>
<p>Having no rehab since return home</p>	<p><i>Yes absolutely.</i> Because I...she provided what I needed. <i>And so you didn't get much input in hospital.</i> I didn't, no.</p>	
<p>Being let down by promised services</p>	<p><i>And have you had any rehab since coming home?</i> I've had nobody – I haven't seen a soul. <i>No physio or anything?</i></p>	<p>27:00</p>
<p>Expecting physio and aids but not getting help</p>		

<p>Having to push to get help</p>	<p>There was supposed to be physiotherapist come – they haven't turned up. They were supposed to help me learn to walk up the stairs. There was supposed to be someone come to fit banisters up. My daughter had to phone up and say she was cross and that she'd help me up the stairs – which she did – and we didn't have a banister, and they came that day, but that's all we've had. We've had no other help at all.</p> <p><i>And when did the referral to the centre happen, Shirley, what stage was that?</i></p>	<p>27:30</p>
<p>Not knowing who referred</p>	<p>Well that came about – about ten days ago.</p> <p><i>So that was done by the GP or...(hospital?)</i></p> <p>(I don't...I) honestly don't know.</p> <p><i>Ok. OK. So the first thing you knew about it was when you got the letter from the centre?</i></p>	<p>28:00</p>
<p>Having phone call from centre Saying she would try anything when asked about the centre</p>	<p>Well when she phoned from the centre. She phoned and asked me was I interested. And I said I would try anything once (<u>laughs</u>)</p> <p><i>So what...what does going to the centre mean to you?</i></p>	<p>28:30</p>
<p>Feeling isolated by not knowing what the centre can do Being told the centre could help her Not understanding why she needed to see another doctor Praising GP Accepting GP's advice/expertise although more pain</p>	<p>I honestly don't know I feel a little bit isolated because I don't know. She explained what was going to happen, that there would be Speech Therapy, that they could maybe help me with my reading, and my understanding of what happened to me, and that kind of thing, and that there was going to be a doctor that would see me, but I didn't understand why I needed to see him because my GP is excellent. He actually came here on the day that we phoned him up and he spent an hour here and he was really, really chatty....and he really was good. He's reduced my medications so I'm feeling pain again but he felt that was necessary.</p> <p><i>So no...no real sense of what the centre....</i></p>	<p>29:00</p>
<p>Having the impression that the centre was a good place before accident</p>	<p>I don't...I mean I know of the centre because I've been with people who've been there, and they have got positivewhat they said was positive, you know that they felt that they was being helped...so I got that impression that it was a good place to go– but I don't honestly know why. (<u>laughs</u>)</p>	<p>29:30</p>
<p>Not knowing why the centre would be good</p>	<p><i>OK.OK.</i></p> <p>Do I make sense?</p> <p><i>Absolutely you make sense. Do you have any sense of what – if you go there – you would expect to happen to you more specifically?</i></p>	<p>30:00</p>
<p>Expecting physical progress to be checked Being upset by reading difficulty Being dependent on daughter for reading Being told reading could be helped</p>	<p>No – that they would check my physical progress and that they would check my mental progress and help me with my ...my reading maybe – that was one thing she did specify that they could help me with my reading because I find that upsetting...you know that I have to keep asking my daughter to read letters for me. She doesn't even bother to bring me my mail now, she opens them and tells me what's in there.</p> <p><i>So you don't really know what to expect. Do you know ...do you have any particular hopes for it rather than expectations?</i></p>	<p>30:30</p>
<p>Hoping for a friendly environment Acknowledging never good at going to new places</p>	<p>Well I hope it'll be a friendly place I'm not very good – I never have been – at going somewhere strange...of going you know into a crowded place. I'm not very good with – I suppose I'm not I'm just not very good with being there as a first time, so I find that</p>	<p>31:00</p>

<p>Being concerned about first visit Worrying that transport means she has to stay until allowed to go home</p>	<p>concerning. I find the idea that transport is being provided and that kind of makes you feel as if you've got to stay until they can bring you home, even if you don't want to. <i>So that feels a bit trapping?</i></p>	
<p>Feeling trapped/not in control Seeing transport as taking control away from her Being controlled by the centre Not wanting to be controlled Wanting to be able to leave at her choice</p>	<p>It does – it feels as if I've got to be there for a specific time because that's your decision...or their decision rather because you're not part of it, so it will be their decision if I'm going to stay x number of hours or whatever and I would rather not be in that position. <i>Sure</i> Because you know you feel like you need to get up and go when you've had enough. <i>So it sounds as if you sort of expect that they will be in charge?</i></p>	31:30
<p>Feeling the centre would be in charge and she would have no say Fearing what she thinks would not matter</p>	<p>They....Yes I feel as if they are in charge and that I've got to do whatever they want me to do and I feel as if they are in charge of me...where I've got...you know I suppose you know what I think doesn't matter. <i>So where do you think that idea's come from – because of what happened in hospital?</i></p>	32:00
<p>Knowing the phone call suggested everything could be helped, felt like taking over</p>	<p>I suppose it's ...yeah it probably is...and because of the conversation we had, you know, on the telephone. I can't remember who I spoke to - I've no memory of her name, I just know that it was female...and everything that I said I'd got problems with she said 'We can help' and it was like she was taking over. you know – the like 'we can help' was like taking over...saying that they can sort that out for you.</p>	32:30
<p>Being told they could sort it out for you</p>	<p><i>So how should it be? You're the expert – you're the person who's had this happen. What do you think you need?</i></p>	33:00
<p>Needing someone to talk to and being ignored in the beginning</p>	<p>Well I needed someone to talk to – right at the beginning. When I asked for someone that should have been provided. I knew that I needed someone to talk to.</p>	
<p>Being affected by bad early experiences</p>	<p><i>And having not had that and you've got to this point here, what do you need now do you think?</i></p>	33:30
<p>Wanting someone to listen Acknowledging family role as supportive Telling daughter she should be proud of herself Praising daughter for being honest</p>	<p>Well someone still to talk to that can listen – but when...you know...I did have I mean my daughter's been excellent, and my son in law's been good, but she has been excellent. You know she's got to be proud of herself – I keep telling her that, but she says I'm her mum and that's what she's supposed to do but you know she's been there for me to talk to, to ask questions, and she's been really honest. And my brother has been good. My sisters have been OK. My mum's been good – you know they've given me someone to talk to.</p>	34:00
<p>Being able to talk to family</p>	<p><i>So you've had it within the family?</i> Within my family. <i>Do you think it's still useful to have someone who's not part of the family?</i></p>	
<p>Thinking she could talk to someone about how she feels Fearing she cannot explain clearly</p>	<p>I think it would be possible that I could talk to someone, explain how I feel. I'm not very good at explaining though. <i>Well you've done pretty well today – made sense all the way. So in terms of what you feel a service should do...one is make sure they're caring, (make sure that...)</i></p>	34:30

Wanting rehab not to be overwhelming	(Yes. Make sure you're in a comfortable) environment and that it's not overwhelming.	
Wanting comfortable environment	<i>Yeah. That's important.</i>	35:00
Thinking best to be seen in home environment as in control	I think so yes. I think that you shouldn't feel as if you're going to be overwhelmed. <i>What do you think might help that?</i> Well I suppose you know if they could come to see you. You could be in a familiar environment then. This is home. I'm comfortable talking to you, because you're in my home and that's, you know, that's a comfortable environment.	
Knowing she can control home environment/ ask people to leave	<i>Yeah I get that.</i> And I mean I could ask you to leave (<u>laughs</u>) if you were being unreasonable. <i>Absolutely and I would go.</i>	35:30
Acknowledging OK with researcher	And yeah I mean...I would never do that because I'm polite and I'm OK with it. <i>But it sounds like it's... it makes you feel really quite anxious (the idea of going out somewhere)</i>	
Being anxious about going out Fearing repeat of hospital experience Not wanting to return to hospital/residential home	(It does make me anxious of going out). The thing was I had a bad experience in the hospital, and I didn't enjoy it and I really, really never want to go back. I ...I mean I didn't even enjoy the residential home. I went to the home and I remember going there— being taken by ambulance on a Thursday - no Wednesday – Wednesday lunchtime, I arrived about one o'clock. I didn't see a human being except for trainee nurses until afternoon next day. I was put in a room, my clothes were unpacked for me, I was given food and medication and that's all.	36:00
Being left alone in residential home	<i>So I can see that sense of being controlled.</i>	
Feeling controlled	And also being abandoned.	36:30
Feeling abandoned	<i>Yeah and lonely. It sounds like it's - it's been a very isolating experience in many ways.</i>	
Feeling isolated by experience – only she knows what is was like	It has yes. And you know it's because it's really personal – what happened to me, happened to me. It didn't happen to anyone else so it is isolating. It's personal but it's affected our whole lives. My daughter planned to go back to work full time next year and she can't do now, because she's going to be my carer. So you know it's spoilt our lives. And the young man that caused this didn't get very much punishment either.	37:00
Knowing it has affected whole family Knowing her daughter has changed her plans to care Feeling angry that other driver not punished more		
	SECTION REDACTED TO MAINTAIN CONFIDENTIALITY	
Wanting answers to questions about recovery	<i>That's tough. What..I mean....if...if ...there's lots of things I think it would be helpful as you've said, to talk through. If they could create a welcoming environment that wasn't overwhelming, what would you like from rehab then? Or hope for?</i> Well I would hope that they could answer some of my questions – like my eye – it worries me. You know...and all the things that concern me.	38:30

<p>Needing physical help to walk better Needing someone with chair if she walks far</p>	<p><i>So information?</i> Yes. My physical ability is in need of help because although I can walk, and given patience and time I can walk quite a long way but I need someone with a chair (<i>laughs</i>) ... because I you know if I need to sit down I need to do it now.</p>	<p>39:00</p>
<p>Hoping to improve physically Hoping to improve memory Hoping to improve life</p>	<p><i>So...but you would hope to improve that?</i> I would hope to be able to improve my physical ability. I would hope to be able to improve my memory...and just ...hope to improve my life.</p>	<p>39:30</p>
<p>Needing to cooperate Needing to try hard Pushing herself has got results so far Taking over rehab in hospital Deciding what she could/ couldn't do herself Wanting to go at own speed</p>	<p><i>And what do you see your role in rehab?</i> Well I think I need to be cooperative. And I need to try hard. I a...I do push myself quite a lot. I mean my daughter was told that I would be in rehabilitation for a year...in the hospital and I wasn't. It was only three months because I really pushed myself. And I really do need to try – I...I...I had a reputation of taking over (<i>laughs</i>) you know and telling that I can do this, I can do that and I was able to do it. So I did...I am pushing myself hard...but I only want to go at my speed. I don't want to go at someone else's speed.</p>	<p>40:00</p>
<p>Needing to feel in charge of herself</p>	<p><i>And that's back to the sense of someone else taking over?</i> Yes. <i>So really it's about you being in charge of your own rehab?</i> I do need to feel that I'm in charge of myself.</p>	<p>40:30</p>
<p>Needing explanation for tasks</p>	<p><i>And what if you do tasks and you don't get why you're doing them?</i> Well then they need to explain it, don't they? <i>Would you feel able to ask?</i></p>	
<p>Needing plain English not medical jargon</p>	<p>Yes I think some of the things that you know they produce, they make it sound medical and I don't understand that...but if they make it sound like it's ordinary English and that you...you can understand it then you need to have it explained. If they make it sound medical then I probably wouldn't ask questions but if they could ask me how I felt then I'd probably be honest and tell them.</p>	
<p>Being shut down by medical words Needing to be asked how she is</p>	<p><i>It's all about being on your wavelength?</i> Yes. Yes I'm afraid it is. <i>Don't be afraid – sounds good. And what about the future? How do you view the future?</i></p>	<p>41:00 41:30</p>
<p>Feeling she hasn't much of a future Having life but no future Seeing herself as only a problem to people unless she can improve Having hope that she can improve Seeing getting teeth as making her feel more human Struggling to manage trip to dentist</p>	<p>Well I don't actually have very much of a future. I've got life because the hospital gave me that, but I can't really...unless I can improve myself and get myself back then I can only be a problem to people. <i>Do you have hope that you can improve?</i> Oh yes. Once I can get my teeth I will feel more human...the problem is that the hospital wouldn't provide them, so we've got to go to the dentist and that's difficult</p>	<p>42:00</p>
	<p>SECTION REDACTED TO MAINTAIN CONFIDENTIALITY</p>	
<p>Being told by granddaughter she was glad she did not die Being treated as before once home</p>	<p>that was the first thing my granddaughter said to me – 'I'm glad you didn't die Nanny'. But since I've been home they've treated me the same as they used to – in the hospital they didn't.</p>	<p>45:30</p>

<p>Being glad she did not die Having a meaning to life in family</p>	<p><i>Are you glad you didn't die?</i> Oh yes. Yes I am. So there's a meaning to life?</p>	
<p>Acknowledging difficult for other family to visit</p>	<p>Yes ...there is a... meaning to life and it's through my grandchildren, and my family. My daughter. My own family are good – I've got mum and sisters and brother and they come to see me quite often but they live a long way away. They live in K –that was where I was born and brought up – in S.... in K, so that's where all my family live so they find it difficult to get here – it takes three hours each way. So they do find it a little bit difficult to come – mum doesn't drive so ...</p>	46:00
<p>Feeling family make life worthwhile</p>	<p><i>But it's your family and here that make life worthwhile?</i> Oh yes that's what makes it worth living.</p>	46:30
<p>Hoping to recover completely</p>	<p><i>Yeah. Do you...how far do you hope you will recover?</i> I hope that I will recover completely. That my leg will get... I mean this leg is OK, but this leg doesn't cooperate – it doesn't lift quite so well – it needs help (<i>laughs</i>) but I can get upstairs, I can come downstairs, I just can't do anything fast. I was a rusher and I used to run up the stairs and rush everywhere and hurry up and do things</p>	47:00
<p>Acknowledging cannot do anything fast any more</p>	<p>and I think I was – I used to start work at six o'clock in the morning and not finish until eleven o'clock at night and I was quite happy doing that – I had variety because I was a carer – I went caring from six o'clock till about eleven o'clock – I looked after the children till my daughter came home and then I went back to work. And I loved it – I thought I was a good carer – because I cared.</p>	47:30
<p>Comparing past life lived at speed/rushing/busy</p>	<p><i>Which is what you want from others.</i> And I wanted to make – I always made it – and I want someone like I behaved. I just wanted to make their life better, and that's what I set out to do.</p>	48:00
<p>Seeing herself as a good carer because she cared</p>	<p><i>So probably you'll find that the people around you now want to do that for you too.</i> Oh yes my daughter does – definitely. My mum does. My sister said that when I can walk a little bit better, she's going to take me home and spoil me (<i>tearful</i>)</p>	48:30
<p>Wanting someone to care for her as she cared for others</p>	<p><i>So there's...there's sort of things you can look forward to?</i> Oh yes. Yes there are things to look forward to – as long as I can get better.</p>	49:00
<p>Setting out to make people's lives better</p>	<p><i>And is there anything I haven't asked you about Shirley that you feel is particularly important to you know what you expect or hope from rehab or from recovery?</i> No I don't think so. I mean I just want someone to help me get better. You know not physically better – not mentally better but physically is important to me.</p>	49:30
<p>Knowing family want to look after her</p>	<p><i>And mentally you feel you've got there?</i> Mentally I feel as if I....I don't feel as if I've got brain damage at all. I mean just my eye which the hospital explained to me, my brain bled and the blood could have settled on the back of the eye and damaged the muscles but that it could recover so I've got to be patient. I'm afraid I'm not very patient, with my physical problems.</p>	49:30
<p>Having things to look forward to – if she can get better</p>	<p><i>It's not easy to be patient.</i></p>	49:30
<p>Wanting to be helped physically</p>		
<p>Feeling she has not got brain damage</p>		
<p>Understanding that eye problem results from bleed in brain</p>		
<p>Being told she must be patient</p>		
<p>Not being a patient person</p>		

<p>Thinking she has done what she can to help her eyes</p>	<p>No. <i>OK but nothing you think I haven't asked you that would be important?</i> No I mean I feel as if I did explain to her that I could see double vision and she thought that there was probably something they could help me with there but I think I've ...I've controlled that by keeping the eye closed when I'm trying to concentrate and only opening it when I'm exercising it. <i>So you're doing what you can?</i></p>	<p>50:00</p>
<p>Doing what she can</p>	<p>I'm doing what I can yeah. <i>Ok. Are you happy to...</i></p>	<p>50:30</p>
<p>Having no appetite Being told appetite can be affected by BI</p>	<p>I mean at first I was not eating– I had no appetite – but the physiotherapist did some research because I never felt hungry and she did some research and she said because of my brain injury that was affecting my appetite. I had to concentrate on it – but I'm getting better – since I've come home I've eaten three times a day – maybe not enough but you know I'm half the size of what I was. I've gone down two...two dress sizes so – my trousers are a size ten now they were fourteen before. So I have lost a lot of weight but I'm eating OK.</p>	<p>51:00</p>
<p>Eating better but not much Having lost weight/ two dress sizes</p>	<p><i>You are now?</i> Yes. <i>OK. Well let's stop there.</i> OK.</p>	<p>51:19</p>

Appendix 5:2 Categories (Shirley)

<p>Coming to in hospital</p> <p>Being in a coma for three weeks</p> <p>Praising hospital for pain control</p> <p>Knowing bones were broken</p> <p>Having surgery on hand</p> <p>Being stopped from walking</p>	<p>INITIAL HOSPITAL TREATMENT</p>
<p>Having physio in hospital x2</p> <p>Having one excellent student</p> <p>Being helped by student</p> <p>Writing to commend student</p> <p>Seeing several different young SLT/girls</p> <p>Being asked questions by SLTs</p> <p>Asking to see psychologist</p> <p>Getting second opinion from specialist</p>	<p>HAVING REHAB IN HOSPITAL</p>
<p>Insisting on coming home</p> <p>Knowing she would be better at home</p> <p>Being thought unreasonable about coming home</p>	<p>BEING DESPERATE TO GET HOME</p>
<p>Having no rehab since returning home</p> <p>Praising GP</p> <p>Having phone call from centre</p> <p>Not knowing who referred to centre</p> <p>Acknowledging OK with researcher</p>	<p>RETURNING HOME</p>

<p>Having to push to get help</p> <p>Having to find dentist who can help logistics</p> <p>Struggling to manage trip to dentist with daughter</p>	<p>STRUGGLING TO FIND HELP</p>
<p>Not knowing where she was</p> <p>Having no memory x3</p> <p>Having no memory of pain</p>	<p>LACKING MEMORY OF EVENT/AFTER</p>
<p>Having individual memories</p> <p>Remembering isolated incidents</p> <p>Remembering doctor talking to her</p> <p>Remembering her daughter's voice when in coma</p> <p>Knowing the voice was her daughters</p> <p>Hearing voice giving permission to let go/die/be with husband</p> <p>Knowing daughter was giving her permission to die</p> <p>Not remembering husband dying</p>	<p>QUESTIONING EARLY MEMORIES</p>
<p>EXAMPLES REDACTED FOR CONFIDENTIALITY</p>	<p>BEING CONVINCED OF FALSE MEMORIES / BELIEFS</p>
<p>Struggling to come to terms with regained memory</p>	<p>STRUGGLING TO COME TO TERMS WITH REALITY/MEMORY</p>

<p>Not being told what was happening</p> <p>Not making sense of what was happening</p> <p>Knowing she was in hospital but not remembering</p> <p>Feeling anger justified IF she knew what had happened</p>	<p>NOT MAKING SENSE OF EVENTS</p>
<p>Not being able to make sense of her behaviour</p> <p>Not being able to associate being difficult with self view</p> <p>Hating that she made life hard for people</p> <p>Being unreasonable as expected husband to come to see her</p>	<p>DOUBTING SELF</p>
<p>Not believing what people said</p> <p>Not being reassured by what people said</p> <p>Checking that daughter did talk to her in coma</p> <p>Being told she was difficult to cope with</p> <p>Struggling to accept her reported behaviour</p> <p>Being told she was difficult/demanding in hospital</p>	<p>DOUBTING OTHERS</p>
<p>Trusting others' accounts</p> <p>Trusting daughter's accounts</p> <p>Accepting what told</p> <p>Trusting mother's accounts</p> <p>Understanding that eye problem caused by bleed in brain</p> <p>Knowing there were records of her bad speech</p> <p>Being told by doctor that her speech had been bad</p>	<p>TRUSTING OTHERS</p>

<p>Knowing what happened must have caused pain</p> <p>Understanding facts of what happened</p> <p>Knowing about injuries from physical evidence</p>	<p>ACCEPTING PHYSICAL EVIDENCE</p>
<p>Knowing family were told she would die x2</p> <p>Being aware that family told she only had six weeks to live</p> <p>Proving them wrong by surviving</p>	<p>PROVING PREDICTIONS WRONG</p>
<p>Being told she couldn't walk</p> <p>Having fixed idea in head because told she couldn't walk</p> <p>Being told sight was hopeless</p> <p>Being told sight may correct itself</p> <p>Being given time scale for eye/one year</p>	<p>GETTING CONFLICTING ADVICE</p>
<p>Knowing about stroke</p> <p>Being a carer for people after stroke</p> <p>Seeing improvements and lack of progress after stroke</p>	<p>HAVING LIMITED KNOWLEDGE ABOUT STROKE</p>
<p>Knowing nothing about BI</p> <p>Lacking knowledge of how BI affects people after accidents</p> <p>Not connecting stroke/BI</p>	<p>NOT LINKING STROKE/BI</p>
<p>Not linking BI and self</p> <p>Feeling she has not got brain damage</p> <p>Feeling BI alien</p> <p>Not feeling brain damaged</p> <p>Feeling it happened to another person</p>	<p>NOT SEEING SELF AS BI</p>

<p>Being affected by bad experiences in hospital</p> <p>Fearing repeat of hospital experience</p> <p>Not wanting to return to hospital/residential care</p> <p>Being convinced she would die if she slept</p>	<p>FEARING HOSPITAL EXPERIENCE</p>
<p>Feeling isolated by experience – only she knows what it was like</p> <p>Telling her daughter she felt neglected</p> <p>Feeling abandoned</p> <p>Being alone and distressed</p> <p>Feeling neglected in hospital</p> <p>Being left alone in residential home</p> <p>Feeling alone/left without explanation</p>	<p>FEELING ABANDONED/ISOLATED BY HOSPITAL EXPERIENCE</p>
<p>Being very distressed</p> <p>Being distressed</p> <p>Feeling panicked</p> <p>Panicking if people were late</p> <p>Fearing others had had accidents</p> <p>Being anxious about going out</p>	<p>FEELING DISTRESSED/PANICKED</p>
<p>Feeling trapped/not in control</p> <p>Not wanting to be controlled</p> <p>Not being able to control her thoughts/feelings</p>	<p>FEELING TRAPPED/CONTROLLED</p>
<p>Having carers for washing/dressing</p> <p>Being aware of pain</p> <p>Acknowledging cannot do anything fast any more</p>	<p>HAVING PHYSICAL LIMITATIONS</p>

Being told she is help together by metal	
Feeling scars and lack of teeth	
Knowing her eyesight is damaged	
Finding vision confusing	
Finding reading difficult	
Being upset by reading difficulty	
Having no appetite	
Having lost weight/two dress sizes	
Eating better but not much	
Knowing memory is 'at fault'	
Being terrible with names/faces	HAVING COGNITIVE LIMITATIONS
Not remembering the day	
Fearing she cannot explain clearly	
Feeling frustrated by not being able to work	HAVING FUNCTIONAL LIMITATIONS
Feeling better physically	IMPROVING PHYSICALLY
Being told her speech is now OK	
Sorting out her speech	IMPROVING SPEECH
Making herself understood	
Reading better	IMPROVING COGNITION
Memory gradually improving	
Remembering more now	
Remembering daily life	
Remembering distant past	

<p>Feeling more in control mentally</p> <p>Improving at home</p> <p>Coping fine at home</p> <p>Acknowledging granddaughter now treating her as before</p> <p>Being treated as before once home</p> <p>Using support as hand aches</p> <p>Needing someone with chair if she walks far</p> <p>Practicing reading on granddaughter's books</p> <p>Reading books at right level</p> <p>Being dependent on daughter for reading letters</p> <p>Understanding she cannot work</p> <p>Wanting to look normal/not be seen as disabled</p> <p>Expecting to be judged on physical (ugly) appearance</p> <p>Thinking looking normal will help her be treated as normal</p> <p>Seeing getting teeth as making her feel more human</p> <p>Thinking medics judged her by her behaviour</p> <p>Acknowledging medics could not know she was reasonable</p>	<p>IMPROVING EMOTIONALLY / PSYCHOLOGICALLY</p> <p>IMPROVING FUNCTIONALLY</p> <p>BEING TREATED AS HERSELF</p> <p>ADAPTING</p> <p>FEELING JUDGED BY APPEARANCE- NOT BEING NORMAL</p>
--	--

<p>Feeling angry that other driver not punished more</p> <p>EXAMPLES REDACTED</p> <p>FOR CONFIDENTIALITY</p> <p>Knowing it has affected whole family</p> <p>Knowing daughter distressed</p> <p>Knowing daughter told to say goodbye</p> <p>Knowing granddaughter feared she would die</p> <p>Knowing granddaughter has worried about her</p> <p>Knowing granddaughter wants her back doing normal things with her</p> <p>Describing difficulties for daughter's stage of life/young children</p> <p>Not being the same for grandchildren</p> <p>Reassuring granddaughter by showing her eye</p> <p>Feeling guilty/bad about being unreasonable</p>	<p>BLAMING OTHER DRIVER FOR RTA</p> <p>FEELING GUILTY FOR EFFECT ON FAMILY</p>
<p>Seeing herself as only a problem to people unless she can improve</p> <p>Relying on daughter</p> <p>Feeling bad about relying on daughter</p> <p>Knowing her daughter has changed her plans to care</p> <p>Being looked after by daughter</p>	<p>BEING A BURDEN</p>
<p>Hating role reversal</p> <p>Being hard to accept she needs help</p> <p>Wanting to be helping daughter</p> <p>Feeling strange about being looked after</p>	<p>HATING ROLE REVERSAL</p> <p>/NEEDING HELP</p>

<p>Seeing rehab as teaching you to be as normal as possible</p> <p>Having to come to grips with normality</p> <p>Hoping to recover completely</p> <p>Having hope that she can improve</p> <p>Hoping to improve life</p> <p>Hoping to improve physically</p> <p>Hoping to improve memory</p> <p>Questioning if she needs rehab as she feels normal</p> <p>Having the impression that the centre was a good place before accident</p> <p>Not knowing why the centre would be good</p> <p>Being told the centre could help her</p> <p>Feeling isolated by not knowing what the centre can do</p> <p>Being concerned about first visit</p> <p>Thinking best to be seen in home environment as in control</p> <p>Knowing the phone call suggested everything could be helped felt like taking over</p> <p>Being told they could sort it out for you</p> <p>Being controlled by the centre</p> <p>Feeling controlled</p>	<p>SEEING REHAB AS MAKING NORMAL</p> <p>HOPING TO RECOVER FULLY</p> <p>HOPING TO IMPROVE</p> <p>NOT KNOWINGWHAT REHAB SERVICE CAN DO</p> <p>FEARING BEING CONTROLLED BY REHAB (AS IN HOSPITAL)</p>
--	--

<p>Seeing transport as taking control away from her</p> <p>Worrying that transport means she has to stay until allowed to go home</p>	
<p>Wanting rehab not to be overwhelming</p> <p>Wanting comfortable environment</p> <p>Hoping for a friendly environment</p>	<p>WANTING COMFORTABLE/ FRIENDLY SETTING</p>
<p>Being let down by promised services</p> <p>Expecting physio and aids and not getting help</p> <p>Getting response to requests</p>	<p>WANTING PROMISES TO BE KEPT</p>
<p>Expecting physical progress to be checked</p> <p>Wanting to be helped physically</p> <p>Needing physical help to walk better</p> <p>Being told reading could be helped</p>	<p>EXPECTING HELP WITH SPECIFIC AREAS</p>
<p>Feeling like an examination</p> <p>Feeling she was being examined but managed well</p> <p>Being asked questions in hospital</p> <p>Being asked general knowledge questions</p> <p>Acknowledging failing questions would have given useful info</p>	<p>FEELING EXAMINED</p>
<p>Being encouraged to try</p> <p>Being encouraged if she felt she couldn't do something</p>	<p>BEING ENCOURAGED</p>

<p>Feeling there was no point in trying when told couldn't walk</p> <p>Managing to do tasks with encouragement</p> <p>Being told she must be patient</p> <p>SLTs following paper tasks – not thinking about what they were doing</p> <p>Seeing SLTs as just doing what they 'had to do'</p> <p>Thinking SLTs not really interested</p> <p>Needing someone to care</p> <p>Knowing she needed someone to care</p> <p>Believing she had a relationship with someone</p> <p>Feeling someone took time and trouble</p> <p>Having necessary evidence by doing more than necessary</p> <p>Having evidence of caring from student putting herself out</p> <p>Being helped by caring person</p> <p>Praising student</p> <p>Having student provide what she needed</p> <p>Needing to tell student she would not have survived without her help</p> <p>Finding physio student did care</p> <p>Appreciating student taking extra care</p> <p>Student's help meaning a lot</p> <p>Needing to talk to someone</p> <p>Knowing she needed to talk about it</p> <p>Asking several people to talk and getting nothing</p>	<p>WANTING TO FEEL THERAPISTS ENGAGED/ INTERESTED</p> <p>NEEDING PEOPLE WHO CARE</p> <p>NEEDING TO TALK</p>
--	---

<p>Repeatedly asking to talk to someone</p> <p>Needing someone to talk to and being ignored</p> <p>Thinking she would talk to someone about how she feels</p> <p>Having no-one to talk to</p> <p>Not having opportunity to talk</p> <p>Not being given someone to talk to</p> <p>Wanting someone to listen</p> <p>Being heard</p>	
<p>Feeling centre would be in charge and she would have no say</p> <p>Fearing what she thinks would not matter</p> <p>Needing to be asked how she is</p>	<p>FEARING HAVING NO VOICE</p>
<p>Being kept in the dark (eyesight and information)</p> <p>Thinking medics not truthful with her because of her behaviour</p> <p>Wanting answers to questions about recovery</p> <p>Feeling she could have been told the truth</p> <p>Seeing medics as avoiding confronting her with truth for fear of upsetting her</p> <p>Being helped to understand</p> <p>Finding information out for her</p>	<p>WANTING HONEST INFORMATION</p>
<p>Needing plain English not medical jargon</p> <p>Being shut down by medical words</p> <p>Being told appetite can be affected by BI</p>	<p>NEEDING CLEAR LANGUAGE</p> <p>NOT MEDICAL JARGON</p>

<p>Not understanding why she needed to see another doctor</p> <p>Needing explanation for tasks</p> <p>Needing to feel in charge of herself</p> <p>Knowing she can control home environment – ask people to leave</p> <p>Wanting to be able to choose when to leave</p> <p>Deciding what she could/couldn't do herself</p> <p>Taking over rehab in hospital</p> <p>Wanting to go at own speed</p>	<p>WANTING TO BE IN CONTROL</p>
<p>Trying</p> <p>Needing to try hard</p> <p>Saying she would try anything when asked about the centre</p> <p>Pushing herself has got results so far</p> <p>Correcting poor speech</p>	<p>TRYING HARD</p>
<p>Needing to cooperate</p> <p>Exercising eye as told</p> <p>Being told to practice opening eye</p> <p>Thinking she has done what she can to help her eyes</p>	<p>DOING AS TOLD/ ACCEPTING ADVICE</p>
<p>Comparing past life lived at speed/rushing/busy</p> <p>Combining work and child care for daughter</p>	<p>COMPARING WITH PAST LIFE STYLE</p>

<p>Living with daughter before accident</p> <p>Being experienced in childcare</p> <p>Being foster parent/child minder</p> <p>Describing role with daughter before accident</p> <p>Being trusted by daughter to look after children</p>	
<p>Not being a patient person</p> <p>Setting out to make people lives better</p> <p>Seeing herself as reasonable</p> <p>Seeing herself as calm/reasonable</p>	<p>COMPARING PAST SENSE OF SELF</p>
<p>Comparing with past as carer of others</p> <p>Wanting someone to care for her as she cared for others</p> <p>Seeing self as good carer because she cared</p>	<p>COMPARING PAST AS CARING FOR OTHERS</p>
<p>Being terrified of dentist always</p> <p>Acknowledging never good at going into new places</p>	<p>ACKNOWLEDGING PAST ANXIETIES</p>
<p>Being able to talk to family</p> <p>Knowing family want to look after her</p> <p>Acknowledging family support</p> <p>Telling daughter she should be proud of herself</p> <p>Praising daughter for being honest</p> <p>Acknowledging difficult for other family to visit</p>	<p>HAVING FAMILY SUPPORT</p>

<p>Feeling she hasn't much of a future</p> <p>Having life but no future</p> <p>Having things to look forward to – IF she can get better</p> <p>Being glad she did not die</p> <p>Having a meaning to life in family</p> <p>Feeling family make life worthwhile</p> <p>Being told by granddaughter she was glad she did not die</p>	<p>HAVING LIFE BUT NO FUTURE</p> <p>UNLESS SHE RECOVERS</p> <p>HAVING MEANING IN LIFE</p>
---	--

Shirley : Second stage categories

<p>INITIAL HOSPITAL TREATMENT HAVING REHAB IN HOSPITAL BEING DESPERATE TO GET HOME RETURNING HOME STRUGGLING TO FIND HELP</p>	<p>Hospital care</p>
<p>LACKING MEMORY OF EVENT/AFTER QUESTIONING EARLY MEMORIES BEING CONVINCED OF FALSE MEMORIES/ BELIEFS STRUGGLING TO COME TO TERMS WITH REALITY/MEMORY NOT MAKING SENSE OF EVENTS DOUBTING SELF DOUBTING OTHERS TRUSTING OTHERS ACCEPTING PHYSICAL EVIDENCE</p>	<p>Making sense of events</p>
<p>PROVING PREDICTIONS WRONG GETTING CONFLICTING ADVICE</p>	<p>Conflicting advice</p>
<p>HAVING LIMITED KNOWLEDGE ABOUT STROKE NOT LINKING STROKE/BI NOT SEEING SELF AS BI</p>	<p>Lacking knowledge of stroke/ BI</p>

FEARING HOSPITAL EXPERIENCE	Impact of hospital experience
FEELING ABANDONED/ISOLATED BY HOSPITAL EXPERIENCE	
FEELING DISTRESSED/PANICKED	
FEELING TRAPPED/CONTROLLED	
HAVING PHYSICAL LIMITATIONS	
HAVING COGNITIVE LIMITATIONS	
HAVING FUNCTIONAL LIMITATIONS	
IMPROVING PHYSICALLY	Improving
IMPROVING SPEECH	
IMPROVING COGNITION	
IMPROVING EMOTIONALLY/ PSYCHOLOGICALLY	
IMPROVING FUNCTIONALLY	
BEING TREATED AS HERSELF	
ADAPTING	
FEELING JUDGED BY APPEARANCE-NOT BEING NORMAL	Judgement and Blame
BLAMING OTHER DRIVER FOR RTA	
FEELING GUILTY FOR EFFECT ON FAMILY	
BEING A BURDEN	
HATING ROLE REVERSAL/NEEDING HELP	
SEEING REHAB AS MAKING NORMAL	not knowing about rehab
NOT KNOWING WHAT REHAB SERVICE CAN DO	

HOPING TO RECOVER FULLY	Hoping	
HOPING TO IMPROVE		
FEARING BEING CONTROLLED BY REHAB (AS IN HOSPITAL)	Expectations of services	
WANTING COMFORTABLE/ FRIENDLY SETTING		
WANTING PROMISES TO BE KEPT		
EXPECTING HELP WITH SPECIFIC AREAS		
FEELING EXAMINED		
BEING ENCOURAGED		
WANTING TO FEEL THERAPISTS ENGAGED/ INTERESTED		
NEEDING PEOPLE WHO CARE		
NEEDING TO TALK		
FEARING HAVING NO VOICE		
WANTING HONEST INFORMATION		
NEEDING CLEAR LANGUAGE NOT MEDICAL JARGON		
WANTING TO BE IN CONTROL		Expectations of self
TRYING HARD		
DOING AS TOLD/ACCEPTING ADVICE		
HAVING FAMILY SUPPORT	Expectations of family	
COMPARING WITH PAST LIFE STYLE	Comparing with past	
COMPARING PAST SENSE OF SELF		
COMPARING PAST AS CARING FOR OTHERS		
ACKNOWLEDGING PAST ANXIETIES		
HAVING LIFE BUT NO FUTURE UNLESS SHE RECOVERS	Doubting future	
HAVING MEANING IN LIFE		

Appendix 6 Comparison analysis example

Constant Comparison: Reorganised categories 1-21

Out of the blue 7	OUT OF THE BLUE
Ignoring personal experiences 5	
Having warning signs/conditions 4	
Misinterpreting symptoms 7	QUESTIONING SYMPTOMS/SEVERITY
Questioning/acknowledging severity 6	
Not knowing what was wrong 4	
Not meeting expectations of stroke/BI (including media advert) 7	
Developing first symptoms 16	ACUTE/EARLY CARE
Having hospital care 35	
Early days 8	
Having residential care 4	
Being back at home 22	
Having limited knowledge of stroke/BI 11	KNOWLEDGE OF STROKE/BI
Lacking knowledge of stroke/BI 9	
Misunderstanding stroke/BI 5	
Having negative expectations of stroke 4	

Knowing impact of stroke varies 4	KNOWLEDGE OF REHAB
Not knowing what to expect of rehab 20	
Not knowing therapy roles 9	
Expecting rehab to help 9	
Rehab getting you back to normal 5	
Defining rehab 4	
Wanting a magic fix 2	
Having existing prejudices about disability/depression 2	PRE-MORBID PREJUDICES
Setting in wider context/stage of life 21	LIFE CONTEXT
Being affected by bad experiences in hospital 9	HOSPITAL EXPERIENCES
Early impact of severe communication deficit 1	
Having experience of rehab in hospital 13	REHAB EXPERIENCES
Having community rehab 5	
Having variable experience of rehab 2	
Being given conflicting predictions/time scales/advice 7	CONFLICTING INFORMATION

<p>Trying to fill memory gaps – trusting and doubting 14</p> <p>Questioning reality/confusion 9</p> <p>Questioning early memories – real or false 7</p> <p>Lacking memory/awareness of events 7</p> <p>Making sense of events 6</p> <p>Remembering the event 1</p> <p>Why me? 7</p> <p>Fearing the future 7</p> <p>Fearing another event 7</p> <p>Questioning the cause 4</p> <p>Questioning the future 2</p> <p>Paradox – using injured brain to sort out brain 1</p>	<p>FILLING MEMORY GAPS</p> <p>QUESTIONING CAUSE/FUTURE</p>
<p>Recognising improvements 38</p>	<p>IMPROVING</p>
<p>Wondering if it is just a matter of time 6</p> <p>Impact of time on hope 3</p> <p>Improving rapidly at first 3</p> <p>Impact of improving on hope 3</p>	<p>TIMING/SPEED OF IMPROVEMENT</p>

Slowing of recovery 7	SLOWING RECOVERY
Hitting a brick wall 5	
Improving and stalling 4	
Regretting wasted time/opportunities 3	
Severity as a factor in recovery 1	
Recognising limitations 70	ACKNOWLEDGING LIMITATIONS
Recognising emotional /psychological impact 34	
Stagnating/being bored 6	
Being isolated 2	
Adapting to limitations/needs 17	ADAPTING TO LIMITATIONS
Having no choice – having to adapt 8	
Deteriorating over time 7	DETERIORATING
Deteriorating 3	
Not improving 1	
Comparing with past self 25	COMPARING WITH PAST SELF
Being the same 11	
Being a changed person 10	
Having retained abilities/roles 7	
Being the same but not the same 3	
Changing positively 1	

Feeling guilty for effect on others 15	FEELING GUILTY/BEING A BURDEN
Wondering about blame 5	
Being a burden 4	
Judging self 3	
Feeling judged 8	BEING JUDGED
Being judged/invisible disability – looking normal 7	
Being seen as incapable 3	
Being judged on physical appearance – not looking normal 2	
Comparing with others +ve or –ve 6	COMPARING WITH OTHERS
Acknowledging family/friends support 14	HAVING SUPPORT
Expecting/hoping for full recovery 18	HOPING
Doubting full recovery/miracle cure 15	DOUBTING
Hoping to improve, not recover fully 11	
Impact of experience on expectation of recovery 2	
Wanting to turn the clock back 1	
Putting on a brave face/hiding negatives 10	KEEPING DOUBTS AT BAY
Trying to keep doubts at bay/hang on to hope 7	
Trying to normalise feelings 4	

Despairing 5	DESPAIRING
Adjusting expectations for the future 9	ADJUSTING/ACCEPTING
Coming to acceptance 2	
Taking stock – new priorities 11	TAKING STOCK/NEW MEANING
Finding a meaning in life 7	
Wanting to help/give back 5	
Acknowledging positives from experience 9	POSITIVES
Expecting help in relevant specific areas 55	EXPECTING EXPERT HELP
Struggling to find specialist help 16	
Wanting expert/specialist staff 13	
Wanting people who understand the condition 6	
Wanting joined up service 1	
Expecting a rationale for tasks 10	EXPECTING RATIONALE
Expecting tasks to be practicable 2	
Wanting information/explanations 18	EXPECTING INFORMATION
Expecting information to be at the right level 4	
Expecting guidance/direction 13	EXPECTING GUIDANCE/DIRECTION

Expecting timely help 9	GETTING TIMELY HELP
Wanting to have a voice/be heard 16	EXPECTING TO HAVE A VOICE
Wanting to feel people care 12	EXPECTING CARE
Wanting friendly setting 2	
Wanting respect/dignity 4	EXPECTING CARE/RESPECT
Being seen as equals 3	
Wanting to be treated as an individual 2	
Having someone to talk to 10 (nb interview as opportunity to talk 7)	SOMEONE TO TALK TO
Expecting encouragement 9	ENCOURAGEMENT
Wanting honesty from staff 5	HONESTY
Not expecting answers 2	
Expecting family needs to be considered 24	EXPECTING HELP FOR FAMILY
Doing things own way 11	BEING IN CONTROL OF REHAB
Directing own rehab/keeping control 9	
Choosing which advice to follow 9	
Setting own goals 3	
Having the biggest part to play 2	

Trusting experts 15	TRUSTING EXPERTS
Doing as told 14	
Trying hard/proving self 13	TRYING AND TAKING OPPORTUNITIES
Taking opportunities 10	
Rising to the challenge 7	
Keeping busy 4	
Pacing 2	
Having a positive attitude 8	ATTITUDE/MOTIVATION
Finding motivation 6	
Being open to learn 5	
Being honest 3	
Expecting to be supported by family 7	EXPECTING FAMILY SUPPORT
Being treated normally 3	
Working together in family 2	
Accepting not everyone is able to help 1	

Reorganised Categories 1-21

OUT OF THE BLUE

QUESTIONING SYMPTOMS/SEVERITY

ACUTE/EARLY CARE

KNOWLEDGE OF STROKE/BI

KNOWLEDGE OF REHAB

PRE-MORBID PREJUDICES

LIFE CONTEXT

HOSPITAL EXPERIENCES

REHAB EXPERIENCES

CONFLICTING INFORMATION

FILLING MEMORY GAPS/MAKING SENSE

QUESTIONING CAUSE/FUTURE

IMPROVING

TIMING/SPEED OF IMPROVEMENT

SLOWING RECOVERY

ACKNOWLEDGING LIMITATIONS

ADAPTING TO LIMITATIONS

DETERIORATING

COMPARING WITH PAST SELF

FEELING GUILTY/BEING A BURDEN

BEING JUDGED

COMPARING WITH OTHERS

SUPPORT

HOPING

DOUBTING

KEEPING DOUBTS AT BAY

DESPAIRING

ADJUSTING/ACCEPTING

TAKING STOCK/NEW MEANING

POSITIVES

EXPECTING EXPERT HELP

EXPECTING A RATIONALE

EXPECTING INFORMATION

EXPECTING GUIDANCE

GETTING TIMELY HELP

HAVING A VOICE

SOMEONE TO TALK TO

EXPECTING ENCOURAGEMENT

EXPECTING HONESTY

EXPECTING CARE

EXPECTING RESPECT

EXPECTING HELP FOR FAMILY

BEING IN CONTROL OF REHAB

TRUSTING EXPERTS

TRYING AND TAKING OPPORTUNITIES

ATTITUDE/MOTIVATION

Appendix 7:1 Sample Memo (Shirley)

Shirley describes being in hospital and early rehabilitation, marked by the relationship she formed with a physiotherapy student who appeared to be the only member of staff who cared. She was desperate to get home and praised her GP, as the only contact she has had since discharge from hospital. She and her family have had to struggle to get help.

The period in hospital was deeply distressing for Shirley, who had no memory of the accident in which she was injured or of subsequent care when in a coma. As she began to recover some memories came back, such as hearing her daughter's voice giving her permission to 'let go' if she wanted. However she questioned these early memories, being uncertain as to their veracity, and at the same time had false memories that she believed to be true. This confusion of reality and false beliefs meant she could not make any sense of events around her. She has continued this struggle subsequently, as she has been told by others that she behaved unreasonably and was difficult to cope with. This was out of keeping with her sense of self, and she both doubts others' accounts and herself, and feels guilty about her behaviour if true. She has been hugely affected by this period of confusion and her inability to make sense of what happened in hospital.

She does trust some accounts from other people, such as her daughter and mother, and some of what she has been told about her medical condition, but has sought confirmation when possible for both her own memories and others accounts, by checking with people and looking at the physical evidence of her injuries. Trusting experts may be affected by the fact that she has proved their predictions wrong – having been given six weeks to live and that she would not walk. She has conflicting advice to contend with as well, having been told her sight was hopeless by one and that she could recover within a year by another.

Shirley's hospital experience has affected her greatly, and she seems – while lacking factual memories – to have some emotional memory of her time in hospital as being abandoned and neglected, fearing to sleep as she thought she would die, and being distressed and panicked by the thought that family might be involved in accidents if they were late visiting. She felt trapped and had no control over her situation or over her physical, mental and emotional state.

She did have some prior knowledge of stroke as she worked as a carer in peoples' homes, and her clients included stroke sufferers. However she does not make links between brain injury and stroke, and therefore cannot see any similarities in her condition and her former clients. She does not see herself as 'brain injured' and that the concept is alien to her, suggesting a narrow view of brain injury as 'mental' impairment.

She describes having limitations now in physical ability (including vision), thinking, and functioning. However she is able to see improvements and progress – she feels better

physically, can now speak clearly, read better and remember more. She feels more in control mentally, and is coping well in the home within her limitations. She uses adaptations and accepts the need to practice skills in order to improve further.

She also describes being treated as herself again at home, rather than as a disabled person. She wants to be seen as normal, not as disabled, but fears she is judged by her physical appearance, which was affected by facial fractures and loss of teeth in the accident. In hospital she was judged by her early behaviour and feels that staff did not realise she is a reasonable person.

She blames the driver of the car that hit her for the accident and feels anger that he has not been severely punished for what he did. This anger she sees as justified – and admits that if she had been aware in hospital of what happened to her she would have understood being angry and behaving badly – but she did not know what had happened so had no reason for her behaviour.

Shirley – despite not being at fault in the accident – feels guilty because the whole family has been affected. Her daughter was told she would die, and was distressed in hospital, and now has to cope with her disability and the demands of young children and financial losses. Her injury is in the broader context of a life where she provided the childcare and finances that enabled the family to afford their home and lifestyle. She sees herself as a burden, and feels bad about relying on her family when she has always been the carer. She hates this role reversal, which goes against her sense of self.

Her view of rehabilitation is that it makes you as close to normal as possible, and part of her hopes to recover fully, although she admits her hopes are of improvement rather than normality. She does not know what rehabilitation can achieve, and while she acknowledges that the service has a good reputation, she does not know why or what it does.

She is very anxious and fearful about attending rehab and this links in to her early hospital experience and the retained emotional memories and fears of that time. She thinks that the service will control her – as happened in hospital – and that she will not have the ability to get away if she is unhappy there. She hopes for a comfortable and friendly environment, and that promises made will be kept – unlike her experience of community services after discharge. She would expect help in specific areas of physical ability and reading, but notes that in hospital she felt as if she was being given an examination. She wants to be encouraged to try.

She found in hospital that SLTs visited her and appeared to read tasks by rote, doing what they had to with no interest or engagement with her as a person. Alongside that experience she had one student who demonstrated her involvement and caring by doing extra and she feels she would not have survived without her help. These two contrasting experiences lead her to prioritise caring in staff – she wants people who take time and trouble and have a relationship. Her memory in hospital is that she requested someone to talk to and did not get this opportunity, and believes that this is important – she wants to talk and be heard – to have a voice and know that what she thinks and wants matters.

She believes that she was kept in the dark in hospital as people feared upsetting her, but that actually she needs honest information, and to be helped to understand. This needs to be in clear language without medical jargon.

In terms of her expectations of herself, she needs to feel in charge of what happens to her. She wants to be able to choose when to do things and when to leave and to go at her own speed. She expects to try hard and to do as she is told/accept advice if it makes sense to her.

Shirley compares her life to how it was before – busy and active, combining work and family responsibilities and being trusted and competent. Her sense of self is wrapped up in being a carer within work and at home, and the transition to being cared for has been very difficult. She also sees herself as rational and in control, so has struggled with being told that she was unreasonable and out of control in hospital. This conflict continues to bother her, and she has not managed to make sense of her early behaviour.

Some aspects of how she was are influencing her current approach to treatment – she needs dental treatment but has a life-long fear of dentists to overcome, and she has always struggled in going to new places, so visiting the rehab centre would have been intimidating even without the influence of her hospital experiences and fears.

Shirley acknowledges her family support and how much she depends on them, and desperately wants to be able to recover so she is not a burden. At the moment, unless she recovers, she sees herself as having 'life but no future'. At the same time however, she is glad she survived and hopeful of recovery, as her family provide meaning in her life and make her want to continue to make progress.

Appendix 7:2 Sample Memo : Expectations of recovery

Participants all recount areas in which they have recovered at least to some extent, be it cognitive, communicative, fatigue, physical and function. Many can also identify areas they feel are retained and are unaffected. However there is a paradox in that recovery is seen as both giving hope and making life harder. As individuals recover they become more aware of the difficulties and continuing impairments that they face.

There are also some apparent contradictions in the statements made – one man describes his role as ‘Dad’ being the same and yet later describes the changes in what he is able to do with his son.

Despite retained or improved abilities and functioning, however, all are also aware that they have continuing limitations and difficulties. Some acknowledge that issues are mild or minor, but others are more profound. There is a sense of ‘hitting a brick wall’ at times. Limitations may be physical, cognitive, medical (for example developing epilepsy), fatigue level, pain and in functioning in various roles. Not having enough to do or not being able to do much are recurrent themes, with several participants fearing stagnation and boredom. Driving and financial worries are significant to many.

A major area of concern is that of emotional/psychological well being. Many describe being more moody or emotional. Several report a significant level of depression or anxiety – at least two participants admitted suicidal ideation in conversation following the formal interview – or OCD. The knock-on effect of such feelings is seen in anxieties about going out alone, questioning the future and coping, and in worrying thoughts and dreams. More broadly there is an impact on confidence, decision making, and getting one’s ‘mojo’ back. These feelings seem to be worsened by a feeling of isolation and not being understood by others – especially if there is no clear physical disability.

There is a sense shared by many, although not all, participants, of judging and being judged. There are criticisms of services and emergency care that lead to negative judgments by the participants, but much more likely is feeling judged by others. Worries include fearing being seen as a ‘time-waster’, as ‘skiving’, as ‘incapable’, as ‘deficient’ and feeling a fraud (until she attempts to do something). Many perceive negative responses from others, and a few acknowledge that they may be over-sensitive to such things and so contribute to the overall picture. Fear of being judged leads many to try to hide their problems – this may be by covering up or avoidance of situations or people. Another interesting thread is the comparison a few make with how they were before, recognising that they would have judged people in this way in the past and therefore now assume others see them in that way. The comparison with past views of disability is related to the stigma faced by people in society who have difficulties that are perhaps harder to understand than physical, visible problems.

The fear of being seen as having 'depression' is interesting. Several make a point of saying that they are depressed but have a good reason as it is the result of having the stroke or BI, and construct this as more acceptable than 'just' being depressed for no good reason. This suggests a link to the way in which depression is viewed and judged by the wider society and perhaps by the participants themselves before this event. There is a stigma to admitting a mental illness. Some try to cover up their feelings by putting on a brave face, often only letting their guard down within the family.

Those clients who do not have obvious physical impairments struggle with the invisibility of their difficulties, whether psychological-emotional or cognitive, and it is this that seems to underlie most fear of judgement. The only physical issue faced that also had an impact on wanting to hide was facial disfigurement, following craniectomy. The invisible nature of problems leads to a paradox of wanting people to understand why they cannot do what they did before but at the same time trying to hide the difficulties so they are not judged.

Feelings of self blame, shame and guilt are commonly expressed. Two participants with no memory of the accidents in which they were injured, wonder if they were at fault and try to cover up and defend against such accusations by providing reasons for the accident that takes responsibility away from them. As awareness grows of the residual problems and impairments many participants express guilt at the impact they have had on their family. They worry about relying on others, the impact on others' health and well-being, the strain caused when partners have to take on responsibility. This is not a universal experience – some see their families as strong and able to cope, and one man clearly sees it as his wife's duty to care for him and learn how to do it properly.

These feelings of being judged and of blame/guilt seem to relate to the expectations of recovery. People begin by expecting to recover and, as time goes on and the problems remain – or even seem to grow as awareness dawns and greater demands exist in their lives – they become more aware of others' reactions and the effect of their brain injury on others in their environment.

At the outset it seems people expect and hope for full recovery. The early improvements lead people to expect recovery to continue at that pace. This is especially so if there is experience – as in one woman – of family members who did speedily return to full functioning, with minimal residual issues. There are comments about 'returning to normal' and 'getting back to normal' and 'coming out the other side'.

Time goes on and the awareness of the continuing limitations grows. At this point – which often seems to be the point between hospital and starting community rehabilitation, so may be affected by returning home – doubt begins to creep in. In many interviews participants stated categorically that they expect to recover or cannot countenance not recovering, and in the same interview make less explicit reference to making adaptations and the possibility of not recovering. People are, at this stage, beginning to question full recovery.

Expectations are changed and adjusted in some way in most cases. Some may retain a wider expectation – such as getting back to work and having earning potential – but begin to acknowledge the need to adjust on specific issues – such as needing to change the type of work. Another example is recognizing long distance walking may be replaced by easier walks. Some hold contradictory beliefs about problems at this stage and have great uncertainty about what will be possible. Most however do have examples of adjustments and adaptations they have already made to cope with daily life – even if these are seen as short term changes. Many use equipment to cope. The issue of work for those who were dependent upon an income is significantly distressing, but many are by this stage questioning the need to change work or tasks, or wondering if they will actually be able to work again.

A factor in expectations of recovery is time. As time goes on and problems remain, participants move from hope/expectation of recovery, through a period of doubt and some adaptation, to what? At the stage of most interviews this is the point at which hope is reducing and doubt is increasing, but there is still considerable hope even though there is an admission of not knowing. Those clients who had very strong hopes at onset, may struggle most when time goes on without recovery – as illustrated by one client whose hope based on family experience. In addition some clients do not receive help in a timely way – one was not seen for a year post stroke, so had no specialist advice or support for a long time. In both these examples the individuals moved from hope and doubt into despair, and suicidal ideation. Another client was interviewed following re-referral who was twelve years post-injury and he had moved into a level of acceptance, despite acknowledging he still had difficulties and needed help.

That client too expressed feeling depressed early on and lacked help, but was told that the time scale for recovery was past before he got any specialist help. He, in retrospect, thinks he did not therefore expect to recovery. Participants often were given somewhat different information about time scales, either contradictory or conflicting in some way, which also impacted on expectations of recovery.

Being told something does not equate to believing at an emotional level. Some were told by some staff that recovery would be within a given time scale and by other staff that the recovery could continue for a long time – even years. Some take on the short scale and used it as motivation to work hard at this stage. Others ‘chose’ to hold on to the belief that recovery can go on for a long time.

It is not just time *per se* but also the pace or speed of improvement is a major factor for people as they move from hope to doubt. Many questioned how long it was taking and – while acknowledging they had been told it would be slow – still could not accept or understand why. Many also described the unpredictable nature of progress – stalling and gaining, being able to do a party trick one day and not the next – and the frustration of this. Expectations vary with such abilities, as does mood. Many struggle to cope with set-backs and many regret what they see as wasted time early on when rehabilitation was not offered or help was not timely.

Expectations of recovery relate to the comparisons made with how participants viewed themselves before the brain injury. All, to varying extents, made comparisons with their former abilities, activities, knowledge and values. There is a strong sense of wanting to be 'normal' again, and the initial expectation and hope relates to resuming the life style and roles they had before. Some can see elements which are the same – in their approach, perhaps, or in their future plans, but largely at this stage comparisons are negative. The most positive aspects were seen in the participant who had had the longest to adjust and had developed a new skill and could see the value in having been more present for his children.

There were some comparisons made with others – some saw others in acute care as worse off or as not trying hard enough, for example, but this experience perhaps related more to the ability and willingness to engage in rehabilitation than to recovery *per se*.

Appendix 7:3 Sample Memo : expectations of rehabilitation

The terminology is an area for debate – are the following expectations or hopes/wants? This seems to vary in the way individuals express themselves, but failure to meet these expectations/hopes seems likely to impact on the therapeutic process and possibly on eventual outcomes. It is failure in some of these areas at an earlier stage in the process that has led people to hold these hopes/expectations, as they believe they have suffered by omission or inappropriate interventions. It is notable that many select single individuals for praise in early rehabilitation, often based on the establishment of a strong therapeutic relationship rather than on expertise – in one case it was a student – and suggesting the need for human interaction in what is an isolating and frightening experience.

The expectations need to be considered in two ways – not just what is expected but also the belief that rehabilitation per se is worthwhile and can achieve results. This may relate to pre- and post-event factors that influence expectations of recovery, and there is an assumption too that if people want to attend rehabilitation they are expecting it to be helpful in some way.

Self

All participants accept that they have a role in rehabilitation and none expected to hand over the process to the professionals entirely. There is an expectation that individuals will retain control of their own rehabilitation to some degree. This may mean overtly wanting to be seen as the ‘director’ and main player, or more subtly having the ability to choose which advice to follow and doing things his or her own way. Despite this need to stay in control there is also an acknowledgment of the need to trust the experts and do as they are told/be open to learning – which may appear to contradict the need to be in control but links to the expectations of services in terms of expecting to know why tasks are given.

There is an acknowledgement that having a positive attitude will help, and alongside this a desire to put on a brave face and hide negative feelings. Keeping busy and active, and finding personal motivation, are also mentioned. Taking opportunities offered, rising to the challenge and trying hard (while acknowledging the risks of doing too much too soon) is important – sometimes linked to the fear of judgment and the need to be seen to be trying and to prove yourself. Motivation is for some related to the guilty feelings resulting from the effect on those around them, and seeing themselves as a burden. Others are clearly motivated by the need to resume the roles that previously gave life meaning – as a parent or provider, for example.

Services

One person mentioned the expectation that a specialist service would be ‘joined up’ and that different members of the team would talk to each other and enable an overview and plan for rehabilitation. Those who had experienced delays or had to struggle to find appropriate specialist help expected that rehabilitation would be provided in a timely way

– probably those who had no such delay would have shared this expectation but assumed this was the general experience.

All expected specialist help in the areas they deemed relevant to him or herself – physical, cognitive, communication, social, vocational, financial, and psychological/emotional. The expectation was that this would be provided by people with expertise and specialism in the field, and also that staff would ‘understand’ the condition. Therapists and clinicians are expected to offer guidance and direction – many commented on not knowing what to do after leaving hospital and being left without guidance – and when specific tasks are given a clear rationale is expected, and tasks are expected to be practicable.

Expectations are not, however, limited to the area of clinical specialism and expertise, but also encompass the broader therapeutic relationship. Some mention wanting honesty from staff, most expect to be encouraged and to feel that staff are engaged with them and caring, seeing them as equal individuals in need of respect and dignity in a friendly environment.

A highly significant area is that of emotional and psychological support. Some clearly want – although perhaps rarely expect - formal professional help with mental health issues. Many felt let down in acute care as they did not have anyone to talk to and desperately wanted this opportunity. All – in some way or another – needed to have a voice. All too often people felt their views and feelings were sidelined or ignored, or that they were responded to in a tick-box manner rather than heard as individuals.

There is an expectation that information will be provided – especially from those who are still struggling to make sense of their experiences, and that it will be provided at an appropriate level to understand, not in jargon.

While there is an acknowledgment that not all family members will want to take up such offers, there is an expectation that they will be given opportunities for emotional support, practical help/advice or information.

Family/Others

Families are seen as critical to making progress and enabling people to be at home, and there is acknowledgment of the role they play in most cases. While there is an expectation of support, there is also the fear of being a burden, and one person accepts that not all are able to offer support. Most helpful for some is being treated as normal with humour and openness. In some cases there is an expectation that partners will be part of therapy (which may or may not be shared by partners) to greater or lesser degrees.

Interestingly two couples stood out at interview as being different. In one case the expectation was that rehabilitation staff should offer information and support to the partner not in order to help the partner, but in order to tell the partner how to do a better job as a carer. In another case there were marked mixed messages in the interaction

between the couple, with overt hostility observed but only positive expressions made during the interview. In both cases later information indicated some degree of abuse within the relationships prior to and following the event.

Meeting expectations

It may seem logical that, if expectations of services, self and others are met, rehabilitation will be a rewarding experience, but what if expectations are not that hopes will be met but that rehabilitation cannot do anything? The pre- and post-event factors that influence expectations of recovery may also pertain in terms of expectations of response to rehabilitation and the perceived value of rehabilitation.

Appendix 8:1 Focus Group Information sheet

Expectations of Rehabilitation after stroke or brain injury :

Information sheet September 2013

Invitation

A discussion/focus group has been organised for the purposes of service development. However the content of the discussion is relevant to research I am carrying out through the University of Sheffield, and I am asking if you would give your consent for a recording of the discussion and responses to follow-up questions to be used in the research.

It is important that you understand why the research is being done and what it will involve for you **before** you decide to take part.

Please read this information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you need more information. Take time to decide whether or not you want to take part.

What is the project about?

Clients are being interviewed about their views and expectations about recovery and rehabilitation after Acquired Brain Injury. These interviews take place before they start rehabilitation with us, and are being analysed in line with grounded (qualitative) theory methods.

As a secondary piece of research I am interested in looking at whether clients and clinicians share expectations about recovery and rehabilitation.

Why have I been chosen?

You have been chosen because you are a clinician with the rehabilitation centre.

Do I have to take part?

No. It is entirely up to you whether you take part or not. If you do agree you will be asked to sign a consent form. As attendance at the meeting is part of your role at the centre, if you do not wish to give consent, any contribution you make to the

discussion will be deleted from the transcript of the recording that is used for research purposes. Those comments will continue to be used for any service development purposes.

What would I have to do?

You will be attending the discussion group on September 25th for the purposes of service development. This will be audio recorded and notes will be taken. If you agree to your comments being included in the research analysis, you will also have opportunity to follow-up with further comments after the meeting, **if** you choose to do so. If you are happy to give consent for your comments to be used in the research but are unable to attend the meeting, your comments can be included and I will be happy to circulate the discussion questions to you.

Are there benefits/risks?

It is hoped that the information gathered will help to improve the service for people in the future, and may also be of value to other services working with people who have had brain injuries.

If you feel that the use of this for research purposes would inhibit your comments and affect the value of the session for the service you should not consent, and your contributions will be deleted.

What if something goes wrong?

If you are unhappy about any aspect of the research and how it affects you, you can either talk to me or to the project supervisors, whose address is at the end of this sheet.

Will this information be kept confidential?

All information about you will be kept strictly confidential within the project. You will not be identified in any reports or publications. When the project has been fully reported, all personal information and recordings will be destroyed in line with the centre's confidential waste disposal practice

The audio-recordings of the interviews may be used in academic reports and in conference presentations/lectures, but your name will not be included in or alongside these recordings.

No-one outside the project will have access to the original recordings. Your name and personal details will be kept separately from the recordings and other data.

What will happen to the findings?

The research findings will form a PhD thesis for The University of Sheffield. There may be additional reports published from the research. The findings may be shared via professional conferences and academic lectures. However, you will not be identified personally.

Who is behind the research?

There is no funding for this research. It is part of a University Research Degree, and has been approved by the Department of Human Communication Sciences Research Ethics Review Panel, in accordance with procedures at the University of Sheffield.

It is undertaken with the agreement of the centre.

You can get more information by contacting:-

Rosemary Gravell, Lead Researcher

Or

Prof. Shelagh Brumfitt / Dr Richard Body, Project Supervisors

Dept Human Communication Sciences, University of Sheffield,

Claremont Crescent, Sheffield, Yorks S10 2TA

0114 222 2406

s.m.brumfitt@sheffield.ac.uk

Complaints

We hope that taking part in this research will not present any problems for you. However, if you have concerns that you do not feel can be addressed by me, then you can use the University's standard complaints procedure by contacting the following.

1. The project supervisors: Professor Brumfitt and Dr Body (as above)
2. Professor Patricia Cowell
HCS Director of Research
Dept Human Communication Sciences, University of Sheffield,
Claremont Crescent, Sheffield, Yorks S10 2TA
0114 222 2406 p.cowell@sheffield.ac.uk
3. The Registrar & Secretary
The University of Sheffield
Firth Court, Western Bank, Sheffield S10 2TN
0114 222 1100 registrar@sheffield.ac.uk

Appendix 8:2 Focus Group Participant Consent Form

Title of Research Project: **Expectations of rehabilitation in the post-acute stage after brain injury.**

Name of Researcher: Rosemary Gravell

Participant Identification Number for this project: **Please**
initial box

1. I confirm that I have read and understand the information sheet dated *September 2013* explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I give permission for my interview to be audio-recorded.

4. I give my permission for parts of the recording to be used at academic Conferences/for educational purposes.

5. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

6. I agree to take part in the above research project.

Name of Participant

Date

Signature

Lead Researcher

Date

Signature

To be signed and dated in presence of the participant

Appendix 9: Focus Group Questions

Expectations of Recovery and Rehabilitation after Acquired Brain Injury

Rosemary Gravell

Service Development Objective/aims:

To explore our own perceptions and attitudes towards recovery and rehabilitation in order to:

- Understand and gain insight into our own attitudes/beliefs.
- Understand the range of views and beliefs within the IDT
- Try to establish a consistency of approach towards clients

Research Objective :

To explore the beliefs/expectations held by clinicians in relation to recovery/rehabilitation after Acquired Brain Injury, and consider these in relation to the expectations held by clients.

Structure of the session:

To record discussions based on the following questions, and develop from notes (and transcript if appropriate) a summary of the views expressed. This may then inform the development of a team approach/philosophy and training.

Questions:

1. Expectations of recovery

What are your beliefs regarding recovery after ABI? What factors are most relevant?

What do you think affect clients' expectations of recovery?

2. Expectations of rehabilitation

What expectations do you hold in relation to rehabilitation – what do you expect of clients/yourself/others?

What do you think clients prioritise from rehabilitation services?

3. Beliefs regarding discharge readiness

When do you believe it is the right time to discharge a client from our service?