

**Living with a severe acquired brain injury as an inpatient in a  
neuro-rehabilitation unit:  
An interpretative phenomenological analysis**

**Catherine Heather Bamford**

A Thesis submitted in partial fulfilment of the requirements  
of the University of Hertfordshire for the degree of  
Doctor of Clinical Psychology

The Programme of study was carried out in the  
School of Psychology,  
University of Hertfordshire.

August, 2007

## 1. ABSTRACT

**Background:** Until recently, qualitative researchers have avoided interviewing participants with brain injuries because of the ethical and practical dilemmas which may arise and because it has been argued that they may not be able to reflect and accurately report upon their experiences. Therefore, little research has been produced which explores the personal experience of living with a brain injury. Recently, however, some researchers have challenged the view that people with brain injuries are unsuitable as interviewees in qualitative research and have, through their own research, highlighted the importance of understanding their views and perspectives in order to provide them with the best care and rehabilitation.

**Aims:** With this in mind, and in line with current calls for more research gaining the brain injured person's perspective, this study attempted to gain an in depth understanding of what it is like from the brain injured person's perspective, to live with an acquired brain injury. The study focussed upon the *experience of gaining consciousness following a brain injury, the experience of living with permanent memory loss, the experience of gaining awareness of deficits, the experience of losing an identity and adjusting to a new identity, the impact on relationships with friends and family and experiences as an inpatient in a Brain Injury Unit. Sources of strength and coping mechanisms* were also explored.

**Method:** Semi-structured interviews were conducted with six individuals who had severe acquired brain injuries and were inpatients in a post-acute neuro-rehabilitation unit. The verbatim transcripts of the semi-structured interviews were then analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** The analysis produced four master themes. These were: 'Piecing together the past and becoming aware of the present', 'The transition from old self to new self', 'Sources of strength and survival' and 'Experiences in rehabilitation'. A description of these themes is presented with the corresponding subordinate themes.

**Conclusions:** The clinical implications of the research and guidance for future research are discussed. The study produced a valuable insight into the personal experience of living with a severe acquired brain injury that could be used to inform rehabilitation interventions. The results also indicated that people with acquired brain injuries may experience Post Traumatic Growth.

## **ACKNOWLEDGEMENTS**

I wish to thank Dr Pieter Nel and Dr Ana Bajo for their support and guidance. I would also like to thank Adrian for helping me keep things in perspective.

## DEDICATION

For Daddy

## TABLE OF CONTENTS

	<i>Page Number</i>
1. ABSTRACT	104
ACKNOWLEDGEMENTS	105
DEDICATION	106
2. INTRODUCTION	111
2.1 Background	111
2.2 ABI research	112
2.21 Overview	112
2.22 The history of ABI research	112
2.3 Neuro-rehabilitation	114
2.4 Focusing research on the personal experience of brain injury	116
2.5 The National Service Framework for Long Term Conditions	117
2.6 Post Traumatic Growth in acquired brain Injury	117
2.7 Aims and research questions	119
3. METHODOLOGY	121
3.1 A qualitative research approach	121
3.2 Interpretative Phenomenological Analysis	121
3.3 Design	123
3.4 Participants	124
3.41 Recruitment strategy	124
3.42 Inclusion criteria	125
3.43 Exclusion criteria	125
3.44 Context of the study	125
3.45 Table 1: Aetiology of referrals to the neuro-rehabilitation unit	127
3.46 Table 2: Description of participants	127
3.5 Ethical Considerations	128
3.51 Informed consent	128
3.52 Confidentiality	129
3.53 Over researched participants	129
3.54 Potential distress	129

3.6	<b>Data Collection</b>	130
	<b>3.61 Semi Structured Interviews</b>	130
3.7	<b>Data Analysis</b>	130
	<b>3.71 Analytic procedure</b>	131
	<b>3.72 Writing up</b>	132
3.8	<b>Reliability and Validity Issues</b>	132
	<b>3.81 Peer review</b>	133
	<b>3.82 Triangulation</b>	133
	<b>3.83 Reflexivity</b>	134
3.9	<b>Challenges of interviewing people with severe brain injuries</b>	135
	<b>3.91 Potential challenges</b>	135
	<b>3.92 Strategies used to mitigate challenges</b>	135
4.	<b>RESULTS</b>	137
4.1	<b>Overview</b>	137
4.2	<b>Table 3: Master Themes and corresponding superordinate themes</b>	138
4.3	<b>Piecing together the past and becoming aware of the present</b>	138
	<b>4.31 Gaining consciousness</b>	139
	<b>4.32 Second hand memories</b>	140
	<b>4.33 Learning the hard way</b>	141
4.4	<b>Transition from old self to new self</b>	144
	<b>4.41 Grief reaction</b>	144
	<b>4.42 Feeling foolish</b>	146
	<b>4.43 Impact on relationships</b>	147
	<b>4.44 Hopes and fears about the future</b>	151
4.5	<b>Sources of strength and survival</b>	153
	<b>4.51 Spirituality</b>	153
	<b>4.52 Other sources of strength</b>	154
	<b>4.53 Giving up bad habits</b>	155
4.6	<b>Experiences in rehabilitation</b>	156
	<b>4.61 Positive experiences</b>	157
	4.611 <i>Positive experiences with rehabilitation staff</i>	157
	4.612 <i>Support from other inpatients</i>	
	4.613 <i>Rehabilitation instilling self_esteem, optimism and motivation</i>	158
	4.614 <i>Importance of independence</i>	159

<b>4.62</b>	<b><i>Negative experiences in rehabilitation</i></b>	160
4.621	<i>Relationships with patients and staff</i>	160
4.622	<i>Institutionalisation</i>	161
<b>5.</b>	<b>DISCUSSION</b>	162
<b>5.1</b>	<b>Overview</b>	162
<b>5.2</b>	<b>What is it like to live with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit?</b>	162
<b>5.21</b>	<b><i>The experience of gaining consciousness</i></b>	163
<b>5.22</b>	<b><i>Relying on second hand memories</i></b>	164
<b>5.23</b>	<b><i>The experience of gaining awareness of cognitive and physical deficits</i></b>	165
<b>5.24</b>	<b><i>The process of losing a pre-injury identity and adapting to a new identity</i></b>	166
5.241	<i>Grief Reaction</i>	166
5.242	<i>Feeling foolish</i>	167
5.243	<i>Hopes and fears about the future</i>	167
<b>5.25</b>	<b><i>The impact on relationships with friends and family</i></b>	168
<b>5.26</b>	<b><i>The experience of being an inpatient in a neuro-rehab unit</i></b>	169
<b>5.27</b>	<b><i>Sources of strength and coping mechanisms (Post-Traumatic Growth)</i></b>	170
<b>5.3</b>	<b>Significance of the study</b>	171
<b>5.4</b>	<b>Reflexive considerations</b>	172
<b>5.5</b>	<b>Clinical Implications</b>	173
<b>5.6</b>	<b>Strengths and limitations of the study</b>	176
<b>5.61</b>	<b><i>Methodology</i></b>	176
<b>5.62</b>	<b><i>Originality and novel research findings</i></b>	177
<b>5.63</b>	<b><i>Authors transferable skills and prior clinical experience</i></b>	177
<b>5.64</b>	<b><i>Amount of usable data from interviews</i></b>	177
<b>5.65</b>	<b><i>Validity</i></b>	178
<b>5.66</b>	<b><i>Sample size</i></b>	178
<b>5.67</b>	<b><i>Member validation</i></b>	179
<b>5.7</b>	<b>Future research</b>	181

<b>6. CONCLUSIONS</b>	183
<b>7. REFERENCES</b>	185
<b>8. APPENDICES</b>	191

## 2. INTRODUCTION

The brain is one of the most complex objects in the known universe. Even today, despite technologies which allow researchers to peer inside it and to examine its function at the cellular and sub cellular levels, much remains to be understood about the human brain. (Hill, 1999, p.839)

### 2.1 Background

Acquired brain injury (ABI) refers to non-degenerative damage to the brain that has occurred since birth (Whitfield, 2003). 'Acquired brain injury' is a widely used, inclusive term that refers to brain injuries in the following three categories: Traumatic brain injury (TBI) (for example, road traffic accidents or falls), and non traumatic brain injuries in the following two categories: hypoxic-ichaemic (for example, cerebrovascular accidents or prolonged status epilepticus) and 'other medical' (for example, tumours, stroke or metabolic disorders). It does not relate to a congenital disorder, a developmental disability or a process which progressively damages the brain, such as dementia (Whitfield, 2003).

The resulting damage to the brain from an ABI can alter the individual's physical, cognitive and psychological capabilities. Consequences of ABI vary enormously and each case is unique, as different types of brain injuries can affect various brain structures to varying degrees. Depending on the severity and location of the injury, ABI may lead to permanent impairments in multiple areas of functioning. These can include physical impairments (e.g. fatigue, paralysis, seizures, motor problems, agnosias, bowel/bladder dysfunction), cognitive impairments (e.g. intellectual ability, attention, memory deficits, learning deficits, language impairments, communication and organisational difficulties), psychosocial problems (e.g. unemployment, relationship breakdown, sexual dysfunction and social isolation) and emotional problems (e.g. inappropriate behaviour, mood disorders) (Howes *et al.* 2005; Morris *et al.* 2005; Murray & Harrison, 2004).

ABI can have a profound, long term and negative impact on the individual's daily life and the life of their family (e.g. Jumisko *et al.* 2005; Wood, 2005). Moreover, many

who have sustained an ABI also develop long term mental health problems such as depression and anxiety as they struggle to adjust to the consequences of their injury (e.g. Chamberlain, 2006; Morton & Wehman, 1995). Neuro-rehabilitation services across the UK provide a valuable source of support for individuals with ABI and their families in helping them rebuild their lives and in addressing their complex needs.

## **2.2 ABI research**

### **2.21 Overview**

A vast amount has been written by researchers and clinicians about Acquired Brain Injury (ABI) and the physical, social, cognitive and psychological consequences (e.g. Lezak, 2003; Lovasik *et al.* 2001; Morton & Wehman, 1995). This research has influenced and informed clinicians within neuro-rehabilitation services, and in turn has also influenced the care of and advice given to brain injured individuals and their families.

### **2.22 The history of ABI research**

Quantitative research dominates the ABI literature and it has focussed upon two main areas (Howes *et al.* 2005). Firstly, there has been a significant body of research on statistical outcomes after brain injury, for example, survival rates or the degree of severity of injury. Secondly, a large proportion of quantitative research has focussed upon specific areas of brain injury outcome, for example, intellectual ability or memory, through the use of psychometric tests that have been devised by health care professionals (Howes *et al.* 2005; Morris *et al.* 2005). Overall, most ABI research has focused upon the presence of symptoms and deficits following ABI (Morris *et al.* 2005). Although it provides powerful empirical evidence, it is important to highlight the fact that quantitative research cannot capture brain injured individuals' perspectives, opinions and personal experience (Howes *et al.* 2005; Morris *et al.* 2005).

In addition to quantitative research focusing upon specific areas of brain injury outcome, there is also a smaller and more recent body of research (qualitative and quantitative) that addresses the psychosocial impact of brain injury (e.g. Gan &

Schuller, 2002; Katzberger & Oder, 2000). The majority of this research has relied upon objective accounts from carers or relatives of the brain injured individual, or professionals working with brain injured individuals. Very little research, however, has focussed upon the perspectives and opinions of brain injured individuals themselves on the psychosocial impact of their brain injuries (e.g. Chamberlain, 2006; Howes *et al.* 2005; Morris *et al.* 2005; Opperman, 2004). Up until recently, most researchers had deemed people with brain injuries to be unsuitable providers of accurate accounts of the psychosocial impact of their injuries, mainly because of their cognitive deficits and lack of insight (Howes *et al.* 2005). People with cognitive impairments are often unable to accurately recall and articulate experiences, feeling and perceptions, meaning that interviewing them can be a difficult task, fraught with pragmatic and methodological challenges (Paterson & Scott-Findlay, 2002). For example, people with speech difficulties are often not selected for qualitative research because researchers believe that the effort required to obtain substantial interview data will be overwhelming (Hutchinson & Wilson, 1992). Recently, however, qualitative researchers have challenged the view that brain injured persons are not suitable as interviewees, on the grounds that it undermines the importance of their perspectives to our understanding of their lived experience and, in turn, in informing rehabilitation interventions (e.g. Howes *et al.* 2005; Jumisko, Lexell & Soderberg, 2005). Other authors, such as Crowe (1998) and Thorne and Paterson (1998) have argued that populations with cognitive disabilities represent a unique culture in which memory and recall are cultural representations. They argue that it is important, therefore, that these people be included in research to learn about their experience of living with their disability.

Paterson and Scott-Findlay (2002) also argue for involving brain injured individuals in qualitative research. Their research involved interviewing six participants with moderate to severe traumatic brain injuries in order to determine the allocation of rehabilitation services post injury. They reported that despite the effort and occasional frustration in interviewing these people, the data provided was essential to the research question and contributed significantly to the research findings.

Despite the apparent need for research from the brain injured person's perspective and more widely, from the perspective of people with cognitive disabilities in general,

researchers have generally avoided interviewing this population because of the ethical and practical difficulties (Paterson & Scott-Findlay, 2002).

Given the lack of qualitative research into the personal experience of brain injury, it is not surprising that some recent studies provide evidence to suggest that people with brain injury experience a lack of understanding from those around them, including rehabilitation professionals, of what it is like to live with a brain injury (e.g. Darragh, Sample & Kreiger, 2001; Jumisko *et al.* 2005; Morris *et al.* 2005; Swift & Wilson, 2001). For example, Morris *et al.* (2005) carried out thirty two semi-structured interviews with survivors of TBI in order to identify aspects of outcome that they considered important. The results revealed that areas of outcome important to people with TBI, (such as difficulties in group conversation, negative reactions of others due to lack of understanding), had received little attention in the literature and therefore may be overlooked by health care professionals in developing suitable rehabilitation interventions.

### **2.3 Neuro-rehabilitation**

Mazaux and Richer (1998) present a three stage model of neuro-rehabilitation. Different rehabilitation units, post brain injury, tend to focus on problems occurring at each of the three stages of the model. In the first 'acute' stage, the main focus is to address physical complications and facilitate the return of clear consciousness. This stage usually takes place on medical and surgical wards. At the second stage of rehabilitation, referred to as the sub-acute rehabilitation stage, mobility and cognition problems are addressed and other activities of daily living. Most inpatient rehabilitation units focus on this stage of recovery and also on physical skills such as continence and walking. In the final stage of rehabilitation, referred to as the post acute stage, the goals are to achieve physical, domestic and social independence, with an aim towards patients being able to participate in activities in the community.

Headway, an established charity supporting the rehabilitation of individuals with brain injuries, describes neuro-rehabilitation in terms of:

...a process of change through which a brain injured person goes, seeking to regain former skills and to compensate for skills lost. Its aim is always to achieve

the optimum levels of physical, cognitive and social competence followed by integration into the most suitable environment.' (Headway: The Brain Injury Website: <http://www.headway.org.uk/sitePages.asp>)

In contrast, Hill (1999), a doctor who suffered a traumatic brain injury and wrote a journal article describing her own experiences as a patient in a neuro-rehabilitation unit, reported the following:

It would appear from my reviews of the literature that much of the work since the 1970s focuses on the TBI person's deficits and comparisons with their pre-injury selves...I know that I am no longer the same person I was prior to TBI and hence there is little to be gained in comparing me with the previous being in terms of the progress that I have made (Hill, 1999, p.841).

Hill (1999) argues that the emphasis on comparison of the post-injured to the pre-injured self is a self-defeating process. Hill (1999) feels that rehabilitation professionals should focus on helping patients develop new and adaptive behaviours, taking the new situation of the TBI patient into account, instead of trying to restore an original pattern of behaviour. Furthermore, Morris *et al.* (2005) and Hill (1999) provide evidence through their research that neuro-rehabilitation may not always meet the needs of brain injured persons and that they may not feel understood by rehabilitation professionals.

#### **2.4 Focussing research on the personal experience of brain injury**

Researchers have now begun to reconsider excluding brain injured individuals from research and are beginning to provide some valuable and novel findings which are informing rehabilitation interventions and improving our understanding of the personal experience of brain injury (Nochi, 1997). A recent body of phenomenological qualitative research has emerged which has focussed upon gaining the brain injured person's own experience and perspectives on a number of relevant issues.

For example, O'Callaghan *et al.* (2006) carried out semi-structured interviews with ten people with moderate to severe TBI in order to find out about the experience of gaining awareness of deficits following a brain injury. Themes arising from the

interviews revealed that participants' knowledge of deficits was acquired through personal discovery and from the reaction of others, often from outside the rehabilitation environment. Rehabilitation provided a normalising and supportive setting which helped participants in acknowledging and providing explanations of their brain injuries. The authors found participants' emotional reactions to learning about their brain injuries resonated with psychological models of grief, an area neglected in the brain injury literature (O'Callaghan *et al.* 2006).

Another recent example is a study by Jumisko *et al.* (2005) who carried out semi-structured interviews with twelve participants who had lived with TBIs for four to thirteen years. In the interviews, participants described how they felt they had 'lost their way' and had struggled to adapt to their new self post injury. 'Losing their way' included experiences of gaining consciousness and waking up to the unknown, changes and losses in relationships and experiencing the body as an enemy. Participants described their struggle to adapt to their new self in terms of searching for an explanation for their TBI, wishing to be treated with respect and struggling with recovery.

Howes *et al.* (2005) investigated six women's experience of brain injury using Interpretative Phenomenological Analysis (IPA). The major themes derived from this study were: an awareness of change, the emotional reaction, struggling to make sense and the struggle to adapt and accept what had happened. The 'changes' that the women were aware of were cognitive and physical changes and also changes in social interaction and personal relationships. Their emotional reaction included intense feelings of anger, anxiety, depression and fear.

Other qualitative studies focusing on the brain injured person's perspective include O'Flaherty and Douglas, (1997) who researched the subjective experience of long term cognitive communicative impairments following TBI and Opperman (2004) who researched brain injured persons' experience of returning to work.

Specifically relating to stroke, research has been carried out to gain patient perspectives on how stroke sufferers recognise and respond to their stroke (McKevitt *et al.* 2004, cited in Morris *et al.* 2005), their experience while in hospital, the strategies they have used to manage their illness (Pound *et al.* 1995, cited in Morris

*et al.* 2005) and their information needs following stroke (Wiles *et al.* 1998, cited in Morris *et al.* 2005).

In his book containing fifty personal papers reporting the personal experiences of health care professionals who had acquired brain injury, Kapur (1997) reported that these papers covered areas of research that had been neglected in traditional textbook accounts of brain injury. Overall, the amount of research addressing the personal experience of ABI, including strokes, remains small but has provided some new and valuable evidence that has enriched the ABI literature.

## **2.5 The National Service Framework for long-term conditions**

The National Service Framework for long term (neurological) conditions (2005) is a 10 year plan setting standards for care within the NHS of individuals with chronic neurological conditions including ABI. Central to this NSF is an emphasis upon creating a more person-centred service for people with long term conditions (Department of Health website: [www.nhs.uk/England/AboutTheNHS/Nsf/LongTerm Conditions.cmsx](http://www.nhs.uk/England/AboutTheNHS/Nsf/LongTermConditions.cmsx)). The current research, therefore, is in tune with this emphasis, and in valuing the role of the brain injured individual in understanding their needs.

## **2.6 'Post traumatic growth' in acquired brain injury**

In the last decade there has been a growing amount of research into 'Post Traumatic Growth' (PTG) in the trauma literature (e.g. Bamford, 2006; McGrath & Linley, 2006). There is now wide consensus that people may report positive as well as negative psychological changes following a traumatic event (Bamford, 2006; Linley & Joseph, 2004; McGrath & Linley, 2006). These positive changes are most commonly referred to as PTG and research has demonstrated that trauma can motivate individuals to make positive personal and social changes in their lives (Linley & Joseph 2004; Joseph & Linley, 2006). As a result of this, research into the treatment of traumatised people has shifted its focus from purely negative reactions and Post Traumatic Stress Disorder (PTSD), to the possibility of PTG and its therapeutic implications (Joseph & Linley 2006; Linley & Joseph, 2004 both cited in Bamford, 2006). For example, interventions for people who have experienced trauma have been developed from the

notion of PTG, and focus upon strategies of building resilience, emotional intelligence, optimism and intrinsic motivation (Csikszentmihalyi & Selega, 2006). PTG has been documented following a range of traumatic life events, for example, head injury (McGrath & Linley, 2006) and illness and surgery (Bower *et al.* 2005).

The positive changes that have been reported following trauma can be summarised under three broad headings: improved interpersonal relationships, positive change in perception of self and emerging or developing philosophy in life (Bamford, 2006; Linley & Joseph, 2006). Interpersonal relationships have been reported to improve after a traumatic event, through people valuing friends and family more and feeling an increased compassion and altruism towards others. Positive changes in the perception of self post-trauma have been reported in terms of a greater sense of personal resilience, wisdom and strength and a greater acceptance of a person's vulnerabilities and limitations. In relation to an emerging or developing philosophy in life, related positive changes in the literature have included finding an appreciation for each new day, renegotiating what matters in life in the knowledge of the fragility of life and changes in spiritual beliefs (e.g. Joseph & Linley, 2006; Calhoun & Tedeschi, 2004; Shaw *et al.* 2005; Tedeschi *et al.* 1998).

As ABI is considered a traumatic event, and people with ABI experience post traumatic reactions (McWilliams *et al.* 2003), the concept of PTG is now emerging in the brain injury literature (Howes *et al.* 2005; McGrath & Linley, 2006; Nochi, 2000). The research interest derives from an awareness that the characteristics of individuals with brain injury who report positive changes may provide useful information for neuro-rehabilitation clinicians, in helping clients to successfully adjust to changes post injury. The emphasis on positive change has also been in response to brain injury researchers and rehabilitation professionals having tended to focus solely upon the brain injury deficits and symptoms, (e.g. Peterson *et al.* 2005).

Although some recent research has indicated that people with severe brain injuries *do* experience PTG (McGrath & Linley, 2006) there is not enough research to support these findings conclusively and there is also discussion in the literature about whether or not it is possible for brain injured person to experience PTG (Mailhau *et al.* 2005; McGrath, 2004). The process of PTG is underpinned by changes in cognitive schema (Bamford, 2006), and some researchers argue that because brain injured

persons often have significant cognitive deficits, it may not be possible for them to experience PTG (McGrath & Linley, 2006). Also, PTG is often experienced through the strengthening of interpersonal relationships following a trauma (Bamford, 2006), and because relationship breakdown is a common occurrence post brain injury, this may also reduce the likelihood of brain injured individuals experiencing PTG (McGrath & Linley, 2006; Oddy, 1996). The debate continues in the literature as there is no conclusive evidence to prove or disprove whether people with brain injuries can experience PTG. There is therefore a need for further research in this area.

## **2.7 Aims and research questions**

The aim of the current study was to combine two emerging avenues of research in the brain injury literature, that is, the personal experience of brain injury, and the concept of Post Traumatic Growth (PTG). Specifically, this study aimed to explore and capture the personal experience of living with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit, using an interpretative phenomenological approach (IPA) (Smith & Osborn, 2003). In relation to the experience of living with a severe acquired brain injury, the study focussed upon exploring the experience of gaining awareness of one's deficits and the process of adjustment and adaptation. Also, in relation to living with a severe acquired brain injury, the study focussed on the experience of being an inpatient on a neuro-rehabilitation ward. Participants were given the opportunity to talk about positive as well as negative experiences in order to explore whether or not they may have experienced PTG. The other areas of exploration in relation to the main research question were chosen because they had been neglected in the brain injury literature and were considered to be interesting and relevant topics that could be used to inform brain injury rehabilitation interventions.

In order to carry out the above aims, the following research question was formulated:

**What is it like to live with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit?**

In relation to this question, the following areas of interest were explored:

- The experience of gaining consciousness
- Living with permanent memory loss
- The experience of gaining awareness of cognitive and physical deficits
- The process of losing an old identity and adapting to a new identity
- The impact on relationships with friends and family
- The experience of being an inpatient in a neuro-rehabilitation unit
- Sources of strength and coping mechanisms

In order to address the research question, and the areas of interest relating to the research question, a semi-structured interview lasting around an hour was devised. (A full interview schedule including prompts can be found in Appendix 1.) This included six broad areas of questioning covering:

1. First memories after the brain injury occurred.
2. The experience of living with permanent memory loss.
3. The experience of gaining awareness of ones deficits.
4. The impact of brain injury on relationships with family and friends.
5. Positive and negative experiences in neuro-rehabilitation.
- 6 Sources of strength and survival (in relation to post traumatic growth).

Participants were prompted to talk about both positive and negative experiences that they may have had in relation to the areas of questioning, in order to allow exploration of possible post traumatic growth.

## METHODOLOGY

### 3.1 A qualitative research approach

The primary aim of this research study was to explore the personal experience of living with a severe acquired brain injury (ABI) and also to explore how these individuals make sense of their personal experiences. A qualitative approach was therefore chosen to capture in-depth information about the individuals' personal accounts. A qualitative design was also chosen because of the limited evidence base in this area and the exploratory nature of the research. Qualitative research differs from quantitative research in that it does not test hypothesised relationships, causal explanations or the degree of generalisability across samples and the wider population (Hicks, 2000).

In order to capture and retain the individuals' personal accounts, participants were interviewed using a semi-structured interview schedule (see Appendix 1). Rubin and Rubin (1995) recommend that semi-structured interviews are suitable for qualitative exploratory studies that examine areas with a limited research evidence base (such as, the lived experience of acquired brain injury). Semi-structured interviews provide greater flexibility than structured interviews, generate richer data and also allow the researcher to follow interesting or new areas that arise during the interview (Smith, 1995).

### 3.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (e.g. Smith, 1995; Smith *et al.* 1999; Smith & Osborn, 2003) was chosen as the preferred methodology for this study for a number of reasons. Firstly, IPA is consistent with the aims of the research, by offering a methodology that is capable of exploring and capturing a person's lived experiences in detail (Smith, 1996). Furthermore, IPA has been used to address a wide range of issues in health and clinical psychology, and more recently, in brain injury research (e.g. Howes *et al.* 2005; Murray & Harrison, 2004) and specifically, acquired brain injury (Brown *et al.* 2006)

It was felt that IPA was a more suitable approach than other qualitative approaches. Discourse analysis, for example, was considered as a less appropriate approach than IPA because of its focus on the role of language in constructing social reality, in contrast to focussing on understanding personal experience (Willig, 2003). Furthermore, despite the similarities between the approaches, IPA was favoured over Grounded Theory as a qualitative approach, because it has been argued that IPA adopts a more psychological approach than Grounded Theory, which is viewed as more of a sociological approach (Willig, 2003). Grounded theory focuses upon the unfolding of social processes as opposed to capturing personal experience. Overall, IPA is considered as the most suitable qualitative approach to capturing individuals' personal experiences and their world, rather than creating a 'theoretically saturated' account of the social processes as an explanation for the research subject (Willig, 2003).

The IPA approach was founded by Smith (1996) and is philosophically rooted in symbolic interactionism, with its primary focus on how meanings are constructed by individuals (Smith, 1996). The aim of IPA studies is to give a detailed account about the views and meaning making of a small group of people, rather than make more general claims for a larger group or population, as in quantitative methodology (Smith *et al.* 1999). It is 'phenomenological' in that it aims to explore personal as opposed to objective experience through an individual's account, opinions or views on a particular subject or event (Brocki & Wearden, 2006). The 'interpretative' component of IPA is that meaning making is viewed within an individual's social and personal context and therefore IPA can be viewed as drawing upon both constructivist and social constructivist traditions. IPA involves a two stage interpretation process, that is, as the participant tries to make sense of their personal world, the researcher also tries to make sense of the participant and their rationale (Smith & Osborn, 2003). Interpretation of the data is dependent upon the research participants' abilities to articulate their thoughts and experiences adequately and by the researcher's ability to reflect upon the participants' accounts and analyse them (Brocki & Wearden, 2006). In the current study, it is important to acknowledge that individuals with acquired brain injury may experience expressive and receptive communication difficulties and other cognitive deficits that may limit interpretation and make the analytic process difficult. (This issue will be considered in more detail in the Discussion, section 5.6).

The IPA approach requires the researcher to form an interpretative dialogue with the data from the semi-structured interviews, in order to obtain the participants 'insider perspective' during analysis. The IPA approach acknowledges the inevitable influence of the researcher's own views, assumptions and beliefs upon the interpretation of the participants' account, and it is therefore important for the researcher to reflect upon this explicitly (Smith *et al.* 1997). The analytic account produced from the interview data is viewed as a joint product of reflection and collaboration from both the participant and researcher (Smith *et al.* 1997).

A key characteristic of IPA is that it requires a level of homogeneity in the sample used in the research. The collective term 'acquired brain injury' (ABI) incorporates a variety of aetiologies (see section 2.1) and therefore can lead to a range of cognitive and physical impairments. Despite these differences, a small number of researchers have used IPA to explore the experiences of people with a range of acquired brain injuries: For example Brown *et al.* 2006 used IPA to explore how people construct their experiences of acquired brain injury and the challenges they face afterwards. The twenty four participants in the study had a range of acquired brain injuries, including stroke, brain tumour, brain haemorrhage and traumatic brain injury. In the current study, the sample was considered homogenous because participants all shared the experience of having severe acquired brain injuries and they were all inpatients in the same neuro-rehabilitation unit. Also, they all had physical and cognitive deficits as a result of their brain injuries. Despite these commonalities, it is acknowledged that the subjective experiences of the participants in the current study may have differed in relation to the type of acquired brain injury that they had incurred. This is discussed further in section 5.7.

### **3.3 Design**

The current study employed a cross sectional qualitative research design, using Interpretative Phenomenological Analysis (IPA) (Smith, 1995; Smith, 1996; Smith & Osborn, 2003) to analyse verbatim transcripts of the semi-structured interviews.

### **3.4 Participants**

#### **3.41 Recruitment strategy**

A Consultant Clinical Neuropsychologist and Research Psychologist in a post-acute NHS inpatient neuro-rehabilitation unit, agreed to oversee the identification of suitable potential participants for the study. They were provided with a protocol of the study so that they were aware of what would be required of participants if they took part in the study. A 'shortlist' of potentially suitable participants was devised from the patients in the rehabilitation unit. This shortlist was devised by the clinicians overseeing the recruitment process, who had considerable knowledge of and daily contact with the patients. They ensured that the shortlist was based upon the exclusion and inclusion criteria listed below.

Smith and Osborn (2003) suggest that five or six participants is an adequate sample size for a study using IPA, provided that the interviews yield adequate data to allow in depth analysis of similarities and differences between cases. Therefore, in line with the philosophy of IPA research, the aim was to recruit at least six suitable participants. Once the shortlist was devised, the Research Psychologist who was assisting in the recruitment process, approached the potential participants and asked them for their written consent to agree to be approached by myself about the study (see Appendix 4). Consent was sought for the patient's name and contact details. This procedure was repeated until six potential participants were identified from the inpatient ward, with their written consent to be approached about the study.

These potential participants were then contacted individually and private appointments were arranged in order to inform the participants about the study, using the information sheet as a guide (Appendix 3). Potential participants were given the option of up to twenty four hours to make a decision about whether they wanted to take part in the study. They were also given the opportunity to ask any further questions that they might have about the research. A consent form was given to and read to the potential participants (see Appendix 6). The consent form also sought permission for the interview to be recorded and for access to the participant's medical file. Participants were asked to sign the consent form. Copies of the consent form

were provided for the participant to keep and a copy was also placed in their medical file.

A mutually convenient date and time for the interview were then arranged with the participant. The researcher made sure that the interview did not clash with any rehabilitation activities in the Unit by liaising with the ward staff. The participant was provided with written confirmation of the appointment (Appendix 7) The Brain Injury Unit ward staff were also made aware verbally of the appointment for the interview and the time and date of the interview were noted in their medical file.

### **3.42 Inclusion criteria**

1. Participants should have an acquired brain injury
2. Participants should be over 18 years and inpatient at the neuro-rehabilitation unit.
3. Participants should have the ability to give informed consent, based on psychiatric assessment.

### **3.43 Exclusion criteria**

Participants were excluded if they:

1. Were unable to give informed consent to participate in the study.
2. Would severely struggle to participate in the interview process, such as patients with very low intellectual functioning, poor insight, poor verbal skills, poor attention or concentration, antisocial behaviour or any other psychological, cognitive or physical difficulties that might cause significant difficulties in the interview process.
3. Were involved in other research projects in the neuro-rehabilitation unit during the time of recruitment and data collection for the current study.

### **3.44 Context of the study**

Participants were recruited from a post-acute neuro-rehabilitation unit in Hertfordshire which provides specialist assessment and rehabilitation for adults with moderate to

severe acquired brain injury who require treatment for cognitive, behavioural and neuropsychiatric problems. The Unit has fifteen inpatient beds and is staffed by a specialist multidisciplinary team including Neuropsychiatrists, Clinical Psychologists, Behavioural Nurses, Speech and Language Therapists, Occupational Therapists and Physiotherapists. Patients are mainly referred to the Unit from the areas of Barnet, Enfield and South Hertfordshire, a mainly white, urban population of varied socio-economic status. Occasionally, referrals are also made to the service from other areas of the UK and these are considered on a case by case basis, dependent on NHS funding and patient needs. Between 1995 and 2006, there were 136 referrals to the service. 76% referrals were of White British origin, 10 % were of African origin, 11 % were of Asian origin, 1 % were mixed race and 1 % were of other ethnic origins. (Referral information gained from internal service audit).

The table below summarises the aetiology of referrals to the neuro-rehabilitation unit between 1995 and 2006 (Information gained from internal service audit).

**3.45 Table 1: Aetiology of referrals to neuro-rehabilitation unit**

<b>Cause of ABI</b>	<b>Frequency (N = 128)</b>	<b>Percent %</b>
<i>Traumatic Brain Injuries:</i>		
Road Traffic Accident	39	30
Fall	11	9
Assault	13	10
<i>Other Brain Injuries:</i>		
Subarachnoid Haemorrhage	13	10
Alcohol Related	9	7
Anoxia (cardiac arrest, status epilepticus)	17	13
Encephalitis	11	9
Space Occupying Lesion	3	2
CVA (Stroke)	5	4
Other	3	2
Unknown	4	4

The following demographic information was gained from the patients' medical files. All participants incurred severe acquired brain injuries. Alias names have been provided for confidentiality purposes.

**3.46 Table 2: Description of participants**

<b>Participant Alias Name</b>	<b>Sex</b>	<b>Age</b>	<b>Cause of ABI</b>	<b>Time since injury</b>	<b>Marital Status</b>	<b>Ethnic Origin</b>	<b>Profession prior to injury / class</b>
Bob	Male	52	Cerebral anoxia	4 months	Single	White British	Taxi driver / working class
Sue	Female	48	Stroke	3 months	Divorced	White British	Unemployed / working class
Anna	Female	24	Assault	18 months	Single	White British	Unemployed / working class
Peter	Male	37	Assault	7 years	Single	White Irish	Unemployed / working class
Neil	Male	54	Brain tumour	2 years	Divorced	White British	Manager / electrician / middle class
Paul	Male	51	Stroke	2 months	Married	Black African origin	Electrician / working class

### **3.5 Ethical Considerations**

Ethical approval was granted for the study by Barnet, Enfield & Haringey Local Research Ethics Committee (LREC) and the documentation to support this can be found in Appendix 10.

#### **3.51 Informed consent**

Patients unable to give informed consent were automatically excluded from the study (see exclusion criteria in previous section). Information about whether or not the patients had the ability to give informed consent (based upon Psychiatric assessment) was gained from the patient's files during the recruitment process. Signed Consent was obtained from patients for access to their medical files.

Informed consent to participate in the study was ensured through providing an information sheet (See Appendix 3) detailing key information about the study, including the purpose of the study, the method to be used and how data will be kept confidential. To ensure that participants did not feel obliged to take part in the research, the information sheet also informed the participant that they had the right to withdraw from the study at any time and that this would not affect their level of care. Participants were given the option of up to twenty four hours to decide whether or not they wished to participate in the research and were then asked to give their written and verbal consent (See consent form in Appendix 6) if they wished to participate in the study.

### **3.52 Confidentiality**

All identifying information about the participants was removed from the write up of the study. Recordings, transcripts and other research materials were kept securely and confidentially at the author's home address and participants were informed verbally and in their information sheet that all recordings and identifying information would be destroyed following completion of the research.

### **3.53 'Over researched' participants**

Inpatients who were actively involved in other research at the neuro-rehabilitation unit were automatically excluded from the study to ensure that they were not over-involved in research activity.

### **3.54 Potential distress**

There was a possibility that participants might become distressed when discussing potentially upsetting issues, such as facing death and coming to terms with their brain injury. Participants were assured, both verbally prior to the interview and in the information sheet, that they did not have any obligation to answer the questions in the interview and that they could stop the interview at any time. This procedure aimed to minimise the distress levels of the participants. Furthermore, any participants who would be prone to significant psychological distress were excluded from the study.

Exclusion of these patients was based on the professional opinions of a senior Clinical Neuropsychologist within the Unit and senior ward staff, as well as information gained from patient files. In addition, if participants did become distressed, they were made aware of professionals within the rehabilitation team whom they could approach if they felt they required further support. This procedure was verbally agreed with relevant staff members. Furthermore, in the event of a participant becoming distressed, the interview would be stopped and only resumed if the participant gave their consent. If the interviewer had significant concern about the participant's levels of distress they would inform relevant clinicians within the rehabilitation team, with the consent of the participant.

### **3.6 Data collection**

#### **3.61 *Semi-structured interviews***

A semi-structured interview schedule was devised (see Appendix 1) relevant to the specific research topics and study aims. The interview schedule was developed through discussion with experts in the Brain Injury field and also experienced qualitative researchers. Due to the exploratory nature of the research, the semi-structured interview schedule was not prescriptive, in order to allow for further probing of any areas of interest that might emerge (Smith, 1995). Questions were initially delivered in an open-ended and non-directive manner and further specific probing was used where necessary (See Appendix 1). The schedule was reviewed after each interview with the aid of an 'interviewer response sheet' (See Appendix 2). The interview response sheet enabled content and process issues to be recorded.

### **3.7 Data Analysis**

Interpretative Phenomenological Analysis (IPA) was the method used to analyse the interview data, as described by Smith (1996) and also Smith and Osborn (2003). Knowledge of quality issues in qualitative research (e.g. Brocki & Wearden, 2006; Sandelowski, 2004) were used in the analytic process. In addition, supervision was gained from an experienced IPA researcher. An expert in brain injury research was also consulted. The overall aim of the interview analysis was to produce a list of

themes that would provide a representation of the participants' experiences and perceptions (Smith, 1996).

### **3.71 Analytic procedure**

The analysis was carried out using the recommended procedure described by Smith and Osborn (2003).

To begin with, the transcripts were analysed on a case by case basis. The transcripts were each read and listened to several times by the researcher and initial analytic notes on the transcript were made, in the left hand column (See Appendix 8 for sample analysis and audit trail). These notes summarised the content of the interview and experiences of the interviewee as well as anything that seemed interesting or significant such as initial associations or themes.

The transcripts were then re-read and analysed at a deeper level, using the initial analyses in the left hand column as well as the transcript, to guide the process. The right hand columns were used to note emerging theme titles, by clustering together themes with shared meaning. These themes continued to evolve as analysis continued and reorganised or merged together when appropriate. The process was repeated several times using the transcript, the notes in the left hand column and the emerging theme titles in the right hand column. In keeping with the phenomenological nature of IPA, words or phrases used by the participants themselves were used as labels for the emerging themes. The emerging theme titles were connected and grouped together to form superordinate themes with sub-themes within them. At this stage in the analysis, interpretation of the transcripts were also influenced by related theoretical and research literature to produce more abstract concepts and psychological interpretations. The hierarchy of themes from each individual interview were summarised in a table for the next stage of analysis.

Each interview transcript and recording was analysed using the same process until all six transcripts had been analysed to this stage. Commonalities in the themes that began to emerge throughout this process were considered for analysis at a later

stage, but the researcher also remained open to any new emerging themes within each interview.

The analyses from all six transcripts were then integrated to produce a master list of themes. Differences and similarities in themes were considered and noted. A table of super-ordinate themes comprising all six analyses was produced. The superordinate themes were clustered to produce master themes in terms of shared meaning, represented across the analyses and these were given a title. Again, these were checked against the original transcript for accuracy (See Appendix 9). Supervision was also used to reflect upon the list of master themes and refine or reconsider their grouping if necessary. A final list of master themes was then produced, with their corresponding subordinate themes for the group as a whole. (See Appendix 9). This final stage of the analysis enabled the researcher to understand and communicate the experiences and perceptions of the individuals with acquired brain injury.

In addition to the analytical procedure, the researcher also kept notes to summarise the researcher's thinking and feeling during the analysis. This was also done while the interviews took place and was used to contribute to the analysis and development of themes.

### **3.72 Writing up**

The master list of themes developed in the final stage of analysis was used as the basis for writing up of the results. Quotations and extracts from the transcripts were used to illustrate the core themes derived from the analysis and relating to the research questions.

### **3.8 Reliability and validity issues**

Regarding the methodological issues of reliability and validity, several key papers were useful in offering guidance of what is considered as quality and rigour in qualitative research and also more specifically, in IPA (e.g. Brocki & Wearden, 2006; Elliot *et al.* 1999; Horsburgh, 2002; Sandelowski, 2004; Spencer *et al.* 2006; Yardley, 2000). Guidelines from these key papers were considered in relation to issues of validity and reliability that emerged in the current study.

The main issues derived from these papers are summarised in the following section. Quality and rigour were considered using the following checks of validity and reliability: peer review, triangulation and reflexivity.

### **3.81 Peer review**

A method of maintaining credibility and to ensure coherence is a peer review, where one or more auditors are asked to review and give their comments on the researcher's analyses. My Thesis supervisor, an experienced IPA researcher, audited the analysis of the first interview. In addition, the fourth interview was audited by the author's field supervisor, a Research Psychologist at the Brain Injury Unit where the participants were recruited. Auditors read through the interviews to identify themes and then examined the researcher's analysis to see if similar or corresponding themes had been produced. Both auditors agreed with the themes that the researcher had derived from the transcripts, and therefore the analyses appeared to be an acceptable reflection of the interviews.

### **3.82 Triangulation**

Triangulation is based on the assumption that the convergence of data from multiple perspectives can provide confirmation of the validity of research findings. As one of the primary goals of IPA research is that the themes derived from analysis should 'make sense' to readers, triangulation is regarded by Smith and Osborn (2003) as an effective means of establishing credibility and transferability of analysis. Triangulation in this case involved inviting experts within the particular research field (i.e. neuro-rehabilitation) to comment upon the coherence of the analysis and the extent to which links could be made between the researcher's findings and their own personal and professional experience and the claims in the existing literature (Elliot *et al.* 1999; Smith & Osborn, 2003; Spencer *et al.* 2006). Triangulation occurred by informal discussion with an experienced Research Psychologist in the field of neuro-rehabilitation. The experts' comments were considered and incorporated into the final draft of the research. Smith and Osborn (2003) recommend the use of triangulation because the aim of IPA research is for theoretical and not empirical (quantitative) generalisability. A successful IPA study is when readers are able to

make links between findings of the study and their own personal and professional experience as well as make links to the existing literature.

### **3.83 Reflexivity**

Reflexivity refers to sensitivity to ways in which the researcher and the research process have influenced the analysis and data (Spencer *et al.* 2006). Reflexivity considers how the professional, personal, cultural and political beliefs and the assumptions and experience of the researcher may impact upon the analysis of the research data. Qualitative researchers acknowledge that the beliefs and assumptions of the researcher will influence how they interpret their data. It is therefore important for the researcher to make a statement of their own beliefs and assumptions in relation to their study. By doing so, the relationship of these beliefs and assumptions with the interview data can be more fully considered and understood by the reader and researcher (Elliot *et al.* 1999; Yardley, 2000).

I am a 30 year old white British woman from Northern Ireland. I have worked in the area of Clinical Psychology for five years and am currently a Trainee Clinical Psychologist, in my final year of training at the University of Hertfordshire. My interest in acquired brain injury came from both professional and personal experiences. On a personal level, my late grandfather sustained a severe traumatic brain injury in a car accident when my father was a child. I was interested in hearing from my father, about his experiences and memories of the event and the changes that occurred, following my grandfather's accident. On a professional level, I spent a year as an Assistant Psychologist, working in a Neuro-rehabilitation Centre. During this year my interest in acquired brain injury developed, as I had the opportunity to work with this client group and become familiar with the brain injury literature. I was moved by the profound and often devastating effect that brain injury had on people's lives, but often I was also impressed by their resilience and optimism. A decision to propose the current research study was reached by a realisation of the 'gap' in the brain injury research literature from brain injured persons' perspectives. Although researchers had tended to avoid this client group due to the challenges relating to their cognitive deficits, I felt confident that I could carry out an IPA study and communicate effectively with the participants, because of my clinical experience with brain injured

individuals. Overall, it is important to acknowledge that my beliefs and assumptions may have influenced the interpretation of the meaning of the data in this study.

### **3.9 Challenges of interviewing people with severe brain injuries**

#### **3.91 *Potential challenges***

Paterson and Scott-Findlay (2002) discuss the experience of interviewing six survivors of moderate to severe Traumatic Brain Injury (TBI) in their research study to determine allocation of rehabilitation services after brain injury. This was a particularly useful reference for the current researcher in preparing for and understanding the unique methodological and pragmatic challenges that may occur in interviewing people with brain injuries. Paterson and Scott-Findlay (2002) describe the challenges they faced and offer strategies for coping with these concerns:

The participants in their study had difficulty recalling the event surround the time of their injury. The participants also had expressive and receptive dysphasia and as a result of this they did at time ask for questions to be repeated in the interview and did not always understand the questions. Another difficulty encountered in interviewing participants with moderate to severe brain injuries was their poor attention and distractibility. Paterson and Scott-Findlay (2002) also found that participants became progressively fatigued and distracted as the interview progressed. In addition, they found that participants at times experienced difficulties in answering open ended questions and needed further prompting at times to help them answer the questions. Paterson and Scott-Findlay (2002) found that asking participants to recall a story of an event helped them recall information. Finally, Paterson and Scott-Findlay (2002) found that participant responses were sometimes disjointed and fragmented to interview questions that triggered memories or feelings that were distressing.

#### **3.92 *Strategies used to mitigate challenges***

Paterson and Scott-Findlay (2002) recommend that researchers should make decisions about the interviewing process in collaboration with practitioners who have

expertise and experience in interviewing survivors of ABI. Researchers can therefore be made aware of possible problematic scenarios and how to avoid and deal with them. In the current research, advice was sought from an experienced research psychologist in the field of neuro-rehabilitation as to what these problematic scenarios might be. The author found this advice useful, as well as her own previous experience of working with the client group, in preparation for and anticipation of the interviews. Paterson and Scott-Findlay (2002) also recommend a preliminary interview or meeting with the participant prior to the research interview, in order to provide an opportunity for interviewers to acquaint participants with the procedures and to begin developing a rapport with the participants. Similarly, in the current study, the researcher met with the participant prior to the interview meeting, in order to go over the information sheet (Appendix 3) detailing the key points of the study and also gain their consent for participation. This meeting was also found to be useful in developing rapport with the participant.

The importance of interview piloting is also emphasised by Paterson and Scott-Findlay (2002) who explain that the piloting process permits the researcher to evaluate the sequencing and phrasing of the questions in the interview. Bowers (1995) also point out that as many survivors of brain injury become fatigued or agitated easily, interviewers should select questions economically and should determine which questions have the highest priority for achieving the objectives of the research and ask them first. These points were considered in the current study and in the planning of the interview schedule.

## 4. RESULTS

### 4.1 Overview

Through interpretative phenomenological analysis (IPA) of the six semi-structured interviews, four master themes emerged and are the basis of the following chapter. These themes were, '*Piecing together the past and becoming aware of the present*', '*The transition from old self to new self*', '*Sources of strength and survival*', and '*Experiences in rehabilitation*'. The master themes and their constituent subordinate themes are summarised in Table 3 below.

The four master themes and their constituent superordinate themes are explored in the remainder of this chapter, where they are illustrated with verbatim extracts from the interview transcripts. They are presented as one possible account of 'Living with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit. Although a consistent pattern of themes emerged across the participants, the individual experiences within these themes varied considerably. These commonalities and differences are described in the account of the results. The names of the six participants have been changed to protect their confidentiality.

In presenting verbatim extracts from the transcripts, some minor changes have been made by the researcher. Minor hesitations, such as repeated words or words such as "erm" or "eh" have been deleted from the text for readability. In addition, due to the expressive language impairments, participants also used words or phrases that did not make sense or that were unclear. These have also been excluded using dotted lines within excerpts. Dotted lines at the beginning or end of excerpts indicate that the person was talking prior to or after the excerpt.

#### 4.2 Table 3: Master themes and corresponding superordinate themes

<b>Master Themes</b>	<b>Piecing together the past and becoming aware of the present</b>	<b>The transition from old self to new self</b>	<b>Sources of strength and survival</b>	<b>Experiences in rehabilitation</b>
<b>Superordinate Themes</b>	<p>Gaining consciousness</p> <p>Relying on second hand memories</p> <p>Learning the hard way</p>	<p>Grief reaction</p> <p>Feeling foolish</p> <p>Impact on relationships</p> <p>Hopes and fears about the future</p>	<p>Spirituality</p> <p>Other sources of strength</p> <p>Giving up bad habits</p>	<p>Positive experiences</p> <p>Negative experiences</p>

#### 4.3 Piecing together the past and becoming aware of the present

Some participants were able to recall their first memories following their brain injuries, when they regained consciousness, having been in a state of unconsciousness for a prolonged period. For all participants, however, memories of the actual time when they acquired their brain injury were absent. As a result of this 'void' in their memories, their accounts of what happened to them were 'pieced together' from the memories of others (family, friends and health care professionals). Therefore, participants' accounts of the events surrounding their brain injuries were based on the information that they had gained from others and not their own personal memories.

Some participants were emotional when recalling the events '2<sup>nd</sup> hand', whereas others relayed the information with no overt emotional response. The differences in the participants' emotional responses may have been due to factors such as time since their brain injury, insight into the cognitive and physical effects of their brain injury, and emotional regulation.

All participants gave accounts of how they came to learn that they had cognitive and physical deficits as a result of their brain injuries. These were harrowing and devastating experiences for all participants. Some learnt about their brain injuries through personal experiences, realising they could no longer do things that they used to be able to do. Others recalled how they had learnt about the extent of their brain injuries from health care professionals.

#### **4.31 Gaining consciousness**

Anna and Peter were able to recall some of their first vague memories when they regained consciousness following their ABI, whereas the four other participants were unable to recall memories around this time at all. Anna, who had received traumatic brain injuries following a physical assault from her ex-partner, recalled her first memories of waking up in hospital, surrounded by her family. She describes feeling frightened, confused and shocked. She remembered seeing her parents and brother, who were trying to talk to her. Recalling these events was a distressing process for Anna. In the interview she chose to stop talking about this experience of her first memories as they were evidently too painful for her and she became tearful.

*...I can't really remember much, all I can remember, well sort of, is waking up in the hospital, my mum, my dad and my brother there and they're just telling me, trying to talk to me about you're in hospital, and I woke up and I thought I was at home, I didn't know where the fuck I was, it was horrible (voice shakes). (Anna)*

Peter, who also suffered traumatic brain injuries as a result of being mugged by a gang of men, recalled his first memories in hospital after the attack. His account describes what seems like a state of semi consciousness, where he had a degree of awareness of his surroundings, but was also confused and his memories were vague.

*...for some reason I knew I was in hospital because I was um (pause) dreaming a lot...I was you know like dreaming (pause) it seemed like twenty four seven... (Peter)*

#### **4.32 Second hand memories**

All participants described how they had relied on other people to 'fill in the gaps' and provide 'Second hand memories' for them in order to make sense of and understand the events surrounding their brain injury. For example, Anna's family, who were with her when she regained consciousness after having been in a coma for several weeks, told her about things that she had said that did not make any sense to them. However, Anna herself had no recollection of saying these things. Now in a lucid state, Anna was aware, when recalling what she had reportedly said, that she had not made much sense when she first gained consciousness and was confused and disorientated:

*I can't really remember now, everything that was done but apparently I was talking crap, I was coming out with so much stuff like I'd had a baby and about my brother and that's just how much my head wasn't with it, do you know what I mean? (Anna)*

Paul, who acquired brain injuries following brain surgery to remove a benign brain tumour, recalled that it was his wife who 'filled in the gaps' for him and told him about what had happened.

*Well I don't remember much, um, it was my wife that told me what happened that one day I was, my wife told me, I was ill, badly ill, for about a day or two... (Paul)*

Due to the fact that Peter could not recall any of the events around when he was attacked, and had therefore relied on other people's accounts of what had happened to him, made the memories feel unreal or surreal to him, as if they had happened to someone else.

*...you see I seem to be talking about the attack...like (pause) more or less an eye witness who's seen it all sort of thing... (Peter)*

There was a sense of frustration and humiliation in the participants' voices when they recalled their 'second hand' memories. Perhaps they felt frustrated and humiliated about having to rely on others to 'fill in the gaps' in their memories and to have lost the ability to do so themselves.

#### **4.33 Learning the hard way**

Neil, Paul and Anna gave examples of personal experiences to illustrate how they gained awareness of some of their cognitive and physical deficits following their brain injuries. Remembering the times when they realised that they could no longer do things that they used to be able to do, resulted in expressions of despair and distress:

Neil found it devastating to realise that some of his basic academic skills had been impaired following his brain surgery. Prior to his brain injury he had taken pride in his academic skills and used them in his senior management position at work. All participants referred back to their old self and compared themselves with how they used to be before their brain injuries. Neil remembered how well he performed at school, whereas now he felt frustration and despair as he described how he felt the brain damage had affected his academic skills:

*...I've lost all my mental skills, uh my basic maths skills, my English skills, um if I had to write a letter I, I tend to use the computer because it has got a spell checker on it...every evening I sit in the dining room, my hand writing's appalling whereas I excelled in both my English and my maths at school and my hand writing was uh very, very presentable. (Neil)*

Paul, who acquired his brain injury from a stroke, chose to give an example of when he realised that his short term memory had been impaired. For him, it was also a devastating and distressing experience and from reading his account of what happened, there is a sense of him feeling hopeless and humiliated.

*My wife had given me a number to pass on to a friend of mine cos our washing machine broke down and (pause) she phoned me three times (pause) because I had to wait until a nurse was around so the nurse could write it down for me....the number she was giving me I couldn't do it....you know I've just forgotten you know...sometimes I uh actually cry. (Paul)*

Anna chose to give an example of how she realised that her brain injuries had resulted in body co-ordination difficulties. When she visited a local swimming pool with the occupational therapist from the neuro-rehabilitation team, she was devastated and shocked when she realised that she could not swim like she used to be able to.

*It's the first time in about 4 years that I've been swimming. And it made me cry, because it made me realise that I had got brain injury, for the first time...doing breast stroke, I couldn't co-ordinate my arms and my legs and I cried. (Anna)*

The examples provided by the participants, of how they gained awareness of their deficits, were very different. For Neil it was the realisation of the loss of some of his academic skills which devastated him, whereas for Paul it was the realisation of his

short term memory loss and his feelings of helplessness and humiliation in a practical situation where he could not make a phone call for his wife. In contrast, for Anna, it was when she went swimming that she was devastated by her inability to swim as well as she used to be able to. Perhaps the experiences that the participants chose to share in the interview reflected skills which were particularly important to them as individuals, prior to their injury.

In other cases, participants recalled learning about the extent of their brain injuries from medical doctors. Bob was told that he might never regain some of his cognitive skills.

*...doctors have also said there might be some things...that I won't, there are some things I might never ever get back. (Bob)*

Neil was devastated to learn from his doctor that due to his short-term memory impairments he might never work again.

*The consultant seemed so (pause) he just seemed so bitterly disappointed in my progress (pause) and I felt so awful (voice shakes) I really did....He said because of my um short term memory its very very unlikely that I'll (pause) I'll be able to work again, I do find that very very difficult to swallow.(Neil)*

From hearing how participants came to realise the extent of their brain injuries from physicians, I wondered how different this experience was to learning from personal experience and which method had more impact on one's ability to accept what had happened to them.

#### **4.4 Transition from 'old' self to 'new' self**

The theme title was chosen in light of participant's loss of their previous identity and abilities ('old self') and the process or 'transition' they were going through in order to adapt to their new identity and come to terms with their physical and cognitive deficits ('new self'). Given the differences in time since they had sustained their injury, and also the differences in the cause and effects of their brain injury, participants were at different stages in the process of realising and accepting the extent of their brain injuries and the impact on their lives. They also varied in their thoughts and feelings about their current life and their futures. Although there were similarities found in their accounts, there were also marked differences between participants.

##### **4.41 Grief reaction**

Participants expressed what could best be described as a grief reaction for the loss of their 'old self' and made comparisons to how they used to be or how they could be now, had they not had a brain injury. Participants expressed a yearning for their old self and a reluctance to accept their new identity.

Neil chose to use the word 'mourn' to describe how he felt about the impact of the brain injury on his life, to the extent that he feared for the future.

*I just mourn for the life I've lost um because I, it is with trepidation uh I uh face my future. (Neil)*

He made comparisons with how he used to be and what his life used to be like. It seems that by making these comparisons, he was struggling to move on and accept his new identity and self. He had a sense of disbelief about what has happened to him:

*I can remember you know the good times and it just makes me so incredibly sad the way, I just feel um I've been damaged and disregarded and the consequence that the damage has done to me, it's, it's well its just unbelievable (Neil).*

Anna's grief for her old self was expressed through her yearning for her old self and thinking about what life would be like had she not sustained her brain injuries.

*..who knows where I'd be right now. I could be with someone, I could be in love, I could be married, I could be living with someone, I could have a kid. (Anna)*

Sue and Paul, the two participants who acquired brain injuries from strokes, wondered about what might have caused the strokes. Sue felt it might have been her alcohol use, whereas Paul felt that the stress of worrying might have led to him having a stroke.

*..I don't know if it was the alcohol, or the way I was living, um I think it's just everything (pause) with the memory loss, you know? (Sue)*

*Having problems could cause, could have been the cause of my injury, who knows, you know, worry too much, you know? (Paul)*

Overall, participants' sense of disbelief (Neil), yearning for what they have lost (Anna), and a reluctance to let go of the past (Neil), and trying to make sense of what has happened (Sue and Paul) resonate with general theoretical models of the different stages of grief and the process towards recovery, resolution and acceptance of the reality of the loss (e.g. Rubin & Rubin, 1995, Worden, 1991).

As mentioned before, participants were at different stages in the process of accepting what had happened to them. Bob spoke about his memory and that he had accepted that he may never remember certain times in his past.

*I just have to accept that there is...days, weeks or whatever, that eh, may or may not find out about.(Bob)*

As a result of the strain that his brain injury had put on their relationship, Neil had split up with his wife after 30 years of marriage. Although he was devastated by the split, he had come to accept, two years on, that the relationship was over.

*I think I've come to terms that the relationship is um, it's finished and um and there is just no future for us any more... (Neil)*

Paul also demonstrated acceptance of his current situation:

*You just have to learn to adapt to it and get used to it. (Paul).*

#### **4.42 Feeling foolish**

Three participants spoke of the embarrassment that they felt when they experienced the loss of cognitive skills, as a result of their brain injury. They described feeling foolish and having regressed in their abilities. Some described how it felt when others treated them in a childlike manner. This was often coupled with feelings of frustration.

Due to dysphasia caused by his brain injury, Bob described feeling like a child because of the questions he needed to ask in order to clarify what people were asking him.

*I'm sort of fifty odd...and you are looking like someone that's like a five year old again, coz you are asking questions. (Bob)*

One of the consequences of Anna's brain injuries was to become impulsive, probably resulting from frontal lobe damage and consequently a degree of executive dysfunction in her brain. Her father, therefore, felt he needed to help her manage her money so that she did not overspend. Similarly to Bob, Anna felt as if she had regressed to childhood:

*But it just feels like I'm 13 years old again and my Dad's telling me how much I can spend, do you know what I mean? (Anna)*

Sue described feeling 'stupid' because of the impact of her short term memory impairments on her ability to converse.

*I can't hold a conversation without making myself look stupid, I can't remember what they're saying. (Sue)*

#### **4.43 Impact on relationships**

Following their brain injuries, participants experienced changes in their personal relationships with partners, family members and friends. All participants found the impact of their brain injury on their relationships an emotive and difficult subject to talk about. As a result of this, particular care and sensitivity was taken in the questioning around this subject area.

*Catherine: How have your relationships in life changed for you? Would you rather not talk about it?*

*Peter: ...I'll say not really...coz I am getting emotional.*

*Catherine: That's fine, we don't have to talk about it.*

Feelings of guilt were expressed by Peter and Anna when thinking about the 'knock on' effect of their brain injury on the lives of their family.

*It's hard on them knowing that I'm like having an injury... (Peter)*

*I keep thinking if I hadn't put my mum through all that shit, if I hadn't got my mum so worried and that, she wouldn't have got breast cancer. I know that's not true but that was going through my head for weeks after she went. (Anna)*

All participants described how their brain injury had had a negative impact on their friendships and relationships and their accounts describe experiences of loss of close relationships.

Since sustaining her brain injury, Anna had begun to feel distanced from her father and brother. She felt jealousy and anger towards her brother because he had since achieved things in his life that she felt she would have liked to achieved, had she not suffered brain injuries:

*He's got his fuckin life, he's got three kids and all that. Where's my life?  
(Anna)*

She also felt that her relationship with her father had changed and that he no longer understood her.

*I know they are looking out for me, they love me and all that bollocks, but the OT and my Dad say they want me to be happy and they want me to do things that I wanna do...but they don't listen to me. (Anna)*

Paul felt distanced and let down by his friends since he had his stroke and he felt hurt and distressed as a result.

*Catherine: Have your friendships changed since you've had the stroke?*

*Paul: Yes it has changed a lot, like a lot, all friends, um, they um, really let me down as well because when I was well you know they always around me, since I've been ill (pause) they don't want to know (voice quivers) and the the, um, that is stressful.*

Following two strokes directly related to drug and alcohol abuse, Paul felt misunderstood by his family and also felt that his family blamed him for having the strokes. This frustrated Paul and just as Anna felt misunderstood by her father, Paul felt misunderstood by his family too:

*...I think they still blame me you know for having, they blame me...even more this time, I didn't help myself, but they don't understand about (pause) um about um the injury I, they don't really understand the injury. (Paul)*

Paul also talked about how since he had had his strokes, he had found that people who he thought were his friends were not his real friends.

*...my wife got a saying...your friends when your pocket, that's the inside of your pocket was touching the ground (pause) it's sweeping the ground well.. they was always around you yeah?...and now that it's not sweeping... the ground...they don't want to know because I can't give them you know? But that's...friends like their...their selfishness... (Paul)*

Bob felt that his memory loss was responsible for the lack of contact from his friends. He felt responsible for contacting them to tell them what had happened to him, but was unable to remember their contact details.

*I am waiting for three or four names to come through...I can't find their numbers...I don't know where they have gone... (Bob)*

Sue also felt hurt when her family appeared to distance themselves from her.

*She's sort of distanced herself away from me to a point (referring to her daughter since her strokes). (Sue)*

*In all the six or seven weeks that I've been here, none of them, my son, or my husband, my daughter, none of them have come to see me...they haven't, you know? (voice wavering). (Sue)*

Neil's marriage split up as a direct result of the stress on the relationship with his wife, following his brain injury. His sadness was evident as he described how he felt about the end of this relationship.

*...I should have celebrated you know 38 years last month, um and I was absolutely devastated uh my marriage uh was finished um (pause) and again which was another reason why I couldn't see any way forward. (Neil)*

#### **4.44 Hopes and fears about the future**

Despite the devastation of the realisation of their brain injuries, 'grieving' for their old identity and loss of skills and the knock on effect on their personal lives and relationships, three of the participants expressed positivity through their optimism and hope. For example, Paul expressed gratefulness for being alive and his need to remain positive for the sake of his daughter:

*The main thing is I'm still alive and I give thanks for that. (Paul)*

*I've got to be positive because if I'm not positive then I'll get another one (stroke) and that's what I don't want that because I've got a one year old daughter and I want to see her second birthday. (Paul)*

Anna expressed optimism about her future and hopes for having a family and getting married.

*...eventually I can see myself having kids and walking down the aisle, make my Dad happy and all that bollocks. (Anna)*

Bob expressed optimism about improving in rehabilitation over the next 6 months:

*(Referring to his recovery / rehab) ...hopefully, we are all still going forward to it all...maybe another six months. (Bob)*

Sue and Neil, however, were not optimistic about their futures as they were overwhelmed with worry and fear. Sue worried that her memory loss would have a detrimental effect on her ability to form relationships and gain employment in the future.

*I'd like to meet a new person but you know how am I going to be able to find a person...with this what I've got now...such bad uh memory loss...it affects my concentration and my writing and so obviously that's going to have a big affect on...relationships. (Sue)*

*What sort of job...will I be able to get where you haven't got...a memory? (Sue)*

Sue worried that her memory difficulties would affect many aspects of her life and as a result she felt she could not face the future:

*(Referring to her memory) ...coz that's going to affect everything I do in life (voice shakes)... because without it I don't see a future. (Sue)*

Similarly to Sue, Neil recalled when he felt unable to face the future and was overwhelmed by the negative impact on his life.

*...I was so fiercely...um... independent I really really was (pause) uh and the mere thought of being dependent on the state (um)...I couldn't at the time, I just couldn't see any way forward. (Neil)*

Despite her optimism, Anna also had grave fears for her future and at times felt overwhelmed by her current situation:

*Sometimes I wake up in the morning even when I am here and I don't see the fucking point. (Anna)*

*Catherine: How do you feel about the future?*

*Anna: I don't really see much of one. No that's wrong, I should have said that I didn't mean that, I do. But I don't know what it involves (pause) I just want to be happy.*

## **4.5 Sources of strength and survival**

Despite the trauma that participants had endured, the participants were able to draw upon sources of strength that they felt had helped them come through the experience of sustaining an acquired brain injury. As described in section 2.6, PTG can be summarised under three broad headings: improved interpersonal relationships, positive change in perception of self and emerging or developing philosophy in life. In some cases it was unclear whether the examples provided by the participants indicated that they had experienced Post Traumatic Growth. For example, in the two quotations below from Anna and Paul, it was unclear whether their comments about God as a source of strength were evidence of a developing philosophy in life and strengthened religious beliefs as a result of the trauma (PTG) or simply a source of strength the participant would have cited before of the trauma.

### **4.51 Spirituality**

Anna and Paul spontaneously mentioned God as a source of strength through the adversity and trauma of their experience and also as an explanation for their survival:

*My parents were told I was going to die. I came this fucking close to dying. I know I didn't and there gotta be a reason why I am still here. God can't have wanted to take me for a reason and that's why I'm meant to be here sorta thing (Anna).*

*They never thought I would see the next Monday but I did like (pause) and I'm grateful like for God for that (Paul)*

#### **4.52 Other sources of strength**

Other participants cited different sources of strength. Peter felt that it was his strength of character and people around him who had helped him.

*Catherine: What's helped you get through?*

*Peter: ...my willpower to live and manage the day and...persons who have helped me.*

Neil felt that the support he had received in rehabilitation was a profound source of strength:

*...this place it's (voice wavers) it's been a life line for me it really has.  
(Neil)*

The emotion in Neil's voice may have indicated his gratefulness to the rehabilitation services, but perhaps also a fear of losing this source of strength when he left the Unit.

Sue referred to her pet dog as a source of comfort and support. She explained how he had been a companion for her when she went home at the weekend from the Rehabilitation Unit.

*...cos I go home weekends (voice shakes) I went home on Saturday and I don't know he sort of come up and said hello um cos (Dog's name) um I was a bit of a sop you know I taught him how to give me a kiss and a cuddle I did.  
(Sue)*

Unfortunately Sue's dog died while she was in the Rehabilitation Unit. The companionship that her dog provided was apparent when she explained what she felt life would be like if she was at home on her own without her dog.

*Sue: ...if I'd of been at home on my own, I think the depression would have been really really... (pause, voice shakes)*

*Catherine: Yeah, yeah cos I mean (Dogs name) was like a member of your family?*

*Sue: Yeah...my baby.*

#### **4.53 Giving up bad habits**

Four of the participants described how, since their brain injury, their outlook on life had changed. These changes could be perceived as evidence of Post Traumatic Growth following the trauma of their brain injury. It could be argued that the changes described were related to positive changes in their perception of self or related to an emerging or developing philosophy in life, which have been identified as aspects of PTG (Bamford, 2006). In all cases, they made strong statements about how they would not return to the lifestyle that led to their particular brain injury. Anna, who had suffered physical abuse from her partner for a number of years, stated that she would never stay in an abusive relationship again:

*I'm not going to take no shit off no men. Any bloke ever raises their hand to me, even the once, I will never go back to them again. (Anna)*

Paul, whose strokes were related to his lifestyle of heavy drinking, smoking and drug use, stated that he had now stopped smoking and drinking and felt that this was a positive outcome.

*Since the injury I have stopped smoking and that was the plus side of this injury, that's the only plus side, I stopped smoking and like I've stopped drinking... (Paul)*

He also talked about trying not to worry about life because a person cannot change what has happened to them.

*Don't drink and don't smoke (laughs) and don't worry about life, you can't change what's happened. (Paul)*

Sue, whose stroke had also occurred as a result of heavy alcohol use, was now proud that she had been clean for two years:

*I've given up the alcohol which I praise myself because I've been off it for over two years now, totally clean, I am. (Sue)*

#### **4.6 Experiences in Rehabilitation**

All of the participants were inpatients in a post-acute neuro-rehabilitation unit. They were asked to describe what positive and negative experiences they had had (if any) whilst in the Unit.

##### ***Positive experiences***

###### ***4.611 Positive experiences with rehabilitation staff***

Some participants gave positive feedback about their experiences in rehabilitation, for example, three participants (Paul, Sue and Neil) made positive comments about the rehabilitation staff:

*They're very professional here, very professional (Paul)*

*The staff are really, really nice you know, really nice (Sue)*

*I can't praise staff enough because they are wonderful they really, really are, um through their patience um their care... (Neil)*

#### 4.612 Support from other inpatients

Three of the participants spoke of the support they gained from other inpatients at the neuro-rehabilitation unit. Anna felt an attachment towards other patients with whom she had developed friendships, but on the other hand, she felt distressed at the thought of them leaving the unit:

*I know and then they leave and it's like, not a family, I don't know how to put it into words. Not a family, just different friends to talk to...and now they are all fucking leaving and that's going to hurt me when they goes.  
(Anna)*

Sue also valued the relationships she had formed with the other patients in the neuro-rehabilitation unit. She also feared that without this support and if she was at home, she would be on her own and this would make her feel depressed.

*You know there's people here to talk to...otherwise if I'd been home on my own, I think that depression would have been really, really (voice breaks). (Sue)*

Bob also commented on the support he felt from the other inpatients. Due to his expressive communication difficulties it is not completely clear what he meant by his comment, but it is possible that he meant he is comforted by being surrounded by others who have had similar experiences.

*(Referring to rehab) ...we are all the same kind of, more or less together.*

*(Bob)*

#### *4.613 Rehab instilling self esteem, optimism and motivation*

Anna, Paul and Neil all spoke with pride when they gave examples of how they had noticed themselves improving whilst in rehabilitation. For all three participants, it seems that these experiences boosted their self esteem and optimism.

There was a sense of pride as Anna described how she felt pleased that she had successfully gone into town and remembered her way without asking anyone.

*I went up the town, and I come back, didn't ask anyone directions or nothing, and I am really pleased with myself I done that. (Anna)*

Paul spoke positively about how he had noticed his improvement in the six weeks that he had been in rehabilitation and by being allowed to stay in the unit, he felt this was a sign that he could improve further.

*In the six weeks that I have been here I have progressed...very well and...showing them that, they've allowed me to continue my rehab there I will further improve. (Paul)*

Neil had noticed his improvement by no longer needing to rely on certain memory strategies that he needed to use when he first came to the rehabilitation unit.

*When I first went into that room (bedroom) I was having to leave post-its sort of stuck on the side...so I could see them when I first woke up...to*

*remind me where my, my keys and my, my spare cash was but I mean (pause) I got over using those strategies now and (pause) um the strategies I rely on now is I just put different things in different places. (Neil)*

#### 4.614 *Importance of independence*

Bob and Neil cited having some form of independence as a positive aspect of being rehabilitation, as opposed to the experiences they had had in other hospitals.

*This now, here you can get out and about, you can walk out to the shop, if you wanna get the paper... (Bob)*

*I get my independence, I can go walking up to the High Street uh to do my personal shopping. (Neil)*

### **4.62 *Negative experiences in rehabilitation***

#### 4.621 *Relationships with patients and staff*

Participants also gave negative as well as positive feedback about their experiences in rehabilitation. A number of participants spoke of difficulties in relationships with patients and staff. For example, when asked what he found most difficult about rehabilitation, Paul said that it was trying to understand the moods of the other patients on the ward:

*The most difficult thing is definitely the other patients here...understanding their moods. (Paul)*

Peter also spoke of difficulties in relationships in rehabilitation, identifying 'frictions' between patients and staff as something that he identified as a negative aspect of the Unit.

*Catherine: Peter what has not been good in rehab?*

*Peter: Frictions that are around...between um patients and...staff.*

Anna described tension in the relationship between her and her Occupational Therapist (OT). She felt imposed upon, despite realising that rationale behind what the OT was trying to help her with.

*I know she (the OT) is only doing it for my own good, but sometimes I wanna go out and buy whatever I wanna buy but I know I don't have a budget. I know it's for my own good. I do know that. But it is just, I can't wait to be out of here. (Anna)*

#### 4.622 Institutionalisation

Neil and Sue talked about the frustration of feeling institutionalised as an inpatient in the Unit. Despite his appreciation for how the rehabilitation had helped him Neil described how, (after two years as an inpatient in hospitals) he longed for his own space.

*This place has been a life line for me because it really, really has but now I think I've come to the end of the line (pause) and I desperately want my own space. (Neil)*

He uses an example of sharing bathroom facilities with other patients to illustrate his frustration with institutionalisation.

*You know you go in there and people have just peed all over the floor...and they've left excrement on the toilet seat uh. I've just walked away from it, it's foul, it's disgusting it really, really is...that's the sort of thing I find hard to cope with. (Neil)*

Sue referred to waiting around between rehabilitation activities as a negative aspect of being in rehabilitation as an inpatient. This is another example of a negative reaction to institutionalisation.

*We get a lot of time...where there's no lessons going at all... and I'm just sitting for hours in between and I actually said to them I'm not coming in on a Monday because I'm just fed up of sitting. (Sue)*

## 5. DISCUSSION

### 5.1 Overview

The primary aim of the current study was to explore the personal experiences of six individuals who had severe acquired brain injuries, through the use of in-depth semi-structured interviews and Interpretative Phenomenological Analysis (IPA). Very few studies have explored the lived experience of acquired brain injury and it was hoped that the current study would add to a recent growth of literature in this area. The following areas were explored in relation to the main research question: What is it like to live with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit?

1. The individual's experience of gaining consciousness
2. Their experiences of living with permanent memory loss
3. The experience of gaining awareness of physical and cognitive deficits caused by brain injury
4. The process of losing a 'pre-injury' identity and adapting to a new identity
5. The impact of the brain injury on relationships with friends and family.
6. The experience of being an inpatient in a Brain Injury Unit
7. Participants' sources of strength and coping mechanisms through the trauma of their brain injury (with an interest in exploring evidence of Post Traumatic Growth).

### 5.2 What is it like to live with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit?

In this section, the key findings of the study will be considered in relation to the main research question and the specific areas in relation to the question listed above. These findings will be discussed in relation to existing theory and research literature. Following this, reflexive issues will be considered in relation to the study. Clinical implications, methodological issues and suggestions for further research will then be discussed.

### **5.21 The experience of gaining consciousness**

The first area that was explored in relation to the main research question was participants' experience of gaining consciousness following their brain injury. Four of the participants were unable to recall memories around this time, whereas the other two participants, Anna and Peter, had some memories of this time. However, their memories were patchy, confusing and vague. For Anna, remembering this time was traumatic and distressing for her. She recalled how frightened and disorientated she was and remembered awaking to see her family around her bedside. Peter described his memories at this time like being in a dream like state, twenty four hours a day. These descriptions resonate with the 'textbook' depiction of a state known as Post-Traumatic Amnesia (PTA). PTA is a temporary state for most brain injury survivors who recover beyond the minimally responsive state (coma), and may last from a few days to several months (Acquired Brain Injury website: [www.on-with-life.org](http://www.on-with-life.org), 2007). A person is said to be 'out of PTA' when they can give a clear, accurate and ordered account of what is happening around them and can maintain memories for everyday occurrences. When a person is 'in PTA' they are unable to store or retrieve new information and operate in a state of 'now', a frame of memory, beyond which they remember nothing since their injury. People in PTA may demonstrate agitation, inappropriate behaviour, poor social skills and impulsiveness. Traditionally, the length of time 'in PTA' has been considered to be a good predictor of potential for cognitive recovery, with the potential for recovery decreasing as duration of PTA increases (Acquired Brain Injury website: [www.on-with-life.org](http://www.on-with-life.org), 2007). From carrying out a literature review in this area, there is abundant literature available on Post-Traumatic Amnesia as a cognitive state and there is a vast amount of research to support the notion of the length of PTA as a predictor of brain injury outcome, (e.g. Howes *et al.* 2005). There is, however, very little research exploring the personal experience of gaining consciousness and coming out of PTA, after a brain injury (Hill, 1999; Jumisko *et al.* 2005; Newnes, 2006). This is most likely to be because researchers have avoided interviewing people with brain injuries due to the difficulties in interviewing people with cognitive deficits (see Method section 3.9 for further details). There is also the added difficulty of asking brain injured individuals to recall information from a time when their memories were very vague, and accuracy of recall is therefore likely to be affected significantly. Despite the lack of literature in the area, novel and clinically relevant information has been gained from studies which

explore the personal experience of PTA. Hill (1999), for example, described her experience of regaining consciousness after being in a coma. She recalls being able to understand how words were written and their meaning but due to her inability to speak properly, people around her did not realise this. She also described how difficult it was to experience the side effects (including impaired alertness, hepatic disturbances and ophthalmological changes) of anti-seizure medication (which the majority of patients are prescribed after a brain injury). Similarly, in the current study, the personal experience of gaining awareness and 'coming out of' PTA is described by two of the participants. Anna described the fear and trauma of the experience of gaining awareness, whereas Peter described his first memories after his injury being like a dream. Overall, from the limited research available, it appears that the personal experience of gaining awareness following a brain injury is a clinically relevant area to research, and raises important issues on topics (for example experiencing the side effects of anti-seizure medication, Hill, 1999) which have not received attention in the current brain injury literature or have not been considered from the brain injured persons perspective.

### ***5.22 Relying on second hand memories.***

The next area explored in relation to the personal experience of living with a severe acquired brain injury was the experience of living with the permanent memory loss of the events surrounding their brain injury. Participants described how they had 'filled in the gaps' of their memories with information about what had happened to them, that they had gained 'second hand' from relatives. From all participants' accounts of describing what had happened to them 'second hand' there was a sense of bewilderment and distress in what they said. One participant (Peter) pointed out that the process of relying on other people's accounts of what had happened to him, made the brain injury seem like it had happened to someone else and he was an eyewitness. From this comment it was interesting to consider how the effect of permanent memory loss of the events surrounding a brain injury may affect a person's ability to come to terms with and accept what has happened to them. Similarly, Nochi (1997), through in-depth interviews with four individuals who had suffered traumatic brain injuries (TBI), considered how the 'void' created by permanent memory loss is an important concept in understanding how TBI survivors view the causal relationships between the event or accident which lead to their injury,

the brain injury itself and their present difficulties. Nochi (1997) also suggests that the sense of loss that is experienced by people with TBI may come from the memory loss or void that they experience. Interestingly, from his interviews with participants several years after their TBIs, Nochi (1997) found that participants were less focussed upon the void and were less motivated to seek information to fill it than during the first stages of recovery. These findings suggest that as time goes by people with brain injuries may begin to be satisfied with the story they have constructed to fill their 'void'. Regarding implications for clinical practice, Nochi (1997) suggests that neuro-rehabilitation professionals should consider broadening their scope of interventions for memory deficits following brain injury, as the primary focus is upon short-term memory rehabilitation. Nochi (1997) highlights the need to help patients reconstruct past memory (for example in creating a life story book) and in turn, alleviate concerns or anxiety relating to permanent memory loss, particularly in the early stages of rehabilitation. In light of the findings from the current study, this suggestion seems particularly relevant given the distress, confusion and bewilderment displayed by the participants when they gave their accounts of second hand memories. Secondly, Nochi (1997) suggests that rehabilitation professionals should view brain injured persons' memory loss in a broader context by considering its meaning to the client and considering how it may affect the understanding of the self and identity and the trauma that may come from this, as opposed to seeing memory as just another cognitive disorder, focusing on its functional aspect for treatment. Given the apparent 'voids' in the memories of the participants in the current study, and the anxiety and distress displayed, it appears that they may benefit from Nochi's (1997) suggestions.

### **5.23 *The experience of gaining awareness of cognitive and physical deficits***

Some participants gave accounts of how they gained awareness of their physical and cognitive deficits following their acquired brain injuries. For most of these participants, knowledge of deficits was gained through personal discovery and the reaction of others. For example, one participant became aware of some of the physical effects of her brain injury when she went swimming and found that she could no longer co-ordinate her arms and legs in the manner that she was able to before her brain injury. She described becoming tearful at the swimming pool because this experience made her aware of physical deficits that she had not realised she had had before. Another

participant described his frustration and distress through the experience of realising that he had lost some of his 'academic' skills when he had difficulty writing and spelling. Although personal experience and the reaction of others were effective means of helping these persons realise and become aware of their deficits, the experience was emotionally painful and very distressing. Participants also became aware of their deficits through being told by health care professionals. In relation to these findings, O'Callaghan *et al.* (2006) also explored gaining awareness of deficits in ten people with moderate to severe traumatic brain injuries, using in-depth semi-structured interviews and Interpretative Phenomenological Analysis. Similar to the current study, O'Callaghan *et al.* (2006) established that participants found out about their deficits by being told by others or noticing the reaction of others and through personal discovery where they experienced a situation before they realised 'something was wrong'. O'Callaghan *et al.* (2006) found that participants experienced fear, anxiety and perplexity in response to discovery of their deficits. In the current study, participants also experienced distressing emotions in reaction to the discovery of their deficits. Regarding the clinical relevance of these findings, O'Callaghan *et al.* (2006) suggest that rehabilitation should provide an environment that supports the process of acknowledging deficits. Perhaps this could be achieved through supporting patients through the difficult emotions generated by the feelings of loss that they experience when they 'learn the hard way'.

## **5.24 The process of losing a 'pre-injury' identity and adapting to a new identity**

### **5.241 Grief reaction**

In the current study, all participants referred to the experience of loss of their old identity as a result of their brain injuries and the devastation that accompanied this loss. Some participants expressed feelings of disbelief, a reluctance to let go of their old identity (expressed through making comparisons with their 'new self' and 'old self') and searching for a reason or explanation for why they had had a brain injury (also found in study by Jumisko *et al.* 2005), while others expressed a resigned acceptance of their losses. All of these behaviours and reactions to loss are also common characteristics of grief (e.g. Sanders, 1989). Unfortunately, only a few studies refer to the process of adjustment after TBI, and even fewer investigate the

experience or compare it with other theoretical constructs of grief and loss. Some authors argue that survivors of brain injury do not have enough awareness and insight into their deficits and therefore are incapable of grief (Goldstein & Beers, 1998; Millis *et al.* 2001). In contrast, Chamberlain (2006) who interviewed sixty survivors of Traumatic Brain Injury (TBI) about their experiences of recovery, found that after one year post injury, TBI survivors experienced complex grief and emotional suffering. Although the current study also suggests that participants experienced a grief reaction in response to the loss of their 'old self' as a result of their brain deficits, it is clear from the opposing views and lack of literature that further research is needed in this area. Despite the lack of literature, evidence suggests that brain injured persons may experience a grief reaction in response to the loss of their 'old self'. It is important, therefore, that rehabilitation professionals ensure that brain injured individuals are given the opportunity to grieve and are provided with appropriate psychological support.

#### *5.242 Feeling foolish*

Some participants in the current study experienced feeling foolish about and embarrassed by the loss of their cognitive skills. This was part of the process of adjusting to their new identities. Participants described how they felt patronised and misunderstood by others and were treated in a childlike manner due to their cognitive deficits. Similarly, Jumisko *et al.* (2005), who interviewed twelve individuals with TBIs, in order to explore the meaning of living with brain injury, found that they had trouble expressing themselves and they struggled to be understood and respected by other people. The participants in this study also frequently described how they felt insulted by others. Overall, the results of the current study and of the study by Jumisko *et al.* (2005) indicate that professionals and relatives should be more sensitive to the emotional impact of losing cognitive skills.

#### *5.243 Hopes and fears about the future*

In relation to the process of adjustment to their new identity and coming to terms with the loss of their old identity, participants expressed their hopes and fears about the future. Some participants in the current study feared for the future as they were overwhelmed by the negative impact of their brain injury on their lives. Other

participants, however, courageously expressed optimism about the future and hopes of what they wished to achieve. Similarly, Jumisko *et al.* (2005) reported that the participants in their study seemed to have an enormous will to live and showed courage and strength in their suffering. Two of the women in the current study hoped for a romantic relationship in the future. The focus on romantic relationships was also a feature in the results of a study by Murray and Harrison (2004), who carried out a qualitative study using in-depth semi-structured interviews in order to explore the meaning and experience of being a stroke survivor with ten participants. Murray and Harrison (2004) reported that participants had a particular concern about being able sustain romantic and sexual relationships.

### **5.25 The impact on relationships with friends and family**

In relation to the main research question, another aspect of 'living with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit' that was explored was the impact on personal and family relationships. This was a difficult and emotive subject for participants to discuss. Some participants expressed fear and guilt about being a burden to their loved ones and causing them stress and worry. Other participants spoke of the strain that had been put on family relationships and friendships following their brain injury. Participants also spoke of relationships that had broken down or been lost as a result of the changes in their lives following their brain injury and others spoke of how they felt misunderstood and distanced from their loved ones. The sadness and hurt was evident in their voices as they talked about these experiences. Similarly, Jumisko *et al.* (2005) who interviewed twelve participants who had lived with TBI for four to thirteen years, spoke of the strain on their relationships with friends and family. Jumisko *et al.* (2005) reported that this was an enormous source of sorrow for them. The participants in this study also expressed disappointment and bitterness when they realized how people with whom they had regular contact with before the injury were never heard from. In the current study, participants also spoke of similar scenarios and had the same emotional reaction. The participants in the study carried out by Jumisko *et al.* (2005) consoled themselves by saying that sustaining a TBI is a way of finding out who your true friends are and a similar sentiment was expressed by a participant in the current study (Paul). Furthermore, in both the current study and Jumisko *et al.* (2005) found

that for some participants their dog was referred to as a real friend and supporter (Sue).

Unfortunately, the experiences of the participants in the current study and the study by Jumisko *et al.* (2005) resonate with evidence from a large number of other studies suggesting that relationships with family and friends often deteriorate under the strain of acquired brain injury. For example, Oddy *et al.* (1985), assessed the social integration and adjustment of forty nine head injured survivors over a ten year period and found a 40 % divorce rate at 7 years post-injury. At two years post injury participants reported they had fewer friends and fewer social outings. The strain on relationships is often as a result of the psychosocial difficulties that people with brain injuries and their families, encounter, including financial difficulties, social isolation, personality changes, physical disabilities and mental health problems (e.g. Katzlberger & Oder, 2000; Oddy *et al.* 1985; Webster *et al.* 1999).

### **5.26 The experience of being an inpatient in a neuro-rehabilitation unit**

As all participants were inpatients in a neuro-rehabilitation unit, their experiences within this context were explored as an aspect of living with a severe acquired brain injury. Participants were asked to reflect upon any positive and/or negative aspects of their experiences in the Rehabilitation Unit. Regarding positive experiences some participants commented upon the professionalism of staff and the standard of care they had received in the Unit. A number of participants also spoke of the support they felt from other inpatients in the Unit and the friendships that they had developed with other patients 'in the same boat'. Similarly, in their study exploring the experience of gaining awareness of deficits following traumatic brain injury, O'Callaghan *et al.* (2006) found that being with others with the same problems helped to normalise and validate the experience of having a brain injury and reduced feelings of fear and anxiety. Participants in this study also referred to the rehabilitation setting as a supportive environment where explanations of deficits were provided.

Regarding other positive experiences, participants in the current study also gave examples of how they had noticed their improvement whilst in rehabilitation and described how this experience had boosted their feelings of optimism and motivation

and in turn improved self esteem. Also, a number of the participants spoke of how being given some form of independence whilst being in rehabilitation was a positive experience.

Regarding negative experiences, participants spoke about difficulties in relationships with other patients and staff within the Brain Injury Unit. Relating to this, Morris *et al.* (2005) and Hill (1999) also found that brain injured patients may feel misunderstood by rehabilitation professionals. Furthermore, a number of the participants also spoke negatively about experiences as an inpatient in the Unit, including sharing bathroom facilities with other patients who are not hygienic and not having anything to do for prolonged periods of time.

From reviewing the literature, no qualitative studies were found that specifically explored to the personal experience of being an inpatient in a neuro-rehabilitation unit and therefore there was a limit to the extent to which the results of the current study could be linked to the current literature available.

### **5.27 Sources of strength and coping mechanisms (Post Traumatic Growth)**

As discussed in the introduction chapter, there is a growing and established body of evidence that supports the notion that people can experience positive changes or 'post-traumatic growth' (PTG) after trauma and adversity (e.g. Joseph & Linley, 2006). Some aspects of PTG commonly reported in the literature are improvements in interpersonal relationships through valuing friends and family more and feelings of compassion towards others. Other commonly reported features of PTG are a development of a greater sense of personal resiliency, wisdom and strength and a greater sense of one's vulnerabilities and limitations. Also, an emerging or developing philosophy in life, renegotiating what matters in life, an appreciation of the fragility of life and changes or developments in spiritual beliefs (e.g. Joseph & Linley, 2006; Calhoun & Tedeschi, 2004; Shaw *et al.* 2005; Tedeschi *et al.* 1998).

In the current study, the final area of interest explored in relation to the personal experience of 'living with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit' was the sources of strength and coping mechanisms that participants referred to which they felt had helped them. Some participants referred

to God as a source of strength and also as an explanation for why they had survived, in that God has 'spared them' for a reason. It is unclear whether their beliefs in God had changed or developed since their brain injuries, however it is possible that they may have experienced changes or developments in spiritual beliefs which might have been evidence of PTG.

Another participant felt that it was his willpower to live and the support of people around him that had helped him. These comments resonate with having a sense of personal resiliency and valuing friends and family which are features of PTG. It is, however, unclear whether this participant had the same willpower to live and value for his friends and family prior to his brain injury, but it may be that these feelings had developed from the experience of his brain injury and therefore may have been evidence of PTG.

Participants also referred to how, in the aftermath of their brain injury they had a renewed strength and determination to 'give up bad habits', such as giving up drinking and smoking. This indicates that participants had developed an appreciation of the fragility of life and also a greater sense of wisdom and mental strength, both features of PTG. One participant also had a philosophical approach to what had happened to him by commenting that there was no point in worrying about things as one has no real control over what happens to them. In relation to this, an emerging or developing philosophy of life is also a feature of PTG. Therefore, the sources of strength described by participants in the current study might have been evidence of post traumatic growth.

### **5.3 Significance of the Study**

The brain injury literature is dominated by quantitative research, with a particular focus on comparisons between pre and post brain injury cognitive functioning. A number of authors have highlighted the lack of qualitative research available and in the significant lack of in-depth qualitative research exploring the lived experience of acquired brain injury from the brain injured person's perspective (e.g. Howes *et al.* 2005). The current study contributes to the small number of recent studies which have attempted to explore different aspects of the lived experience of brain injury using a qualitative approach. The current study also explored brain injured

individual's experience of Post-Traumatic Growth, an area that has received very little attention in previous research (McGrath & Linley, 2006). Overall this research has made a significant contribution to the brain injury literature in providing a qualitative study exploring the personal experience of brain injury. Furthermore, a very small number of studies were found to have considered the other areas explored in this study (as discussed in sections 5.21-5.28). It is possible that areas of interest that have received little or no attention in the brain injury literature may be overlooked by health care professionals in developing suitable rehabilitation interventions for people with brain injuries (Morris *et al.* 2005).

#### **5.4 Reflexive considerations**

Reflexivity in qualitative research is important to consider in terms of how personal, cultural and political values, interests and influences of the researcher may impact on the analysis process. Reflexivity is also important in considering how the context of the research and the need for the participant to present a particular story may influence their interpretation of the interviews (Elliot *et al.* 1999).

First of all, it is important to reflect upon how being an inpatient may have impacted upon the participants' accounts. It is possible that, although the participants were assured of confidentiality and that what they said would not impact upon their level of care, they may nevertheless, have been reluctant to say anything particularly negative about their rehabilitation experience, in fear that the information may be relayed back to staff in the Unit and cause difficulties. Participants had limited time to build rapport and trust with the interviewer and therefore it may have been difficult for them to 'confide' in them about any difficult experiences in rehabilitation, as well as talk openly about any other personal or sensitive information.

It is also important to consider how participants may have perceived a Trainee Clinical Psychologist and how this may have impacted upon how they answered questions in the interview process. Perhaps participants felt as if their cognitive abilities were being assessed during the interview, knowing that the researcher was also a Trainee Clinical Psychologist. For example, one participant repeatedly apologised for his poor memory in the interview and despite reassurance from the

interviewer, it is possible that he felt that he was being assessed as well as interviewed. Similar issues were raised by Paterson and Scott-Findlay, (2002) who found that after interviewing inpatients within a neuro-rehabilitation setting, that some participants admitted they had worked hard to impress the interviewer with their cognitive ability and independence and this in turn had affected their spontaneity and expressiveness in the interview. Participants disclosed that they had seen the interviewers as health care professionals, who were framed as individuals who assess patients and make decisions about their care. I wondered if the participants in the current study had any similar thoughts about me and also if this had affected their responses in the interviews.

The interviewer at times felt emotionally affected by the sadness of some of the participants' experiences. She felt drawn to act as a therapist as opposed to a researcher, in order to support and empathise with participants when they became distressed. If the interviewer did at times use her skills as a therapist, it is of importance to consider how this may have affected participants' ability to be open and talk freely about their experiences. Perhaps it allowed participants to feel understood and supported, or perhaps it had the opposite effect and made participants withdraw and be less forthcoming about distressing issues.

It is also interesting to note that all participants except one were at least a decade older than the researcher. It is possible that participants may have been less likely to talk openly about sensitive and emotive material to someone younger than themselves. Another factor which may have affected participants' accounts was the issue of gender. Four of the participants were men and two were women. Perhaps participants who were female found it easier to talk to a researcher who was the same gender, and the men found it more difficult to talk openly to me as a young woman.

## **5.5 Clinical implications**

The current research highlighted the experiences, feelings and perceptions of individuals with acquired brain injuries which would be useful and insightful information for any professional working with this population. With this in mind, a presentation outlining the main findings of the study and clinical implications was

given to participants and staff in the Brain Injury Unit following the completion of this Thesis.

The experiences described by participants of gaining consciousness and living with permanent memory loss of the time of their brain injuries were traumatic and distressing. In relation to this, rehabilitation professionals should be mindful of considering post traumatic amnesia and memory loss not just as cognitive states but in a broader context. Clinicians should also consider the psychological meaning of these experiences and their effect on self identity (Nochi, 1997).

Furthermore, participants described the powerful and often devastating experiences of realising their cognitive and physical deficits. Within a neuro-rehabilitation setting, professionals should be sensitive to the potential trauma and devastation of the experiential learning of deficits following brain injury, and should provide the necessary support that may be required.

In relation to the process of losing a 'pre-injury' identity and adapting to a new identity, participants described their experiences of grief for the loss of their 'old self', feeling foolish in adapting to their 'new self' and their hopes and fears for the future. In relation to this, clinicians working with individuals post brain injury should focus on wider issues of identity and role changes and the grieving process that may accompany these, in addition to the traditional focus upon cognitive changes post injury.

The often devastating impact on relationships with family and friends after a significant brain injury is well documented in the literature (e.g. Oddy *et al.* 1985). This study contributed to this body of literature by providing an in-depth and personal insight into the lived experience of relationship difficulties after a brain injury. It is hoped that this study will therefore enrich professionals' understanding of relationship difficulties from the brain injured person's perspective and in turn aid them in supporting these individuals through these difficult experiences.

The positive and negative experiences in rehabilitation, described by the participants, drew attention to the challenges faced by patients in this setting and also to the experiences which facilitate patients in their rehabilitation and recovery. This study

highlighted the support and comfort patients can gain from other patients within a neuro-rehabilitation setting. Professionals working in Neuro-rehabilitation should be sensitive to and aware of the attachments that patients may make to each other and the impact on the losses of these relationships, when they leave rehabilitation. The study also highlighted how being in rehabilitation helped patients be aware of the progress they were making and in turn this instilled self esteem and optimism. Gaining patient feedback on their experiences in rehabilitation, through the feedback questionnaires or confidential interviews, may increase professionals' understanding of the patients' experience and in turn improve their ability to provide them with the appropriate support.

Finally, participants described their sources of strength and coping mechanisms that had helped them persevere through their trauma. Participants referred to God, the willpower to live and the support of others as their sources of strength. Participants also referred to a new sense of strength and determination post injury and one participant demonstrated a philosophical approach to his brain injury (see section 5.28 for how these factors relate to post traumatic growth). It is important to note, however, that it was often unclear whether these sources of strength and coping mechanisms described by the participants had developed since their brain injuries, and therefore possibly providing evidence of PTG, or whether they were already present prior to their brain injuries.

Currently there is a debate in the literature about whether people with severe brain injuries *do* experience PTG. Some studies suggest people with severe brain injuries can experience PTG (McGrath & Linley, 2006) whereas other studies argue that due to their cognitive deficits, it is difficult or impossible for brain injured individuals to experience PTG (e.g. Mailhau *et al.* 2005; McGrath, 2004). The concept of PTG is still being developed and debated in the literature, and whether or not it can exist in persons with brain injuries. Further research, therefore, is needed in the area. The current study, however, supports the notion that people with brain injuries might experience PTG. The traditional focus of psychological treatment for trauma and Post Traumatic Stress Disorder (PTSD) is upon the negative aspects of the traumatic experience. Therapy aims to alleviate the distress caused by the trauma, however it does not use the notion of PTG to do so (McGrath and Linley, 2006). It may be that therapists could adapt their approach when treating trauma, by incorporating the

concept of PTG into psychological interventions. Therapists may be able to encourage the development of PTG by focusing on strategies that build upon factors such as resilience and optimism. This is one example of how the implications of this research could be implemented in clinical practice.

Overall, the clinical implications of this research indicate that rehabilitation professionals may benefit from being better informed about the personal experience and psychological impact of brain injury. Clinical Psychologists working in the field could organise training for other professionals and encourage further research into the personal experience of brain injury, in order to promote these changes in clinical practice.

## **5.6 Strengths and limitations of the study**

### **5.61 Methodology**

Throughout the analytic process in, the author aimed to be rigorous and transparent in the analytic process as well as to adhere to recommendations for ensuring credibility of results (e.g. Elliot *et al.* 1999) and this was a particular strength of the current study.

The choice of using IPA as the qualitative approach for this study was also a strength in that it enabled a productive exploration of the research questions and in successfully developing interesting, relevant and novel findings. As discussed in section 3.2, IPA was chosen as the preferred methodology over other qualitative approaches because of its strength in exploring and capture people's lived experiences in detail. For example, IPA was chosen over Grounded Theory because of its focus on accessing participants' 'lifeworlds' rather than attempting to build a 'theoretically saturated' account of the social processes that explain the phenomenon being researched (Smith & Osborn, 2003). IPA has also been used to address a wide range of issues in health and clinical psychology. Another strength of the study was the researcher's access to expert professional advice within the neuro-rehabilitation setting regarding the participants and also academically from an expert in IPA research. This increased the likelihood of constructing a credible narrative

account from the data and also enabled the researcher to seek advice where needed throughout the research process, in turn developing a high quality of research.

IPA does have limitations, however, and these should also be considered. In order to explore participant's lived experiences it is necessary for them to be able to articulate their thoughts, feelings and behaviours (Willig, 2003). The participants in the current study at times found it difficult to articulate their experiences. Despite this, however, valuable data was still obtained. Also, IPA is dependent upon the representational validity of language to accurately convey rather than construct or constrain a person's experience. In addition, verbalising experiences might alter how they are perceived and understood (Willig, 2001).

### **5.62 Originality and novel research findings**

Another strength of the current study was its contribution to new areas of research, that is, research into the lived experience of acquired brain injury - from the brain injured person's perspective and also the emerging body of research into post traumatic growth.

### **5.63 Author's transferable skills and prior clinical experience**

The author's past experience of working clinically with brain injured individuals enabled her to communicate more effectively with the participants than a researcher who was not familiar with the brain injured population. The author was also confident enough in her abilities to carry out research in this area, whereas many researchers in the past avoided doing so because of the challenges of interviewing individuals with cognitive deficits (e.g. Howes *et al.* 2005). The author was familiar with the possible interpersonal, cognitive and physical deficits that the participants may present with and had experience from their past clinical work in how best to manage these challenges. The author also had awareness that the interviewees might disclose very distressing and traumatic experiences in the interview. As the author had experienced this within her past clinical work with brain injured individuals, she was able to mentally prepare for this and was therefore able to listen to the emotive material in the interviews, whilst remaining supportive and containing.

#### **5.64 Amount of 'usable' data from interviews**

An apparent limitation of the study was the amount of useful data gained from the interviews. The researcher found that although there was useful information gained from the interviews, a significant amount of the interview data was taken up with information that was not useful. For example, participants sometimes had word finding difficulties, were repetitive and had slurred or unclear speech. The researcher found that at times she needed to rephrase her questions in order for the interviewee to understand them and at times, the interviewee was still not able to fully understand the question. As a result of these difficulties, there was a significant amount of interview data which could not be analysed. The interviews lasted for an hour and the researcher found that participants became tired and more easily distracted as time went on. This also contributed to the quality and quantity of useful data from the interviews because as participants' motivation and ability to concentrate deteriorated, this was also likely to affect the answers that they gave to the interview questions. Despite the difficulties and challenges encountered in interviewing the participants, the researcher was able to collect enough data to produce some meaningful and valuable results. Paterson and Findlay (2002) provide an account of the potential difficulties that may be faced in the interviewing people with brain injuries and also recommendations on how to cope with these difficulties. This was a valuable resource in ensuring that the interviews were carried out in the most efficient manner for obtaining the optimum amount of 'usable' data from the interviews.

#### **5.65 Validity**

A query over whether participants had the ability to accurately self report was another potential limitation over the credibility of the interview material, given the impact of their cognitive deficits of their memory and insight. Although participants' brain injuries are inevitably going to limit the accuracy of their memories and insight, it can be argued that the interview data is still useful, as it gives us a personal insight into what it is like to live with deficits in these cognitive areas.

### **5.66 Sample Size**

Overall, as the results of the study are based on the experiences of a small group of participants, the study is modest in its claims, acknowledging that the results may or may not resonate with the wider population of people with acquired brain injuries. The results are, however, useful in providing an insight into the personal experience of living with an acquired brain injury and may provide useful and insightful reading for relevant professionals and patients. Furthermore, the results could be used as the basis of future research in either another similar IPA study or indeed as the basis of a larger quantitative study.

### **5.67 Member validation**

There are different views in the literature about the usefulness of member validation as a method of establishing credibility. Member validation is usually carried out by asking participants for individual feedback on the researcher's analysis and emergent themes from the interview data. Some researchers (e.g. Elliot *et al.* 1999) suggest that member validation is a useful method of establishing credibility, by ensuring that the researcher's interpretations of the semi-structured interviews make sense to participants. Other researchers, however, argue that member validation may be a problematic method of establishing credibility as participants may find it difficult to freely comment upon the researcher's interpretations because of their perceptions of the researcher, perhaps as a more 'powerful' person (Smith, 1996). In the current study member validation was not carried out and this may be perceived as a potential weakness of the study. Other methods of establishing validity and reliability, however, were used in the current study, and these are discussed in the method section (3.81-3.83). The author would have liked to have used member validation as a credibility check. However, following careful consideration of a number of factors, it was felt that the method would not have meaningfully contributed to the credibility of the study.

All of the participants had left the Unit and were living at home when the author was considering contacting them again approximately eight months after their interviews took place. The author sought advice about member validation, from a senior Research Psychologist specialising in the field of brain injury, who advised that it was

not ethically appropriate or useful to re-contact participants. The Research Psychologist suggested that from her experience with this client group it was highly likely that due to their memory deficits, the patients would not remember who the author was, or the contents of the interview. Therefore, participants may not have been able to remember or reflect upon their experiences eight months previously when they were inpatients at the Unit, and therefore this would probably have meant that they would not have been able to give feedback on the accuracy of the interpretations of the results. With this in mind, it is highly likely that the author would not have reached a final conclusion on her interpretations of the interview data from receiving participants' feedback.

From an ethical point of view, the Research Psychologist advised the author of the current study that contacting participants to ask for their feedback on an interview containing sensitive and personal information that they may not remember took place, may cause them confusion or distress.

Furthermore, the participants' ability to be open and honest with their feedback on the interpretations of their interviews may have been affected by their perceptions of the author as a researcher and Trainee Clinical Psychologist (as perhaps a more 'powerful' person, as suggested by Smith, 1996), particularly if they were unable to remember who the researcher was, or the interview itself.

It was also important to consider the risk involved in visiting some of the participants at home, who, because of their brain injuries, may have displayed inappropriate or aggressive behaviour towards the author. Other methods of contacting the participants such as by telephone or letter were not possible either, due to participants' receptive and expressive language deficits.

Taking all of the above considerations into account, it was concluded that it was not possible to obtain member validation in the current study and that it was likely that it would not have been a useful method of establishing credibility.

## 5.7 Future research

Reflecting back upon the current research, the author has learnt a number of important lessons in what may have made the interview process easier and more productive and these learning experiences may be useful for researchers to consider if they were to carry out a similar study. Firstly, the interview lasted one hour – this was partly because it was felt that the participants would not be able to concentrate for longer than an hour and secondly, due to time constraints on the researcher which were partly because of limits in research time and also time limits in taking participants out of rehabilitation time. On reflection, it was felt that in some cases, an hour was in fact too long, and better quality interview data might have been gained if participants had not been as fatigued towards the end of the interview. Therefore, it may be more productive to interview participants for approximately half an hour, and if needed, the researcher should return to the participant after a sufficient break, in order to continue the interview.

Another aspect of the current study was that it covered a range of topics within the research question of the experience of living with a severe acquired brain injury (for example, the experience of gaining awareness of deficits, the impact on relationships, identity issues, experiences in rehabilitation). On reflection, it was felt that it may have been more beneficial to focus on fewer topics in more detail. For example, one or two aspects of the experience of living with a severe acquired brain injury. It was felt that this would be more productive as the researcher felt at times that there was insufficient time to explore research areas in more detail due to time restraints in completing the interview schedule within approximately one hour. This was mainly because of the time taken up with irrelevant material (see strengths and limitations section for details).

In considering the order of questions within the interview schedule, in hindsight it was evident that the wording of questions could have been phrased in a simpler and clear manner, which may have helped participants with speech and language deficits understand the questions more fully and less time therefore may have been taken up in them clarifying what the question meant.

In considering similar research in the future, it might be beneficial for researchers who would like to gain more accurate and rich interview data, to consider interviewing participants with less severe brain injuries in order to gain further insight into the research questions. It might also be useful to limit the population further by researching participants with particular types of brain injuries, instead of participants under the wider 'umbrella' of acquired brain injury. Although there are commonalities in the experiences and perceptions of people within the acquired brain injured population, there are also marked differences between the experiences and perceptions of individuals, depending on the type of their brain injury. For example, a middle aged woman who has suffered a stroke as a result of alcohol abuse may have very different experiences and perceptions to a young woman who has received traumatic brain injuries from being attacked by her partner. The current study, therefore, might have been improved through the use of a more homogenous sample. Future research could develop the current research by addressing the same research question, but with participants with a particular type of brain injury, for example traumatic brain injury, or stroke, or indeed comparisons could be drawn between different populations within the acquired brain injury 'umbrella'.

It would also be interesting to explore how the results of the current study would have differed if the participants had not been inpatients, had been further in their rehabilitation, or if the participants had had less severe brain injuries. These are all areas of consideration which could also be used as the basis for further research.

## 6. CONCLUSIONS

The primary aim of the study was to gain an in-depth exploration of what life is like following a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit, from the brain injured person's perspective. In relation to this broad research question, participants were asked to reflect upon their experience of gaining consciousness following their brain injury, the experience of living with permanent memory loss, the experience of gaining awareness of their physical and cognitive deficits, the experience of losing an identity and adjusting to a new identity, the impact on their relationships with friends and family, their experiences as an inpatient in a Neuro-rehabilitation unit and finally their sources of strength and what coping mechanisms they have used since their brain injury. The use of Interpretative Phenomenological Analysis facilitated the development of a rich detailed account addressing these areas of interest comprehensively.

Four main themes were produced from the research. Firstly, the theme of 'piecing together the past and becoming aware of the present' was identified from the participants' accounts. Secondly, the theme of 'the transition from old self to new self', thirdly 'Sources of Strength and survival' and fourthly, 'Experiences in Rehabilitation' were identified.

Overall the research highlighted the brain injured individual's psychological struggle to adapt to their new identity and come to terms with their cognitive and physical deficits. Their struggle was exacerbated by their significant memory loss and their lack of insight into the effects of their brain injury. Participants referred to the breakdown in their relationships with friends and family and their loss of independence as being particularly difficult to come to terms with. Despite the devastating impact on their lives, however, all participants demonstrated resilience and strength in dealing with their brain injuries.

The results were found to be consistent with existing theory and research literature. The results also provided further insight into the findings of previous studies and new areas of interest were also explored. The results were considered in relation to clinical practice and a need was identified to broaden the focus of current research

beyond the cognitive and physical impact of brain injury and to consider issues such as changes in identity, grief and post traumatic growth.

Overall, this study attempted to provide a refreshing perspective on the impact of brain injury on people's lives, focusing on previously neglected areas and deriving new, interesting and clinically relevant material.

## 8. REFERENCES

- Bamford, C. (2006). Post traumatic growth: A literature review. *Unpublished literature review*. Psychology Department: University of Hertfordshire, Hatfield.
- Bowers, J.E., Meyerowitz, B.E., Desmond, K.A., Bernaards, C.A., Rowland, J.H. & Ganz, P.A. (2005). Perceptions of positive meaning and vulnerability following breast cancer. Predictors and outcomes among long term breast cancer survivors. *Annals of Behavioural Medicine*, 29, 236-245.
- Neuro-rehabilitation. [www.headway.org.uk/sitePages.asp](http://www.headway.org.uk/sitePages.asp) Retrieved 3<sup>rd</sup> December, 2006.
- Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87-108.
- Brown, D., Lyons, E. & Rose, D. (2006). Recovery from brain injury: Finding the missing bits of the puzzle. *Brain Injury*, 20(9): 937-946.
- Calhoun, L.G. & Tedeschi, R.G. (2004). The foundations of post traumatic growth. *Psychological Inquiry*, 15, 93-102.
- Chamberlain, D.J. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*, 54 (4), 407-417.
- Csikszentmihalyi, M. & Selega, I. (2006). *A life worth living: Contributions to positive psychology*. New York, University Press.
- Darragh, A.R., Sample, P.L. & Krieger, S.R. (2001). "Tears in my eyes because somebody finally understood": Perceptions of practitioners following brain injury. *The American Journal of Occupational Therapy*, 55 (2), 191-199.

Elliot, 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.

Gan, C. & Schuller, R. (2002). Family system outcome following acquired brain injury: clinical and research perspectives. *Brain Injury*, 16 (4), 311-322.

Goldstein, G. & Beer, S.R. (1998). *Rehabilitation*. Plenum Press: New York.

Hicks, C. (2000). *Research methods for clinical therapists*. Harcourt Publishers: London.

Hill, H. (1999). Traumatic brain injury: a view from the inside. *Brain Injury*, 13 (11), 839-844.

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing*, 12, 307-312.

Howes, H., Benton, D. & Edwards, S. (2005). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology and Health*, 20 (1), 129-142.

Hutchinson, S., & Wilson, H.S. (1992). Validity threats in scheduled semi-structured research interviews. *Nursing Research*, 41, 117-119.

Joseph, S. & Linley, P.A. (2006). Growth following adversity: theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, 26 (8), 1041-1053.

Jumisko, E., Lexell, J. & Soderberg, S. (2005). The meaning of living with traumatic brain injury in people with moderate to severe traumatic brain injury. *Journal of Neuroscience Nursing*, 37 (1), 42-50.

Kapur, N. (1997). *Injured brains of medical minds. Views from within*. Oxford University Press: Oxford.

- Katzlberger, F. & Oder, W. (2000). Psychosocial sequelae after severe head injury: Interviews of patients and their relatives in comparison. *Psychotherapie, Psychosomatische Medizinische, Psychologie*, 50 (5), 209-214.
- Linley, P.A. & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, 17 (1), 11-21.
- Lovasik, D., Kerr, M.F., & Alexander, S. (2001). Traumatic brain injury research: A review of clinical studies. *Critical Care Nursing Quarterly*, 23 (4), 24-41.
- Mailhau, E., Azouvi, P. & Dazord, A. (2005). Life satisfaction and disability after severe traumatic brain injury. *Brain Injury*, 19, 227-238.
- Mazaux, J.M. & Richer, E. (1998). Rehabilitation after traumatic brain injury in adults. *Disability and Rehabilitation*, 28, 435 – 447.
- McGrath, J. (2004). Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. *Clinical Rehabilitation*, 18, 767-775.
- McGrath, J.C. & Linley, P.A. (2006). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury*, 20 (7), 767-773.
- Millis, S., Rosenthal, M., Novack, T. et al. (2001). Long term neuropsychological outcome after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 16, 343-357.
- Morris, P.G., Prior, L., Deb, S., Lewis, G., Mayle, W., Burrow, C.E., et al. (2005). Patients' views on outcome following head injury: a qualitative study. *BMC Family Practice*, 6, 30-36.
- Morton, M.V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: A review and recommendations. *Brain Injury*, 9, 81-92.

- 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.
- Nochi, M. (1997). Dealing with the 'void': Traumatic brain injury as a story. *Disability and Society*, 12 (4), 533-555.
- Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science and Medicine*, 51, 1795-1804.
- O'Callaghan, C., Powell, T. & Oyebode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation*, 16 (5), 579-593.
- O'Flaherty, C.A. & Douglas, J.M. (1997). Living with cognitive-communicative difficulties following traumatic brain injury: using a model of interpersonal communication to characterise the subjective experience. *Aphasiology*, 11 (9), 889-911.
- Oddy, M. (1995). He's no longer the same person: How families adjust to personality change after head injury. In N. Chamberlain (Ed.) *Traumatic brain injury rehabilitation* (pp 145-182). London: Chapman and Hall.
- Opperman, 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.
- Paterson, B. & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research*, 12 (3), 399-409.
- Peterson, T., Bajo, A., Fleminger, S., Hazan, J. & Winter, D. (2005). *Brain injury survivors' accounts of how sustaining a brain injury has changed their lives. – A qualitative study*. Unpublished research study, Neuro-rehabilitation unit, Edgware Community Hospital, London.

Pound, P., Bury, M., Gompertz, P. & Ebrahim, S. (1995). Stroke patients' views on their admission to hospital. *British Medical Journal*, 311, 18-22.

*Post Traumatic Amnesia*. Retrieved, 20<sup>th</sup> February, 2007 from [www.on-with-life.org](http://www.on-with-life.org)

Rubin, H.J. & Rubin, I.S. (1995). *Qualitative interviewing. The art of hearing data*. Sage Publishers: London.

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research*, 14(10), 1366-1386.

Sanders, C. (1989). *Grief, the mourning after. Dealing with adult bereavement*. Wiley & sons: Toronto.

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.

Smith, J.A. (1995). Semi structured interviewing and qualitative analysis. In J. A. Smith, R. Hare & L. Van Langenhove (Eds.) *Rethinking methods in psychology* (pp 9 - 27). Sage Publishers: London.

Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.) *Qualitative psychology. A practical guide to research methods* (pp 51-80). Sage Publishers: London.

Spencer, L., Ritchie, J., Lewis, J. & Dillon, L. (2006). Quality in qualitative evaluation. A framework for assessing research evidence. *National Centre for Social Research*. Retrieved 2<sup>nd</sup> January, 2007 from [www.policyhub.gov.uk/docs/qqe\\_rep.pdf](http://www.policyhub.gov.uk/docs/qqe_rep.pdf)

Swift, T.L., & Wilson, S.L. (2001). Misconceptions about brain injury among the general public and non-expert health professionals: an exploratory study. *Brain Injury*, 15 (2), 149-165.

The National Service Framework for long term (neurological) conditions (2005). Retrieved on 3rd March, 2007 from [www.nhs.uk/England/AboutTheNHS/Nsf/LongTerm](http://www.nhs.uk/England/AboutTheNHS/Nsf/LongTerm)

*Traumatic Brain Injury*. Retrieved on 10<sup>th</sup> January, 2007 from [www.ukabif.org.uk/WhatisUKABIF/index.htm](http://www.ukabif.org.uk/WhatisUKABIF/index.htm)

Webster, G., Daisley, A. & King, N. (1999). Relationship and family breakdown following acquired brain injury: The role of the rehabilitation team. *Brain Injury*, 13 (8), 593-603.

Whitfield, S. (2003). Treatment and rehabilitation of developmental neuropsychological disorders. In P.W. Halligan, U. Kischka & J.C. Marshall (Eds.) *Handbook of Clinical Neuropsychology*. Oxford University Press: Oxford.

Wiles, R., Pain, H., Buckland, S. & McLellan, L. (1998). Providing appropriate information to patients and carers following a stroke. *Journal of Advanced Nursing*, 28, 794-801.

Willig, J. (2003). Discourse analysis. In J. Smith (Ed.) *Qualitative psychology: A practical guide to research methods* (pp.159-183). Sage Publishers: London.

Wood, R.L. (2005). Waking up next to a stranger. *The Psychologist*, 18 (3), 138-140.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

## 8. APPENDICES

## 8. APPENDICES

	<i>Page No.</i>
<b>Appendix 1:</b> Interview Schedule	196
<b>Appendix 2:</b> Interview Response Sheet	198
<b>Appendix 3:</b> Participant information sheet	200
<b>Appendix 4:</b> Consent form for contact details	204
<b>Appendix 5:</b> Participant summary sheet	205
<b>Appendix 6:</b> Participant Consent form to participate in study	206
<b>Appendix 7:</b> Letter to participants of confirmation of time and date of interview	208
<b>Appendix 8:</b> Audit trail for participant including:	
<b>8a:</b> Extract from interview transcript	209
<b>8b:</b> List of emerging themes from transcript	217
<b>8c:</b> Emerging Themes clustered together	219
<b>8d:</b> Emerging themes clustered with headings	221
<b>Appendix 9:</b> Superordinate themes derived from all interviews. Appendix includes	
<b>9a:</b> Master list of themes for all six participants	224
<b>9b:</b> Master list of themes from all six participants clustered	225
<b>9c:</b> List of themes from all six participants clustered with headings.	227
<b>Appendix 10:</b> Local Research Ethics Committee approval letter	230





