

Experiences of the Process of Adjustment to a Brain Injury: An  
Interpretative Phenomenological Analysis

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## Table of Contents

Abstract .....	62
1 Introduction .....	63
1.1 Setting the Scene, the Traditional Context for Acquired Brain Injury Services	63
1.2 Recent Developments in ABI Services .....	64
1.3 Rationale for the Research.....	81
1.4 Aims of the Research.....	81
1.5 Research Question .....	81
2 Methodology .....	83
2.1 Rationale for the Use of Qualitative Research.....	83
2.2 Exploration of Different Methodologies within Qualitative Research .....	84
2.3 Choosing Which Research Methodology to Apply .....	84
2.4 Philosophical Underpinnings to Phenomenological Methodologies .....	85
2.5 Interpretative Phenomenological Analysis .....	87
2.6 Quality in Qualitative Research .....	91
2.7 Participants .....	93
2.8 Selection Criteria.....	96
2.9 Ethical Considerations.....	98
2.10 Positioning Myself as a Researcher .....	100
3 Results.....	102
3.1 Experiencing a Loss of Control.....	104
3.2 Observed Changes as a Threat to Identity .....	109
3.3 Being Displaced By the Injury: Feeling Unchanged In a Changed World.....	115

3.4	Attempts at Managing a Threatened Identity .....	121
3.5	Enable Me Don't Disable Me: The Role of Support in Recovery.....	126
4	Discussion .....	135
4.1	Summary of Findings .....	135
4.2	Clinical Implications.....	144
4.3	Methodological considerations .....	146
4.4	Suggestions for Future Research.....	148
4.5	Study Reflections .....	150
4.6	Conclusion .....	151
	Reference List .....	153
	Appendix 1: Interview Schedule.....	166
	Appendix 2: Audit Trail.....	167
	Appendix 3: Ethical Approval.....	176
	Appendix 4: Participant Information Sheet.....	179
	Appendix 5: Participant Consent Form .....	182

## Abstract

**Aims:** Acquired Brain Injury (ABI) is often researched from a reductionist perspective, focusing on pathology and dysfunction (Olney & Kim, 2001). More recently there has been a call towards taking a person-centred, global approach; questioning old 'assumptions' about what is currently known, and incorporating the views of the patient (Hill, 1999). This qualitative research study aimed to make a further contribution to the evidence-base by investigating the experience of adjusting to life after ABI.

**Method:** Six participants, (two female, four male) aged 26-49, who had experienced a severe ABI an average of 31 months previously, were interviewed using a semi-structured schedule. Interpretative Phenomenological Analysis (IPA) was employed to analyse the transcripts.

**Results:** Five master themes emerged from the participants' accounts: Experiencing a loss of control; Observed changes as a threat to identity; Being displaced by the injury; Feeling unchanged in a changed world; Attempts at managing a threatened identity, and Enable me don't disable me: The role of support in recovery.

**Implications:** Clinical implications were considered within Bronfenbrenner's (1979, 2004) Ecological Systems Theoretical Framework. Within the Microsystems (the individual's immediate systems such as their body, home and work) participants described a struggle to make sense of their perceived loss of control of their body and brain. They described the importance of making sense of these changes. Clinically there is a potential role for professionals to facilitate how people make sense of their experiences, perhaps moving away from reductionist explanations, which appeared to prevent participants from having hope to influence change. From a Macrosystemic level (the individual's social, cultural and political systems) the participants felt they were less valued and as a result, judged by society and by political systems. Participants' accounts suggested that they wanted to continue to contribute and be valuable in society. An implication therefore is for professionals involved to take more a political stance in influencing how we currently conceptualise people after brain injury, focusing on enablement rather than disablement.

# 1 Introduction

## 1.1 *Setting the Scene, the Traditional Context for Acquired Brain Injury Services*

Acquired brain injury (ABI) is defined in the National Clinical Guidelines for Rehabilitation Following Acquired Brain Injury (Royal College of Physicians & British Society of Rehabilitation Medicine, 2003) as:

An inclusive category that embraces acute (rapid onset) brain injury of any cause (p.7)

ABI therefore includes trauma, vascular accident, cerebral anoxia, other toxic or metabolic insults and infection. The guidelines cite that the number of head injuries that require hospitalisation in the UK occur at an annual rate of 275/100,000. Predicting the outcome of those who have suffered an ABI can prove to be difficult. Patients classified with a severe injury can be known to make a full recovery, whilst those in the mild range can experience long lasting and catastrophic effects (Royal College of Physicians & British Society of Rehabilitation Medicine, 2003 p.8).

Much of the literature relating to neurological disabilities focuses on pathology and dysfunction (Olney & Kim, 2001). Dysfunction following ABI can impact physical, communicative, cognitive and behavioural/emotional functioning (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). As the brain is recognised to control all aspects of bodily and behavioural function, research often takes a reductionist view, attempting to pinpoint function to brain location. Whilst much has been learned from this approach, there is now a growing movement towards more global or holistic perspectives of brain function, emphasising the complexity, plasticity and interconnectedness within the brain. This allows professionals to incorporate individual differences into our understanding of recovery (Hill, 1999).

The sequelae of ABI can have a far reaching impact on a person's ability to function. In the evidence-base, outcome is often measured by a return to employment (Franulic,

Carbonell, Pinto, & Sepulveda, 2004; Oppermann, 2004), community integration (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), and psychosocial functioning, which incorporates interpersonal and family relationships, emotional well-being, and social behaviour (Kendall & Terry, 1996).

The evidence-base has shown that factors that often have an influence on outcome are severity of injury, socioeconomic status, age and pre-morbid factors (Dikmen, Machamer, Winn, & Temkin, 1995; Hoofien, Vakil, Gilboa, Donovan, & Barak, 2002; Schonbrun & Kampfe, 2004; McCullagh, Oucherlony, Protzner, Blair, & Feinstein, 2001; Gollaher et al., 1998; Fleming, Tooth, Hassell, & Chan, 1999). However, as previously mentioned, these variables are not able to predict outcome consistently (Royal College of Physicians & British Society of Rehabilitation Medicine, 2003). Kendall and Terry (1996) conducted a review of the outcome prediction literature and suggested that the evidence-base often yielded inconsistent findings because it failed to account for the influential perspectives of the individual who has suffered the injury.

## ***1.2 Recent Developments in ABI Services***

In the field of rehabilitation there has been a recent drive to take a more holistic, patient-centred approach, focusing on the needs of the individual and tailoring a package of care designed to address these needs. Bajo and Fleminger (2002) draw parallels between this perspective and that of the movement in mental health (Roth & Fonagy, 2005) and ask the question “What works for whom and when?” in brain injury rehabilitation. Like Kendall and Terry (1996), Bajo and Fleminger (2002) suggest that the evidence-base evaluating the effectiveness of rehabilitation interventions fails to take into account the influence of the individual undergoing treatment. Their conclusions include a suggestion that research should place more emphasis on the characteristics of the patient, and advise services to work from the patient’s perspective. Whilst this is an important step, it could be argued that attempting to identify patient characteristics is still not viewing the person holistically. Instead it is breaking down the patient into measurable component parts and perhaps missing valuable information in the process. By conducting research in this way researchers could be continuing to see the person as passive in their

recovery, in that only aspects of their character, which are perhaps outside of their control, can influence their outcome.

The call for a person-centred service comes from both bottom-up (research-led) and top-down (political) perspectives. The National Service Framework (NSF) for Long-term Conditions (Department of Health, 2005) places, as its first quality requirement, the need for a person-centred service. Individuals are to be involved in the decision making process regarding their treatment. An implication for this move towards a more holistic approach is that services will need to consider and address the individual's emotional and psychological wellbeing in addition to addressing the pathology and dysfunction that the brain injury has caused.

Research has found that emotional changes post-injury are common and can be a result of neurological, psychosocial and psychological/psychodynamic changes (Gainotti, 1993). It has been suggested that dealing with the emotional impact of an ABI is crucial in the recovery of an individual (Prigatano, 1995; Hanks, Temkin, Machamer, & Dikmen, 1999) as emotional and behavioural difficulties will have a significant impact on rehabilitation, vocational re-entry and community reintegration. When considering someone's emotional reaction to the injury and its impact, a term that is often used to encapsulate this is adjustment. In the following section I aim to deconstruct the term 'adjustment' and explore how some psychologists have attempted to conceptualise it.

### **1.2.1 Adjustment**

The verb 'adjust' is defined by the Oxford English Dictionary (Oxford Dictionaries, 2005) as:

- 1) to alter slightly to achieve the desired result, 2) to become used to a new situation.

Adjustment therefore is a noun which describes the act of adjusting. According to Lazarus (1969) the term adjustment was developed in psychology as a parallel to the biological term adaptation. Adjustment involves an emotional and behavioural response to changes in the environment. In this way adjustment is seen as the means by which an individual comes to terms with the changes, demands and pressures they encounter



in their social and interpersonal environment or in their internal environment (e.g. the desire for achievement and approval) (Lazarus, 1969).

By definition adjustment is a process; however, it is often only understood and defined as an endpoint. Lazarus (1969) explains that adjustment can be investigated as an ongoing process or as an endpoint. When considering adjustment from the latter perspective we make evaluations about whether someone has adjusted or not. Adjustment therefore could be rated by signs of maladjustment, (the negative approach), the contribution that a person makes in society (the positive approach) or by comparing performance to the statistical norm (the statistical approach). As a process, psychologists are interested in understanding how and why adjustment takes place (Lazarus, 1969).

Psychologists from fields across the lifespan have an interest in adjustment as often people experience difficulties when they are struggling to adjust to a change they are experiencing. A brief review of the literature has found many of the most helpful theoretical frameworks and models relating to adjustment in chronic illness, disability and bereavement literature (Yates, 2003). The following section will outline theoretical frameworks of adjustment that have been found in the evidence-base. Although these have been developed outside of the brain injury literature they have been included because they were felt to be potentially informative for this research. The frameworks included are by no means an exhaustive list, my aim however, is to provide the reader with a general overview of how psychologists currently conceptualise adjustment.

### **1.2.2 Theoretical Frameworks of Adjustment**

Adjustment is used synonymously with the terms, adaptation, acceptance, coping and coming to terms with. A definition of adapting to the changes that are brought about by a physical disability has been provided by Carmaz (1995) who describes it as a process which involves an individual acknowledging their impairment and altering their life to accommodate the losses, reunify their body and self, in socially and personally acceptable ways. Charmaz (1995) outlines a three stage process by which people adapt to impairment. The first involves making sense of the impairment in terms of their body and sense of self. The second involves assessing this changed identity in relation to their future, finding a balance between the losses and gains since this change and

finding value. The third stage involves accepting the illness as an inevitable part of their experience. Within this perspective the author places emphasis on the difference between struggling with illness and struggling against it (Charmaz, 1995). The latter perspective creates a sense of being stuck, grieving for the past self-identity as opposed to building on a current and future self-identity which the individual can value.

Other useful definitions of adjustment, which come from the field of disability, include one by Naugle (1991; cited in Olney & Kim, 2001)

‘a reordering of priorities and a reintegration of the self with a renewed sense of self worth’ (p.142)

Another is from Sidel (1997; cited in Olney & Kim, 2001) who defined it as a lifelong process where disability is gradually incorporated into identity. These last two definitions are helpful in that they reflect the dynamic nature of the process of adjusting, suggesting that one does not reach a point where they consider themselves to be adjusted. Unlike Charmaz’s (1995) definition, they could be seen as lacking an explicit conceptualisation of how an individual might make their way through this process, making them less clinically applicable.

Another contribution to this field comes from Shontz (2007) who outlines six principles relating to disability and adjustment. Shontz challenges two commonly held assumptions: firstly; that psychological reactions to physical disability uniformly disturb or distress and result in maladjustment. Secondly, reactions to disability are directly related to the physical properties of the disability. This suggests that there is a non-linear relationship between the degree of disability and the degree of maladjustment. In addition, Shontz (2007) asserts the importance of not underestimating the complex relationship between the impact that the disability has on the individual and their psychological adjustment. In terms of predicting adjustment Shontz suggests that maladjustment is difficult to predict because it is not simply a result of the physical disability, but of the interaction between the personality, emotionality, self-concept and the disability. Shontz’s (2007) six principles demonstrate how complex the relationship is

between disability and adjustment. These principles helpfully challenge some of the dominant assumptions about why people experience maladjustment and encourage clinicians to consider the individual in all their complexity. However, although these are useful principles, they lack a clear conceptualisation of how they might be applied to influence or change clinical practice.

The field of grief and bereavement provides another helpful conceptualisation of the process of adjusting. Gillies and Neimeyer (2006) developed a model of Reconstruction in Bereavement which explains why an individual may or may not be able to go through the grieving process. Their model is based on the principles of Personal Construct Psychology (PCP) (Kelly, 1955). As a constructivist approach, PCP assumes that all individuals construct knowledge in order to apply meaning to the world and to anticipate events. Gillies and Neimeyer's (2006) model suggests that the loss of a loved one can either be consistent or inconsistent with personal constructions of the world. If the death of a person fits into one's construct of the world, it can be anticipated. Being able to anticipate a loss means the impact is relatively less disruptive when compared to an individual who finds a death is inconsistent with their constructs, meaning it cannot be anticipated. Where the death is inconsistent, old constructions will need to be re-evaluated in order to create new constructs that can once again make events in the world meaningful. The authors suggest that the key areas that are re-evaluated in bereavement are sense making, benefit finding and identity change.

Within the disability, chronic illness and grief literature outlined above, a common theme that has arisen is the role of identity that appears to be important in the process of adjustment. Individuals have been described as needing to come to terms with changes to their physical form, to the losses they have experienced and to the potential changes they may have to make to their future plans. In the following section I will explore the relevant literature in the brain injury field, particularly with regard to what additional challenges brain injury brings to this domain.

### **1.2.3 Adjustment and Brain Injury**

The term adjustment is often used in the brain injury literature, but is rarely defined. In the instances where it has been defined, adjustment is recognised to involve a process, but often only the endpoint is made explicit. Adjustment is frequently referred to as something to be achieved, rather than something to be investigated in itself. This position considers adjustment as a static point that one either reaches or does not, as opposed to a transient state of existence along a continuum, influenced by many factors (Olney & Kim, 2001).

Considering that adjusting to the consequences of a brain injury is cited as the greatest challenge of rehabilitation (Morton & Wehman, 1995 cited in Shotton, Simpson, & Smith, 2007), there is surprisingly little research investigating the process of adjustment in the brain injury literature (Chamberlain, 2006). It has been suggested that these emotional and psychosocial problems have not been researched significantly because of their complexity (Gainotti, 1993; Hanks et al., 1999).

A review of the adjustment literature within the brain injury field reveals that again, much of the work in this area has focused on investigating factors that predict adjustment. These include personal characteristics (Blais & Boisvert, 2007), severity of impairment (Franulic et al., 2004) and the degree of change observed in the individual (Ponsford, Olver, Ponsford, & Nelms, 2003). Much of the research aims to identify who will, and who will not adjust to their brain injury, and what variables might moderate, mediate or impair adjustment. In the above studies adjustment was reflected by mood scales (e.g. the HADS) or was considered 'good' if an individual had a positive outcome (e.g. had returned to work (Franulic et al., 2004)). Individuals were considered non-adjusted if they had high anxiety, depression, low general well-being scores, or were not returning to work. These investigations into adjustment appear to be focusing on the endpoint, as opposed to the process, of adjusting. In one investigation that did consider the experience of this process, Chamberlain (2006) highlighted the need for further research to compare the process of adjustment to theoretical models of grief. This followed her findings that participants described grieving for a past self. Perhaps a helpful model that could be applied is the aforementioned model of Reconstruction in Bereavement (Gilles

& Neimeyer, 2006). Using this framework, post ABI life could be experienced as either consistent or inconsistent with one's personal constructs of themselves and the world. Inconsistencies could result in increased distress and disruption. Adjustment could be seen as the individual having to re-evaluate their personal constructions of the world and attempting to incorporate this meaning into their existing personal constructs. People who appear unable to adjust might have found it difficult to incorporate this new event and subsequent changes into their constructs, or might find themselves unable to let go of their old, now meaningless personal constructions.

Another theory relating to adjustment which was originally developed outside of the brain injury field, but later adapted for it, is Lazarus and Folkman's (1984) theory of Stress and Coping. This theory is cognitive-phenomenological in that the emphasis is on the appraisal of a situation and the resources an individual thinks they have in order to cope with it. It is in this subjective evaluation that an event is determined as stressful or not. If an event is determined stressful but manageable, 'problem-focused' coping strategies are employed. This would involve making changes to the event or actively seeking the skills necessary to manage it. If the event is considered uncontrollable then emotion-focused coping strategies are required which include avoidance, wishful thinking and suppression. This theory suggests that what influences the appraisal are environmental, personal and situational characteristics (e.g. social support, beliefs etc.). This model has been adapted for a brain injury experience (Kendall & Terry, 1996). Kendall and Terry (1996) incorporated pre-injury factors, in addition to cognitive and neurological factors (impact of the ABI), situational variables (e.g. age of injury, additional injuries), personal resources and environmental resources into the model as antecedents to the mediating factors of appraisal and coping. Using this model, the mediating factors were considered central to accounting for the variation in outcome prediction and inconsistent findings reported in the evidence-base. Rutterford and Wood (2006) investigated outcome according to this theoretical framework in an exploratory study. Their results found that there was no support for the mediating effect of appraisal and coping variables between outcome and psychosocial variables. Interestingly however, they did find that outcome prediction improved when these variables were included in a multivariate analysis as

direct predictors. The authors concluded that personality and self-efficacy had the largest impact on long term outcome.

A particular strength of Kendal and Terry's (1996) model was that they incorporated the importance of the role of appraisal and coping in terms of outcome. In a study comparing the use of coping strategies in Traumatic Brain Injury (TBI) and Orthopaedic client groups (Curran, Ponsford, & Crowe, 2000) the authors concluded that there were very similar levels of emotional distress between the groups. In a hierarchical regression analysis they found that handicap, coping strategies and self-esteem were important variables in predicting emotional outcome. There was little support for the impact of neuropsychological factors on implementing coping strategies. No objective neuropsychological assessment measures were collected however, so although the participants all fell in the severe classification of brain injury; it is unclear what impact this had cognitively. Curran et al's (2000) finding was further supported by Finset and Andersson (2000) who conducted a multivariate analysis controlling for potentially confounding variables and found that coping strategies were less dependent on neurological factors than on pre-morbid personality factors and coping repertoire. In their research they compared coping strategy to lesion location and found no significant relationship, however again, cognitive deficits were not assessed.

Building on theories of stress and coping, Perlesz, Kinsella & Crowe (1999) suggested the need for a theoretical framework for adaptation which incorporates the entire family, not simply the individual or main carer. They suggest this framework should include theories of maladjustment (stress and burden), coping, and the process of positive adaptation. These authors called for a focus on qualitative research with families to assist in enhancing an understanding of the pattern of adaptation.

In conclusion, when investigating adjustment following ABI, research often focuses on variables such as coping and compensatory strategies. The evidence-base supports the relationship between psychosocial outcome and the ability to utilise coping and compensatory strategies (Blais & Boisvert, 2007). The process of adjustment however is a complex and dynamic one and to be understood must incorporate individual factors

such as the sequelae of the brain injury, resources and barriers to recovery, life-cycle influences and the individual's social network (Blais & Boisvert, 2005). In a review of this research Blais and Boisvert (2005) revealed a large diversity and inconsistencies observed in the models of adjustment. The authors concluded that this was not helped by a poor definition of the construct of adaptation. These findings suggest that whilst prediction models can help us to generalise our understanding of what strategies will help and hinder an individual in their recovery, a more personal focus might be required to help uncover why some people are able to utilise these strategies, and others not. Perhaps an important focus should be to explore, using qualitative techniques, the meaning and appraisal that the individual has ascribed to their injury and recovery. In the following section I will review some of the qualitative literature in the brain injury field.

#### **1.2.4 Interpretative Phenomenological Analysis and Brain Injury**

Qualitative research developed from a reaction with critical psychology against the application of a modernist science in social and psychological research (Murray & Chamberlain, 1999). One such qualitative method that has been applied in the brain injury field is Interpretative Phenomenological Analysis (IPA). This approach involves investigating the construction of meaning behind a phenomenon, seeing the person who has experienced the phenomenon as expert, and learning from them. In the ABI field it has been suggested that researchers often exclude the views of the individual who has suffered the brain injury, because there is a concern that they will lack the cognitive functioning required to provide an unbiased or objective view of their experience (Brown, Lyons, & Rose, 2006). However an alternative position considers the individual's subjective experience as a reflection of their reality, therefore providing a valuable insight into their internal world (Tyerman and Humphrey, 1984 cited in Howes, Benton, & Edwards, 2005). This position is supported by post-modern theoretical frameworks such as Constructivist and Social Constructionist philosophies (Kelly, 1955; Gergen, 1985) which argue that previous experience, social and cultural influences and language, prevent us from ever being able to be 'objective' and that as a result we are only ever able to present a biased and subjective account of our lives. It is from this perspective that I will be basing my research; I will elaborate on my theoretical position in more detail in section 2.10.

Another argument for moving away from a quantitative, positivist approach is that this research often relies on the views of professionals, carers and family members for an insight into the person with a brain injury's experience. As a result, research often fails to include the views of the individual. This can be criticised for seeing them as passive and unimportant in the process of their own recovery (Medved & Brockmeier, 2008).

There has been a recent movement towards exploring different aspects of life after ABI using qualitative methodologies such as IPA. A particular focus has been on the construct of awareness in brain injury. Understandably awareness is of interest as lacking insight has been found to create problems in engagement with rehabilitation programmes (Dirette, 2002), result in difficulties utilising compensatory strategies and can lead to the psychological distress of the individual and possibly their family members (Wallace & Bogner, 2000).

Using a range of qualitative methods, research has produced themes that helped outline the experience of gaining insight after brain injury. These included becoming aware of change through a comparison of pre and post-injury performance in real world settings (Brown et al., 2006; Dirette, 2002; Howes et al., 2005; O'callaghan, Powell, & Oyebode, 2006), filling in the holes of memory (Brown et al., 2006) and redefining the self (Brown et al., 2006; O'callaghan et al., 2006).

Through qualitative research O'callaghan et al. (2006) constructed a possible model outlining the process of gaining awareness. This began with gaining an awareness of deficits through experience in real life situations and via reactions from others when mistakes are made. Following this an understanding was developed to manage the potential negative reactions to these new insights, but with understanding came a sense of fear, loss or denial. With time, as these changes were accepted, a new sense of self was developed. Furthermore, this piece of research distinguished between neurogenic unawareness (anosagnia) and psychogenic unawareness (denial). Psychological components of unawareness were related to the emotional reactions and were employed as an active, rather than passive process. Neurogenic factors were considered to be related to cognitive impairments preventing learning about the impairments from



occurring. A final aspect was a sense of knowing there were impairments but not understanding them, resulting in a sense of bewilderment. The authors concluded that potential clinical implications involve providing information which promotes understanding and allowing people the chance to experience their deficits in real life settings.

Another qualitative study found that clients had differing opinions to the professionals with regards to what developed their deficit awareness (Dirette, 2002). Whilst there was a relative degree of agreement regarding the amount of awareness gained, the therapists put this improvement down to cognitive testing and discussion about deficits. The clients placed more emphasis on comparing current and pre-injury ability in real-life settings. Whilst it is easy to conclude from this that health professionals are missing something important; the accounts given by clients and therapist are just accounts, and both are valid. It is possible that cognitive testing and discussion provided an intellectualised understanding of what had occurred, but that until this had been experienced 'in vivo' the impact was not fully understood. One could argue that rather than taking an either/or approach, both perspectives should be relevant. Perhaps both processes are needed for awareness to develop.

In a qualitative study exploring the experience of having a brain injury, themes such as developing an 'awareness of change', 'the struggle to make sense' and 'adaptation and acceptance' were reported (Howes et al., 2005). The themes suggested a process of coming to terms with life after injury which involved noticing and then understanding the changes and the emotional reaction that followed. This was followed by a realisation of the world as unjust, which led to feelings of insecurity and vulnerability; these feelings often prevented future planning. The final theme, of adaptation and acceptance involved accepting losses and reconstructing new identities. A positive perspective was often taken which involved valuing life in a more meaningful way. Signs of adjustment were seen as future planning and social engagement.

Sense of self appears to be an important aspect in understanding outcome. In her personal account of the experience of suffering a brain injury, Hill (1999) explains that

her existential self was severely traumatised following her TBI and that she was not the same person. Hill suggested that it is pointless to focus on pre and post-brain injury selves, as this can result in an idealised past, which prevents the development of adaptive behaviours. Hill warns of the power of the language used with TBI patients, (distinguishing from being told you have brain damage, to being told you have severe brain injuries). Her experience of being hopeful was that she was interpreted as disregarding the advice from those who 'knew better'. Hill advised hearing the accounts of the individuals with a TBI to help improve rehabilitative methods. She hopes it will allow professionals to accept the variety of outcomes that are currently seen as anomalies. Whilst Hill's account is thoughtful and insightful, I think it is important to remember that although this was her experience, it does not mean that this will be the same for others. Brown et al. (2006) report having conversations with people with brain injuries who felt they have retained a sense of self. A helpful area of research might be to explore, with people, the similarities and differences between their experiences, attempting to conceptualise how these might be useful in clinical practice.

In a qualitative content analysis of the accounts given by sixty people who had survived TBI Chamberlain (2006) identified themes of grief and regret within the self (about the accident), insensitivity of health professionals, particularly in relation to their hidden symptoms. A third theme was invisibility and being stranded which were interlinked themes connected to leaving hospital and rehabilitation with no continuing support. The 'recovering self' related to a sense of hope in returning to a pre-injury self; this is a theme that has emerged in other narrative accounts (Hill, 1999; Shotton, Simpson, & Smith, 2007). Whilst Chamberlain's (2006) research provides insightful accounts and themes that relate to recovery and the reactions to the injury, it is important to note that this piece of research was being conducted as part of a larger piece of research investigating unmet need in community services. It is possible that the information provided by the participants therefore had an agenda – to highlight limitations in service provision, certainly these are themes that emerge in the narratives.

The research above demonstrates the value of conducting qualitative research in the ABI field and the clinically valuable information that is gained from this approach. In the

following section I aim to move beyond the individual and consider what other factors influence adjustment.

### **1.2.5 Adjustment Beyond the Self**

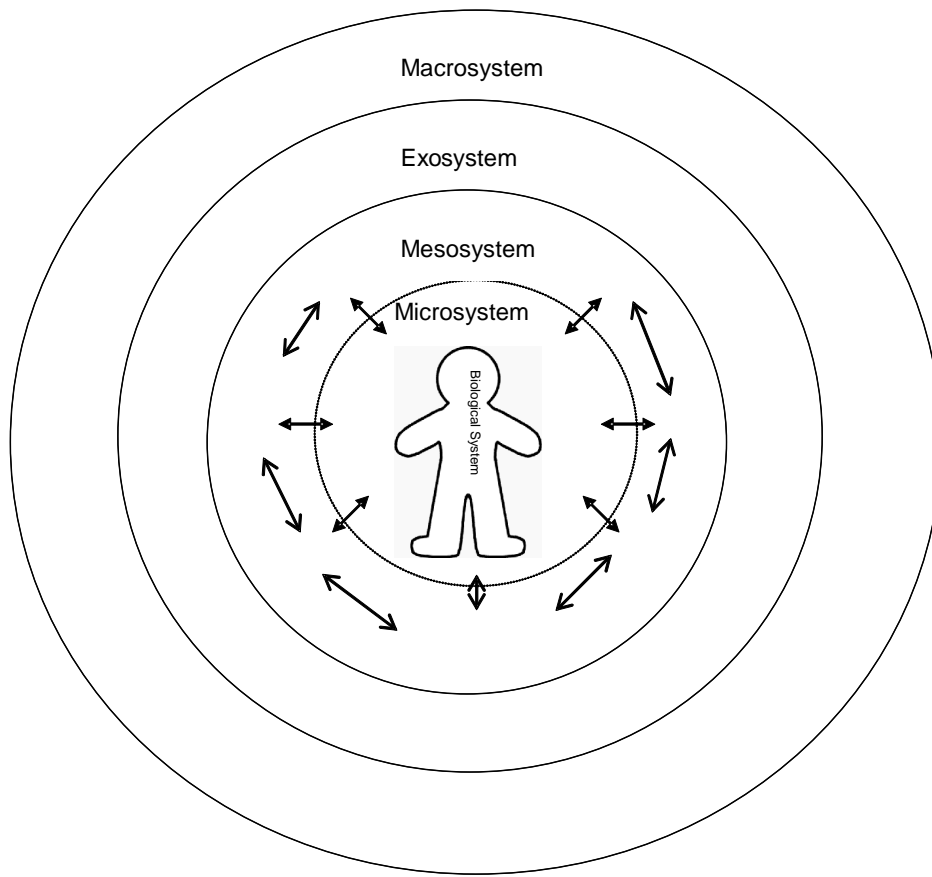
Olney and Kim (2001) argue that although many of the definitions of adjustment consider the individual a closed system, disability, like all social phenomena, should be viewed as culturally and socially mediated. Furthermore, adjustment should be understood more in terms of adjusting one's attitude towards disability and less in relation to adjusting to one's limitations.

This perspective has been reflected in the World Health Organisation's (WHO) framework for understanding health-related disabilities, the International Classification of Functioning (ICF) (World Health Organisation, 2001). The ICF is a tool created to provide a common language and framework for understanding and describing health-related states. The ICF outlines two models for understanding disability; 1) The medical model which views disability as a condition experienced by the individual and caused by a health condition. This model therefore sees treatment of the condition as the intervention of choice and aims to cure the cause. 2) The social model of disability in contrast, sees society as the cause of disability. It is not something the individual experiences directly because of a medical cause. This model puts the intervention back in the hands of society. The ICF states that both models are inadequate and instead calls for a synthesis between them, which it calls the biopsychosocial approach. Within the ICF, the biopsychosocial model sees functioning and disability as outcomes of the relationship between health conditions and contextual factors. Contextual factors include environmental factors (social attitudes, legal and social structures, terrain etc.) and personal factors (age, gender, coping, social backgrounds, education, past experience etc.). Human functioning can be classified at a level of body functioning, the level of the whole person and the level of the person in a social context. As the ICF considers functioning within the social context as important, it further defines the ability to function. To do this it specifies what the individual could achieve in a standardised environment, which aims to neutralise the impact of the environment on the individual's ability (the capacity qualifier), and compares this to their ability to function in their natural social

environment (the performance qualifier); thus identifying what environmental barriers (or facilitators) are being placed on the individual (World Health Organisation, 2002).

A psychosocial theoretical framework that has many parallels to this model is Ecological Systems Theory (Bronfenbrenner, 1979). This theory was developed to understand child growth and development from a personal and systemic perspective. Ecological systems theory focuses on the different levels at which systems can influence an individual's development. According to this framework an individual is nested within sets of environmental structures which have been described as like a set of Russian dolls (see Figure 1). They start with the individual's immediate systems and move out as far as their political and cultural systems. Bronfenbrenner argues that much psychological research considers the individual from a one-sided perspective, investigating the individual but rarely giving equal weight to the role of the environment. Research that does include the environment usually only focuses on the immediate system of the individual. Current research methodology appears unable to incorporate the influence of the wider ecological systems. Ecological Systems theory was developed in order to be able to integrate context into research, its premise is that the relationship between an individual and their environment is bi-directional. Both the environment and the individual must mutually accommodate each other; development is therefore the product of the interaction between them both. From this perspective, in order to understand psychological development, it is necessary to incorporate an understanding of the individual in the context of their existing settings. Bronfenbrenner's systems begin at the Microsystem, this includes the target individual's immediate settings where they undertake activities, roles and has interpersonal relations. These include family, neighbours, school or work, healthcare systems etc. Mesosystems are the next 'layer' in the nest and focus on the relations between the system of Microsystems. Within the Mesosystemic relationships the individual is not directly involved but can nonetheless be indirectly influenced. Examples of these might include the interactions between a child's parents and their school teacher, or the interaction between an individual's partner and their parents (Robbins, Mayorga, & Szapocznik, 1995). Exosystems are the systems that include members of Microsystems, but do not include the target individual. What happens in an Exosystem can affect or be affected by what happens to the target

individual. Examples of Exosystems include the support network of a parent or partner, (Bronfenbrenner, 1979). This support can act as buffers or stressors for the partner, which will influence how they act with the target individual; indirectly affecting their development (Robbins et al., 1995). The final system described by Bronfenbrenner (1979) is that of the Macrosystems. These are described as the broad social forces that have a widespread impact on the individual, e.g. law, politics, cultural belief systems. An example of the role of the Macrosystem in influencing an individual could be with regards to the target individual's healthcare system. For example, if an individual develops a chronic illness, factors that will influence the impact that this has on them will include what healthcare they are entitled to. The individual's experience of the illness might be further influenced by their religious or cultural belief systems in relation to illness and disability. In addition their chronic illness will be indirectly influenced by the individual's ability to engage in their Microsystems, e.g. a person's ability to return to work will be influenced by the company's policy around sick pay and its ability to offer support for a return to work, this is further influenced by government policy around disability discrimination.



**Figure 1: A Diagrammatic Representation of Bronfenbrenner's Ecological Systems Theory**

The Ecological Systems theoretical framework has been applied to the field of family therapy (Robbins et al., 1995; Auerswald, 1971), which works from a Social Constructionist framework. Both Ecological Systems theory and Social Constructionism recognise the role that social and cultural issues can have on influencing an individual's experience and both aim to move away from locating a problem within one person, instead aiming to understand how problems are maintained within systems. Ecosystemic therapists believe that people experience troubles when they have become stuck and are unable to adapt to the changes they face in their environment. A major role in an Ecosystemic intervention therefore is to help the client to get 'unstuck' (Miller, 1997). De Shazer (1983, cited in Miller, 1997) stresses the importance of mapping an individual's troubles in order to understand the social context from which it developed. This is

achieved by asking 'detective questions' to elicit the views of the individual and to establish if there are alternative views from others in the system. Miller (1997) describes how the therapist, having collected the contextual information, must set about intervening with the individual in order to help shift the focus that the individual has on the problem, opening up the potential for alternative explanations. Ecosystemic therapy, according to Miller (1997) is 'semiconstructivist' as there is an emphasis on the role of the individual's perspective in maintaining their troubles. Miller argues that the approach is not radically constructivist because it is still interested in altering the individual's social system, which it recognises as more than just a constructed reality which is "talked into existence" (p.13). Despite this acknowledgement, Miller's description of Ecosystemic therapy appears to place all responsibility on the individual to change either their perspective or the social system that they are in. Although this feels like an important step in considering the system, it seems to be different to Bronfenbrenner's Ecological Systems theory which placed equal responsibility on the individual and their environment for changing. An alternative description of an Ecological intervention comes from Robbins et al. (1995), who wrote that an intervention could be made at any system level. For example it is possible to intervene at an inter-relational level within the Microsystem (working on the interpersonal dynamics between the target individual and another within a Microsystem), or intervening at a Mesosystemic level (e.g. improving a marriage by helping a partner to get on better with her mother-in-law). An intervention at the Exosystemic level could involve improving a child's problematic behaviour by addressing the problems that a parent is experiencing, through the use of support groups. A Macrosystemic level intervention might include a clinician attempting to influence policy and politics at a government level in order to improve the healthcare provision of a particular client group. According to this theory an intervention at any level will have a direct impact on the development of the target individual.

For Ecological Systems theory, a key assumption is that the target individual's behaviour is influenced by these systems and that without them their behaviour would be quite different. In applying this to a person who has suffered a brain injury, an interesting avenue of investigation would be to explore which systems are influencing the individual's psychological adjustment, and in what ways. An interesting development to

Bronfenbrenner's (1979) original theory was his later inclusion of the individual's biological system into their Microsystems, resulting in the theory being renamed the Bio-ecological model (2004). Within this revised account it is possible to incorporate the individual's own biological influences over their development. These changes lend themselves well to the application to brain injury services where it is possible to consider the influence of the individual's biological Micro, Meso, Exo and Macro systems on their development in life after their brain injury.

### ***1.3 Rationale for the Research***

The above research demonstrates that whilst attempts have been made to explore adjustment in the brain injury literature, a significant proportion of this has been measuring it as an outcome as opposed to attempting to understand it as a process. Whilst qualitative research has been growing in ABI, only a limited number of studies have investigated aspects of adjustment, and those that did, have focused on adjustment as an individual and insular experience. Qualitative research investigating the individual experience of the process of adjustment would provide a useful addition to the evidence-base.

### ***1.4 Aims of the Research***

The aim of this research is to conduct a qualitative investigation with participants who have experienced a significant brain injury, gaining a sense of the lived experience of the process of adjusting to life after injury.

### ***1.5 Research Question***

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

**How do people experience the process of adjustment to brain injury?**



The areas of interest identified for exploration were as follows

- Changes to life after the injury
- Changes over time since the injury
- Systemic factors which influence how individuals make sense of their injury
- Systemic factors that help and hinder adjustment

In the following chapter I will outline the rationale behind the methodological approach chosen.

## **2 Methodology**

In the following chapter I will discuss the rationale for using qualitative methodologies in psychological research. I will outline the qualitative approaches considered and my reasons for choosing Interpretative Phenomenological Analysis (IPA). Within this chapter I will outline the current Good Practice guidelines for conducting qualitative research and describe how I have addressed each principle. I will then describe the recruitment process of the participants, outlining selection criteria and ethical considerations. I will end this chapter with a personal reflective account describing my professional and personal interest in the research topic in addition to naming the theoretical and philosophical position from which this research was conducted.

### ***2.1 Rationale for the Use of Qualitative Research***

Qualitative research attempts to explore and represent people's experiences of specific lived encounters (Elliott, Fischer, & Rennie, 1999). It aims to describe, understand and develop theories about human experiences, knowledge and social processes (Starks & Brown Trinidad, 2007). Whilst quantitative research has been developed from a modernist, positivistic position (Ashworth, 1999; Elliott et al., 1999); qualitative research stems from a more postmodern tradition. From this position 'truth' is challenged and the underlying assumptions, cultural and historical influences and biases that inform our sense of 'truth' are questioned. Although there is much that unites qualitative research methodologies, each has developed from its own philosophical position. Starks and Brown Trinidad (2007) advise qualitative researchers to make themselves aware of the differing philosophical perspectives underpinning qualitative approaches, as these are seen to have a significant influence on the nature of the analysis that follows it.

## ***2.2 Exploration of Different Methodologies within Qualitative Research***

Under the umbrella term of qualitative research there are several approaches including, discourse analysis, grounded theory and phenomenological investigations. Whilst each of these share a common emphasis; particularly in holding the participants' experience central (Elliott et al., 1999; Starks & Brown Trinidad, 2007), they also differ quite significantly in the philosophical standpoint from which they have developed. These differences shape the research question, the focus of the analysis, conclusions drawn from the research and how the findings will be relevant. Starks and Brown Trinidad (2007) outline which types of research questions are best addressed by which qualitative methodologies. According to their account, phenomenological investigations are interested in asking questions about lived experiences. The findings from this type of research often allow clinicians to have an enhanced understanding of how people make sense of an experience; hopefully improving clinical practice. Discourse analysis is best suited for the exploration of how knowledge, meaning and identities are shaped by language; it is often used to demonstrate the role of language in influencing outcome and to guide policy. Grounded theory can be used to develop an explanatory account of the phenomenon under investigation. Grounded theories aim to develop a theoretical representation of a social process, imbedded within a social context, which can lead to a generalised theory for clinical application.

## ***2.3 Choosing Which Research Methodology to Apply***

For the purposes of this research, it is possible to imagine that each of the qualitative methodological perspectives could be applicable. In order to decide which research methodology to apply, it was necessary to consider the overall aim of this research. This research hopes to contribute to the evidence-base in neurorehabilitation, to allow practitioners a chance to hear directly from people who have suffered an ABI in order to learn about their personal experience and to inform clinical practice. As hearing from individuals who have suffered an ABI was an identified need in the evidence-base (see literature review Section 1.2.4) it was thought important to start from this perspective.

This research aimed to hear from individuals about their lived experiences, investigating similarities and differences between how they conceptualised the same phenomenon. It is hoped that this may inform clinicians about the role of personal sense-making in the process of adjusting. At this stage, it was felt that not enough was known about the experience of adjusting to life after ABI to begin theorising about how language has shaped this experience, thus ruling out Discourse Analysis. Grounded theory was also considered. However, as this approach aims to develop an explanatory theory of an experience as opposed to hearing about the experience in itself, it was not felt appropriate for this particular project. It was hoped that by hearing personal accounts regarding the process of adjusting to life after a brain injury, clinicians would be able to gain an insight into what it like to go through this process. It was therefore concluded that a phenomenological approach was the most appropriate method to apply to this research. An investigation into phenomenological research methodologies uncovered that there are two approaches which have developed from differing theoretical positions (descriptive and interpretative). It was necessary to decide which of these would be most appropriate for this research; a description of both will be outlined below.

## ***2.4 Philosophical Underpinnings to Phenomenological Methodologies***

Phenomenology began with Hursserl (1970), who attempted to develop a theoretical science of perception (Smith, Flowers, & Osborn, 1997). His interest was in consciousness which he saw as the “condition of all experience” (Dermot, 1999 p.61). Hursserl believed that meaning arose from a determinate relationship between an act of consciousness and its object (Giorgi, 1995) and that in order to understand human motivations, it was necessary to investigate individual subjective perspectives on lived-experiences. This would uncover the essential components of these experiences, thus uncovering what is important in explaining human behaviour (Lopez & Willis, 2004). Hursserl believed that there were universal aspects to human lived experience and that it was possible to access these only when the researcher had bracketed their biases and presuppositions (Ashworth, 1999; Lopez & Willis, 2004). For Hursserl the environment

was not considered important because he saw the relationship between our experience and the environment as one-way, e.g. we could influence the environment but that it did not influence us. Husserl's research methodology was therefore a descriptive phenomenological one. It focused on the researcher purging themselves of any prior knowledge or presuppositions and then intently listening to people describing their lived experiences, in order to extract from them the essential essences of the phenomena under investigation.

A development from Husserl's phenomenological methodology came from his student Heidegger (1962) who introduced the role of hermeneutics (looking for meaning which can be hidden, through interpretation of narratives). Heidegger believed that any phenomenon can show itself in many ways depending on how it is being accessed; as a result he concluded that phenomenology cannot be simply a description of a phenomenon. Instead it must place more emphasis on the role of interpretation to uncover the hidden meanings which are influenced within the context of the social, cultural and historical environments (Dermot, 1999). Heidegger argued that in meaning making, prior knowledge is projected onto objects, persons or processes (Owen, 1995 p.3) and that this will significantly influence any experience (Lopez & Willis, 2004). An important distinction between Husserl's and Heidegger's theories was that Heidegger did not believe it was possible to abstract ourselves entirely from our experiences. Thus implying that in order to understand human motivations and perceptions it is necessary to interpret them within their social, cultural and historical contexts. As researchers, just as for the phenomenon being researched, it is not necessary, or in fact possible, to try to remove all previous knowledge and perspectives. Instead it is necessary to be aware of them and to demonstrate that they are not biasing the research. Heidegger's interpretative phenomenological perspective can be seen to have parallels with that of Social Constructionist theory which is often described as a post-modern movement. This places emphasis on the social origins of meaning and the role of language and culture in shaping individual experience (Neimeyer & Raskin, 2000). A difference between Phenomenology and Social Constructionism however is that phenomenological studies place more emphasis on the role of the individual, seeing experience as more than a construction shaped within the linguistic constraints that culture provides (Eatough &

Smith, 2006a). Thus interpretative phenomenological investigations have been described as having a light Social Constructionist stance (Eatough & Smith, 2006a).

## ***2.5 Interpretative Phenomenological Analysis***

Hermeneutic investigation has been adapted and developed to become a research method, investigating transcripts of interviews in order to make meaning the central focus (Eatough & Smith, 2006b). Interpretative Phenomenological Analysis (IPA) is a relatively new research methodology that has been developed within psychology, and has been applied in health, human and social sciences (Smith, 2009). IPA attempts to try to understand how people make sense of their lived experiences. It is phenomenological as it is interested in meaning making, but it incorporates a double hermeneutic (Smith, 2004) where “the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003 p.51).

Smith (2004) describes IPA as an inductive process: it was developed in order to encourage researchers to be flexible enough to allow unanticipated themes to be heard and incorporated. This inductive approach is achieved through the development of a broad research question to be explored, as opposed to hypotheses to be proven or disproved. Researchers are encouraged to develop a semi-structured interview (Smith & Osborn, 2003), but to be as flexible as possible during the interview process, letting the participant tell their story. Questions and prompts are used to ensure that previously identified and relevant themes are covered but the interviewee should be free and able to bring in new or contradictory accounts. IPA is also defined as interrogative in that the aim of research is to contribute to the existing evidence-base and so individual accounts and experiences are then discussed in relation to it (Smith, 2004).

Central to the IPA process is the exploration of how an individual makes sense of their world (Smith, 2004). This is achieved by asking the participant to take the researcher through their experience in as much detail as possible to allow the researcher to “capture the richness” of it (Eatough & Smith, 2006b p.119). By conducting a phenomenological

case-by-case investigation which privileges each individual's narrative, these individual accounts can then be compared to each other for similarities and differences and then finally examined in the context of the current literature (Eatough & Smith, 2006a). IPA has been described as suitable within the health domain as this idiographic approach, which focuses on individual sense-making of an experience, may allow for an understanding of why individuals with the same health condition may have different experiences of it (Smith et al., 1997).

### **2.5.1 Conducting IPA Research**

IPA offers a set of guidelines for conducting research (Smith & Osborn, 2003; Smith, Jarman, & Osborn, 1999) and although these are not prescriptive, they provide a useful framework particularly for novice qualitative researchers.

IPA begins with the construction of a research question. It has been suggested that IPA is best suited to research into complex phenomena relating to process, novelty or complexity (Smith & Osborn, 2003). Researchers are not to formulate a hypothesis but aim to explore, in detail, the area under investigation. As research begins with a detailed and thorough case-by-case analysis Smith and Osborn (2003) recommend a small sample of five or six participants for a student project. With regards to research participants, it has been suggested that the group should be fairly homogeneous and therefore will use purposive sampling to find a group of individuals who fit a more closely defined experience.

With regards to conducting the interview Smith and Osborn (2003) suggest the use of a semi-structured interview schedule as it prepares the researcher to consider any potentially difficult or sensitive subjects which might need to be worded carefully. In addition the researcher can use it to ensure all previously considered aspects of the experience are covered. Additionally Smith and Osborn (2003) encourage researchers to be vigilant during the interview process for any unexpected topics of conversation and to encourage these.

For the purposes of this research, a semi-structured interview schedule was designed to facilitate conversation about people's experiences of the process of adjustment;

incorporating questions which would consider this perspective from an Ecological Systemic perspective. A pilot interview was conducted with a fellow Trainee Clinical Psychologist, which resulted in amendments to the order and in the wording of questions in the schedule (See Appendix 1).

Smith and Osborn (2003) suggest that the interview schedule allows for approximately an hour or more of recorded conversation. The researcher must remain flexible enough during the interview to let the participant tell their story, exploring unexpected avenues, but also remaining attached to the topic being investigated. The interview is transcribed at the semantic level, showing every word, false starts, significant pauses etc. as these may form part of the analytic process.

### **2.5.2 Analysis**

Analysis begins with a case-by-case idiographic investigation. The transcript is read and re-read many times. Aspects that seem interesting or relevant, thoughts or summaries may be annotated in the left-hand margin. This process is repeated, as each reading can highlight new areas of interest. The next stage involves the individual returning to the transcript and, in the right-hand margin, attempting to take the analysis further, to document emerging themes which are at a “slightly higher level of abstraction and may invoke more psychological terminology” (Smith & Osborn, 2003 p.68). Although this stage of the analysis involves more abstraction, the researcher must stay grounded in the text (Smith & Osborn, 2003). This process has been described as like being attached to an elastic band, where one end must remain fixed in the data, but whereby interpretation can be stretched away from it, to differing degrees of tautness (Smith & Eatough, 2009). During the process of analysis the researcher takes a descriptive and empathic approach, in addition to being critical and interrogative in what the individual has said (Smith & Eatough, 2009). This position encourages the researcher to remain empathic to the accounts of the individual but also to consider what is motivating and influencing their account. Following a completion of the transcript the emergent themes are listed on a page and connections between them are looked for. The list starts chronologically and ends thematically. Smith and Osborn (2003) likens this process to using a magnet, with some themes pulling others in to help them make sense. Within these clusters, a Superordinate theme may emerge; this could be one of the existing



themes or could be a construction of many of the emerging themes. These theme clusters are then checked back with the data to ensure the researchers' interpretations are still grounded in the text. This can be demonstrated by using extracts of the transcript which support the themes. The theme clusters with their Superordinate theme name are then created within a table, constructing a coherent account of the individual's experience. Within each theme are the identifiers demonstrating where in the transcript the themes are supported.

### **2.5.3 Analysing More Than One Case**

When using more than one person's account of an experience, it is necessary to try to represent each of the themes found across the interview transcripts. Smith and Osborn (2003) describe two ways of analysing multiple cases, the first is to treat each transcript separately, conducting an analysis on each and trying to not let each analysis influence each other. The second is to use the themes from the first transcription to orient the analysis for the next. For both accounts it is necessary to remain open to new themes, therefore recognising similarities and differences. This research used the former approach.

### **2.5.4 Levels of Interpretation**

Smith (2004) describes differing levels of interpretation that are possible within IPA, the first involves staying close to the text and reflecting, at an abstract level, what the individual is describing. The second involves the use of metaphor and what this evokes for the participant and researcher about the experience. The third involves an analysis of the temporal referents in the text. This can give an insight into how an individual might be making sense (or struggling to make sense) of an experience, e.g. if someone switches between tenses during an account this might tell us something about a struggle with change. It is important that during the write-up the researcher makes clear which level of interpretation they are applying to the data (Eatough & Smith, 2006b). If analysis has been thorough it should be possible for an independent person to be able to follow the audit trail from the raw data to the end table (Eatough & Smith, 2006b). To demonstrate the audit trail for the purposes of examination an example analysed transcript and the process of clustering has been included in Appendix 2. To ensure

confidentiality is maintained the analysed transcript will not be included in the final submitted version of this thesis.

### **2.5.5 Constructing a Group Account**

Once each of the cases have been analysed, it is necessary to create an overall table of master themes. If each analysis has been conducted individually it is possible to use the Superordinate themes clusters from each analysis and to list them as themes to be re-clustered. At this stage it is necessary for the researcher to be more selective in which themes to privilege and judgements do not need to be made purely on the basis of prevalence within the transcripts. Themes that are particularly rich or illuminative are encouraged to be included. At this stage it is helpful to return to the transcripts to ensure that the researcher's personal agenda is not privileging the selection of themes (Brocki & Wearden, 2006).

### **2.5.6 Writing Up**

The write-up involves translating the analysis into a narrative account explaining the themes that have been elicited. The narrative is interspersed with extracts to support the account. The discussion section could be used to link the narrative account to the current evidence-base; alternatively this could be done within the results section which could also form part of the discussion. For the purposes of this research project the results section will be separated from the discussion.

## ***2.6 Quality in Qualitative Research***

Researchers have developed a set of evolving guidelines regarding conducting qualitative research (Elliott et al., 1999). This has been developed in order to contribute to the process of legitimising it as a research methodology, to assist those required to review theses and manuscripts, to improve quality, and to encourage further development.

The seven guidelines developed will be outlined below, with specific reference to what attempts have been made to address them within this research.

*Owning One's Own Perspective:* Researchers are advised to be explicit about their professional and theoretical orientations and to name their expectations prior to the research, being mindful of how their values, interests and assumptions might influence their understanding. To address this guideline I have included a reflective summary (see section 2.10) and during this research have made explicit any reflections that might have influenced the analytic process, as recommended by Brocki and Wearden (2006).

*Situating the Sample:* Elliott et al. (1999) suggest that researchers describe their participants by including characteristics that might be relevant to the research question. For the purposes of this research the participants have been described in Section 2.7.

*Grounding in Examples:* Elliott et al. (1999) encourage researchers to provide examples to illustrate themes and to demonstrate the analytic process. This is also a suggested requirement in IPA (Smith et al., 1999; Smith & Osborn, 2003) and has therefore been applied in this research (see Results section for more detail).

*Providing Credibility Checks:* Elliott et al. (1999) describe a range of methodologies suitable for checking the credibility of themes or accounts, dependent on the qualitative methodology employed. Options provided include member checking, checking with an additional auditor, comparing differing perspectives and triangulation with external factors. In IPA Smith (2004) emphasises the role of the double hermeneutic, which implies that the researcher's interpretation is as important as the participant's account; making the resulting analysis partially subjective. If this is the case it would suggest that it is not possible to check that the analysis is *right*. It is however important to check that the analysis can be followed through the use of an audit trail. For the purposes of this research transcripts were reviewed by my researcher supervisor who has expertise in IPA and by my field supervisor who has expertise in brain injury. Both of these reviewers were able to follow my analysis and agreed that the themes could be justified within the transcripts. It was not felt appropriate to take the themes back to the participants as many of them had memory impairments and may have been distressed at not being able to recall what they had said. Furthermore reliability checking could be argued as

inappropriate if the purpose of IPA is to offer one of many possible interpretations (Yardley, 2000).

*Coherence:* Qualitative researchers are encouraged to present their analysis in a coherent manner which allows for readers to develop an integrated understanding of all the findings, whilst recognising nuances within them. Within IPA, and therefore this research, the analysis is presented in a narrative account, with excerpts used to illustrate each theme.

*Accomplishing General vs Specific Research Tasks:* Researchers are advised to be specific about the degree of understanding that has been developed, e.g. general or specific. For a general understanding the research must have covered an appropriate range of instances to claim a generalised account. Where a specific understanding is the goal, the researcher must demonstrate that they have conducted a comprehensive piece of research and name the limitations for extending the findings. As IPA research is idiographic (Smith, 2004), the findings for this research will be specific to the research participants, however it is also interrogative and so findings will be considered in relation to the wider evidence-base.

*Resonating with Readers:* The final guideline states that the reader should feel that the researcher has done a good job in capturing the experience of the participants; and that she/he has managed to express, coherently, a difficult or complex phenomenon. In this research it is hoped that it will be possible to present an interpretative account of the participants' experiences, which will then be situated in the context of the current evidence-base, with clinical implications made explicit in the Discussion section.

## **2.7 Participants**

### **2.7.1 Context**

Participants for this research were recruited from the Bedfordshire Acquired Brain Injury Service. This is a county-wide service for people with complex needs following ABI. The Service's role is to work with patients who have suffered a significant brain injury; identifying need through assessment, ensuring that patients have access to the

appropriate services available and to case-manage clients who require access to different funding streams. In addition to assessment and case-management, the service offers a community rehabilitation service for patients, using a holistic approach to identify and work towards person-centred goals. The team is made up of a range of health professionals including Clinical Neuropsychologists, Assistant Psychologists, Occupational Therapists and Rehabilitation Technicians.

Patients can be referred to the ABI Service at any stage in their recovery. The service's referral criteria state that the patient must be a resident in Bedfordshire, have suffered a significant brain injury with verifiable evidence of severity (e.g. a Glasgow Coma Scale Score of less than eight, loss of consciousness for greater than 30 minutes, disorientation in the first twenty-four hours) and have needs which require specialist neurological rehabilitation.

### **2.7.2 Recruitment**

Once ethical approval had been granted for the study (see Appendix 3) I met with the team to discuss with them the aims of the research, and to explain what kind of participant I was hoping to recruit (using the inclusion and exclusion criteria, which can be found in Section 2.8). In addition the team were given copies of the Participant Information Sheet (Appendix 4) and a copy of the research proposal.

The team was asked to consider which patients from their current caseloads might be appropriate. They were encouraged to approach potential participants with the Participant Information Sheet to see if they might consider meeting with me to discuss the potential for them to take part. Participation from the team was supported with regular contact by me, this was aided by the fact that I had worked with the team for several years prior to commencing Clinical Psychology training. The team initially identified six potential participants who had been approached and had agreed for me to contact them. On ensuring that the potential participants met the research criteria however, it was discovered that one participant had experienced their injury during childhood. This was discussed with my research supervisor and we both felt that this individual's experience had the potential to be quite different from the other participants

and so, to ensure as much homogeneity within the sample as possible, they were excluded. A final participant was then identified, bringing the total sample size to six.

All participants were contacted and a time arranged to meet to discuss the research in more detail. Participants chose the location that suited them best. During our initial meeting, the Participant Information Sheet was read through in detail. Five of the participants requested that I read the information sheet to them, reporting difficulties with vision, concentration and problems with reading as the reasons. Following the process of going through the sheet, I asked participants to tell me what they made of the research and asked them a series of questions about what they could expect. All the participants were able to retain enough detail to suggest to me that they were able to give informed consent to the process. Following this, the participant was asked if they wanted to take part in the investigation, all of the six consented (see Appendix 5 for consent form) and a time was arranged for us to meet. At least one week was given for each of the participants, allowing them a 'cooling off period' and an opportunity to change their mind. One participant asked if it was possible for us to carry out the interview on the day of our first meeting and chose not to wait. This was discussed in the presence of their keyworker from the day centre and all agreed that this could go ahead.

All interviews but one were conducted in the participants' homes. This has been supported by Smith and Osborn (2003) who emphasise the importance of researchers making the participant as comfortable as possible.

The table below outlines some descriptive information regarding each of the participants which was collected from the participant's file by a member of the ABI team.

Participant <sup>1</sup>	Gender	Age	Cause of ABI	Time Since Injury	Marital Status	Ethnic Origin	Profession prior to injury / Class
Leanne	Female	35	Anoxia	28 months	Single	White British	Unemployed / Working Class
Jon	Male	32	TBI assault	46 months	Single	White European	Unskilled work / working class
Katie	Female	26	TBI – RTA	38 months	Single	White British	Office worker / working class
Mike	Male	49	TBI	34 months	Married	White British	Manual labour / working class
James	Male	42	Craniopharyngioma with Encephalitis and Hydrocephalus following removal of tumour	24 months	Single	Black British	Truck driver / working class
Brian	Male	34	TBI - Assault	18 months	Single	White British	Driver / working class

**Table 1: Participants**

## **2.8 Selection Criteria**

The inclusion and exclusion criteria for this research will be outlined below

### **2.8.1 Inclusion Criteria**

i) Participants must be patients of the ABI Service. The Service's referral criteria require that patients have suffered a significant brain injury and require specialist neurological rehabilitation. This helped to ensure that there were some commonalities in experience which is required for an IPA research design.

ii) This research aimed to include participants who were two to three years post injury to ensure that they had time to begin adjusting to their ongoing impairments. Two years is cited in the literature as a time when an individual is thought to have reached a plateau in their neurological recovery (Brain Injury Association of Queensland, 2007).

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<sup>1</sup> All participant names have been changed to maintain confidentiality

ii) Individuals were not significantly physically impaired as a result of their injury. Physical disability was anticipated to add a different dimension to the experience of the process of adjustment. To increase homogeneity it was necessary for the participants to have had as similar an experience as possible.

iii) Participants had the capacity to consent

iv) Individuals were English speaking. Although it is possible to conduct qualitative research with people who do not speak English, it was concluded that by including English and Non-English speaking participants, this would increase heterogeneity and was therefore felt unsuitable for this research project.

v) Individuals did not have any significant communication difficulties (e.g. receptive/expressive dysphasia). In order to access the complexity of meaning it was a requirement for participants to be able to express themselves and to not have any problems understanding the spoken word. An interesting further investigation might be to explore the process of adjusting to a brain injury for individuals with communicative or physical disabilities. However, this was beyond the scope and remit of the present investigation.

### **2.8.2 Exclusion Criteria**

As all participants were recruited from the Acquired Brain Injury Service this meant that they had not met the team's exclusion criteria which included: having an uncontrolled mental health illness, misusing drugs and alcohol, or having a progressive neurological condition.

In addition to this, participants for this study met the research exclusion criteria to ensure the sample was homogeneous.

i) Untreated or uncontrolled medical conditions (not related to ABI)

ii) Non-English speaking

iii) Significant communication difficulties (expressive or receptive dysphasia)



## **2.9 Ethical Considerations**

Ethical approval was granted for this research by the Essex 1 Research Ethics Committee. Approval was given to conduct this research, with patients from the Acquired Brain Injury Service, by NHS Bedfordshire Research and Development department. Relevant documentation can be found in Appendix 3.

### **2.9.1 Informed Consent**

As the participants taking part in this study were patients of the ABI Service, it was anticipated that all would have some degree of disability, and that the majority would experience some degree of cognitive impairment. For this reason it was important to ensure that all participants had the capacity to consent to take part in the study.

As the Mental Capacity Act (MCA) (OPSI, 2005) starts from the assumption that every individual has the capacity to make their own decisions, all possible steps were taken to support the individual in the decision making process. This included providing clear written information about the study, providing participants with the opportunity to discuss the research prior to taking part, particularly in relation to this being a qualitative study, and being asked potentially personal questions. The purpose of the research, and what it would entail, was re-discussed prior to commencing the interview and the option of withdrawal at any time was emphasised. Participants' ability to give informed consent was established prior to consent being given (see section 2.7.2 for more detail). Participants were also offered the opportunity to invite a significant other to join them, whilst information regarding the study was provided, in order to help them with the decision making process; only one participant chose to do this.

### **2.9.2 Confidentiality**

Prior to conducting the interview, confidentiality and its limits were explained to the participants. This was also outlined in the Participant Information Sheet (Appendix 4). Participants were informed that all personal identifying information would be removed from the research material (e.g. transcripts, recordings etc.) and would be stored in a

secure location at the researcher's home. With regards to choosing what participant characteristics to include in the write-up, it was decided that descriptive information relevant to the research question, which would help the reader to situate the participant but that doesn't identify them, would be included as outlined in the qualitative Good Practice guidelines (Elliott et al., 1999) previously described in Section 2.6.

### **2.9.3 Affiliation of the Study**

Participants were reassured, verbally and in writing in the Participant Information Sheet (Appendix 4), that their decision to take part in this research project would not influence or affect, in any way, the service they received from the ABI Service.

### **2.9.4 Potential Distress**

An ethical consideration prior to conducting this research was the potential distress that participants might experience when discussing their views about life after their brain injury and the changes it had brought. In order to address this issue, I aimed to ensure that the participant was fully aware of the potential distress they might feel, and to encourage them to consider this when making their decision. The participants were informed, in writing and verbally, just prior to starting the interview that they could stop the interview at any time and could choose not to answer questions if they wanted. Part of the consent process involved participants agreeing that the ABI Service would be made aware if they consented to take part. The limitations of confidentiality were also explained. Participants were made aware that if a breach of confidentiality was required their keyworker from the ABI service would be informed. As a Trainee Clinical Psychologist I was confident that I could use my clinical skills to conduct the interviews sensitively. I was mindful throughout the interviews of the sensitive nature of the questions I was asking and at the end of the interview left time for a debriefing. In addition I asked the participants' keyworker to contact them the following day to see how they were feeling and to ask if they would like me to visit again to discuss any concerns or answer any questions. None of the participants felt this was necessary.

## **2.10 Positioning Myself as a Researcher**

Having explored and justified the use of qualitative research methodologies to answer my research question, it is also appropriate to consider my position in relation to this research topic (Elliott et al., 1999). The following section will outline my professional and personal interest in this subject matter, naming my beliefs and assumptions prior to conducting this research in order to be transparent about how these might have influenced my research.

My interest in brain injury has stemmed from personal and professional experiences. At the age of eighteen my father suffered a subarachnoid haemorrhage whilst working abroad. We were informed that his situation was serious and were told to prepare for the worst. I remember being told a great deal of technical information, none of which I understood, and then we had to wait. My father was flown over to England and we were told that he may have to have surgery to stop the bleed. After a few more days we were informed that his situation was more stable and that the aneurysm had 'sealed itself' so no surgery was necessary. The next few weeks were spent visiting dad in hospital until he was finally ready to return home. My recollections of this experience are blurry and unclear, I am now thirty years old and so twelve years have passed. My father was regularly told that he was incredibly lucky; he returned to work after just a few weeks and experienced no 'significant' impairments. Despite this, this episode was life changing. Not long after this, my father 'upgraded' our family home and began spending more time doing the things he enjoyed. Three years after this he took a redundancy package from his work and retired. Although experiencing no *significant* deficits, he has lost his sense of smell and although he is incredibly active, he can still be anxious about his physical health and worries more about his, and our, well-being. I find that although many years have passed, this episode still feels very much alive for us all as a family.

My professional experiences in brain injury began during my undergraduate degree in psychology, two years after my father's haemorrhage, where I volunteered as a psychology assistant for the Bedfordshire ABI team. After my degree I spent approximately four and a half years working part-time with the ABI team as an Assistant

and Associate Psychologist. My role predominantly centred on assessment and case-management of patients referred to the service. During my time with the team I was offered the opportunity to conduct some research for a PhD qualification. This research adopted a quantitative methodology aiming to assess the utility of a measure of learning potential.

My subsequent training in Clinical Psychology has been on a Constructivist and Social Constructionist course. I have found this to be a richly rewarding experience and one that also made me question my previous assumptions about what I thought I knew. My experience of being on this course is that I began to reflect on my clinical and personal experiences as if I was looking at life through a different lens. My training has encouraged me to question everything and to challenge dominant narratives, particularly those that influence my clinical practice. As I became more familiar with this position I began to reflect on my past work in brain injury, wondering whether this new perspective might have influenced my practice. On reflection I became aware that my predominant focus in the past had been on identifying an individual's strengths and weaknesses in order to develop cognitive strategies to compensate for any difficulties, and to work towards achieving identified goals. In my mind this is a person-centred perspective and is important and valuable work, but I wondered if my Social Constructionist and Constructivist perspective might be able to add more. It could be argued that neuropsychological assessment takes a reductionist stance, attempting to identify aspects of an individual which shapes their outcome. From my philosophical position now, I wonder what meaning these individuals might have given their experiences of brain injury and how this influences their adjustment. As Social Constructionism and Constructivism emphasise the expertise of the individual I was keen to hear what these individuals had to say about their experiences and what they think might help them in their recovery.

It was my hope that in conducting this qualitative piece of research I would provide an opportunity, for the individuals who have suffered an ABI, to tell their stories so that we might learn from them.

### 3 Results

In this chapter I will present the results of the Interpretative Phenomenological Analysis for the six participants' accounts of adjusting to life following a brain injury. Five master themes emerged from an analysis of the semi-structured interviews:

- Experiencing a loss of control
- Observed changes as a threat to identity
- Being displaced by the injury: Feeling unchanged in a changed world
- Attempts at managing a threatened identity
- Enable me don't disable me: The role of support in recovery

In accordance with Macran, Stiles & Smith (1999), the themes do not represent discrete categories and there is overlap between them; but they have been developed as 'heuristic organising categories' (p.422). As discussed in the previous chapter, the themes that have been developed from this data are a result of a double hermeneutic (Smith, 2004) which means that they emerged during the process of me (the researcher) making sense of them (the participants) making sense of their experiences. This account is therefore, to some extent, subjective and unable to reflect all features of the participants' experience. Instead, it focuses on aspects that are relevant to the specific research question stated earlier.

The Superordinate theme clusters from each of the six interviews were listed and became emerging themes. These were then clustered together and from them a number of master themes and subthemes were developed. A table below outlines the five master themes and the subthemes that contributed to them.

<b>Master Themes</b>	<b>Subthemes</b>
<b>Experiencing a loss of control</b>	<i>Feeling like you're starting over</i>
	<i>Putting the pieces of the puzzle together:</i>
	<i>Making sense of a changed self</i>
<b>Observed changes as a threat to identity</b>	<i>Feeling less able</i>
	<i>Struggling with a changed self</i>
	<i>Feeling unable to return to a previous identity</i>
<b>Being displaced by the injury: Feeling unchanged in a changed world</b>	<i>Being displaced from a previous identity</i>
	<i>Feeling unchanged in a changed world</i>
	<i>Judged</i>
<b>Attempts at managing a threatened identity</b>	<i>Accepting the unchangeable</i>
	<i>Getting back to living</i>
	<i>Finding strength from having purpose</i>
<b>Enable me don't disable me: The role of support in recovery</b>	<i>The dilemma of needing to accept help</i>
	<i>Enable me don't disable me: Active vs Passive reception of help</i>
	<i>'In the same boat': The need for acceptance and validation</i>

In the remainder of this chapter I will explore each of the master themes and the subthemes that make them up. Whilst these themes are thought to represent something of the experience for all six participants, there are convergences and divergences between their accounts. As IPA is idiographic and phenomenological in nature (Smith, 2004) the aim of this section is not seeking to make generalisations, but instead is interested in exploring the similarities and differences that participants describe. It could be argued that the variations between experiences are of particular interest as they may tell us more about what contributes to the different accounts that people describe.

Verbatim extracts will be used to illustrate how the participants experienced each theme and to demonstrate how the themes have been grounded in the data<sup>2</sup>.

### ***3.1 Experiencing a Loss of Control***

Overview:

This theme demonstrates the experience of realisation that, following the brain injury, the participants no longer felt fully in control. The experiences described include losing control of the most basic physical functions such as walking and talking, in addition to the more subtle, yet equally as important, emotional, behavioural and mental aspects of their being. In the process of making sense of this loss of control, these participants described a growing realisation that their brain is ultimately in control of everything and that it is only if the brain allows it, that you are able to exert your will. This experience led to a realisation that prior to the injury the symbiotic relationship between the brain and the 'mind' had been taken for granted. Since the injury participants described what seemed like a de-synchronisation between the brain and the mind, leaving them feeling that their previous beliefs about having 'free will' were in fact an illusion because ultimately it was the brain that had been in control. This experience seems somewhat akin to an existential crisis where one is forced to reconsider everything that they had previously believed and accepted to be 'true'. Two participants compared the process of coming to terms with the loss of control as being like children who had to re-learn everything all over again. Participants described a process of making sense of this loss of control which was described by one participant as putting the 'pieces of the puzzle'

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<sup>2</sup> For the purposes of this research minor changes have been made to the extracts included here, firstly to ensure confidentiality (removing or altering any personally identifying information) and secondly to improve readability (by removing repeated words, false starts and words such as erm, unless they formed part of the analysis). Where a word has been implied but not stated this has been included in square brackets [ ] to provide more of a context of the participant's account. Significant pauses have been included where they form part of the analysis (the number of seconds paused are included in brackets). Ellipses (...) indicate missing text.

together. How individuals chose to construct this loss of control appeared to be important in how they then responded to it.

### 3.1.1 Feeling like you're starting over

Five participants described their experience of being different or changed since the injury in a way that suggested they felt they were starting over. Two participants compared this to being like a child again. This evoked a sense of feeling unable, and having to gain mastery over a body that had once been familiar but that was now a stranger. Leanne's account of waking up in hospital following an asthma attack involved her feeling so entirely unable that she described herself as being a vegetable.

*Leanne            First thing I remember is being a vegetable*

*Steph            Being a vegetable?*

*Leanne            Yeah, couldn't walk couldn't speak, couldn't do anything*

Leanne's metaphor tells us a great deal about how she felt during the early stages after her brain injury. She did not describe feeling like a vegetable, but being one. She described not being able to control any parts of her body. Her description was that she remembers this, which suggests that whilst her mind was still active, she no longer felt in control of her body.

Katie, who was involved in a road traffic accident, compared the process of adjusting to life after a brain injury, to being a child again.

*... It's like being a newborn baby and having to learn it all again (Katie)*

This description is replicated by Jon who suffered a traumatic brain injury following an assault.

*... I think basically persons, I think have brain injuries they are like kids again, so they have to learn, to deal with all situations again (Jon)*



Whilst Katie and Jon's accounts suggest experiencing loss, they also hint at hope, both include the concept of learning again indicating that they expected to be returning to their 'adult selves' in the future.

Mike's account of starting over relates to his memories. He described being able to remember his life before the injury but also felt that the people he met in hospital, at the time of his injury, were life-long friends. It was as if Mike had two lives and that the brain injury marked the start of his second.

*Mike And I remember the bloke that was in the bed opposite. And from that, from what I'm saying now is I think well, I started remembering bits then, but now it seems like that's the furthest I can remember back, so I've known them all my life (...)*

*Steph It feels like that's the beginning of your memories?*

*Mike It does yeah*

*Steph But do you remember before that, as a child and growing up?*

*Mike Oh yes, long long*

*Steph You do ok*

*Mike My long-term memory is really good*

The accounts above demonstrate the importance of the brain injury as a life-changing experience which had led the participants to feel that, in at least some parts of their lives, they had to start again. Unlike the others, Brian, who suffered a traumatic brain injury following an assault, did not report feeling that he was starting his life over again. He reported feeling very much unchanged and so does not feature in this master theme at all. Brian's experience was of waking up in a world that was different; this had a significant influence on his experience of adjusting to life after a brain injury and will be explored in the later themes.

### 3.1.2 Putting the Pieces of the Puzzle Together: Making Sense of a Changed Self

Participants' attempts to make sense of the changes they noticed over time varied in terms of how they constructed an understanding of these changes, and in what they found helpful and unhelpful in this process. When and how participants made sense of their changed-self varied significantly. Jon's account suggested to me that he was beginning to make sense of the implications of his injury even during his coma:

*Jon* When I was in a coma I just have all the kind of (...) weird dreams. I dream that I was dead that I have a son in Germany (laughs), then I lost my i.d. I couldn't get out from Germany and I had to marry somebody to be possible for me to get out. Then I was dreaming (...), I was in the hospital but I was like outside and some guys were playing football and were chucking stones on me and cause there was no space for me in the hospital so they put me in some bed outside, in the garden or something, (laughing) so

*Steph* And you remember all of these dreams!!!

*Jon* Then I remember some face, like some green guy, some virtual image I think was probably the guy who was wanted to take me to the other side and I was fighting back to come this side, I remember this some weird face like I don't know, it was not like devils and all this (...) with horns, it was just some virtual image

Jon's descriptions of his dreams during his coma are incredibly rich and seem filled with metaphors that relate to his current circumstances. Jon described dreaming that he had died and had lost his identity. This could be interpreted as being at an existential level as he felt he would never be the same again, or at a more physical level as he suffered severe facial injuries and may have felt he would never look the same. He also described feeling trapped in a country that has historical connotations relating to hostility. Perhaps this related to his experience of being trapped in a coma or in his non-functioning body. Jon described having to make compromises in order to escape his situation (having to marry someone in order to leave) and experienced rejection (both by

the 'guys' who were playing football and by the hospital). Jon's final descriptions were of a 'guy' who was attempting to take him over to the 'other side'. This appears to have given him his reason to fight to come back. The meaning that was given to these memories has perhaps influenced Jon in how he has made sense of the changes and how he plans to tackle them.

Two other participants, Mike and Katie, developed biological accounts of the changes that they experienced after their injury.

*... You've got a certain areas of the brain and you've got the back bit here, right at the back of your head, and that is your emotional side, and I've got a scar on my brain and (...) that's all I know is I've got no emotions (Katie)*

*... Something in your head that gets thinking them things, when you've had the fall it sort of moves round, and something (...), things that were important aren't and things that weren't are (Mike)*

Understandably Katie and Mike both experienced a physical trauma to their brain and as a result recognise that the brain may now be different to how it was previously. The changes they experienced were therefore directly attributed to the trauma. These accounts suggest that Mike and Katie perhaps felt that influencing these changes could be beyond their control.

Leanne described a different experience to Mike and Katie in that she at first attributed the changes she experienced to herself. A possible influencing factor in this is that Leanne suffered anoxia following an asthma attack. As a result she did not experience any direct trauma to her brain, but instead it was starved of oxygen. Leanne described only beginning to make sense of the changes after she was provided with a reason and given permission to accept the impact of the injury.

*Leanne            'Cause I didn't really think it was real. I thought it was just me being stupid and lazy I suppose. But its not*

Steph            When did you realise that?

Leanne         When [the rehab technician] said you need help

James' account of putting the puzzle together serves as a contradiction to the others. James described his struggle to put the pieces of the puzzle together due to a lack of information, a lack of memory and a lack of understanding about what happened to him.

*... One time somebody said that my mum said something and I got aggressive, but I can't remember any of that and it's like, well how aggressive did I get? or, but it's like nobody really explains, like they talk about my brain injury or how am I feeling now, but no one who went to see me says anything about the MRSA or how I was with the MRSA and that. So no I mean sometimes I think about it but I don't ask anybody really now (James)*

James felt unable to make sense of what happened to him, he wanted to be able to move on and tried not to worry about how he was at the beginning, but not having all the information and feeling like information was being kept from him played on his mind. James' description suggests that he felt that there was information out there that would help him to put the pieces of the puzzle together, but he felt unable to ask. As a result he was left worrying about his behaviour and unable to account for it.

The importance of being able to put the pieces of the puzzle together in a way that is meaningful for the individual was illustrated by these participants' accounts. Not being able to account for the changes can leave people feeling confused and uncertain, and although James described trying his best to move on, this obviously still played on his mind.

### **3.2 Observed Changes as a Threat to Identity**

Overview:

Whilst the previous theme related to the realisation of a loss of control and the process of making sense of that; this theme focuses on how the changes that the participants noticed have affected their sense of self. The changes that participants described all

related to feeling less able in some way. For some, the experience was of feeling more vulnerable, for others there was a sense of feeling untrustworthy or like a burden. These changes have prevented participants from returning to important roles in their lives, which understandably impacted their sense of identity. This theme captures the struggles that the participants experienced in relation to coming to terms with these changes.

### **3.2.1 Feeling Less Able**

The experience of suffering a brain injury appears to have left the participants feeling vulnerable in a world that seemed more dangerous and hostile.

*... But now even though I'm a weakling and that, not a weakling, but I'm scared of everything (Leanne)*

*... Mmm, I'm a little bit worried about, a little bit defensive all the time now. (...) 'Cause now I cannot see my left side, so crossing the street, banging in the people in the street if they are coming out of the shops. Sometimes I even take my just walking stick just to let the people know I have some problems (Jon)*

Leanne initially described herself as a weakling, but then corrected herself and explained that she felt scared of everything. This suggested to me that she recognised that she was not as weak as her mind told her, but still felt fearful of everything. Jon described feeling less able to defend himself due to his visual impairments, and had to place the responsibility of protection in the hands of others, using his stick as a way of communicating that he was less able.

Mike experienced feeling less able in terms of taking on responsibility. His loss of his ability to smell and taste left him feeling unable to rely on his senses, making the world feel more dangerous and less predictable than before. Mike described how, in addition to him not feeling able, his wife Jane also worried about him, which evoked a sense of not being trustworthy.

*... If I put a cooker on and the flame went out I wouldn't know, (...) and that would worry Jane. 'Cause if she went out and I was cooking something yeah, well you open the back door 'cause you went outside to have a cigarette and the breeze come and blew that out. For ten minutes that could be out and I wouldn't even realise, I'd still be stirring it. And then all of a sudden I might think oh it's a bit cold out there I'll light the cigarette out before I go outside bom! (Mike)*

For others, the sense of feeling less able was reflected in their statements about having to rely on others more.

*... But I mean I'm living here now back at Julie's house and it's like, it's enough burden her looking after me without me asking questions about certain things (James)*

*Steph Are there things that you are able to do on your own at the minute?*

*Brian Muck around with my cars a little bit*

*Steph Mmm hmm*

*Brian That's about all I am capable of doing*

James and Brian both described feeling that they have to rely on others more: James felt he had to be looked after by his girlfriend Julie and Brian felt that the only thing he was capable of doing on his own was 'muck around' with his cars.

Katie reported a different experience of feeling less able. She described feeling disabled but at the same time had to justify herself to everyone because no one else recognised her struggles.

*... I've actually sustained a brain damage and disability and it's like people I see in the street and they're like talking away and I'm like, I'm disabled I need to sit down I need to sit down, and they're like you're not disabled and I'm like yes I am, and that just changed my life (Katie)*

The term 'walking wounded' is often given to people with a brain injury who experience hidden disabilities. For Katie the experience of her brain injury not being recognised was a negative one. She found having to explain the impact of her injury frustrating as if she had to justify her actions and felt judged by others who did not believe her.

The subtheme of feeling less able was experienced by all of the participants interviewed, the following subtheme involves the participants' accounts of struggling with the changes they experienced.

### **3.2.2 Struggling With a Changed Self**

All six of the participants described struggling with the changes they experienced. For some, the struggles related to their physical changes:

*... The hardest thing is getting tired, I spend half my time tired (Katie)*

For others, the struggle related to worrying about how their changed self was perceived by loved ones:

*... But there's things that's not the same, (...) I get impression now (sighs), (4) (sighs) things I go on about. 'He keeps repeating himself going over and over and over'. And I'm not aware I do it, I do do it sometimes but I must do it more than I think (Mike)*

*... I'm not the same person like before. I am always stressed and I am always arguing but for small things and all this, get frustrated because there were things I could do it but now I can not do it (Jon)*

Mike and Jon have both experienced themselves as changed but did not feel in control of, or even aware of these changes at times. Their struggle related to the impact that these changes had on their relationships with significant others.

Other participants described their struggle to accept their changed roles:

- Steph [your daughter's] very protective?*
- Leanne Extremely protective*
- Steph And is that different to how it was before?*
- Leanne Yeah, I didn't need protecting*
- Steph Do you feel that you need protecting?*
- Leanne Yeah, 'cause it got to the point where I can't go downstairs to the shop on my own. And I don't know what it is.*
- Steph Because of the panic?*
- Leanne Yeah, it's horrible.*
- Steph Is it related to the physical changes you've experienced or is it an emotional...?*
- Leanne It's all in my head*

*... And because of my job, because I'm a lorry driver, I was a lorry driver (James)*

Leanne experienced an almost complete role-reversal with her teenage daughter who she relied on for protection. Leanne recognised that her fear was all in her head, but this did not make it any less horrible for her, perhaps it worsened the struggle that she had with it. James' struggles related to the lost role he experienced since his injury. The brain tumour that James had to have removed from his brain resulted in the loss of his peripheral vision and therefore the loss of his driving license. In focusing on the tenses that James uses in this extract (I am a lorry driver, I was a lorry driver) and the fact he had to correct himself, a possible interpretation is that his struggle involved feeling unable to let go of the lost role. This is also reflected in Brian's account who described how he will be disabled, as if he was not quite ready to accept this yet:

*... Simple thing like I'm having to use a disabled mobility scooter to get around on, 'cause I'm going to be disabled (Brian)*



### 3.2.3 Feeling Unable to Return to a Previous Identity

The final subtheme that makes up this master theme relates to the participants' descriptions of feeling unable to return to their previous identity. Having described the losses they had experienced and the struggles they faced in coming to terms with them, this subtheme focuses on the meaning that participants gave to the losses how this affected their sense of self:

*... I would like to be back working, doing what I was doing, but I don't know if I would be able to manage it because I would get too tired (...) I might actually phone them this afternoon to see if I can go back to work (Katie)*

*... I tell you, I do, strange as it sounds, I'd love to be able to get up early in the morning, cup of tea get ready boom, in my van go to work, come back just be able to do that (...) it's frustrating. But it's, you know, one of them things innit? (Mike)*

Katie and Mike both described a desire to be able to get back to work. Mike felt frustrated by this loss but accepted it as unchangeable; Katie on the other hand described worrying that she may be unable to manage, but still concluded that she might give it a try. These differing perspectives of the same situation influenced how Mike and Katie saw themselves and their potential to return to their previous roles. The other participants described struggling with the personal impact of having to depend on others:

*... All these persons around me they are important because since I don't have my independence again I am depending on everybody on helping me back again. So I lost the most important thing, what I came from, to this country was to create my independence of my family and to get independence but now I lost it again and so I am depending on my friends. And all the people that can help me, from the ABI team, to the doctors I am depending on all these people (Jon)*

*... Julie does look after me and that and I think she's looked after me well, but it doesn't seem like we've got an adult relationship anymore (James)*

*Steph What else is different for your life at the minute?*

*Brian Not being able to pick my daughter up, take her to school or take her and her friends to school and, there's all sorts of silly stuff. Shopping is a pain in the arse, I have to make do and go myself and waiting till me dad not on holiday he can take me*

Jon, James and Brian described struggling with the changes to their lives which meant that they had to rely on others. They reported feeling dependent on these people but paradoxically, whilst they needed this support, it was also what made them most aware that they were unable to return to their previous identity. Brian, for example, described how he had to rely on his father to take him to the shops and how he was unable to fulfil some of the duties that he used to do for his daughter. In some sense Brian had become a child again, through the loss of his role as father and through his renewed dependence on his own dad. James also described the loss of his adult role; through his changed relationship with his partner.

In summary, this master theme captures the experience of struggling with the changes and losses brought about by the injury and how these had been experienced as a threat to each individuals' sense of identity.

### ***3.3 Being Displaced By the Injury: Feeling Unchanged In a Changed World***

Overview:

In addition to the participants' descriptions of a changed self they also paradoxically felt unchanged in a world that was treating them differently. Whilst the previous master theme addressed how the participants experienced and struggled with changes they noticed; this theme focuses on how, as a result of the brain injury, others started treating them differently. It explores how the participants experienced other people's judgements and what impact this had on them. All participants described feeling that they had been *prevented* from returning to important roles within their previous lives, including their

work and parenting roles. This has had a significant impact on their sense of self and how they felt they were viewed by the wider systems.

### **3.3.1 Being Displaced From a Previous Identity**

The two female participants who were both mothers talked about their experiences of being prevented from returning to their roles as mum:

*... I discharged myself from hospital because they were going to take Sarah away. Zoe came to me and said, they're going to take Sarah away if you don't, if you don't come home. So I told a nurse and the nurse told the social services, and they took Sarah away anyway. I was angry. Then, 'cause Zoe's only 15 then, she went before they took her. (...) But she was 15 then, so basically she had an older mind and she said no, I'm going to stay with my mum, you can't take me away. (...) Then since then, we've been glued at the hip. They're not gonna, they took one baby they aren't going to take another one (Leanne)*

*... But I can't understand, all those people that have had brain damage and everything, and they're mothers, they always get their children back, when they've come out of hospital rehabilitation. (...) Why have I lost my children? (Katie)*

Both women experienced the system as judging them as unfit to be mothers and as a result had prevented their children returning to them. Their accounts suggest confusion about how the system came to this conclusion which has clearly caused them distress.

Other descriptions of feeling displaced include being prevented from returning to other valued roles such as work:

*Steph What's the first thing you do remember?*

*Brian Not being able to drive, not being able to go to work ,really gets to me (... ) it's my livelihood, I've done it since I've left school (... ) I've been a mechanic, I've done mechanics all the time I've serviced buses,*

*coaches, lorries. I keep them all on the road, but now I can't even touch them*

Brian was asked about the first thing that he remembered; this was in the context of a conversation about his recollections of the early days of the injury. For Brian his first memory was the loss of his work role. He described being prevented from (not being able to) returning to work and not being able to touch the vehicles that he used to service. The importance of work for Brian goes beyond his income. It was also all he had ever known (he'd done it since he left school) and how he added value to society (servicing vehicles, keeping them on the road).

James and Jon both described a sense of displacement, not just from immediate systems like family and work but also from society itself:

*... I don't think I feel part of anything anymore. I don't feel like I'm part of a family I'm just here. I know I'm not a member of the working public anymore because I don't do anything, you just get fed up with them things it's just like being nothing, it's like existing that's all I'm doing. Existing at the moment, where I'd love to do more (James)*

*... 'Cause they keep saying to me. I didn't have the right to reside in this country. But I was always I didn't understand that, I was always fighting back, with the forms. How I didn't have the right to reside in the UK, if I was here for five years, I was working, taking my tax like a normal person, a citizen, so I treated like a normal person so normally (Jon)*

These experiences illustrate how important a sense of belonging is and how, after the brain injury, all the participants experienced judgement from the wider system that prevented them from returning to valued roles in their lives.

### 3.3.2 Feeling Unchanged in a Changed World

In addition to the sense of displacement, participants also described feeling unchanged. Whilst in the previous master theme they acknowledged changes, in this subtheme they provide accounts of feeling the same. Often their descriptions are in the context of being treated quite differently to how they would have expected prior to the injury.

*... Big mistake, you don't tell me what I can and can't do. I mean I've got a mind and I can use it. I might have brain damage and everything, but at the end of the day you've still got a mind at the back of your head and I can still decide what I'm going to do (Katie)*

*... [The health professional] said, (...) I think the chances of you returning to work, (...) I'd give you an eight to ten percent chance no more than that. (...) I thought no disrespect but he can't be right with that (Mike)*

Katie and Mike both acknowledged that their injury has had an impact but both described a struggle to see why people were seeing or treating them so differently. Katie experienced being told what to do, when she felt quite capable of making her own decisions. Mike experienced being told not to trust his own judgement in relation to his hopes for recovery. In fact, further on in the interview Mike explained how he later came to a realisation that the predictions this man made might be right. However, his experience at the time was that he could not accept this man's predictions about him being permanently changed.

Jon reported feeling like the same person inside:

*Steph Are there any parts of you that are the same?*

*Jon (8 )That's a good question actually (3) parts of me that are the same (6) no I think (2) I am still the same person inside (Jon)*

My interpretation of this extract focused initially on the degree of time that Jon gave this question. Jon was asked if there were parts of him that were the same; after

consideration his answer went one step further to conclude that he was the same person. Jon had experienced changes, which have been described in previous themes, and yet he felt like the same person. The time that Jon took (seconds indicated in brackets) to reach this decision suggests to me that he was uncertain whether or not he was the same. Jon's conclusion that he was the same 'inside' suggests that he may not have felt the same on the outside. An interpretation of this statement is that the differences Jon was aware of were more about how he was being perceived (and therefore treated).

Brian's account of feeling unchanged in a changed world reflects his aforementioned struggle to see changes in himself. Brian described finding things harder, but attributed this to changes outside of him, although he did acknowledge this change was connected to the brain injury:

*Steph*            *Why do you think it's harder?*

*Brian*            *Because it's a lot more complicated (...)*

*Steph*            *Why do you think they, how do you think they ended up to being more complicated?*

*Brian*            *Probably down to the head injury*

*Steph*            *OK tell me a bit more about that, what happens for you, when you're trying to look at it, that makes it feel more complicated?*

*Brian*            *Dunno just there's so much more involved, the speedo the motors the aerial everything it's just ongoing*

All of these descriptions suggested to me that the participants were experiencing people and things in their lives as different since the injury. It was as if the brain injury had changed everything around them, leaving them feeling surprised or confused and relatively unchanged themselves.

### 3.3.3 Judged

This final subtheme relates to the personal meaning taken from the experiences of being perceived as different. All participants described a negative experience of feeling judged after the injury.

James and Mike's experiences relate to feeling judged and rejected by people they know:

*... It does 'cause sometimes if you get people round, no disrespect, they'll talk and I sometimes think, they're talking round me, I feel like I'm eight years old (Mike)*

*... Well I feel lonely sometimes because, don't know why but some of my friends they don't come round any more, and [I] just sometimes just feel lonely (James)*

Mike felt as if he was being talked to like a child, whereas James felt confused by the perceived abandonment of his friends, resulting in him feeling lonely.

For others, the experience of judgement came from society:

*... It's like a lot of people think maybe those that got brain damage and whatever, they're stupid, they're spastics, they're crippled, disabled (Katie)*

*... It is horrible (4) you read about these losers on benefits. And I have to justify to myself there's a reason why that's why I'm on that, but its horrible (Leanne)*

*... But sometimes I don't like to take it [my stick] because it makes me feel inferior, a little bit down from the rest of the people, and I don't like to, I just want to be treated exactly the same as everybody else (Jon)*

Brian described a society that had lost respect for him. He felt he had been respected, and perhaps even feared, but since his injury, he felt this had changed.

*... I've been a doorman since I was sixteen; I took the qualifications, police qualifications, all the qualifications what I needed, I done them all. And they were throwing snowballs, and they go oh fuck off you fat cunt (...) fair play I am bigger, but they got no right to call me fat and (...) yell and everything else. I wanted to get hold of them and smack em one (Brian)*

All the participants' descriptions denote an experience of being judged because of the brain injury and its subsequent impact. The participants indicated this as being disrespectful, isolating and distressing. The experience of feeling judged left participants feeling that, since the brain injury, they no longer feel welcome or valuable in the context of their society.

### **3.4 Attempts at Managing a Threatened Identity**

Overview:

This theme aims to capture how participants responded to the changes they experienced in their lives. A factor that mediated their response to these changes was how they made sense of the loss of control they experienced (as described in the earlier themes). Participants described differing ways of managing these changes, ranging from passively accepting the shift in power between the brain and the mind, to deciding to fight their brain for the lost control. Between these two extremes were attempts to come to terms with the losses and changes that had been experienced, which involved finding ways to maintain previously valued role and drawing strength through the process of finding a purpose.

#### **3.4.1 Accepting the Unchangeable**

This subtheme relates to the acceptance that certain losses or impairments are unchangeable. Participants' descriptions suggested they took this approach as a means of letting go of aspects of their past lives, in order to be able to move on.



*... 'Cause I like it as I am, I like not to be bothered. (...) I don't want to go into town and order something, why would I want do to that. And I don't (...) want any more friends. I'm happy (...). Change it and you're dead. I don't want it to change. That's all I want (...). And if they said to me you have a choice, live your life as it is now, or go back to how it was. I want here 'cause I know this now (...) I know that (...) nothing's going to cure my memory yeah some things are going to come, I'm going to be able to go down town on my own and, but that's not now and I can't think that ahead (Leanne)*

*... There's a lot of things that aren't right I know that. I've now got to the stage where I personally, I finally think, pleased with what's happened, I'm walking around I'm getting a bit better, I know who my grandson is now, getting a bit better a bit better. But I know in my opinion I'll never be the same as I was (Mike)*

In Leanne's account she clearly stated that not only had she accepted her current situation, but she preferred it to her previous life. Leanne explained that she felt happy with the way things were, because they were that way. Leanne accepted her life as unchangeable, because change felt difficult ('change it and you're dead') and frightening ('I want here 'cause I know this now'). This point of view allowed Leanne to accept the changes and losses she experienced since the injury ('nothing's going to cure my memory'), but left her feeling nervous about change in the future ('I can't think that ahead'). Mike described feeling pleased with the improvements he had made but had reached a conclusion that he would never be the same person as he was before. Perhaps as a way of managing this, he pre-empted this acknowledgment with a statement of all the abilities he had recovered.

An example of a contradiction to the experience of accepting the changes as unchangeable came from Brian who, as previously mentioned, did not accept that he was any different. As a result he experienced a dilemma, one in which he was unable to look forward, because he kept looking back.

*... [!] keep looking back on I'm a mechanic I can do it! leave me alone, fuck off.  
I'm good if I'm left alone (Brian)*

Brian refused to accept the judgements placed on him as being less able and, as a result, was in a standoff between his position and the position of the system preventing him from returning to his previous identity. This will be explored in more detail in the final master theme (Enable me don't disable me: The role of support in recovery).

### **3.4.2 Getting Back to Living**

Other attempts employed by the participants to manage their threatened identity involved refocusing their attention on living their lives again. This involved turning their attention away from the brain injury and focusing on making valuable contributions once again.

*... You have to keep more active if you can, more active, so don't stop and start thinking about you cannot do this, you cannot do that, you cannot have this your life back. You just have to try to do it (Jon)*

*... Well I got to the stage where I think, I'm pleased with that pleased with this, pleased with this, hopefully I can do that, but we'll just see how it goes (...). Otherwise what am I gonna do, sit here looking out there thinking I used to do that, I used to do that, getting depressed and low and I don't want to get like that (Mike)*

Mike and Jon both described adopting a position which would not allow them to dwell on their losses. In this approach they both accepted their losses, but took the view that they could either dwell on them, or could find a way to focus on the positives and still have hope for the future. Mike and Jon described how, from this position, they felt they could turn their attention away from the injury, back to their lives. Katie described a similar intention but approached it slightly differently. She kept her focus on the goal that she was trying to achieve, and rather than worrying about the journey (which might take her longer or be more difficult), she only focused on whether she could achieve it or not:

*Katie It's like when I've got the determination in the back of my head to think yeah I'm going to walk to (town) I will do it. As long as I've got my trainers on and as long as I've got a bottle of water with me*

*Steph Mmm, you'll do it*

*Katie Mmm. And it's knackered sometimes but as long as there's benches or walls or something that I can just sit down occasionally, I can do it*

Brian described a similar experience, placing emphasis on being left alone to get back to living.

*Brian Yeah , I've been a lot better since I've been in my own house (...)*

*Steph What, what made the difference? What kind of things were you better at, now that you've got your own house?*

*Brian The getting the decorating done and doing all sorts of bits and pieces is a lot better for me*

These descriptions suggest that it is of great importance to participants to become an active member of society again, feeling able to contribute. This is emphasised by James who did not feel that he had been able to get back to living but who longed to be able to.

*... I want a goal out of life I don't just want to be stuck in and doing nothing. I just want to get on with my life, you know I want to do things I mean I don't want to be indoors watching tele, vegetable for the rest of my life, I'd like to get up and be able to do something. Yeah I really would (James)*

James' statement indicates how important it was for him to have a goal and to be getting on with life. Like Leanne he described himself as feeling like a vegetable, doing nothing. All the participants' accounts emphasised the importance of having independence and in taking an active approach to life.

### 3.4.3 Finding Strength from Having Purpose

The last subtheme to make up this master theme is the participants' attempts to find strength from having purpose. Participants drew significance from their experiences, which they used to help them manage the threats to their sense of self:

*... Whatever it is to do for me to feel better and to get better I do it. I trust the doctors in that hospital (...). They saved my life. This was not just a goal for me for survival it was a goal for them to keep me alive. Because the chances were not so many (...). They have achieved something and now in the future they are going to be ready if in for different situations, or worse or the same or similar than mine (Jon)*

*... I was speaking to my nan the other day. And she said the only reason you're doing all this is because of your granddad. (...) My granddad passed away in 2004, the only reason I'm doing so well is cause of my granddad (Katie)*

Jon described how his recovery made valuable contributions to the evidence-base and how the doctors who saved his life had learnt from it, and so may be able to help others in the future. Jon incorporated the doctors' achievement into his narrative making him feel part of something bigger again. Katie described how she felt she was doing well because of her grandfather, something which perhaps gave her strength and enabled her to keep fighting.

*... Why that helps me to cope I suppose is because I didn't die and there was so much wrong with me that I should have died, so maybe there is some hope for me out there, to get better and because I am alive still and that and to get on with my life (James)*

James looked for meaning from his survival, concluding that because he lived, he should have hope; this appeared to give him strength.

Mike and Leanne described positive changes in their lives after the injury:

*... But now, if I was sitting outside on the doorstep and I see people I know, I've known getting off the bus "alright Mike" "yep yep". Sit there, but if I see someone getting off with a walking stick, stroke, then I'll go over there and give them a hand (Mike)*

*Leanne But we're happy. But we're happier than ever*

*Steph Happier than even before the injury?*

*Leanne Yeah, we're closer*

Mike described how he felt changed since his injury and although he did not explicitly say that this was a change for the better, it seemed from his description that he was acknowledging that the brain injury had made him more considerate of others. Leanne described an improvement in her relationship with her daughter who she felt closer to and happier with since the injury.

The significance that the participants drew from their experiences varied between drawing strength from feeling that their experience might help others, finding reasons to stay strong and have hope, and in growing or improving in some way from the experience of the brain injury. Participants found these experiences as a helpful means of managing the threats to their identity, allowing them to feel part of something bigger again.

### ***3.5 Enable Me Don't Disable Me: The Role of Support in Recovery***

Overview:

This final theme relates to the process of accepting and receiving help and support from friends, loved ones and health professionals. Participants described facing a dilemma when it came to asking for or accepting support. Accepting help meant participants had to be ready to accept the fact they might need help, and then be ready to accept the implications of what it might mean to accept help. Participants described the danger of being patronised by those offering support; and explained that whilst their changes can

make them feel like a child, they did not appreciate being treated like one. Participants described differing experiences of receiving the help that was offered. This included seeing help as a means to get back to their previously valued roles, or as a way to maintain the 'child' role that they felt they had been placed in. In addition participants emphasised the value of being able to socialise with people who had been through similar experiences, allowing them to feel accepted and validated by people who understood their situation.

### 3.5.1 The Dilemma of Needing to Accept Help

This first subtheme focuses on the dilemma that the participants faced in deciding whether to accept help or not. They explained how accepting help meant that it was necessary for them to admit to the need for it. This resulted in having to face up to the losses and to be prepared to take the steps necessary to address them. Leanne described not feeling ready for this and fearful of inviting more change into her life:

*Leanne At the moment I'm extremely down*  
*Steph Do you think that's related to life and the brain injury?*  
*Leanne Yeah*  
*Steph And yet you say that you wouldn't want anything different?*  
*Leanne 'Cause I don't like change. Probably I would, 'course I would.*  
*'Course I would.*

Jon described making a compromise in order to overcome his dilemma of needing to accept help:

*... But then some different situation I'm going to need help from the doctors and from these persons they help me. Whatever I can, whatever you can do it by yourself, you should try it fight it by yourself, but like I say its all different situations come day-by-day it comes (Jon)*

Jon accepted that he might need help at times but resolved to try on his own first. This approach allowed him to maintain his independence and to be active in the decision of when to request, or accept, help offered.

Katie and Mike described their emotional reactions to receiving help as initially being one of frustration and feeling judged and criticised, although both recognised that there may be a real need to accept help:

*... When (...) your wife or someone you really trust (...) tells you, and you think, well they don't think they can do it, it gets you down, you think well why are they knocking me all the while, but they're being honest and truthful (Mike)*

*... I just hated doing some of the things, (...) there was all these different lessons that you had to do a day. Why are they trying to get people to learn all the, to learn all that again. But in a way I can see why they are making people to learn how to do it again, because I mean if they had lost the capacity to do that through their injury (Katie)*

Brian's account serves as a contradiction to this subtheme in that he did not see a need for help:

*... I'm really disabled. Yeah bollocks! (Brian)*

Although Brian wanted his life to be different, he experienced a dilemma because he felt he was in a stand-off between himself and the systems that were preventing him from returning to his life.

*Steph Do you think if you were able to get behind the wheel of a car you'd be adjusted?*

*Brian Yeah*

*Steph Ok so that's the only thing that's getting in the way*

*Brian Yeah*

*Steph And... but it sounds like that's not going to be happening for a while is that right?*

*Brian Yeah*

*Steph So what will you do in the meantime to adjust? Will you be able to adjust?*

*Brian Er I dunno*

*Steph So you're kind of stuck?*

*Brian Yeah*

Brian's extract demonstrates how his decision to not accept a need for help has left him feeling stuck. This theme demonstrates how the decision of whether to accept the need for help carries implications. Not accepting the need for help can preserve a sense of self-identity, but can also lead to strained relations and a stand-off between an individual and their surrounding systems. Accepting the need for help threatens a sense of identity and invites change into life. Either way; for the participants, this decision was an important one and suggests that it should not be taken lightly.

### **3.5.2 Enable Me Don't Disable Me: Active Vs Passive Reception of Help**

All participants experienced support that helped or hindered the process of adjustment. Participants described positive experiences of support which enabled them to be more independent:

*... Try to do it, that's why now me and some guys in Headway last week, (...) they ask us, what do you want more from Headway? We were discussing this and we want to take more initiative for some projects (...), be able to set a target for us like a project we want to do this, I have to fight it I have to be normal (Jon)*

*... The support worker's here, lovely, good bloke, but if the support worker wasn't here, the chances of me getting up on a sunny day and doing it are nil. It's hard*



*to say, 'cause, I can say this wants doing that wants doing, I love doing it (...) but if I was on my own I just don't do it (Mike)*

These experiences of receiving support allowed Mike and Jon to be more independent. Both recognised that the support was necessary but saw it as a stepping stone. Other participants describe the experience of support which has led to them feeling disempowered and de-motivated:

*Steph Is there anything that you think would be good for me to know to help me understand what it's like to adjust to life after injury?*

*Leanne Don't badger people. (...) Like saying you can you do it when you know that they'd struggle. And you force them to do that (...) and then you take two steps back. It's encouragement. There's so many ways people encourage. Some people can be really harsh (...). Like me, be harsh and I just won't do it.*

*... Well, you're an adult, (...) If they want to see whether you did know how to do it, ask you whether you'd know how to do certain things, (...) you could explain to them how you, you think it should be done (Katie)*

Katie and Leanne both experienced feeling disempowered by the help that was being offered to them. Leanne felt she had been pushed beyond her potential and explained how she preferred to be encouraged rather than pressurised into her recovery. Katie highlighted the delicate balance that professionals face in working with people who have impairments. Whilst earlier she accepted that she felt like a newborn baby, she did not appreciate being treated like one. In suggesting that professionals could ask the individual what they are capable of, she implied that she would have preferred to have a more active role in her rehabilitation, to have felt listened to more and to have been trusted more.

James discussed what he thought would help him to have felt more enabled:

*... I think if the person who's got the injury has got a bit more freedom, to do things I think if my friends had been more around, it would help (...) and having something to do every day, would be a hell of a lot better, (...) to make sure you know you get back in the community and to feel you know you're not just stuck in would help more (James)*

James' account highlights the importance of having more freedom, support and independence. Whilst James seemed to know what he needed he did not yet feel that he had it, suggesting that he was waiting for something or someone to enable him to get there.

Katie described the potential risk of help being offered in a way that could keep them in their child roles:

*... Its just like other people out there who've had brain damage, (...) they'll think well why should I get out of bed and do that when so and so could run around doing that for me. I'm just going to be lazy just let them do it for me. The thing is though after a while it gets so boring just laying in bed; I mean do you want someone round running after ya being mummy (...) or do you want to prove you can do something and prove your independence (Katie)*

Katie's account demonstrates how important it is for clinicians and carers to be mindful of how the help offered is presented. She described feeling that helpers could be 'mummy' suggesting that she would therefore be the child, being looked after. From this perspective the help offered could be experienced as disabling as it prevents people from growing back into their adult selves.

Brian described what I found to be a surprising experience of receiving help. Based on his descriptions in earlier themes about not experiencing himself as changed and not recognising a need to change, he spoke highly of the ABI team, who came in regularly to help him.

*Brian*            *They are really really good and I wish they are around with every head injury person*

*Steph*            *Mmm mmm so you really value that support?*

*Brian*            *Yeah*

*Steph*            *Do you think you need that support?*

*Brian*            *(sighs) Not that you need it but it's good for you*

*Steph*            *Mmm mmm*

*Brian*            *You know or I don't know what I'm doing, oh fuck, but so and so will come up, blah blah blah yeah! Oh yeah just naturally go back to how you were*

What struck me in this extract was that in talking about the support he received from the ABI team Brian was able to admit that, on occasion, he didn't know what he was doing. Perhaps it was because he felt that the team helped him to get back to 'it' (just naturally), rather than them having to come in to do things for him, that Brian felt able to admit to his struggles.

Brian's account, along with the others, provide an interesting insight into how support can be offered and received as enabling or disabling to the individual. The potential clinical implications of this theme and the others will be discussed in more detail in the Discussion chapter (section 4.2).

### **3.5.3 'In The Same Boat': The Need for Acceptance and Validation**

Four of the six participants talked about their experiences of being with people who have also experienced a brain injury. Of the two who did not mention this experience, one attended a day resource centre for people with brain injury and the other had once been part of a group but was not any more.

Leanne's account emphasises how she has replaced her old networks with her new friends from Headway:

*... I've got a social network now, that's them lot [friends from Headway] I know they won't treat you bad , they don't steal off you, they tell you the truth. And that's that (Leanne)*

Leanne's account suggested that she viewed people outside of this group as untrustworthy and dangerous. This may relate to how she saw herself (as vulnerable) and the world (as dangerous) since the injury:

Mike, Jon and Brian talked about the positive experience of being with people who can understand what you are going through.

*... Yeah it's fantastic you know (...) if I say something I don't feel like I'm the odd one out because they genuinely know what I'm on about because they're all in the same boat (Mike)*

*Steph            So it was weird to not be around other people with head injuries?*

*Brian            Yeah*

*Steph            Can you tell me why it was weird?*

*Brian            Because I was in, it was like a group of us*

*Steph            Yeah*

*Brian            And we understood what everyone had been through*

*... You realise after your accident there is still life after the accident, it's not finished (...). It's still people are in the same situation same boat, or different boat or different situation, but we are all in the same like group. So, but you are still alive you have to live you have to fight it back to get your life back (Jon)*

The experiences were all positive and a common thread between them involved the value of being with people who could be trusted and who understand what the participants were going through, helping them to validate their experience.

This master theme demonstrates how participants experienced support from friends, family and professionals and how different support systems fulfilled different needs in their process of adjusting. The participants described the dilemmas they faced with regards to accepting the need for help and how important it is to be mindful of how help is offered (enabling independence versus highlighting impairments and emphasising losses).

Having summarised the master themes, the following chapter forms the interrogative aspect of IPA research (Smith, 2004) where the findings will be considered in relation to the existing evidence-base.

## 4 Discussion

In this chapter I will draw together the findings from this investigation and consider them within the context of the evidence-base and in relation to the research question: How do people experience the process of adjustment to a brain injury? This chapter will begin with a summary of the main findings for the research. Each of the master themes will then be considered in relation to the existing evidence-base, and where necessary will introduce new literature for themes that were unexpected. Having considered all the master themes I will then reflect on the potential clinical implications of the findings, before considering methodological issues that have arisen from this project. This chapter ends with suggestions for future research and my reflections on the research process.

The primary aim of this research was to investigate people's experiences of the process of adjusting to life after brain injury. Areas of interest for exploration were:

- Changes to life after the injury
- Changes over time since the injury
- Systemic factors which influence how individuals make sense of their injury
- Systemic factors that help and hinder adjustment

### 4.1 *Summary of Findings*

Participants were able to provide a rich account of their experiences of adjusting to life after their brain injury. These accounts incorporate changes on an inter- and intrapersonal level. Participants described having to form a new relationship with their body and brain, both of which felt different and like strangers to them. They then had to come to terms with other changes and losses they encountered within their immediate systems such as work, friends, and family. In addition, participants explained how the

brain injury meant they felt judged and no longer valued by society. They felt displaced by their injury and this prevented them from returning to important aspects of their lives such as work and parenthood. These changes left participants feeling threatened in terms of their identity and as a result they had to develop strategies to manage this threat. The approach that they took appeared to be related to how they made sense of the threats (e.g. as unchangeable, temporary or irrelevant). Finally, participants described the role of support and how this could be helpful and unhelpful for them. Participants described wanting to be enabled to return to independence rather than kept in a disabled role by having to passively accept support offered. The role of social support from others who were 'in the same boat' was also important as it allowed participants to feel accepted and valued again.

In the following section I will consider the master themes in relation to the evidence-base.

#### **4.1.1 Experiencing a Loss of Control**

Participants' account of experiencing a loss of control of their physical selves was an unexpected finding in this research. As a result I will be introducing new literature into the discussion section; this approach has been supported in qualitative research (Smith, Flowers, & Larkin, 2009).

Participants described having a changed relationship with their body and brain, which resulted in them experiencing it as almost separate to them and unfamiliar. This experience has been described by van Manen (1998) who outlined several ways to relate to our body in illness and health. The modality which appears to relate to this account is of 'the encumbered body'. This usually follows from illness where our body can be experienced as rebellious or unreliable. This forces our 'self-forgetful' state, (where we take our body for granted), to be replaced with a conscious more objective view of it. This seems to fit with the participants' accounts of not feeling in control, forcing them to externalise the control onto their 'rebellious' brain. The experience for participants, of having a changed relationship to their body and brain seems to be central

to understanding how they experience the process of adjusting to life after the injury. Van Manen (1998) also emphasises the importance for individuals to form explanations in order to integrate their changed self. The participants in this research used several methods to explain and integrate these changes. These ranged from medical to personal/philosophical attempts. The medical explanations, which took a more reductionist approach in explaining how the brain was responsible for everything, appeared to leave participants feeling hopeless for their potential to bring about change. It could be argued that providing reductionist explanations could further increase the participants' sense of separation and de-synchronisation from their brain and body as it does not provide a way for them to work towards integrating or influencing these changes. The experiences described within this master theme relate to Bronfenbrenner's (2004) most immediate Microsystem, that of the biological being.

#### **4.1.2 Observed Changes as a Threat to Identity**

In this master theme participants described how, as a result of feeling unable to return to important roles and responsibilities in their lives, they experienced a threatened identity. Other studies supported this research's findings that participants feel different following their injury (Chamberlain, 2006; Hill, 1999; Howes et al., 2005; O'callaghan et al., 2006). This experience has been equated to grieving for a pre-injury self and a comparison of these experiences to models of grief has been recommended (Chamberlain, 2006).

This research considered the master themes in relation to themes identified within the grief literature (Genevro, 2004); in particular to Rubin's (1999) Two Track Model of Bereavement which was mentioned in another brain injury paper (O'callaghan et al., 2006) and Gilles and Neimeyer's Model of Meaning Making in Bereavement (2006). In Rubin's (1999) model of bereavement, the process of grieving involves an individual learning to live their life following the death of a significant other and finding a way to internalise the deceased. Difficulties may arise when this process becomes stuck, e.g. when focusing on the deceased prevents the individual from getting back to living his/her life. This model resonates with the participants' accounts of struggling to accept the losses and changes that they had experienced, in particular with Brian, and so it is



possible that Brian might be seen to be having a 'complicated grief reaction' (Genevro, 2004) to the loss of his previous self. An argument against conceptualising Brian's experiences as grief however, is that it does not take into account any of the other ecological systemic influences which might be preventing him from returning to his life (such as the government preventing him from returning to driving).

The model of Meaning Reconstruction in Bereavement (Gilles & Neimeyer, 2006) suggests the importance of sense making, benefit finding and identity change following the death of a loved one. Within this account it is essential for individuals to strive to make sense of their experiences in order to process them. Aspects of this model could be applied to the participants' accounts (in particular the importance of sense making and identity change) and can explain why participants may have felt stuck. From a constructivist perspective (Kelly, 1955), being stuck could occur when an individual is unable to loosen their pre-injury constructions of themselves. In this situation they could be applying the same, now defunct, construct systems to their changed lifestyles. It could be argued however, that these processes do not necessarily support the theory that participants are grieving, as the role of meaning making is relevant to all life-events (Bruner, 1990). Furthermore, whilst it has been argued that using grief as a framework for patients could help them make sense of their experiences to life after brain injury (O'callaghan et al., 2006), this can also run the risk of implicitly suggesting that the pre-injury self is 'dead' and cannot be recovered. It also places all responsibility on the individual to adjust to this loss. Further argument against the use of a grief framework comes from the participants themselves. They described feeling fundamentally like the same person, but had experienced a lot of changes which were making it difficult to return to important roles and relationships. Participants' accounts suggested that they experienced the changes and losses as a threat to their identity but did not feel that they had lost their sense of self. This raises important questions about whether we are more than the sum of our collective roles and responsibilities. According to Bronfenbrenner (1979), a role reflects the individual's societal position and therefore encapsulates who a person is; a role therefore is grounded in the Microsystem but reflects a Macrosystemic position too. The fact that participants experienced a threat to their identity supports this

view. However their attempts to manage this threat, appears to mediate this, allowing them to maintain their sense of self.

In summary this research suggests that overall; participants acknowledged experiencing changes in themselves but fundamentally felt like the same person. This finding is supported by other research in the brain injury field (Shotton et al., 2007; Medved & Brockmeier, 2008).

### **4.1.3 Being Displaced By the Injury: Feeling Unchanged In a Changed World**

Whilst the previous theme addressed the changes participants experienced within their Microsystems, this theme reflects changes experienced at a Macrosystemic level. Bronfenbrenner's (1979) Macrosystem represents cultural beliefs, ideologies and societal structural influences such as government. In this theme participants described feeling displaced within these wider systems, they attribute this to beliefs held about them because of their 'disability'. This was another theme that was unexpected, but was one that was implied by Olney and Kim (2001). They suggest that disability is culturally and socially mediated, implying that it has an equal responsibility in defining disability. This position parallel's Bronfenbrenner's (1979) view that the relationship between an individual and their environment is bi-directional and that development occurs from an interaction between the two.

According to Lazarus' (1969) conceptualisation of psychological adjustment (see Section 1.2.1), a positive outcome can be gauged through an individual's contribution to society. This view is supported by the participants' descriptions of feeling judged and displaced. They described how the systems involved had passed judgement on them as being incapable of returning to valued roles such as work and parenthood, but who paradoxically rejected them for not continuing to be off value. Understandably this left participants feeling frustrated and confused. It could of course be argued that the participants' beliefs in their ability to return to their roles were not reflective of their actual abilities and were a result of poor insight into their impairments, which could be organic

or psychological in cause (O'callaghan et al., 2006). The participants' accounts suggest that they felt this decision was based on a biased judgement. Their uncertainty about the rationale for these decisions left them feeling stuck and looking backwards toward their old life. Other research has spoken about the importance testing out capabilities (Brown et al., 2006; Durette, 2002; Howes et al., 2005; O'callaghan et al., 2006) in real life settings and so it could be argued that these participants 'denial' is actually a function of being unable to test their abilities in order to gain insight.

Despite the judgements that participants described experiencing, they still thought of themselves as relatively the same. Participants' accounts suggested that, in addition to experiencing changes, society had also changed how it saw them. This raises the important question of whether participants were describing a form of discrimination on a societal level. Olney and Kim's (2001) paper implies that not enough emphasis is placed on incorporating how society's views of disability influences an individual's identity. Their suggestion is that individuals may need to reject societal expectations and create their own norms to live by. I would argue that this still places all responsibility on the individual to change and that a further step could be to address societal expectations and norms, challenging how individuals with brain injury are currently seen, written and spoken about. This approach has been written about more in the mental health field in the development of a Social Inclusion and Recovery Model (Repper & Perkins, 2003). Within this approach the medical model is critiqued as failing patients whose mental health conditions cannot be cured, meaning that their roles and responsibilities are indefinitely suspended. According to Repper and Perkins (2003), unlike physical health services, which have provided patients with rights and have given them the term 'disability', the mental health services are still shrouded in stigma. I would argue that within the brain injury field, patients fall somewhere between physical and mental health services, as individuals often have hidden or potentially misunderstood disabilities leaving them open to discrimination. Repper and Perkins (2003) suggest that the Recovery Model requires a change in thinking, leading to inclusion to roles, activities and facilities. This appears to be what the participants of this study were also requesting.

Whilst important steps have been taken to make the patient central and actively involved in their treatment planning following ABI (Bajo & Fleminger, 2002; Department of Health, 2005), participants' accounts highlight how they can feel judged and displaced from their lives. This suggests that more needs to be done at either a societal level or at an individual level in order to bring more congruity between how people who have suffered a brain injury understand their changed selves, and how others do.

#### **4.1.4 Attempts at Managing a Threatened Identity**

Whilst the previous two themes outlined the perceived causes of the threats to the participants' identity, this theme focused on their attempts to manage them. As mentioned previously, despite the threats experienced, participants reported feeling like the same person. They explained that they had achieved this by coming to terms with aspects that were unchangeable and by finding other ways to continue with valued roles and responsibilities. Considering these attempts in line with the dictionary definition of adjustment (adjustment involves altering something to achieve the desired result) (See Section 1.2.1), participants could be seen to have managed to keep the values that are important to them, but have simply changed how they achieve them. The participants' accounts appear to match other descriptions of the process of adjustment including Charmaz's (1995) who suggested that adjustment involves making sense of the impairment, assessing the changed identity, finding values and accepting the illness. Naguel's definition (1991), which emphasised the importance of a reordering of priorities, also appears to resonate with the findings.

Chamberlain's (2006) qualitative investigation into the experience of surviving traumatic brain injury revealed some themes that shared similarities with this research's findings, e.g. involving a self viewed differently and the loss of valued roles. It is possible, however, that the focus of Chamberlain's study (unmet need in community services) influenced her findings, as many of the themes related to feeling dissatisfied with the treatment they received, these themes were not replicated in this research.

Another interesting aspect of this research was that participants commented that they did not think that they were adjusted yet. This suggests that participants expected further changes to come. All participants were over 18 months post-injury, most were over two years post-injury. Given the fact that two years is cited as a time when an individual has reached a plateau in their neurological recovery (Brain Injury Association of Queensland, 2007), this suggests that psychological issues also have an important role in contributing to the process of adjustment.

A psychological model of change, developed for conceptualising assimilation of problematic experiences through psychological therapy, comes from Stiles (2002; Stiles, Elliott, Llewelyn, Firth-Cozens, & Margison, 1990). According to this model, individuals who encounter problematic experiences need to incorporate them into their schemas to move from warded off painful experiences to understood and mastered ones. Within this model individuals move from active avoidance to vague awareness; then once the problem has been defined, the individual can develop insight, work it through and problem solve until the distressing experience can be integrated into their schemas. This process has parallels with the differing attempts that participants described. It is possible that participants were at different stages in this process, and some certainly talk about coming to terms with the changes over time. Other research has identified similar themes relating to a recovering sense of self and suggest the importance of developing this construction in relation to society and culture (Nochi, 2000; Wright & Kirby, 1999).

#### **4.1.5 Enable Me Don't Disable Me: The Role of Support in Recovery**

Within this theme participants describe the role of support in helping them to re-connect with meaningful roles, uncover ways to fulfil valued roles and to be enabled to get back to life. As previously described, participants experienced some support as unhelpful as it left them feeling patronised and feeling as if they were being treated like a child. This kind of support was perceived as not helping participants back to valued and fulfilling roles. Instead it highlighted the losses and impairments they had suffered. This approach could be argued as being reductionist in that it emphasises what the individual

cannot do, as opposed to what they can. The support that the participants found helpful was that which allowed them to be active in their decision making. Participants valued being able to take initiative, identifying their needs and working towards them. This approach is supported in the government's National Service Framework (Department of Health, 2005) which emphasises the importance of patient-centred service where the individual is actively involved in planning their care. Being active in the decision to accept or receive help could be seen as supporting Lazarus and Folkman's (1984) Theory of Stress and Coping which was adapted for a brain injury population (Kendall & Terry, 1996). Within this model, participants who have appraised a situation to be stressful, but manageable, engage in actively seeking out or applying skills to cope. Situations thought not to be manageable result in emotion-focused coping strategies such as avoidance, wishful thinking and suppression. This model however, places a significant emphasis on the individual and does not account for the appraisal of external systems. As an example we consider Brian, who appraised his return to work as manageable but could not utilise problem-focused coping skills because his Macrosystem had appraised him as not able. He therefore was only able to use strategies such as wishful thinking to manage this.

As participants talked about the importance of feeling enabled, a brief review of the literature on enablement in brain injury was conducted. Enablement is often equated with a return to work and community roles. Some papers noted a shift towards a more positive position, focusing on integrating participants back into their previous environments (Wehman, Targett, West, & Kregel, 2005). However they also noted the considerable variability in return to work statistics (Kowalske, Plenger, Lusby, Lusby, & Hayden, 2000). Despite the positive changes, the emphasis of investigations still focus on factors outside of the individual's control such as severity of injury, impairments, lack of insight etc (Kowalske et al., 2000). Integrating the views of the individual on what they think could help would be a useful contribution and would model the ethos of enablement.

Another aspect of this master theme was the participants' accounts of the value of being with people 'in the same boat'. This allowed them to feel equal to others and respected.

The importance of having peer support has been investigated by Hibbard et al. (2002) who demonstrated a positive impact on factors such as, sense of empowerment and quality of life. Within this research, some participants' accounts suggested that having a social network with people who have suffered an ABI allowed them to make sense of their experiences, but also paradoxically to forget them and to feel 'normal' again.

This final master theme highlights the importance of participants feeling active, valued and accepted in their own lives. Being with people 'in the same boat' allowed some participants a chance to feel 'normal' in the face of a society who no longer saw them this way. The potential clinical implications of this, and other the other master themes will be outlined in the following section.

## **4.2 Clinical Implications**

The participants' accounts highlighted several possible areas for clinical development within the brain injury field. Across each master theme I felt aware of areas for development that services and participants might benefit from, which would allow them to address some of the struggles participants faced. In line with the overall theoretical framework of this research the clinical implications will be framed with the Ecological Systems theory (Bronfenbrenner, 1979; 2004).

At a Microsystemic level participants described struggling to come to terms with the changes they experienced. At a physical level participants experienced an externalised and 'encumbered self' (van Manen, 1998) and demonstrated the importance of looking for explanations to allow them to understand and integrate their bio-microsystemic changes. Van Manen (1998) recommends the role of explanations as healing either through alleviating anxiety or by providing a 'name' for the problem so that it can be integrated into the person's life. A potential implication for this is to work with ABI patients to bring about an awareness of the changes they have experienced. Participants' accounts mirrored Stile's model of assimilation of problematic change for psychological interventions (2002; Stiles et al., 1990). This adds further support for an increased role for psychological therapy to facilitate participants' adjustment. A possible psychological intervention might be to simply help people develop a coherent

understanding of the changes that they have experienced and to empower them to feel able to influence the impact of these changes.

According to Bronfenbrenner (1979, 2004) the Mesosystem involves the relations between people in the individual's Microsystems, but those which do not include the individual themselves. Participants' accounts did not directly address their experiences of adjusting in relation to their Mesosystems, but implied an increased complexity within it. Participants describe the involvement of health professionals coming into their Microsystems. This was experienced as both helpful and unhelpful depending on the perceived motives of the staff. The potential role of healthcare professionals in facilitating discussions and sharing a developed understanding of an individual with others in their Microsystem could facilitate re-engagement into their roles. E.g. other research has highlighted a potential role for clinicians to work closely with employers who can begin to have doubts about an individual returning to work when they are faced with the "realities" of employing someone with a head injury (Kowalske et al., 2000).

The clinical implications for the Macrosystem would result in a challenge to the way that society currently thinks, writes and speaks about people who have suffered acquired brain injuries. This attempt to challenge the dominant reductionist narrative has already begun in the mental health field with the development of the Recovery Model (Repper & Perkins, 2003). The Recovery Model (Repper & Perkins, 2003) parallels the epistemological position of Social Constructionism (Gergen, 1985). It challenges society to question its language, which is viewed as an "invisible restraint" confining people within a deficit-focused paradigm (Walker, 2006). The participants' accounts suggested they felt judged and displaced as a result of their injury, feeling frustrated and confused about the reasons for being prevented from returning to a valuable position within society, and in feeling confined to a different social group (Breakwell, 1986). The participants explicitly and implicitly referred to the role of the government in their accounts, which was perceived as powerful and influential in their experience. If, at a government level, brain injury is considered from a purely medical, reductionist position and therefore from a deficit-focused perspective, it is easy to understand how people are less likely to want to take 'risks' in facilitating re-integration. It is therefore the



responsibility of professionals involved to take more a political stance in influencing how we currently conceptualise people after brain injury, focusing on enablement rather than disablement.

### **4.3 *Methodological considerations***

Whilst this research has generated some rich and insightful accounts from the participants about their experiences of adjusting to life after brain injury, it is important to consider the methodological implications of using IPA. As discussed in Section 2.5, IPA is phenomenological and idiographic in nature. The aim of IPA is to gain a rich understanding of how participants make sense of their lived experiences. IPA is thought most appropriate for research questions that relate to process, novelty and complexity (Smith & Osborn, 2003) and so was thought appropriate for this research. As participants were able to provide rich and detailed accounts which revealed expected and unexpected themes to emerge, this suggests that IPA was an appropriate methodology for this study.

Unlike most quantitative research methodologies, IPA does not seek to prove or disprove hypotheses, driven from a positivist philosophical underpinning. The findings that emerged from this research therefore should not be generalised to all individuals who have experienced a severe ABI. IPA is however interrogative (Smith, 2004) as it aims is to feed back into the existing evidence-base in order to understand participants' experiences in relation to it. This research established themes within the participant's experiences that were supported within the evidence-base and themes that were less well supported.

For all IPA analysis it is important to consider the role of the double hermeneutic in the development of the themes (see Section 2.5). This means that the findings are partially subjective and whilst all attempts were made to be transparent and rigorous in my analysis (through the use of the audit trail which was reviewed in supervision), an implicit assumption in IPA research is that if the same research was conducted by another researcher, different themes may have been privileged. The implications of the double

hermeneutic is that the study cannot make objective, empirical claims for the results, and that generalisability is therefore somewhat limited.

Methodological limitations that may have been relevant in quantitative research such as the possibility of selection bias will not be as relevant in this investigation. Although it is possible that the sample selected by the ABI team were chosen for a reason (e.g. appraised as 'adjusted' or thought to be able to provide a 'good account'), IPA does not make claims about transferability and generalisability of findings. It is important to be explicit that the findings from this research are not being claimed to represent all individual's experience within the ABI field.

Although IPA has shown itself to be appropriate within a brain injury population, other qualitative research methodologies would also lend themselves to brain injury research. As discussed in Sections 2.2 and 2.3, the range of qualitative methodologies available must be chosen carefully as each will shape the research question, the focus of the analysis, and the conclusions that can be drawn (Starks & Brown Trinidad, 2007). This research aimed to gain an insight into the participants' personal experiences of adjusting to life after brain injury and, as such, a phenomenological approach was considered suitable. An alternative approach to this type of research could have taken a more sociological perspective using grounded theory. Grounded theory research (Glaser & Strauss, 1967) could have asked the question: how does the process of adjustment after brain injury take place? This approach would have used purposive sampling but would have aimed to reach saturation, including as many participants as necessary to understand the process of adjustment in all possible environmental conditions (for example, including all types of possible rehabilitation, and including people at all levels of adjustment). Grounded theory would have attempted to generate a theory which aimed to explain the process of adjustment. Based on this research, a possible outcome using grounded theory might have highlighted the role of expectations placed on the individuals following their injury and the role of discrimination and social inclusion as factors that might affect the participant's process of adjustment. Another alternative qualitative approach could have taken a social constructionist focus on the use of language using Discourse Analysis (Potter & Wetherell, 1987). The goal of this type of

research might have been to explore how language is used to create and reflect identities and roles (Starks & Brown Trinidad, 2007). A discourse analysis research question might have been: What discourses are used by participants who have experienced an acquired brain injury and how do they shape identities, roles and relationships? This type of research would focus on the interaction between people (e.g. other participants or the interviewer), investigating how meaning is created between them. A hypothesised outcome following this type of research might focus on the participants' acceptance or rejection of the dominant narratives in brain injury. According to the participants in this study, dominant narratives appeared to centre on disability and the medical reductionist accounts of the changes post brain injury. These accounts appeared to leave participants disempowered and hopeless for the future. Alternative narratives that participants developed appeared to allow them to feel empowered and in control and left them hopeful for the future. Future research might consider applying these different qualitative research methodologies with participants who have experienced a brain injury. Other suggestions for future research will be discussed below.

#### ***4.4 Suggestions for Future Research***

An important finding from this research was that these participants were more than able to provide a rich and meaningful account of their experiences of adjusting to life after brain injury. Other research has suggested that people with ABI are excluded because their accounts are viewed as untrustworthy (Brown et al., 2006). This research recommends more qualitative investigations including individual's with brain injury.

All participants were asked about how they found the interview experience. Although for some it was challenging, all reported feeling pleased they had done it, and some found talking about their experience beneficial. In the previous section, psychological interventions were suggested to facilitate the development of a coherent narrative of the participants' experience (Stiles et al., 1990; Stiles, 2002). A possible avenue for future research could be to investigate, from a quantitative or qualitative perspective, the benefits of participants receiving a psychological intervention on their adjustment.

Whilst research has suggested that problems with insight may have a negative impact on a person's ability to engage in rehabilitation, some participants from this research have explained how they feel confused about the reasons for being excluded from previous roles. This has been supported in other qualitative investigations where people who had brain injuries explained the importance of testing out their impairments in the real world (Brown et al., 2006; Dirette, 2002; Howes et al., 2005; O'callaghan et al., 2006). Future research might benefit from exploring what role "testing out" can play for participants who appear to lack understanding or insight into their impairments.

One of the potential clinical implications that arose from this research was the need to understand how the beliefs of people in the individual's Microsystem could affect adjustment. Exploring the beliefs and dilemmas that people such as employers face when making decisions about an employee's return to work, after ABI, might be useful. Qualitative investigations into these beliefs might highlight societal constructions or assumptions about people with brain injury that could be challenged or tested.

A final possible area for future research might include qualitative or quantitative investigations into the indirect impact of an ABI patient's family receiving support. Whilst this research did not focus on the impact that the ABI had on the support network of the individual, other research has highlighted the impact of the injury on the family (Blais & Boisvert, 2005; Blais & Boisvert, 2007; Perlesz, Kinsella, & Crowe, 1999; Ponsford et al., 2003; Perlesz, Kinsella, & Crowe, 2000). Participants in this research did describe how their injury had affected friends and family, this supports the quality requirement outlined in the NSF identifying the need for support for family members (Department of Health, 2005). A suggestion from this research is to conceptualise the need for support for family and friends as part of the individual's Exosystem (Bronfenbrenner, 1979). This would result in support having an indirect impact on the adjustment of the individual who has suffered a brain injury. Future research could investigate what, if any, impact provision of support has for the individual.

## **4.5 Study Reflections**

I wanted to end this chapter with my reflections on the process of conducting this research. This is important as it highlights the thoughts, preconceptions and assumptions that I brought with me into this investigation and demonstrates the personal journey I made conducting it. Owning my own perspective is one of the recommendations made in the Guidelines for Qualitative Research (Elliott et al., 1999) as it enables transparency and legitimises qualitative research methodologies.

Prior to commencing this research investigation I noted down in my reflective diary feelings of apprehension about starting the research interviews. I felt concerned that participants' accounts would be 'concrete and limited'. To compensate for this I developed a detailed interview schedule with a lot of prompts to use 'just in case'. Drawing up to the time of my first interview I noted feeling excited as if I was going to be listening to people with a brain injury for the first time, this is despite the many years I had worked in this field. I felt excited and uncertain about what I was going to encounter.

For each of my interviews I was surprised and impressed by the participant's ability to reflect on their experiences and to express themselves. I noted being aware that my fears about having to use all my prompts were unfounded. I found that I easily became immersed in conversation with the participants and felt genuinely curious about their stories. This left me wondering about all the missed opportunities I had in the past when working in this area. I think what prevented this as an assistant was that I often had very specific tasks to carry out (such as neuropsychological assessment). A fundamental role within ABI services is to identify need and this is traditionally done through assessment. This made me wonder about what the patients made of this approach.

Having concluded this research project, I am aware I have a new passion towards privileging those voices which may be subjugated. As a result of this research I see people who have suffered an ABI in a new light. I feel that this investigation has allowed me to turn my attention away from what patients are not able to do, and towards the strength and resilience that they have demonstrated. I feel passionate about disseminating this research in order to share their stories and to potentially challenge

some assumptions that might be held about people who have suffered acquired brain injuries.

At the start of this research process, when I chose to conduct a qualitative project, I was made aware of how much hard work was required. Whilst I cannot disagree with this point, I was pleasantly surprised by how enjoyable the process was. As I conclude this piece of research, I recognise the strengths of both quantitative and qualitative approaches, but find that my experience of conducting research in a way that allows the participant to be the expert fits well with my Social Constructionist and Constructivist roots.

#### **4.6 Conclusion**

The key findings drawn from this investigation revealed that many participants described experiencing changes following their ABI, both within themselves (*Experiencing a loss of control & Observed changes as a threat to identity*) and in how they were perceived by society (*Being displaced by the injury: Feeling unchanged in a changed world*). Participants described experiencing these changes in a way that threatened their identity. As a result they attempted to find ways to come to terms with these changes which allowed them to look forward, rather than back (*Attempts at managing a threatened identity*). Participants explained the role of support that they received (*Enable me don't disable me: the role of support in recovery*). They suggested wanting to be enabled to return to independence rather than to be kept in a disabled role, but acknowledged a dilemma in having to admit to the need for support. The role of social support from others who were 'in the same boat' was also important as it allowed participants to feel accepted and valued again.

This research suggests possible roles for clinicians in helping help people who have suffered an ABI to develop a coherent understanding of the changes that they have experienced and to empower them to feel able to influence the impact of these changes. In addition there is a potential role for professionals to take more a political stance in

influencing how we currently conceptualise people after brain injury, focusing on enablement rather than disablement.

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## Appendix 1: Interview Schedule

- Tell me what you remember about when the injury happened?
  - *Prompts: what happened understanding of injury (Prognosis, cause, type)*
- Tell me what life was like before the brain injury?
  - *Prompt: important people, home, work routines, leisure activities*
  - *What was good, what wasn't good*
- Tell me what it was first like for you after the injury?
  - *Prompts: recollections, changes, Differences, similarities, sense of self*
- What has life been like since then?
  - *Prompts: challenges, changes, thoughts and feelings over time*
  - *Roles, activities, relationships, identity, sense of self*
  - *Have you noticed any differences in your life since the injury? (positive + negatives)*
- What's not changed since the injury?
  - *Prompts: roles, activities, relationships, sense of self?*
- When/Where are you most aware of your brain injury?
  - *Prompt: e.g. time of day?, at work when you are on your own, with friends/family?*
  - *Prompts: why?*
- When/where are you least aware of your brain injury?
  - *Prompt: e.g. time of day?, at work when you are on your own, with friends/family?*
  - *Prompts: why?*
- Do you think you are adjusting to life after the injury?
  - *Do others think you are?*
- Are there areas you think you have adjusted to more than others?
- What do you think it takes to adjust to a brain injury?
  - *Prompt: how does this happen*
- What helps you to adjust to life after a brain injury?
  - *Prompts: systems (relationships, roles, activities, sense of self, wider systems)*
  -
- What stops you adjusting to life after a brain injury?
  - *Prompts: (relationships, roles, activities, sense of self, wider systems)*

## Appendix 2: Audit Trail

Chronological List of Participant Four's (Mike's) Emerging Themes (with location of repeating themes)

Emerging Themes	Page nos
detaching from the brain injury	1
new life (self) after injury	1, 2
still connected to pre-injury self	2
trying to understand impairments	2
using comparison to make sense	2, 38
can't be trusted	2, 9, 10, 21, 25, 26, 27, 30, 31, 37,
embarrassed by childlike behaviour (not in control of behaviour)	2, 3
accepting impairments by focussing on the positives	3,5,6, 14, 16,22,38
won't let it get me down	3
not making everything about the injury	3,5, 15, 17, 24, 28, 29, 37,
measuring progress through comparison with others (in the same boat)	3, 6, 8, 11, 27, 28, 29, 38
developing insight	3,4,6,9,
by listening to the professionals	3
getting hopes up based on early recovery	4, 33,
Trusting the professionals	4,7,8,10, 29,33,34,35
trying to understand	4, 5,
passive optimism for the future	4, 6, 29, 32, 33,
comparing experience to those in the same boat	4, 16, 19,
struggling to understand the loss of motivation	5, 26, 27, 32, 37, 38
focussing on the losses is depressing	6
learning to accept losses by trusting the motives of those you listen to	6, 33, 34, 36,
worrying more about the impact on loved ones	7,12, 33, 36,
focussing on the positives	7,8,16,21,26,28
relying on the professionals	9,32
not taking the impairments personally	10
function of ? not taking the impairments personally	10,11
unfairly judged	10,11

importance of finding things to be grateful for	11
accepting impairments (Losses)	11
relying on others for insight	12,22,27,33,34
having to accept the opinions of others	12
priorities changed	12
increased awareness of vulnerability	12,13,26
worry more about others	13
not feeling responsible for actions	14
missing out on life's pleasures	14,31
vulnerable	14
importance of being trusted and valued	15,18,26
loss of being trusted and valued	15,
normalising the experience	15,19,20,23,
acknowledging losses by focusing on the positives	16,22
trying to get the brain working	16,29,32,34,(36),39
brain in control	13,16
still valued by social network	17,18,20
lost friendships	18
loss of being valuable	20
focussing on the positives	7,8,16,21,26,28,
post self still places importance of being busy / active	24
importance of being with people in the same boat	24,25
importance of not standing out	25
treated like a child	25,30,31
importance of still having value	25
acknowledging progression by looking back	26
increased awareness of vulnerability	12,13,26
finding reasons to be grateful	28,30,39
importance of being treated the same	29
function of being valued and trusted	31,32
the function of accepting losses (to move forward)	32
gaining insight from performance	33
dwelling on losses means not looking forward	35
you can't rush recovery	35
not acknowledging the impact is being disappointed	36
loss of independence	37

Table of Super-ordinate Themes for Participant Four (Mike)

<b>The regressing impact of the injury</b>			
<b>Emerging Themes</b>	<b>P. Nos.</b>	<b>Sub Themes</b>	<b>Examples of theme Clusters</b>
new life (self) after injury	1,2	<b>Regression to childhood</b>	p.2:97- 105 She said that every time (2) erm she came to visit me on the ward every day I'd be sitting on the side of the bed with a carrier bag with all the sweets and my fruit bowl emptied in it waiting to go home (sighs) ... I just kept doing it and doing it
embarrassed by childlike behaviour (not in control of behaviour)	2,3		
not feeling responsible for actions	14		
treated like a child	25,30,31		
importance of being treated the same	29	<b>Being different (not wanting to stand out)</b>	p. 25: 1228 - 1232 I get there and I think....conversation and I think, if I say something I don't feel like I'm the odd one out because they genuinely know what I'm on about because they're all in the same boat
importance of not standing out	25		
Missing independence	37	<b>Missing independence</b>	<b>p.37: 1828-1835</b> erm well I was always capable of doing things for myself everything, I'm not saying I was brain of Britain but I was good at the jobs I did,....I could do it all myself and I find it hard, now that I have to be reminded or helped all the while, because, its horrible to say it but sometimes I sit there and think grrrr
trying to get the brain working	16,29,3	<b>Fighting the brain for control</b>	<b>p.32:1593 – 1598</b> I have got to the stage now rightly or wrongly where I just think to myself yeah that might come back you've got to keep persevering you've got to keep trying. Just keep trying, keep trying. Its not, if it can be done it will be done. If you can you will. But if you can't do it you can't do it P4 you've just got to accept that
you can't rush recovery	2,34,39		
brain in control	13,16, 35		



## The losses

<b>Emerging Themes</b>	<b>P. Nos.</b>	<b>Sub Themes</b>	<b>Examples of theme Clusters</b>
unfairly judged	10,11	<b>No longer trusted or valued</b>	<p><b>p.30:1487-1500</b>                      but I've got no smell I've got no taste ... Cause if she went out and I was cooking something yeah well you open the back door cause you went outside to have a cigarette and the breeze come and blew that out. For ten minutes that could be out and I wouldn't even realise then all of a sudden I might think oh it's a bit cold out there I'll light the cigarette out before I go outside bom!</p>
loss of being trusted and valued	15		
loss of being valuable	20		
lost friendships	18		
Can't be trusted	2 9 10, 21, 25, 26, 27, 30 , 31		
loss of independence	37	<b>Loss of independence</b>	<p>p.37: 1832-1834                      I could do it all myself and I find it hard, now that I have to be reminded or helped all the while,</p>
missing out on life's pleasures ? loss of control?	14,31	<b>Loss of control (of senses)</b>	<p>p.14:691-693                      So I see a plate come in, coorrer lovely I know that looks nice but I can't smell it and I can't taste it.</p>
increased awareness of vulnerability	12,13,26	<b>Loss of sense Security (increased vulnerability)</b>	<p><b>p.12: 600</b>                      well I, (sighs). I don't know I seem to get more erm erm worried about things or people</p>
vulnerable	14		
worrying more about the impact on loved ones	7,12, 33, 38		
worry more about others	13		
priorities changed	12		

### Trying to understand the impact

Emerging Themes	P. Nos.	Sub Themes	Examples of theme Clusters
using comparison to make sense measuring progress through comparison with others (in the same boat) comparing experience to those in the same boat importance of being with people in the same boat	2, 38, 3, 6, 8, 11, 27, 28, 29, 38 4, 16, 19, 24,25	<b><i>Importance of using comparison to make sense</i></b>	P2 70-72 long term memory is really good which seems strange because short term isn't but that's a lot of people in headways' in the same boat sort of thing
trying to understand struggling to understand the loss of motivation trying to understand impairments	4, 5, 5, 26, 27, 32, 37, 38 2	<b><i>Struggle to understand changes</i></b>	p.5: 243-250 P4 I can say this wants doing that wants doing I love doing it, if he comes no problem at all, or if my wife comes out no problem at all, but if I was on my own I just don't do it. I why do you think that is? P4 I've no er I've .. that's motivation that is. I've got no problem, I've got no idea about that because I was always motivated before the accident
acknowledging progression by looking back gaining insight from performance accepting impairments (Losses)	26 33 11	<b><i>Developing insight over time</i></b>	p.33: 1645-1649 p4 The driving has really surprised me because getting back driving this and that and to get nine points where I never ever had a point. I mmm P4 In that short period of time so now I know it's the tiredness

### Finding reasons to come to terms

<b>Emerging Themes</b>	<b>P. Nos.</b>	<b>Sub Themes</b>	<b>Examples of theme Clusters</b>
the function of accepting losses (to move forward)	32 36		p.32: 1609-1617 ... over the last three four months the last three four months I've finally realising certain things are the way they are and not keep huffing and puffing and ...I've now got to the stage where I'm not saying ....I won't be able to do it again. There's a good chance I will but you've got to take it a bit at a time and see see where it comes
not acknowledging the impact is heading for disappointment			
function of ? not taking the impairments personally	10,11 4, 33,	Accepting losses in order to be hopeful for the future Accepting what you cannot control	p.6: 262-269 er, you know I did, it did bug me at first but you just get to the stage, I think you just get to the stage, well I got to the stage where I think, I'm pleased with that pleased with this, pleased with this, hopefully I can do that but we'll just see how it goes and then you just got to you just go to, otherwise what am I gonna do, sit here looking out there thinking I used to do that I used to do that getting depressed and low and I don't want to get like that
getting hopes up based on early recovery (= later disappointment)	4, 6, 29, 32, 33,		
passive optimism for the future			
finding reasons to be grateful	28,30,39	Focussing on the positives to avoid depression	p.3: 110 – 119 I'm glad that I can, there's a lot of things that aren't right I know that. I've now got to the stage where I personally I finally think, pleased with what's happened, I'm walking around I'm getting a bit better, I know who my grandson is now, getting a bit better a bit better. But I know in my opinion I'll never be the same as I was. ...I'm not saying that ohhh cause its getting depressed I don't get depressed or think about it
won't let it get me down	3,		
importance of finding things to be grateful for	11 7,8,16,21,26		
focussing on the positives	,28,		
acknowledging losses by focussing on the positives	16,22 3,5,6,14,16,		
accepting impairments by focussing on the positives	22, 38 6		
focussing on the losses is depressing	35		
dwelling on loses means not looking forward			

## Not making the injury central as a way of moving forward


<b>Emerging Themes</b>	<b>P. Nos.</b>	<b>Sub Themes</b>	<b>Examples of theme Clusters</b>
still connected to pre-injury self	2	Importance of working to regain pre-injury values	<p>p.31: 1549-1555</p> <p>I are there other times when you're not thinking about it</p> <p>P4 erm, yeah there are there are times you know if I'm.. if I was doing something round the mother in laws or something for that lady at headways</p> <p>I yeah like tiling again</p> <p>P4 I just I just blank it all out.</p>
still valued by social network	17,18,20		
importance of being trusted and valued	15,18,26		
function of being valued and trusted	31,32		
importance of still having value	25		
post self still places importance of being busy / active	24		
detaching from the brain injury	1	Minimising the impact of the injury	<p>p.3 121-125</p> <p>I don't. but I've now come to the the conclusion that I'm <i>not</i> ever going to be like I was before the accident. One because (2) its three years ago now, but like if it's a couple of years in, I'm going to be five years older so I'm getting a bit, I'm going to be a bit slower or my memory, but there's things that aren't going to improve that much.</p> <p>p.5: 218-224</p> <p>you know your hearings not, my hearings not 100% correct now, but in fairness that could be because you get a little bit older and your hearing gets a little bit or if you work in a factory that could possibly be a problem as well or because you bang your head that could be a possibility in all, so without definitely ruling out one you can't say that its not a little bit of that its not a little bit of that</p>
not making everything about the injury	3,5, 15, 17, 24, 28, 29, 37		

not taking the impairments personally	10 15,19,20 ,23,	Accepting changes as uncontrollable	<p><b>p.15: 743</b></p> <p>P4 I tell you, I do I I, strange as it sounds, I'd love to be able to get up early in the morning, cup of tea get ready boom, in my van go to work, come back, just be able to do that. Sometimes I sit on the doorstep before I go to headway, sitting there, people go by in vans that know me and they give me a wave and I think oh you're lucky and they're probably thinking corr he's lucky sitting there</p> <p>I (laughs) yeah</p> <p>P4 but its..its its frustrating</p> <p>I mmm</p> <p>P4 but its you know one of them things innit?</p>
normalising the experience			

## The paradox of depending on others for adjustment

<b>Emerging Themes</b>	<b>P. Nos.</b>	<b>Sub Themes</b>	<b>Examples of theme Clusters</b>
developing insight by listening to the professionals	3 9,32 4,7,8,10, 29,33,34,35, 12 22,27,33,34 12 6, 33, 34, 36,	Actively deciding to rely on others for insight	p.12: 571 – 579 p4 that changed because my OT said when that was happened, “P4 you’ve got to accept that if (my wife) says, (wife) when you see him getting that sort of way, say p4 go and have a little lay down”. I used to, I would say “don’t say that, I’m not tired I don’t want to go”. Sort of right ok, go and have a lay down and I know that when I get up I’ll feel better P mmm, so kind of trusting (wife) when she’s seeing it P4 its good its good, you’ve gotta you’ve got to be like that
relying on the professionals			
trusting the professionals			
relying on others for insight			
having to accept the opinions of others			
learning to accept losses by trusting the motives of those you listen to			
			p.34: 1714-1722 So you’ve got do. I I will accept that I will, when people say things I take into account and I think well they know what they’re doing they’re not being disrespectful just trying to annoy me or anything. They’re being honest. They’d love to be able to say you’re going to be fine this that but they can’t....so just listen to what they’re saying. They know and if they suggest it blah blah blah it could well work.

## Appendix 3: Ethical Approval

  
**National Research Ethics Service**  
Essex 1 Research Ethics Committee  
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12 August 2008

Mrs Stephanie Uprichard  
Trainee Clinical Psychologist  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

Dear Mrs Uprichard

**Full title of study:** How do people experience the process of adjustment to a brain injury? An IPA Study  
**REC reference number:** 08/H0301/92

Thank you for your letter of 07 August 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Vice-Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

**Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

Stephanie Uprichard

Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.r4forum.nhs.uk>.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	Version 5.8	27 June 2008
Investigator CV		04 June 2008
Protocol	Version 1.1	04 June 2008
Covering Letter		28 June 2008
Letter from Sponsor		27 June 2008
Interview Schedules/Topic Guides	Version 1.1	04 June 2008
Interview Schedules/Topic Guides	Version 1.1	04 June 2008
Participant Information Sheet	1.2	01 August 2008
Participant Consent Form	1.2	01 August 2008
Response to Request for Further Information		07 August 2008
Explanation of the purpose of the study		
CV Pieter Willem Nel		
UMAL certificates		01 August 2007
Transcription confidentiality non-disclosure agreement	Version 1.1	04 June 2008
CV Gary Allan Kupshik		

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

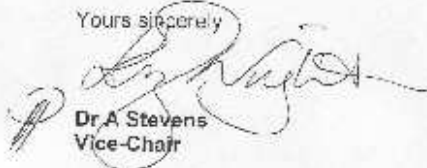


08/H0301/92

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr A Stevens  
Vice-Chair

Email: liz.wrightcr@ece.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Nick Wood  
Research Tutor  
Doctorate in Clinical Psychology  
College Lane  
Hatfield  
Herts  
AL10 9AB

# Appendix 4: Participant Information Sheet

Version 1.2 (1<sup>st</sup> August 08)

## How do people experience the process of adjustment to a brain injury?

### Participant Information Sheet

#### Part One:

##### **Invitation to take part:**

You have been invited to take part in a piece of research being conducted by Dr Stephanie Uprichard, Trainee Clinical Psychologist.

Before you decide if you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please feel free to talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen if you decide to take part. Part 2 gives you more detailed information about the conduct of the study.

This information sheet hopes to answer any questions you might have about the research. If there is anything you are unclear about or want more information about, please feel free to contact me on the telephone number below.

##### **What is the purpose of the research?**

This research hopes to gain a better understanding of what it is like for people to adjust to life after a brain injury. This research is being carried out as part of a doctoral training programme in Clinical Psychology at the University of Hertfordshire.

##### **Why have I been invited to take part in the study?**

Several patients from the Acquired Brain Injury Service have been invited to take part in this research. It is hoped that those who agree to take part will share with the researcher their experiences of life after their brain injury.

##### **Do I have to take part?**

It is up to you to decide. We will describe the study in this information sheet and you will have an opportunity to discuss it with the researcher. If you agree we will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive in any way.

##### **If I agreed, what would be involved?**

If you agreed to take part in this research you would meet with Stephanie Uprichard, Trainee Clinical Psychologist. She would talk to you about the research, to make sure you knew what it would involve. She would ask you to sign a consent form, which would show that you agreed to take part. You would then agree a time and place to meet. At the beginning of this next meeting, Stephanie would check to see if you had any further questions and to see if

Stephanie Uprichard

you have changed your mind. If you feel ready to continue, she will interview you about your experiences for about an hour. This interview will be recorded. After this you will have an opportunity to meet with her again so that she can answer any further questions or address any concerns you might have.

**What kind of questions will she ask?**

This research is interested in understanding what your experiences are of adjusting to life after your brain injury. Stephanie will ask you questions about the brain injury, including your thoughts and feelings about it. She will ask you if you have experienced any changes in your life and how you feel about these. She will ask you about how life after the brain injury is different to your life before it and what you think has contributed to these changes.

**What will happen to this information?**

The recording of the interview will be typed out so that the information can be looked at in detail. The aim of this is to uncover common themes that are important in understanding the process of adjusting to a brain injury. A professional transcription service may be used; in this case, confidentiality agreements will have been signed. Both the recordings and the typed out transcripts will be made anonymous and kept in a locked storage facility.

In addition to the information collected from the interview, Stephanie will also ask consent to collect some background information from your ABI records about the brain injury you had. Stephanie will be supervised throughout this research by two supervisors (Dr Pieter Nel, Consultant Clinical Psychologist, University of Hertfordshire and Professor Gary Kupshik Consultant Clinical Psychologist, ABI), this means that they will have access to all the information she has collected and will oversee the research.

Anonymised sections of the information collected from the interview may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research project.

As part of the doctoral programme, Stephanie will write up a report of her research. Within this report she may include anonymous extracts of the interview to illustrate themes that have been discussed. These extracts will not include any information that could identify participants. The researcher, Stephanie, will also write a shorter article for publication in an academic journal, this may also include brief anonymous extracts of the interview. Again, these extracts will not include any information that could identify participants.

Stephanie will ask you if you would like to hear what she finds from her research, if you do she will arrange to meet with you to share this.

**What are the possible disadvantages and risks of taking part?**

You will be asked to discuss your views about life after your brain injury, and to think about the changes that the injury has brought. This could be potentially distressing for and every measure will be taken to minimise the risk of distress. If during the interview you feel distressed, you will be given the choice of not answering a particular question, taking a break or stopping the interview altogether.

Following the interview, Stephanie will be available if you feel you need some time to talk about any issues raised. Stephanie will be able to advise you of who you can talk to if you need further support.

**What are the potential benefits of taking part?**

We cannot promise the study will help you, but the information we get from this study will help improve the treatment of people who have suffered a brain injury.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part Two.

**Part Two:****What will happen if I don't want to carry on with the study?**

If you decide you want to withdraw from the study you should let the researcher (Stephanie Uprichard) know. She can be contacted on the phone number given at the end of this information sheet. If you have completed the interview you will be asked what you would like to happen to the data. It can either be included in the data, or destroyed. Either option is perfectly acceptable. Your decision of whether to take part or withdraw from the study will not affect the care you receive from the Acquired Brain Injury Service.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher (Stephanie Uprichard) who will do her best to answer your questions, alternatively you could contact Stephanie's research supervisor, Dr Pieter Nel through the University of Hertfordshire (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the NHS premises will have your name and address removed so that you cannot be recognised.

As with any health professional, there are limits to confidentiality. If during your meetings with the researcher (Stephanie Uprichard, Trainee Clinical Psychologist) you disclose any information which suggests that either you, or someone else, is at risk of harm then she is obliged to breach confidentiality and inform someone (this is likely to be a clinician from the Acquired Brain Injury Service). Stephanie will do her best to discuss this with you first.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Essex 1 Research Ethics Committee.

**Contact Details:**

Stephanie Uprichard

Trainee Clinical Psychologist

Messages can be left for her through the Team Administrator for the ABI service (01582 709037)

Dr Pieter Nel

Consultant Clinical Psychologist

Academic Supervisor, University of Hertfordshire, 01707 285077

# Appendix 5: Participant Consent Form

Version 1.2 (1<sup>st</sup> August 08)  
 Patient Identification Number:

## CONSENT FORM

### How do people experience the process of adjustment to a brain injury?

Name of Researcher: Stephanie Uprichard (Trainee Clinical Psychologist)

Please  
Initial  
box

1	I confirm that I have read and understand the information sheet dated 1 <sup>st</sup> August 2008 version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals involved in the research, where it is relevant to my taking part in this research (this includes Stephanie Uprichard, and her Research Supervisors, from the University of Hertfordshire and NHS Trust), I give permission for these individuals to have access to my records.	
4	I agree to the ABI team being informed of my participation in the study	
5	I agree to take part in the above study.	
6	I agree to having the interview audio recorder	
7	I understand that brief anonymous extracts of the interview may be used to illustrate important points raised	
8	I understand that as part of her training, Stephanie is required to write a report and a shorter article for publication, which may include brief anonymous extracts of the interview.	

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature