

# **THESIS**

**Young persons' constructions prior to and following parental brain injury**

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## 1. ABSTRACT

Despite extensive research into the impact of brain injury on individuals and their adult relatives, much less is known about the impact of parental brain injury on child relatives. The aim of the study was to identify if there was a relationship between changes in how children construed themselves and their parents following the brain injury and adjustment, and to identify if there was a relationship between structure of the child's construct system and level of adjustment. There were four hypotheses to be tested. Hypothesis one predicted that larger changes in how young people construe themselves and significant others following parental brain injury compared to how they were construed prior to parental brain injury would be associated with poorer adjustment. Hypothesis two predicted that more structured 'before acquired brain injury' constructs in comparison to the structure of 'after acquired brain injury' constructs would be associated with poorer adjustment. Hypothesis three predicted that more superordinate 'before acquired brain injury' constructs in comparison to 'after acquired brain injury' constructs would be associated with poorer adjustment. Hypothesis four predicted that tighter construing would be associated with better adjustment following parental brain injury. There were 10 participants in the study aged 10-17 who had a parent with a brain injury. Each participant completed a repertory grid and the Personality Inventory for Youth, a measure of adjustment. It was found that larger distances between how children construed themselves or their parents currently compared to how they were construed pre-injury were related to poorer adjustment. There was also found to be a relationship between relative intensity of the post-brain injury construct system and some aspects of adjustment. There was no significant relationship between adjustment and relative superordinancy of post-injury constructs or adjustment and tightness of construing. Future research is indicated to verify the findings of this study, and to explore possible interventions for young people experiencing poor adjustment following parental brain injury.

## **CHAPTER 2**

### **INTRODUCTION**

This thesis sought to explore if there was any relationship between the adjustment of children who have a parent with a brain injury and the construct system utilised by the child. Therefore, this chapter will commence with definitions of brain injury and adjustment. A review of the literature will then follow, initially focusing on research with adult relatives of individuals who have experienced a brain injury, before progressing on to the impact parental brain injury has on child relatives. This will then be followed by reviewing relevant literature from a Personal Construct Psychology (PCP) perspective.

#### **2.1 BRAIN INJURY**

The United Kingdom Acquired Brain Injury Forum (UKABIF) define acquired brain injury (ABI) as a

Non-degenerative injury to the brain occurring since birth. It can be caused by an external physical force or by metabolic derangement. The term ‘acquired brain injury’ includes traumatic brain injuries, such as open or closed head injuries, or non-traumatic brain injuries, such as those caused by strokes and other vascular accidents, tumours, infectious diseases, hypoxia, metabolic disorders (e.g. liver and kidney diseases or diabetic coma), and toxic products taken into the body through inhalation or ingestion.(UKABIF, n.d.)

Prevalence rates of ABI are difficult to establish as studies vary as to whether they include non-traumatic brain injury or traumatic brain injury (TBI) alone. Prevalence rates are further complicated as some studies are based upon admissions to Accident and Emergency (A&E) departments, and some clients may not access this service.

Headway (n.d.) reports a range of prevalence rates for the occurrence of brain injury in the UK. These reported rates include an estimated 1 million people attending A&E in the UK following head injury. Further data provided includes that men are two-three times more likely to experience a TBI in comparison to women, with the likelihood increasing to five times more likely between the ages of 15 and 29. Additionally, over 130,000 people have a stroke each year in England and Wales with approximately 450,000 people living with severe disability as a result of stroke.

Furthermore, 500,000 people living in the UK have a history of meningitis. Bryden (1989) reports an estimated prevalence of TBI-disabled survivors in the UK as 100-150 per 100 000 population.

McLaughlin (1992) and Urbach and Culbert (1991) report that as the majority of brain injuries occur in the under-35 age group, an age when many families have children, it is likely that many children's lives are affected by parental brain injury.

Brain injury can result in a wide range of symptoms and difficulties and it can have adverse effects in different areas of human functioning. These include cognitive, motor skills, physical, emotional and social behaviour (Wilson, Herbert, and Shiel, 2003). Rao and Lyketsos (2000) describe the neuropsychiatric sequelae of brain injury as including cognitive deficits, mood disorders, anxiety disorder, psychosis, apathy, behaviour or dyscontrol disorder and other difficulties such as sleep disturbance and headaches.

## **2.2 ADJUSTMENT**

The Oxford English Dictionary (2011) defines adjustment as “The process of adjusting; setting right, regulating, arranging, settling, harmonizing, or properly disposing; freq. in contexts of emotional adaptation”.

A crucial question regarding adjustment therefore is what processes are involved with adapting or becoming used to a situation, and in what areas of the personality or behaviour is adaptation needed? As the focus of this study is regarding children and adolescents, the remainder of this section will focus on adjustment in the context of this age group.

In an early study examining personality adjustment in children aged nine to thirteen years old, Rogers (1931) comments that “maladjustment is thought of as synonymous with bad behaviour” (p.1). However, he adds that maladjustment is “a consciousness of the gap between reality and desire, and then behaviour which is designed to bridge or to cover up that gap” (p.1). He emphasises the importance of not only the existence of a gap between real situations and desired ones, but that the difference must be felt. He also adds that measurement of adjustment is difficult, as there are frequently subtle attitudes involved, in comparison to easily measurable qualities. It appears then that adjustment in children is not measurable by examining bad behaviour alone.

A more recent view of adjustment within adolescents suggests that there are three areas of adjustment, namely school, friends and family (Scott and Scott, 1998). These areas may be evaluated by examining academic performance, peer relations and satisfaction with family relationships. The authors also emphasise the relationship between the person and the set of circumstances that an individual may need to adjust to, and that adaptation can be viewed within a specific domain or activity. Therefore it is possible that an individual may appear to be well adjusted in some areas of life, but not others.

To further explore adjustment in child and adolescent relatives of parents with a brain injury, a full literature search was conducted.

## **2.3 LITERATURE SEARCH**

The parameters of the literature search were initially set to include publications between 1987 and 2011. However, due to the low number of relevant articles identified, literature written prior to this and those that had been cited within the identified literature were also acquired.

### **Systematic Search**

The search terms listed below were used in different combinations using Boolean terms and applied to each database.

- Brain injury, traumatic brain injury, acquired brain injury, ABI, TBI, head injury
- Child relatives, children, parent, parental, family, families
- Adjustment, impact, effect,
- Repertory Grids, Personal Construct Psychology, Personal Construct Theory, PCP,

The databases used in the literature search include:

- PsycINFO
- Web of Science

### **Reference List Search**

Reference list searches were conducted from those papers obtained through the systematic search. Emerging relevant papers were sourced to ensure a thorough review of the literature.

### **World Wide Web searches**

- Internet search engines such as ‘Google’ and ‘Google Scholar’ were used to search for additional relevant material using the search terms outlined above.
- Brain injury websites sites such as Headway and UKABIF were visited to access any relevant information.

## **2.4 MODELS OF ADJUSTMENT**

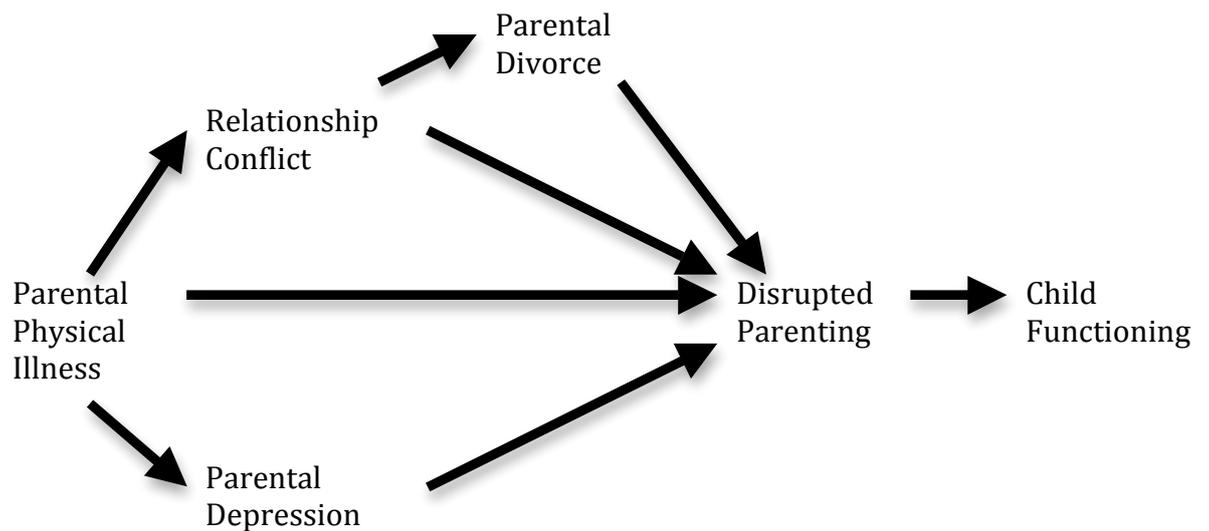
The literature search was unable to identify any models that relate to child adjustment following parental brain injury. Therefore, models from other potentially relevant areas will be considered. These will include a model that explores how parental physical illness impacts upon child functioning. Cognitive and personal construct models of responses to trauma will also be examined. Models of trauma will be considered as the parental brain injury may be experienced as a trauma in terms of both a devastating event being experienced by the family, and the possibility of the injury shattering the child’s belief system, or how the child construes the world.

### **Parental Illness and Adjustment**

Armistead, Klein and Forehand (1995) offer a model of how parental physical illness may influence child functioning (Figure 1). The authors propose that disrupted parenting is a key mechanism that accounts for the relationship between parental physical illness and child functioning. The authors elaborate the concept of disrupted parenting to include factors such as reduced support for the child, reduced parental discipline efforts, neglect of the child due to the family being reorganised around the illness, changes in family routines and absence of the parent. However, the authors state that disrupted parenting alone is insufficient in explaining the relationship between parental illness and child functioning. It is suggested that wider contextual issues such as conflict, divorce or parental depression may partially explain child functioning in families with parental physical illness. A strength of the model is that it incorporates both direct disruptions to parenting as a consequence of the illness and indirect disruptions due to mood and relationship difficulties that parents may experience as a consequence of the illness. A criticism of the model is that child functioning can be considered a broad concept, and it is possible that a child may perform well in some aspects of functioning but not others. The authors note that whilst their model may explain some of these aspects of functioning well, such as

aggression or noncompliance, the model may not sufficiently explain other aspects of functioning such as somatic symptoms, which may be more readily accounted for by other explanations such as modelling.

**FIGURE 1**  
**Schematic Model of how Parental Physical Illness Influences Child Functioning (Armistead, Klein and Forehand, 1995).**



### **Personal Construct Model of Trauma**

An early personal construct model of trauma (Sewell and Cromwell, 1990; cited in Sewell, 2005) suggests that a fragmented trauma-related construct subsystem may be formed when an individual is faced with an extreme experience that cannot be construed in relation to their other life experiences. The model further proposes that individuals who experience PTSD may develop an outlook that is only validated by the traumatic experience and not by other aspects of their life. Sewell (2005) describes how this model has been elaborated to include the view that those with ongoing symptoms of PTSD may have a tendency to become 'stuck', repeatedly utilising only one or two core constructs when construing their experiences. Construing in relation to both events and social encounters can be disrupted following experiencing a traumatic event. If construing of events is disrupted, the world may appear to lack a sense of order, resulting in catastrophic anticipations and anxiety. If social construing is disrupted, this may result in difficulties in anticipating social encounters, and consequently may result in individuals isolating themselves.

### **Cognitive Models of Trauma**

A widely accepted cognitive model of posttraumatic stress disorder (PTSD) was proposed by Ehlers and Clark (2000). The authors postulate that individuals experience PTSD symptoms when they continue to process memories of the traumatic event in a way that produces a sense of current threat. The perceived current threat is accompanied by intrusions, symptoms of arousal and feelings of anxiety. The symptoms are maintained by behavioural and cognitive responses that may reduce the perceived threat in the short-term, but perpetuate the difficulties by preventing cognitive change. Whilst this model was proposed for adults, Meiser-Stedman (2002) examined cognitive models of trauma in relation to children and adolescents, including the Ehlers and Clark (2000) model, and concluded that the models offer a framework for understanding PTSD in children and adolescents. An element of the cognitive models of PTSD that may be particularly relevant in the context of child relatives of parents with a brain injury may be that the brain injury created circumstances that shattered the child's beliefs and assumptions about the safety of themselves or their parents. This may be particularly strong if the child experienced a threat to their injured parent's life at the time of the injury.

### **2.5 BRAIN INJURY RESEARCH**

It is likely that those who experience an ABI and their relatives have no previous experience of ABI. Therefore, in the general population, knowledge about the consequences of ABI is likely to be unknown, or based upon knowledge obtained through the media. Chapman and Hudson (2010) conducted a survey that explored beliefs held about brain injury in the United Kingdom. 322 people completed a questionnaire that consisted of 17 true/false statements regarding head injury and recovery. A third of participants had either experienced a brain injury themselves, or knew a close friend or relative who had experienced a brain injury. The authors found that there was no association between personal experience of a brain injury and knowledge of a brain injury. The authors also found that misconceptions about brain injury and recovery were common. Particular misconceptions that were highlighted included a misunderstanding of the nature of unconsciousness, under-estimating the extent of memory difficulties that can occur and misconceptions regarding the complexities of recovery and future risk of subsequent brain injury. The findings of this study are important, as it highlights expectations that those who either directly or

indirectly experience brain injury might have. The authors give the example of those who hold the view that a full recovery from a severe brain injury is possible if the patient works hard enough, which may lead to unrealistic expectations from both the patient, their relatives and may generate unsympathetic reactions from friends and colleagues.

### **The Impact of Brain Injury Upon the Family**

Before exploring the literature relating to the families of individuals with an ABI, it is first important to consider what is meant by the term family. Goldenberg and Goldenberg (2008) define the family as “a natural social system that occurs in a diversity of forms today and represents a diversity of cultural heritages” (p.23). Carr (2006) also describes the family as a unique social system for which “membership is based on combinations of biological, legal, affectional, geographic and historical ties. In contrast to other social systems, entry into family systems is through birth, adoption, fostering or marriage and members can leave only by death” (p.5). Whilst this social system traditionally meant a married couple and their biological children, it might also include step-parents, foster parents, and informal kinship adoptions. It might also include single parent households, with divorced or separated parents living outside of the main family home. In the context of brain injury, it is possible that an injured parent lives separately from their children, either due to separation or divorce, or due to the injured parent requiring ongoing specialist residential accommodation.

In a review paper regarding the impact of brain injury on the family, Brooks (1991) comments that “the impact of a head injury was at least as great for family members as for the patient, and often family members were far more distressed than the injured person” (p. 155). He goes on to reflect that adjustment not only occurs within individual family members, but within the family system as a whole.

Acquired brain injury within the family has been likened to a bereavement or grief. However, Testani-Dufour, Chappel-Aiken and Gueldner (1992) comment that unlike the families of those who do not survive, grief is not something that can be worked through and a return to life pre-injury resumed. Rather they state that a sense of limbo is apparent as the losses associated with brain injury are never final, prognosis is uncertain and therefore grief is experienced more intensely and feels more disorganised as it is unclear exactly what losses are being mourned. Possible losses outlined by the authors include companionship, emotional support, pre-morbid

personality, income, roles, hopes and dreams. In a study examining the impact of disability within the family, Banks (2003) found that families of stroke survivors likened some experiences to that as though “a stranger in the body of a loved one has intruded into the family circle, and there is no social model for grieving the loss of the person they once knew” (p.368).

Leathem, Heath and Woolley (1996) examined the degree of role change, social support and stress in relatives of individuals with a TBI. Twenty-nine relatives participated in the study, which included 18 parents and 11 partners. A role change questionnaire was administered that explored four areas of potential role change; ‘household activities’, ‘finances’, ‘social life’ and ‘relationship’. Scores were obtained by measuring degree of change compared to prior to the injury occurring. The Arizona Social Support Interview Schedule was also included, which examined material aid, physical assistance, intimate interaction, guidance, feedback and social participation. Measures that examined levels of stress and health were also administered. The authors found that partners experienced greater levels of role change compared to parents, but that both groups experienced the greatest role change in their relationship with the brain injured person. The authors suggest that degree of role change is less for parents, as their new role is a continuation of, or an extended or exaggerated version of their previous role of parent. It was also identified that partners experienced more health problems than parents. Additionally there was a higher positive correlation between stress and health problems amongst partners in comparison to parents. The findings of this study are limited due to the small participant numbers in each group. It is also limited in that it only explores adult relatives, either as parents or partners, and does not explore the effect on child relatives of people with a brain injury. The authors’ finding that there is a greater change in role for partners, due to the similarity or extension of the caring role for parents, may be significant when considering child relatives. If their brain-injured parent is more dependent and requires increased support, alongside a decrease in their ability to parent their children, this is likely to result in an increased role change for child relatives, particularly if they are required to fill some of the roles their injured parent held previously.

A study examining marital relationships also found that a major change in role was reported by the female partners of men who had sustained a brain injury (Gosling and Oddy, 1999). The study was an in depth exploration of the marital and sexual

relationships of 18 heterosexual couples where brain injury had occurred between one and seven years previously. Questionnaires were administered with the female partners that examined health symptoms and sexual satisfaction. The scores obtained on these measures were supplemented by asking the female partners open questions regarding perceptions of their relationship and anticipation of the future. The injured male partners were briefly interviewed afterwards, and the sexual satisfaction questions were administered. The authors report that the findings from the questionnaires indicate that female partners' perception of the current marital relationship was significantly worse than how they perceived it to be prior to the injury, with the mean scores of current perception falling in the 'marriages with severe problems' range of the measure used. Unfortunately, the authors do not provide mean scores for either currently or prior to the injury, nor is the qualitative descriptor provided by the measure of the relationship for prior to the injury given, so it is difficult to make meaningful comparisons. Effect sizes are not reported, nor is it clarified if the significantly lower ratings are referring to a level of clinical significance being reached, or if it refers to the difference in scores being statistically significant. Several major themes were identified by the authors on analysis of the interview transcripts. Role change was identified by many, with 10 female partners stating that their relationship with their partner was more akin to that of a parent or mother. Another theme to emerge was regarding the injured partner's feelings, which were identified by some as gratitude towards the non-injured partner. Another issue that emerged was that of difficulty in identifying the injured partner's feelings. A common theme was that relationships were no longer equal, and that the non-injured partner had more, or total responsibility. Most female partners found it difficult to identify positive aspects of their relationship, but some were able to comment on commitment, friendship and mutual affection. Several women expressed concern regarding the effects of the brain injury on their children. Stress, stigma and financial difficulties were raised as effects that the children might experience. It was reported that the presence of children in the home did not impact upon the female partner's perception of the quality of their relationship, but the same was not true for the injured male partners, who gave significantly lower ratings of marital satisfaction when there were children living at home. The authors felt that this may support the view that injured men may compete with their children for attention from their partners.

A review of the literature exploring psychosocial outcome within families

following brain injury highlighted that most studies focused on primary caregivers such as parents or spouses (Perlesz, Kinsella, and Crowe, 1999). It was also identified that most of the research reviewed measured outcome by measuring stress or burden in relatives. The authors noted a lack of research that identified families who do not report high levels of stress, burden or distress. The studies reviewed by the authors indicated that different relationships brought different types of stress and burden with them, with spouses being more likely to experience role change and have concerns about the effect their injured spouse's injury would have upon their children. The authors also highlighted that there was very little literature exploring the impact on child relatives.

In summary, research that explores the impact of ABI on relatives identifies that most research has been conducted with adult relatives, who are usually spouses or parents, despite a common theme to emerge from the literature that spouses are concerned about the effect parental ABI may have on their children. Much of the existing research focuses on the stress and burden experienced by relatives rather than attempting to learn more about those relatives who do appear to adjust well to the consequences of ABI within the family. The change in role experienced by the relative was also found to be an important factor, although this was found to be more significant for spouses compared to parents. It is therefore possible that child relatives of individuals with an ABI may experience a significant role change, particularly if care demands are high.

## **2.6 CHILD RELATIVES AND ADJUSTMENT**

### **Child Relatives of Parents with Other Long Term Conditions**

As there are few studies examining the impact of parental brain injury on child relatives, literature relating to the impact of other long-term chronic conditions will also be explored. Whilst the consequences of ABI are complex and unique, it is felt that some similarities to other long-term conditions are present in terms of ongoing physical, emotional or cognitive difficulties.

Pakenham, Bursnall, Chiu, Cannon and Okachi (2006) conducted a study that explored the psychological impact of being a caregiver to a parent with an illness or disability. Several variables were explored including adjustment, coping strategies, social support and appraisal, with the results for young people who were caregivers

and those who were not being compared. The authors categorised caregivers as those who had a parent with an illness or disability, regardless of whether the young people considered themselves to be carers or not. Non-caregivers were those who did not have a parent with an illness or a disability. There was a total of 245 participants aged 10-25, which included 100 caregivers and 145 noncaregivers. The types of parental illness or disability experienced were coded as physical illness, mental illness, physical disability, sensory disability, brain injury or other. The majority of illnesses/disabilities were coded as physical illness (68%) and 2% were coded as a brain injury. The authors found that caregivers reported higher somatisation and lower life satisfaction in comparison to noncaregivers. They also identified that there was a greater impact on caregivers where there was more contact with the ill or disabled parent, and where there was a greater degree of functional impairment, the parental illness being more unpredictable and the parent having a mental illness. Worrying about parents and caregiver discomfort were associated with lower social support, maladaptive coping and poorer adjustment. However, caregiver confidence and perceived maturity were related to adaptive coping. There was no difference found between caregivers and noncaregivers on subjective health status, anxiety, depression or positive affect. A strength of the study is that there were a high number of participants in the study. A limitation is the assumption that all young people who have a parent with an illness or disability are caregivers. A further limitation in the context of this project is that the study includes young adults up to the age of 25, which is older than the target group of this project.

Siskowski (2006) found that of over 11,000 US schoolchildren survey respondents, 6714 had a family health situation. Of those 6714 students, 4166 reported adverse effects on their education. These adverse effects included missing school or after school activities, being unable to complete homework and interruptions to thinking/studying time. A total of 2585 students thought that their family member's health situation hindered their learning. These findings suggest that a large proportion of school age children who have a health situation within the family report their education and learning being impacted upon. However, the study does not report which family member experiences the health problem. It is therefore impossible to determine how many respondents were commenting on the impact of parental illness.

In a review paper exploring interventions with children who have a parent with a chronic somatic illness, Diareme et al (2007) report that parental illness may impact

upon children in several ways. The authors report that somatic symptoms may be common in latency age children due to the children identifying with an ill parent. They add that the emotional impact of having an ill parent may lead to poor concentration, intrusive thoughts, poor achievement at school or social withdrawal. It was also reported that poor coping in the parents increased the likelihood of problems in the children (Nelson and White, 2002; cited in Diareme et al 2007). In some cases, resiliency was reported as it was found that there was no psychopathology in children who had a parent with Multiple Sclerosis (Weinart and Catanzaro, 1994; cited in Diareme et al, 2007). Diareme et al (2007) also observe that most interventions are groups, which are beneficial intervention choices as they allows for wider treatment availability, lower costs and provide peer support and a feeling of belonging in children who may feel isolated and alienated due to their parent's health condition (Fobair, 1997; cited in Diareme et al, 2007).

Parentification refers to the process of children and adolescents taking on adult, parental or spousal roles and responsibilities prematurely (Stein, Rotheram-Borus and Lester, 2007). A study into the long-term impact of parentification of child relatives who had parents living with HIV/AIDS found that despite there being short-term negative consequences, the long-term outcome was more positive (Stein et al, 2007). The study was a follow up to an earlier study where it had been found that early parentification of children with parents living with HIV/AIDS was predictive of emotional distress, substance abuse and conduct problems six months later (Stein et al, 1999; cited in Stein et al, 2007). A total of 213 young people participated in the follow up study and completed positive parenting attitudes, adaptive coping skills, emotional distress and alcohol and tobacco use measures. Baseline data regarding parentification, emotional distress and alcohol and tobacco use was also available from the original study. The authors found that although early parentification was a predictor for increased alcohol and tobacco use at baseline, it was a strong predictor of lower alcohol and tobacco use six years later. Early parentification was also a predictor of more adaptive coping skills six years later. Furthermore, early parentification was not predictive of emotional distress at follow up.

Although early-onset Alzheimer's disease (EOAD) is a degenerative condition, it shares similarities with ABI in that symptoms may include cognitive and behavioural changes. In a case study exploring the impact of EOAD on the child relatives of a 50-year-old man, Gelman and Greer (2011) found that the children

experienced parentification, in that they took on adult roles. The children also experienced depression, shame, anger, resentment and social isolation. They also experienced a grieving process for the loss of their previous relationship with their father. The authors also reviewed an intervention used with the family. The intervention was based on a life course perspective, family systems theory and structural family therapy. The life course perspective component of the intervention explored the timing of life events from the context that it is not the typical time of life for young children to have a parent with Alzheimer's disease or to care for their parents. The structural family therapy component of the intervention explored and sought to increase understanding of how the family had been restructured due to their father's EOAD, and helped the family to reduce the parental roles the children were taking and increase the child roles for them. The authors observed that there was a lack of both support groups and services for child relatives of parents with EOAD. The authors found a specialist summer camp for child relatives of parents with EOAD, which the children involved in the case study were able to attend. The children reported that the camp was helpful because they were able to be with others who had similar experiences and share strategies for living with a parent with EOAD. A strength of the case study is that it was able to take an in depth exploration of the circumstances of this family. However, a limitation of this approach is that the findings cannot be generalised to wider populations.

In summary, the brief review of the literature that explores the impact of parental illness and disability shows mixed findings. Whilst the majority of studies found poor outcomes including somatic symptoms, emotional difficulties, lower life satisfaction, difficulties with education and learning, substance abuse and conduct problems, some found other aspects such as increased resiliency. Factors associated with poorer adjustment included degree of impairment in the parent, parentification, particularly in relation to short-term outcome, the presence of parental mental illness and poor parental coping. The merits of group interventions were also highlighted.

### **Child Relatives of Parents with an Acquired Brain Injury**

As identified in the review of the literature for adult relatives of individuals with ABI, a common theme to emerge was that research regarding the impact of parental brain injury on child relatives was limited (Daisley and Webster, 2009; Florian and Katz, 1991; Pessar, Coad, Linn, and Willer, 1993; Tyerman, 2009;

Urbach, Sonenklar, and Culbert, 1994). Florian and Katz (1991) add that children can be considered to be additional victims of brain injury and that this is an important consideration for professionals considering children as possible clients in their own right and in supporting parents to help their children cope with and understand brain injury. Losses experienced due to the impact of acquired brain injury may include grieving over the change in parental roles and changes in their parents' relationship (Testani-Dufour, et al., 1992)

Urbach (1989) identifies several factors that may affect a child's response to parental ABI. He divides these into two clusters. Firstly, factors relating to the parent: severity of the ABI, the chronicity of the parents' post-injury sequelae, type and stability of symptoms experienced, the relationship with the child prior to the ABI and the gender of the parent. Secondly, factors relating to the child which may affect the child's response include the child's age at the time of the ABI, their mastery of developmental tasks, pre-injury experiences, gender of the child, duration and consistency of exposure to the injured parent and presence of a physically and emotionally available non-injured parent. A later paper (Urbach, et al., 1994) added a further cluster incorporating family/system factors. These included family cohesion and adaptability, family income and standard of living, status of disability, forced changes of residence, changed routine, new family members in the household, less recreation time, social isolation, embarrassment, marital conflict and likelihood of divorce.

Urbach (1989) also recommends formal research study to investigate the children of brain-injured parents and identifies several areas of need. These identified areas include obtaining information about the severity of the brain injury, interviewing both the child and the non-injured parent and measuring the degree of family burden. Further recommendations include psychiatric screening of the child using a general symptom checklist, symptom scales, for example for anxiety and depression, evaluation of school performance, teacher's evaluations of the child's behaviour and social adjustment and comparative data from control children. The areas identified by Urbach (1989) seem to tap into several areas of adjustment such as behavioural, social, emotional and educational.

Pessar et al. (1993) looked specifically at the impact parental brain injury had on child relatives' behaviour. Twenty-four non-injured parents completed the Child Information Form, which consists of 11 questions regarding their child's behaviour

and 12 questions regarding any changes in the injured parent's parenting since the time of the injury. This measure explored the degree of change compared to prior to the brain injury and scores were either -1 or -2 for those changes that were seen to be negative, and 1 or 2 for changes considered to be positive or improvements. A score of 0 indicated no change in the item being measured. Measures that explored the injured parents' behavioural changes, the injured parents' motor and sensory disabilities and both the injured and non-injured parents' symptoms of psychiatric distress were also included. The authors report the results as indicating that 22 families reported negative changes in their child's behaviour when compared to prior to the parental brain injury. However, some of these negative changes appear to be small, for example the mean score for emotional problems was -0.28. However, the mean difference for relationship difficulties with the injured parent was larger at -0.70. Twenty-three non-injured parents reported negative changes in the parental behaviour of the injured parent. Mean scores on subscales indicated larger negative changes with mean scores of -0.79 for not fulfilling parental role, -0.139 for negative behaviours and -0.72 for reduced positive behaviours. The authors report that injured parent variables of age, age at time of injury and male gender were significantly correlated with 'acting-out behaviour' in children. However, these same variables were not correlated with emotional difficulties in the child. No aspect of parental behaviour change in the injured parent was correlated with acting out behaviours in the child. Furthermore, negative behaviours in the injured parent were not correlated with acting out, relationship or emotional difficulties in the child. Conversely, reduced parental performance in the non-injured parent was correlated with all three components of children's behavioural change. This study identifies that it is not just changes within the injured parent that are significant in examining the impact of ABI within families, but also factors regarding the non-injured parent as well. A limitation of the study was that it looked at family units rather than looking at children of multiple sibling families on an individual basis. This then makes it harder to explore individual factors within the child that may lead to a greater or lesser degree of behavioural change.

Butera-Prinzi and Perlesz (2004) conducted a small qualitative pilot study with four children whose fathers had an ABI. Effects noted in the study were the difficulties the children had coping with and adjusting to the behavioural and personality changes in their fathers and the loss and grief of losing their 'real fathers'.

The children interviewed for the study were able to recall fond and detailed memories of their fathers and their relationship with them prior to the ABI. The children also expressed fears of family disintegration, for example that their mother would leave because things were too difficult, and concerns about the change in social support and financial situation. Some of the children identified positive coping skills and positive changes as a result of the ABI. For example, one child felt that she now had more time with her father, whilst another felt that a benefit was that she now had greater responsibility and independence. A strength of this study was that the authors did not appear to make the assumption that parental ABI would negatively impact upon child relatives. The authors sought to explore the impact ABI had, but were keen to explore both potential positive and negative effects. A limitation of the study is that the sample size of four children was very small, and is therefore unlikely to be representative of other children's experiences of having a parent with an ABI. As the study focuses on children with a father with an ABI, it does not explore the impact of having a mother with an ABI.

Other studies have not found any significant difference between the behaviour of children who have a parent with a brain injury and children who do not (Uysal, Hibbard, Robillard, Pappadopoulos, and Jaffe, 1998). However, this study was different in comparison to those reported above as it compared children with one injured and those with two non-injured parents. It was found that children with an injured parent did experience more depression. A strength of the study was that one of the measures used (Children's Problems Checklist, modified) did not solely explore behaviour, but also examined emotion, self-concept, peers and play, school, language/thinking, concentration, activity level, motor control, values, habits and health. Whilst this measure is very comprehensive and takes a broad view of adjustment, it does not explore family relationships. A further difficulty with the Children's Problems Checklist is that it was designed for children aged 5-12, yet used on children aged 7-18. The authors stated that they adapted the wording of the questions for adolescents; however, it was not normed for the older age group, which may limit its validity. This is significant when interpreting the clinical relevance of scores obtained on the measure.

The importance of taking a broad view of adjustment, and considering the child's own perspective is outlined by McLaughlin (1992), who states that "one cannot assume that because the child continues to eat, play, or do well in school, they

are not experiencing illness or injury-related stress”, (p.12). The author also notes that parental reports of adjustment may not be accurate.

In a review of the literature, Daisley and Webster (2009) highlight the degree of role change that may occur following parental brain injury and comment that the child may become ‘parentified’ and perceive the injured parent as though they are a child. They also identify an emphasis on negative outcomes within the literature, particularly with behavioural and emotional adjustment; with much less attention paid to physical, social, and educational factors, quality of life, and family and peer relationships. They also observe that not every child has adjustment difficulties following parental ABI, but that the factors influencing a child’s response are not well understood.

The main theme to emerge from the literature exploring the impact of parental ABI on child relatives is a general lack of research in this area. Other themes to emerge include the importance of taking a broad view of adjustment that should incorporate not only behavioural aspects, but also academic, social, relationship and emotional factors as well. Whilst some studies did appear to take a less broad view in exploring adjustment, a study that did take a broader view (Uysal, et al., 1998) unfortunately used a measure that was not specifically designed for the age group with which it was used.

## **2.7 PERSONAL CONSTRUCT THEORY, BRAIN INJURY AND ADJUSTMENT**

Kelly (1955) first developed Personal Construct Theory and his fundamental postulate states that ‘a person’s processes are psychologically channelized by the ways in which he anticipates events’. Essentially Kelly viewed people as scientists who attempt to make sense of their world and anticipate events based on previous experience. He identified that we each hold a finite number of dichotomous constructs that we use in order to do this. Butler and Green (2007) elaborate on this concept by describing children as ‘architects of their own reality’ in that they only know the world through their own perceptions of it.

Urbach (1989) comments that children with a parent who experience a brain injury are faced with a challenging adjustment in that their parent may sustain behavioural, emotional and personality changes. He reports that to a variable degree, children may be faced with a different parent in the same body. This is relevant from

a Personal Construct Psychology (PCP) perspective, as the child, faced with such changes, may have to modify their own Personal Construct system in light of their experience. Kelly describes the concept of anxiety as an awareness that one's current construct system is not able to accommodate new experiences (Walker and Winter, 2007) and therefore individuals find themselves in the position of their experiences falling outside the range of convenience of their own construct system (Bannister and Fransella, 1986). It is therefore possible that the consequences of parental brain injury invalidate the child's construct system, resulting in a major reconstruing process within the child. As highlighted above, the experience of a brain injury within the family has been likened to grief or bereavement. Neimeyer (2009) comments that "grieving is a process of reconstructing a world of meaning that has been challenged by loss" (p. 306).

The PCP literature on post-traumatic stress may also be relevant when considering the impact of a brain injury within the family. Sewell (2005) observes that a pertinent feature of PCP theory in relation to understanding trauma is found in Kelly's fundamental postulate, which relates to how individuals anticipate events. A trauma disrupts the process by which events are anticipated, and a similar process may occur due to acquired brain injury.

Tyerman (2009) describes the use of repertory grids as helpful when addressing psychological adjustment in adults who have sustained a brain injury. The repertory grid is the primary assessment tool used within PCP and is "essentially a structured interview procedure which allows the investigator to obtain a glimpse of the world through the 'goggles' of their subject's construct system" (Winter, 1992, p.21).

In a case example presented by Tyerman (2009), a principal components analysis illustrated that the brain-injured client construed himself distantly from his family and others, and illustrated the isolated position he occupied post-injury. It was also reported that the constructs that emerged were heavily influenced by the brain injury, for example 'brain injured', 'non-driver' and 'non-head injury expert'. However, a limitation of this evidence is that it relates to one case example presented by the author. No evidence from a study consisting of multiple participants, or further case examples were presented.

Whilst Tyerman's (2009) case example relates to the brain-injured person themselves, given the devastating impact an ABI can have on the family, it is likely

that ABI in a parent will strongly impact upon the child's construct system as well. As repertory grids are reported to be helpful in adults with a brain-injury in relation to psychological adjustment, it is likely that this may be worth exploring in relation to the psychological adjustment of child relatives following parental ABI.

Winter, Metcalfe and Shoeb (1997) used repertory grids to explore the construing of significant others of individuals with an ABI and the relationship with recovery in the brain-injured client. The significant others who participated in the study included predominantly parents and partners, but also included siblings and children. In repertory grid technique, elements may be considered examples of a topic that are used to systematically discover an individual's constructs (Jankowicz, 2004). The elements used in the study were provided by the researchers and included the client now, before the injury and following rehabilitation, how I would like the client to be, how I would like to be, a brain-injured person, a mentally ill person, a mentally handicapped person, a physically disabled person, an epileptic person and a normal healthy person. Constructs were elicited using triads of these elements. The strongest finding of the study indicated that tighter construing in significant others was related to greater recovery in the brain-injured clients. Tight constructions refer to those constructs that offer definite statements of structure and where meaning can be clearly specified, whereas loose constructions may vary in their meaning (Epting, Gemignani, and Cross, 2005). The authors suggest that tight construing in significant others may be helpful due to many brain-injured clients having a tendency to construe loosely. They further suggest that tight construing may be helpful in coping with stress. Other findings outlined in the study include longer length of time elapsed since the brain-injury being related to the significant other construing the client as less like how they would like them to be. Recovery was also found to be related to significant others perceiving themselves to have changed to a greater extent post-injury. There was also found to be greater improvement in those whose significant other had a more favourable anticipation of the clients' outcome following rehabilitation. Importantly it was not only how significant others construed their brain-injured relative but also how they construed themselves that predicted recovery.

The aim of the study (Winter, et al., 1997) was to explore the relationship between significant others' construing and recovery following brain injury. The direction the study took was to explore the impact that construing had on the brain-injured client, but did not address the impact that construing had on the significant

others themselves. This naturally leads one to ask, what is the impact of construing style on the significant other themselves? The concept that tighter construing is helpful in managing stress may be relevant to the present study, as this may also facilitate adjustment following a brain injury in a significant other. Therefore it is possible that there may be a relationship between tightness of construing and level of adjustment in a child who has a parent with a brain injury.

In summary, a PCP approach to exploring the impact of parental ABI may be indicated in several ways. Firstly, major reconstruing within the child may occur as a result of the parental ABI. The sequelae of ABI may cause changes within the injured parent and the roles that they are able to fulfil, to the extent that some children may have the experience of their injured relative being like a new parent in the same body. Furthermore, as a result of these potential changes, the roles of the non-injured parent and their children may also adapt in response to them. This may result in major changes in how child relatives construe themselves and their significant others, which might be distressing to the child.

Secondly, the structure of the construct system may be relevant in that where the construct system relating to life before the brain injury remains dominant, or provides a more structured view of the world, as compared to the construct system relating to life after the injury,, the child may find themselves in a position where their construct system is unable to accommodate new experiences.

Thirdly, a study looking at the construct system of adult relatives identified a link between construing style and outcome in the person with a brain-injury and that tighter construing may be helpful in coping with stress (Winter et al., 1997).

Finally, repertory grids have been found to be useful in working with people with an ABI when addressing issues of adjustment (Tyerman, 2009).

## **2.8 HYPOTHESES**

The hypotheses have been designed to explore both the relationship between level of adjustment and possible changes within the structure of the construct system used by children following parental ABI, and possible changes with how significant others are construed.

### **Hypothesis 1**

Larger changes in how young people construe themselves and significant others following parental brain injury compared to how they construed themselves and significant others prior to parental brain injury will be associated with poorer adjustment of the young person.

### **Hypothesis 2**

More structured 'before acquired brain injury' constructs in comparison to the structure of 'after acquired brain injury' constructs will be associated with poorer adjustment of the young person following parental brain injury.

### **Hypothesis 3**

More superordinate 'before acquired brain injury' constructs in comparison to 'after acquired brain injury' constructs will be associated with poorer adjustment of the young person following parental brain injury.

### **Hypothesis 4**

Tighter construing will be associated with better adjustment of the young person following parental brain injury.

## **CHAPTER 3**

### **METHOD**

#### **3.1 DESIGN**

The study was a correlational design. The aim of the study was to explore relationships between self-reported level of adjustment and how children construe themselves and family members prior to and following their parent experiencing an ABI. A further aim was to explore relationships between tightness of construing and adjustment, in addition to exploring the structure of the construct system used in relation to adjustment. A qualitative content analysis of constructs was also completed to provide a richer analysis of the data.

#### **3.2 PARTICIPANTS**

Participants were children aged 10-17 who had a parent with an ABI.

Inclusion criteria were;

- The parental brain injury occurring a minimum of 6 months previously
- The child being able to clearly recall life before the brain injury occurred
- The child having contact with the injured parent (although this was not restricted to those living with the injured parent)
- The child possessing good use of the English language to ensure that they could engage in the interview

Children with a significant learning disability or significant cognitive impairment were not included in the study.

Participants were recruited via two sources, Headway, a national charity for individuals and families who have experienced an ABI, and an NHS Community Neurorehabilitation Team. The initial plan was to recruit solely through non-NHS organisations, but due to a poor response rate, it was decided to seek ethical approval to recruit through the NHS Community Neurorehabilitation Team at a later date. A total of two participants from two families were recruited via Headway, and a total of eight participants from seven families were recruited through the NHS Community Neurorehabilitation Team.

Of the two participants recruited through Headway, one family responded to an advert placed on the Headway Facebook page (Appendix A). The second family

was approached by a community support worker, employed at a local branch of Headway.

Participants recruited through the NHS Community Neurorehabilitation Team were initially identified and approached by their Team Clinicians during a routine appointment.

All potential participants expressing an interest in the study, regardless of source of recruitment, then received a telephone call from the author to provide further information regarding the study. For those agreeing, information sheets were then sent to the family. This included a parent version of the information sheet (See Appendices B1 & B2) and an age appropriate information sheet for the child identified as potentially taking part in the study (See Appendices C1, C2, D1 & D2). Feedback regarding the age appropriateness of the language content of the child information sheets was sought from a Consultant Speech and Language Therapist.

### **3.3 MEASURE OVERVIEW**

The review of the literature identified that a majority of the research took a narrow view of adjustment and tended to focus primarily on behavioural and/or emotional difficulties. It was therefore decided to identify a measure of adjustment that incorporated wider factors, had good reliability and validity and was appropriate for the age group being targeted for this study. In addition to the measure of adjustment, repertory grids were chosen, as they would be able to provide the specific data required to answer the hypotheses.

#### **3.3.1 Demographic Data**

Basic demographic data was obtained for each family in order to describe the sample. This included:

- Gender of child
- Ethnic Group
- Current age of child
- Age of child at the time of the parental ABI
- Time since parental ABI
- Parent with ABI (mother or father)
- Type of ABI

- Severity of ABI
- Whether or not the child resides with the parent with the ABI

The gender, current age and age at time of injury were obtained during the screening process, but other data was obtained as an initial task during face-to-face interviews. This enabled a rapport to be built prior to commencing the repertory grid and administering the adjustment measure. Where possible, type and severity of brain injury were verified in the brain injured parent's notes. This was only possible for participants recruited through the NHS Community Neurorehabilitation Team and was felt necessary, as not all clients knew which severity rating their brain injury had been classified as. Permission was obtained from the brain-injured client to seek this information in their clinical notes.

Duration of Post-traumatic Amnesia (PTA) or Glasgow Coma Scale (GCS) were both accepted as ratings of brain injury severity. PTA and GCS are common methods to classify severity of brain injury (Lezak, Howieson, and Loring, 2004). Brain injuries may be classified as mild (PTA 1 hour or less, GCS13-15), moderate (PTA 30mins-24hours, GCS 9-12) or severe (PTA 24hours+, GCS <8) using these methods (Rao and Lyketsos, 2000). None of the parents recruited from Headway were aware of being told their PTA or GCS rating. Therefore they were asked if they had been told whether their, or their spouse's, brain injury was classified as mild, moderate or severe. PTA or GCS score was available in the clinical notes for 3 out of 7 families recruited through the NHS Community Neurorehabilitation Team. For the 4 families where information could not be verified in the clinical notes (families where the brain injury was a stroke or subarachnoid haemorrhage), the disclosed severity rating was recorded.

Type of brain injury was either classified as either TBI, stroke, subarachnoid haemorrhage (SAH) or hypoxia.

Current age, age at time of the brain injury and time since the brain injury were all measured in nearest number of whole years.

### 3.4 MEASURES OF ADJUSTMENT

#### 3.4.1 Personality Inventory for Youth (Lachar and Gruber, 1995)

The Personality Inventory for Youth (PIY) is a 270-item self-report questionnaire that requires true/false responses to a series of statements. It is designed to evaluate the emotional and behavioral adjustment, family interaction, and neurocognitive and attention-related academic functioning of youths aged 9-19 years old. It provides adjustment scores in the following domains:

- Cognitive Impairment (the young person's perception of intellectual and learning abilities)
- Impulsivity and Distractibility (inattention, impatience, impulsivity and bravado)
- Delinquency (socially unacceptable behaviours)
- Family Dysfunction (relations between family members and some aspects of parental behaviour)
- Reality Distortion (symptoms of psychosis and feelings of alienation)
- Somatic Concern (somatic symptoms and health concerns)
- Psychological Discomfort (symptoms of anxiety and depression)
- Social Withdrawal (social discomfort and social introversion)
- Social Skills Deficit (peer relationships)

Raw scores on the PIY are converted to T scores. The minimum score obtainable is 35 and the maximum obtainable score is 90. Separate scoring templates and clinical cut-off points are provided for males and females, but no distinction is made for age. Higher T scores indicate poorer levels of adjustment.

Whilst this measure is lengthy to administer, it was chosen due to the broad range of types of adjustment that it measures. One of the key limitations of current literature exploring the adjustment of child relatives of a parent with an ABI is that it is limited in the areas that are explored, for example, focussing just on negative behaviours that may be displayed by the child.

A further advantage to the PIY is that it is a self-report measure. It was felt to be preferable for participants to complete a self-report measure, as the view of the parents may differ from the child. This was felt to be particularly important given that

the study sought to explore the child's viewpoint in terms of how the child constructed the world.

The importance of taking a broad view of adjustment and obtaining the child's perspective of their own adjustment is highlighted by McLaughlin (1992).

The PIY has excellent validity and reliability. Internal consistency is very good with coefficient alphas obtained on the PIY scales ranging from .74-.92 with a median of .85 and PIY subscale coefficient alphas ranging from .44-.84 with a median of .73. Temporal stability of the PIY is also very good with PIY scales obtaining test-retest reliability estimates ranging from .76-.91, with a median of .83 with the PIY subscales ranging from .58-.88 with a median of .73 (Lachar, 2004). The subscales that comprise the PIY also have good concurrent validity with other measures that examine similar constructs (Lachar and Gruber, 1995).

A limitation of the PIY in the context of this study is that the questionnaire is American and there are no UK normative data.

### **3.4.2 Parental Rating of Child Adjustment**

Whilst the focus of the study was on the child's perception of their own level of adjustment and how they construe themselves and significant others, it was felt that it would be beneficial to briefly explore parental perception of child adjustment. A disadvantage of self-report measures, such as the PIY, is that respondents may not answer accurately, for example due to individuals not wishing to be seen in a bad light or because they lack awareness or insight into difficulties that they might experience. The use of multiple sources or other perspectives is a useful methodological strategy to compensate for this disadvantage (Barker, Pistrang and Elliott, 2002). Therefore, a short question designed for the purposes of this study was presented as part of the initial information gathering stage of the interview. The parent(s) present at the interview were asked to answer the following question.

*“On a scale of 1 to 10, with 1 meaning not at all adjusted, and 10 meaning completely adjusted, how well adjusted do you think your child is since the brain injury?”*

If both parents were present, they were asked to come to a consensus so that a single parental rating was obtained.

### 3.5 REPERTORY GRID

A structured interview was designed to enable completion of the Repertory Grid. Methods and strategies for completing repertory grids are outlined by Jankowicz (2004), and the method described below takes into consideration the specific aims of this study and the age group of the participants. Repertory grids have been found to be an appropriate tool to use with children and adolescents, and have been used in both research and clinical practice (Butler and Green, 2007; Cipolletta, 2011; Fransella, Bell, and Bannister, 2004; Hicks and Nixon, 1989; Karppinen, 2000; Sewell and Cruise, 2004; Vranjesevic, 2003).

The first stage of the structured interview was to elicit the set of elements to be used. For each participant this consisted of five elements prior to the brain injury, and the same elements subsequent to the brain injury. All participants had themselves their mother and their father as elements (with the exception of 2 single parent families, where there was minimal contact with the father). Participants were then asked to think of two other people whom they were close to, whom they also knew before the brain injury occurred. Whilst participants were encouraged to choose elements from within their family, if there were no other family members close to the participant then other elements were chosen, for example, one child chose her childminder and another child chose a close friend.

The second stage of the structured interview was to elicit constructs using the 'triadic' method. 'Before ABI' constructs were elicited by generating triads from elements 1-5, who were all family members or people the child was close to prior to the ABI. 'After ABI' constructs were elicited by generating triads from elements 6-10, who were the same family members or people the child was close to used for elements 1-5, but the children were asked to think about these people after the brain injury occurred. To elicit the 'before ABI' constructs, children were shown three randomly selected flashcards with the names of elements 1-5 written on them. The children were asked to think of a way in which two people on the cards were similar, but different from the third. Flashcards were used to help the children do this, so that they could move the flashcards around, and physically group two people together and keep the third person separate in a way that they chose. Once the children had identified a word that described how two of the elements named on the flashcards were similar, they were asked to identify the opposite pole to the construct identified. This was done with prompts such as "So, if people aren't X, what is the opposite of

X?” Many children did this spontaneously, by automatically giving both poles of the construct without further prompts for example “me and my mum are agreeable, but my dad is argumentative”. A total of five “before ABI” and five “after ABI” constructs were elicited.

Nine participants were able to generate constructs using the triadic method. Some were assisted in doing this by using flashcards with the names of elements written on them, whilst others were able to do so without any visual aids. One participant found it extremely difficult to elicit constructs using the triadic method, and continued to struggle to generate constructs when the dyads of elements were used. Therefore single elements were used to elicit constructs. For example, this was done by asking the participant to think of a word that described each element to generate the emergent construct. The implicit construct was generating by asking “If a person isn’t X, what would they be like”. Once this approach was adapted, the participant was able to generate both poles of the construct with ease. Use of single elements to elicit constructs has been documented in several cases (Butler and Green, 2007; Fransella, et al., 2004; Walker and Winter, 2007).

Once all 10 constructs were elicited each element was rated for each construct on a scale of 1-7 with 1 representing one pole of the construct, 7 representing the opposite pole of the construct and 4 being the mid point indicating that neither pole of the construct describes the element being rated. Any rating between 1 and 7 could be selected to indicate the degree to which each construct described the element being rated.

### **3.6 COMPUTER PROGRAMMES USED TO ANALYSE THE REPERTORY GRIDS**

#### **3.6.1 Idiogrid (Grice, 2002)**

Individual grids were analysed using IDIOGRID, a software package specifically designed to analyse repertory grids. An individual grid Slater analysis was conducted for each participant’s grid. The following data was then extracted;

### ***Distances Between Elements***

The standardised Element Euclidean Distances were obtained for the following pairs of elements:

- Self before ABI- Self after ABI
- Mother before ABI-Mother after ABI
- Father before ABI-Father after ABI

Additionally, parents were also grouped according to who had received the ABI to provide the following pairs;

- Injured parent before ABI- Injured parent after ABI
- Non-injured parent before ABI – Non-injured parent after ABI

The distance between each pair of elements gives an indication of how similar or different a participant construes them to be, and will therefore be used to measure changes in how the young people construe themselves and their parents following the parental brain injury in order to test hypothesis one. A distance of less than 0.5 is considered to indicate the two elements being construed similarly, whereas a distance exceeding 1.5 is considered to indicate that the elements are construed very differently. A distance of 0 would indicate that the elements are construed identically, and a distance of 1 would be expected to be achieved by chance (Winter, 1992).

### ***Measure of Relative Intensity***

The measure of intensity is a measure of construct system structure and was first developed by Bannister (Bannister, 1960). It examines the relationships between constructs used in a repertory grid, with a high intensity score indicating that each construct implies other constructs rather than being used independently and therefore a more cognitively simple construct system. Conversely, the lower the intensity score, the more loosely-knit the constructs, which suggests a more cognitively complex construct system (Fransella, et al., 2004).

Hypothesis two predicts that poorer adjustment will be associated with more structured ‘before acquired brain injury’ constructs in comparison to the structure of ‘after acquired brain injury’ constructs. Hypothesis two will therefore be tested by measuring the relative intensity of ‘before ABI’ constructs in relation to ‘after ABI’ constructs.

The measure of relative intensity was calculated by examining the construct correlations generated by the Slater analysis and adding the square of all of the correlations between constructs 1-5 (before ABI Intensity) and the square of all of the correlations between constructs 6-10 (after ABI Intensity). The Intensity measure has been found to have good test-retest reliability (Feixas, Lopez Moliner, Navarro Montes, Tudela Mari, and Neimeyer, 1992; Smith, 2000) and good convergent reliability when compared to other structural measures of differentiation (Baldauf, Cron, and Grossenbacher, 2010; Feixas, et al., 1992). The ‘after ABI Intensity’ score was then subtracted from the ‘before ABI Intensity’ score. This figure was the measure of relative intensity used for analysis. A negative figure suggested that the ‘after ABI’ constructs were more intense in comparison to the ‘before ABI’ constructs. A positive figure suggested that the ‘before ABI’ constructs were more intense in comparison to the ‘after ABI’ constructs. The measure of relative intensity has also been used in previous studies (Winter, Goggins, Baker, and Metcalfe, 1996)

### ***Measure of Relative Superordinancy of Constructs***

Superordinancy of constructs can be described as a relative term, and refers to the hierarchical nature of constructs (Fransella, et al., 2004). Superordinate constructs are defined as “constructs that include others as one or more of the elements in their contexts” (Fransella, 2005, p.255) whereas subordinate constructs may be defined as “constructs that are included as elements in the context of others” (Fransella, 2005, p.255). Relative superordinancy or subordinancy is not seen as being fixed, but as varying over time (Fransella, et al., 2004).

Hypothesis three predicted that more superordinate ‘before acquired brain injury’ constructs in comparison to ‘after acquired brain injury’ constructs would be associated with poorer adjustment of the young person.

The percentage sum of squares may be used to identify the superordinancy of individual constructs (Bannister and Salmon, 1967; in Winter, 1992). As ten constructs were elicited for each participant in this study, each construct would be expected to have a percentage sum of squares of 10 if each construct were given equal weighting by the child. The measure of relative superordinancy was calculated by examining the descriptive statistics for constructs generated by the Slater analysis and adding the percentage sum of squares for constructs 1-5 (before ABI) and constructs 6-10 (after ABI). The total percentage sum of squares for the ‘after ABI’ constructs

was then subtracted from that for the ‘before ABI’ constructs. This figure was the measure of relative superordinancy used for analysis. A score of zero would indicate that ‘before ABI’ and ‘after ABI’ constructs had equal weighting. A negative figure would suggest that the ‘after ABI’ constructs were more superordinate in relation to the ‘before ABI’ constructs. A positive figure suggested that the ‘before ABI’ constructs were more superordinate in relation to the ‘after ABI’ constructs. Therefore a positive figure would indicate that there has been less change in the construct system used by the child, as the pre-ABI constructs remain dominant.

### ***Tightness of Construing***

Hypothesis four predicted that tighter construing would be associated with better adjustment of the child following parental brain injury.

Tightness of construing was measured by extracting the Percentage Variance Accounted for by the First Factor (PVAFF), which was available from the Eigenvalue Decomposition data. Higher scores indicate tighter construing or a more unidimensional construct system, whereas lower scores indicate looser construing, (Winter, 2003). The PVAFF has also been found to have good test-retest reliability (Caputi and Keynes, 2001; Smith, 2000) and good convergent reliability when compared to other structural measures of differentiation (Baldauf, et al., 2010). Scores range from 0 to 1.

### **3.7 CLASSIFICATION SYSTEM FOR PERSONAL CONSTRUCTS (Feixas, et al., 2002)**

The Classification System for Personal Constructs (CSPC) is designed to analyse the personal constructs that have been elicited by PCP assessment tools such as the repertory grid. The authors of the measure state that the CSPS can be used as a qualitative tool to explore the content of constructs that complements more quantitative measures of construct structure.

The CSPC consists of 45 categories, which are grouped into six hierarchical areas. These are:

1. Moral
2. Emotional
3. Relational
4. Personal

5. Intellectual/operational
6. Values and interests

Two additional categories were later added to the system, which are ‘existential’ and ‘concrete descriptors’. For each category, the authors provide examples of constructs as illustrations to aid coding.

Both construct poles are considered together when classifying constructs. The system is hierarchical in nature to increase the reliability of the measure. This means that constructs are only rated at the highest category for which they fit.

The reliability of the CSPC was assessed by two independent judges, rating a total of 843 constructs. The authors report good reliability of the measure and the total percentage of agreement between raters was 87.3%. It was also reported that in all of the 45 categories of the CSPC the raters agreed in a minimum of 66.7% of cases.

For the purposes of this study, all constructs by all participants were rated using the eight categories of the CSPC. Constructs were divided into two sets, dependent on whether the constructs were elicited from ‘before ABI’ elements or ‘after ABI’ elements. All constructs were also rated by a second independent rater to check for reliability. The independent rater was a trainee clinical psychologist who was familiar with the CSPC, as they were also using it in their own research project. There was a total percentage of agreement of 50% on construct classifications between the Chief Investigator and the independent rater. Where there was a discrepancy between ratings, a consensus was obtained between raters, and this final classification was used in the final analysis.

Once every construct in both ‘before ABI’ and ‘after ABI’ sets had been rated, these were converted to percentages of frequency of occurrence.

### **3.8 METHODOLOGY**

Regardless of source of recruitment (Headway or NHS Community Neurorehabilitation Team), once parents had expressed an interest in their child taking part in the study, the parents were telephoned by the author and given brief details about the study and to screen for suitability of the child (e.g. age of child, time since injury). Those parents whose children were suitable for participation and who continued to express an interest were then provided with both the parent and age appropriate child information sheets (See Appendices B1, B2, C1, C2, D1 & D2). Parents were invited to contact the author if they had any questions arising from the

information sheets or if they wished to proceed with taking part in the study. A mutually convenient appointment was then made for those who wished to take part in the study. Participants and their parents had the choice of meeting in their own home, and either their local Headway branch or at the Community Neurorehabilitation Team depending on source of recruitment. All participants and their parents chose to have the interview conducted in their own homes.

At the appointment, the participants and their family members were asked if they had any further questions, or wished to discuss the information sheets. Both the child and at least one of their parents were then asked to read and sign age appropriate consent forms (See Appendices E1, E2, F1, F2, G1 & G2). The opportunity to ask questions regarding the consent form was given and checks were made to ensure that all parties understood the form. Once consent had been obtained the families were given the choice of having the parent present or absent during the administration of the PIY and the structured interview for the repertory grid. Whilst it is acknowledged that the presence of the parent might have influenced the children's responses in the interview, it was felt that it was important to offer this option to ensure that the child felt safe and comfortable taking part in the study. Four (40%) families chose to have the parent(s) present during the interview, whereas 6 (60%) of families chose not to have the parent(s) present during the interview. In all four cases where a parent was present during the interview, it was the mother who accompanied the child. In two instances the accompanying mother was the injured parent, and in two instances the accompanying mother was the non-injured parent. Regardless of the decision for the parent(s) to be present or absent for the latter part of the interview, demographic information was obtained with both the child and parent(s) present. Following this, the children then completed the PIY by responding true or false to the questions. The author read these out, and additionally child participants were given the option of having a question book to read at the same time. Following completion of the PIY, the structured interview to complete the repertory grid was conducted. Following the completion of the interview, debrief information was given (See Appendices H1 & H2), in addition to the opportunity to discuss any issues arising from the interview or to answer further questions.

### **3.9 DATA ANALYSIS**

The non-parametric test Spearman's Rank Order correlation coefficient (one-tailed, except where indicated) was used due to the small sample size included in the study. Strength of the correlations reported is based on Cohen's (1988) recommendations of  $r=.10$  to  $.29$  or  $-.10$  to  $-.29$  indicating a small correlation,  $r=.30$  to  $.49$  or  $-.30$  to  $-.49$  indicating a medium correlation and  $r=.50$  to  $1.0$  or  $-.50$  to  $-1.0$  indicating a large correlation. Due to the limitations of the small sample size used for the study, only medium and large correlations with an alpha value of  $p=0.05$  or less will be commented on.

### **3.10 PARTICIPANT FEEDBACK**

Participants and their parents were offered the opportunity to receive information regarding the findings of the study once the study was completed. Participants were able to leave contact details for information to be forwarded to, and were able to choose to have the information sent through the post, or electronically via email. Participants and their families were not offered the opportunity to have their individual PIY scores or their repertory grid information fed back. Participants were informed of this prior to engaging in the study.

### **3.11 POWER CALCULATION**

An a priori power calculation was done to determine sample size. Assuming a modest correlation of  $r=.30$  a sample size of 49 would be required to detect this correlation with a power of  $.80$  and an alpha error of 10% (one tailed). Assuming a substantial correlation of  $r=.50$  the sample size required to detect it with a power of  $.80$  and an alpha error of 5% (one tailed) is  $N=23$ . The power calculations were conducted with the computer programme G\*Power.

### **3.12 ETHICAL CONSIDERATION**

Ethical approval for the study was granted by the University of Hertfordshire Ethics Committee in July 2010 with the plan to recruit participants from Headway (See Appendix J). However, following a poor response rate NHS Ethical approval for the study was gained in January 2011 (See Appendix K) with final R&D approval being granted in March 2011 (See Appendix L). Each ethics committee raised different points about information that should be included on information sheets and

consents forms, resulting in different versions of the forms being used for those recruited through Headway and those recruited through the NHS Clinical Neurorehabilitation Service. Amendments requested by the UH ethics committee included 1) stating that the chief investigator had criminal records bureau (CRB) clearance, 2) rewording a comment on the children's information sheet explaining the need to pass on any information disclosed that the child may be at risk and 3) providing information that a break could be taken, if needed, during the interview process. These amendments were made prior to final ethical approval being granted. The amended sheets were submitted to the NHS ethics committee, who then made subsequent recommendations for amendments. Full details of the NHS ethics committee recommendations can be found in Appendix I. Final ethical approval was granted following these amendments being made.

### ***Consent***

Informed consent was sought from all participants and their parent(s). This is in keeping with the increasing recognition of the importance of obtaining informed consent from children, as opposed to assent from child participants and proxy consent from adult guardians (Tisdall, Davis, and Gallagher, 2009). Consent was obtained verbally during initial telephone contact (parental only) and then also in writing prior to completing the interview (child and parent). This was in the form of a written information sheet and consent form. These were sent to the participant prior to meeting with them to carry out the interview so that they had time to read and prepare any questions they may have had for the chief investigator. The consent form explicitly stated that the child could withdraw/be withdrawn from the study at any time without giving any reason. Due to the potential difficulty in understanding the information that may have occurred due to either the age of the child, or the parental brain injury, time was taken to ensure that all parties clearly understood the information given to them, to ensure that informed consent was being given.

### ***Potential distress to participants***

The total anticipated length of each appointment was approximately two hours. Breaks were offered to the child at regular intervals to minimise levels of tiredness and maximise comfort. The option to conduct the interview over more than one session was also offered. Engaging in the interview to complete the repertory grid

may have been potentially distressing for the children as they would be discussing how they perceive people close to them both before and after their parent experienced a brain injury. However, it was anticipated that some participants may have found it a valuable experience and welcomed the opportunity to consider the areas addressed in the research. The questionnaires given to the children may have indicated that they were experiencing poor levels of adjustment, or the questions asked may have raised issues for the children. All families, regardless of level of distress, or score on measure of adjustment were given the contact details of a support group in the local area and the local Headway office. Information regarding other sources of support was also provided, for example young carers' websites. If there were particular concerns about the levels of distress a child participant experienced during the research, I would initially have been able to draw upon my clinical psychology skills in trying to minimise the impact of this distress. If there were ongoing concerns I would have discussed the child with my field supervisor, who has a special interest in working with child relatives of individuals with a brain injury. I would also have sought permission to contact the family GP, or encouraged the family to contact the GP if the family or child had concerns that there were ongoing psychological, mood or adjustment difficulties. If information were to be disclosed that suggested that the child was at risk of harm or abuse I would have contacted the child's local social services team.

### ***Confidentiality***

Confidentiality was maintained at all times. All grids, questionnaires and data were anonymised by using a coding system, for example, using numbers on questionnaires/grids instead of names. The coded data was stored in a password-protected file. The coded paper copies of the grids/questionnaires were kept in a locked container that could only be accessed by the chief investigator.

## CHAPTER 4

### RESULTS

The sample will be initially described in terms of demographic characteristics. This will then be followed by a summary description of the elements chosen by participants when completing the repertory grid. Additionally, descriptive statistics for each variable will be presented. The results of the test of each of the four hypotheses will then be presented in turn. This will take the form of several correlational analyses for each hypothesis, due to the PIY being broken down into several scales. This will then be followed by a qualitative analysis of the content of the constructs selected by participants, and will compare the content of 'before ABI' constructs and 'after ABI' constructs. Finally, two case examples will be presented, the first being an example of a participant who was well adjusted as measured by the PIY and the second being an example of a participant who was poorly adjusted as measured by the PIY.

#### 4.1 DEMOGRAPHIC INFORMATION

There were a total of ten participants in the study. As can be seen in Table 1, four participants were male and six participants were female. The mean age of participants was 12.30 (range 10-17, std. dev. 2.16). The mean age of the participants at the time of their parent's injury was 8.90 (range 6-14, std.dev. 2.56). The mean number of years since the parental brain injury had occurred was 3.50 (range 1-5, std.dev. 1.65). In three cases the participant's mother had an ABI, and in seven cases the participant's father had an ABI. The most frequently occurring cause of the brain injury was stroke (N=5), and the second most frequently occurring cause was traumatic brain injury (N=3). One of the parental brain injuries was classified as an hypoxic brain injury and one of the parental brain injuries was classified as a subarachnoid haemorrhage. All of the participants lived with the parent who had an ABI.

**TABLE 1**  
**Demographic Information**

<b>Gender</b>	Male	4	Female	6
<b>Ethnic Group</b>	White British	9	British Bangladeshi	1
<b>Current Age</b>	Mean = 12.30	Std. Dev. = 2.16	Range = 10-17	
<b>Age at time of ABI</b>	Mean = 8.90	Std. Dev. = 2.59	Range = 6-14	
<b>Time Since ABI</b>	Mean = 3.50	Std. Dev. = 1.65	Range = 1-5	
<b>Parent With ABI</b>	Father	7	Mother	3
	Stroke	5	SAH	1
<b>Type of ABI</b>	TBI	3	Hypoxic	1
<b>Severity of ABI</b>	Mild	2	Moderate	4
	Severe	4		
<b>Lives with parent with ABI</b>	Yes	10	No	0

#### 4.2 SUMMARY OF ELEMENTS SELECTED BY PARTICIPANTS

All participants chose five elements. Each element was considered ‘before the ABI’ and ‘after the ABI’. All participants selected themselves and their mothers. Eight participants selected their father as an element. Two participants did not live with their father, and had minimal contact with him, so they did not select him as an element. In both cases, the separation occurred prior to the brain injury, which was therefore not connected to the breakdown of the family home. Examples of other elements selected include siblings, grandparents, aunts and uncles and close family friends. A breakdown of the choice of elements can be found in Table 2.

**TABLE 2**  
**Summary of Frequency of Selected Elements**

<b>Element</b>	<b>Frequency</b>
<b>Self</b>	10
<b>Mother</b>	10
<b>Father</b>	8
<b>Sibling</b>	5
<b>Sibling-in-law</b>	1
<b>Grandparent</b>	7
<b>Aunt/Uncle</b>	4
<b>Family friend (adult)</b>	1
<b>Friend (child)</b>	3
<b>Childminder</b>	1

### 4.3 DESCRIPTIVE STATISTICS OF VARIABLES

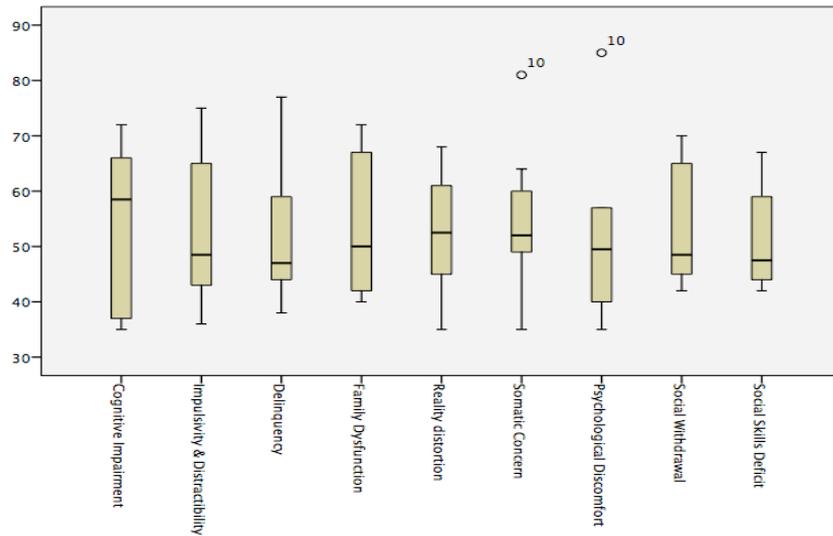
A summary of the data for each variable is provided. Firstly, means, range of scores and standard deviations are supplied for each of the scales that comprise the PIY and the parent rating of child adjustment. These results can be found in Table 3. Furthermore, the means, range of scores and standard deviations for the measures extracted from the grid may also be found in Table 3. Furthermore boxplots of the scores for each of the scales that comprise the PIY can be found in Figure 2 and boxplots for data extracted from the repertory grids can be found in Figures 3, 4, 5 and 6.

As can be seen from examining the table and Figure 2, the scores for all of the PIY scales reflect individuals who fall both within the well-adjusted (below 60) and poorly adjusted range (above 60). However, the scores for the Psychological Discomfort Scale mostly fall within the well-adjusted range of scores with the exception of one outlier.

**TABLE 3**  
**Descriptive Statistics for Variables**

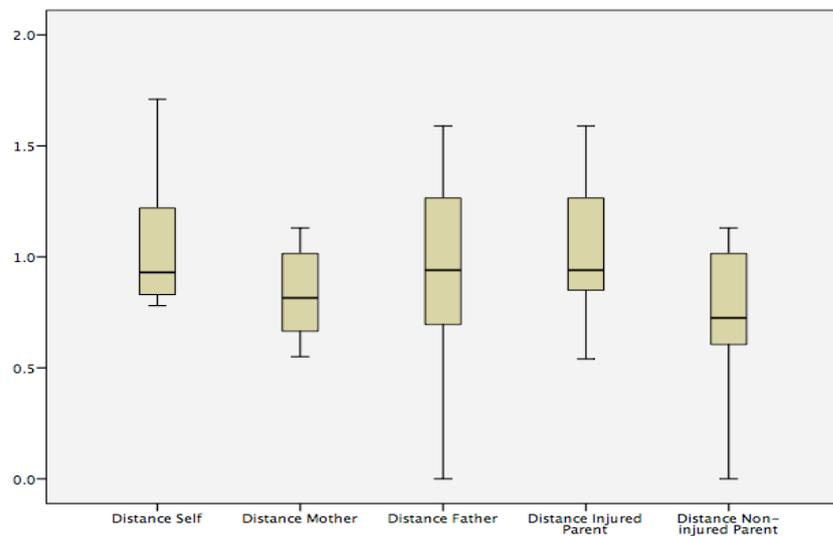
Measure	Mean	Range	Std. Deviation
Cognitive Impairment Scale	53.30	35-72	14.84
Impulsivity and Distractibility Scale	52.60	36-75	13.53
Delinquency Scale	52.60	38-77	13.33
Family Dysfunction Scale	52.80	40-72	12.22
Reality Distortion Scale	52.80	35-68	11.16
Somatic Concern Scale	53.90	35-81	12.56
Psychological Discomfort Scale	51.10	35-85	14.28
Social Withdrawal Scale	54.00	42-70	11.30
Social Skills Deficit Scale	51.10	42-67	8.92
Parent Rating of Child Adjustment	7.30	4-9	1.64
Standardised Euclidean Distance Self 'Before ABI'-Self 'After ABI'	1.11	0.78-1.71	0.31
Standardised Euclidean Distance Mother 'Before ABI'-Mother 'After ABI'	0.82	0.33-1.18	0.28
Standardised Euclidean Distance Father 'Before ABI'-Father 'After ABI'	0.92	0.00-1.59	0.49
Standardised Euclidean Distance Injured Parent 'Before ABI'-Injured Parent 'After ABI'	0.98	0.33-1.59	0.37
Standardised Euclidean Distance Non-injured Parent 'Before ABI'-Non-injured Parent 'After ABI'	0.73	0.00-1.13	0.37
Relative Intensity	0.0365	-2.40-2.60	1.59
Relative Superordinancy	1.97	-5.19-17.01	6.61
Tightness of Construing Measure	55.45	30.16-83.81	18.18

**FIGURE 2**  
**Boxplots Illustrating Data for PIY Scales**



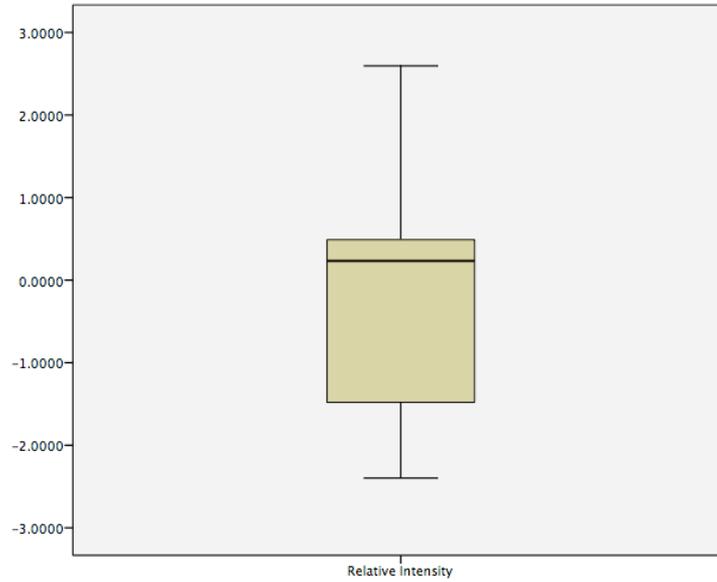
When the standardised Euclidean distances are examined (Figure 3), a range of scores is shown that reflects both similar and dissimilar construing of elements following parental brain injury. However, it should be noted that the range of distances for mothers is smaller in comparison to the other distances measured.

**FIGURE 3**  
**Boxplots Illustrating Data for Standardised Euclidean Distances**



When Table 3 and Figure 4 are examined, it can be seen the relative intensity scores reflect a range that include individuals with both positive and negative figures, indicating that there are both those whose 'before ABI' constructs are more intense and those whose 'after ABI' constructs are more intense. However, the median score is close to 0, and the interquartile range includes predominantly negative scores.

**FIGURE 4**  
**Boxplot Illustrating Data for Relative Intensity Score**



Examination of the data for relative superordinacy data (Table 3 and Figure 5) shows that the range of scores includes individuals with both positive and negative scores. There was also one outlier score from participant 8, whose score was much higher in comparison to other participants.

**FIGURE 5**  
**Boxplot Illustrating Data for Relative Superordinacy Score**

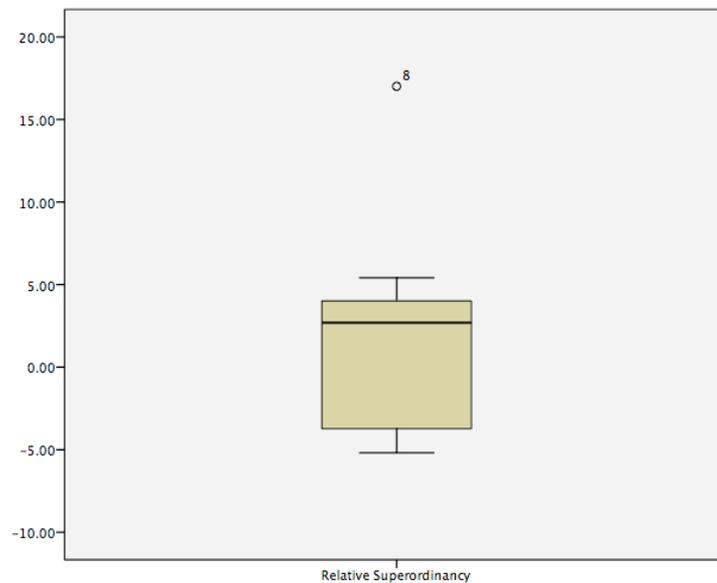
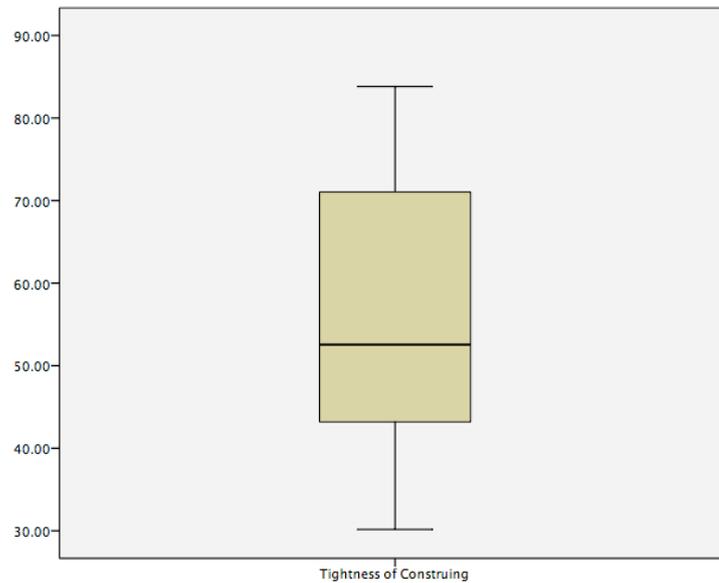


Table 3 and Figure 6 show that tightness of construing scores also reflect scores that represent individuals who construe relatively loosely and those who construe relatively tightly.

**FIGURE 6**  
**Boxplot Illustrating Data for Tightness of Construing**



#### **4.4 TEST OF HYPOTHESIS 1**

##### **4.4.1 Restatement of Hypothesis 1**

Larger changes in how young people construe themselves and significant others following parental brain injury compared to how they construed themselves and significant others prior to parental brain injury will be associated with poorer adjustment of the young person.

##### **4.4.2 Testing of Hypothesis 1**

Hypothesis 1 was tested by exploring the relationship between the scale scores on the PIY and the standardised Euclidean distances of ‘before ABI’ elements compared to ‘after ABI’ elements. A further exploration of the relationship between the parental rating of their child’s adjustment and the standardised Euclidean distances of ‘before ABI’ elements and ‘after ABI’ Euclidean distances was also conducted.

The specific Euclidean distances examined were:

- ‘Self before ABI’ - ‘Self after ABI’
- ‘Mother before ABI’ – ‘Mother after ABI’
- ‘Father before ABI’ – ‘Father after ABI’
- ‘Injured parent before ABI’ – ‘Injured parent after ABI’
- ‘Non-injured parent before ABI’ – ‘Non-injured parent after ABI’

The relationships were investigated using Spearman's Rank Order correlation coefficient.

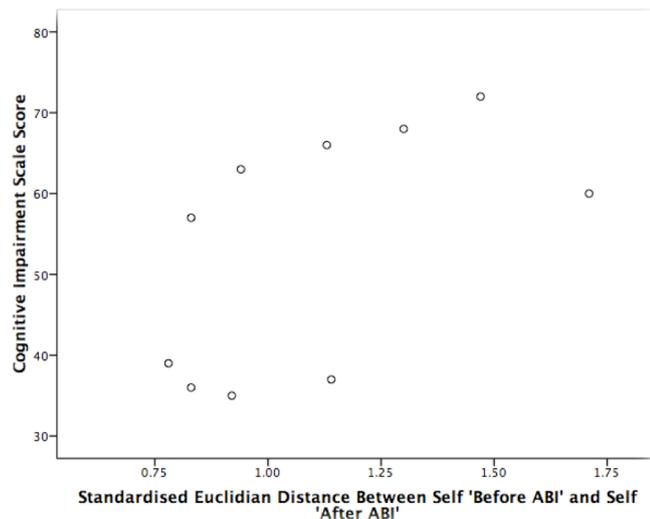
### ***Cognitive Impairment Scale***

#### ***'Self before ABI' – 'Self after ABI'***

There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Cognitive Impairment Scale of the PIY ( $r = 0.596$ ,  $N=10$ ,  $p=0.035$ ). A scatterplot illustrating this relationship can be found in Figure 7. As can be seen in the graph, the data points form a wide band in a pattern indicating a positive correlation.

**Figure 7**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Self Before ABI' and 'Self After ABI' and Score on the Cognitive Impairment Scale of the PIY**

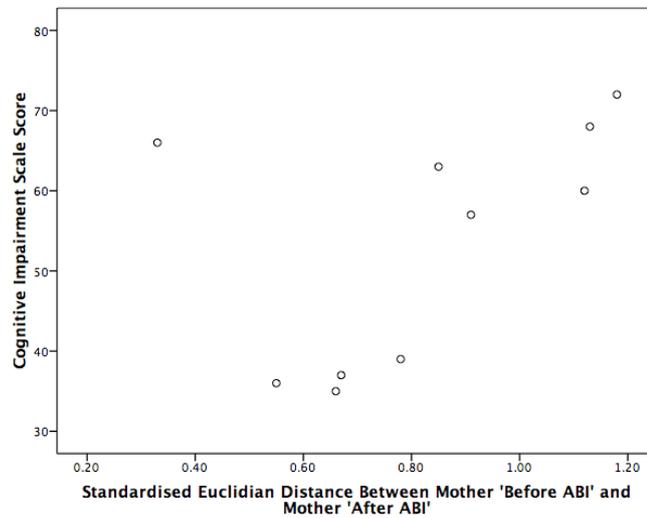


#### ***'Mother before ABI' – 'Mother after ABI'***

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Cognitive Impairment Scale of the PIY ( $r = 0.612$ ,  $N=10$ ,  $p=0.030$ ). A scatterplot illustrating this relationship can be found in Figure 8. As can be seen in the graph, most of the data points fall within a relatively narrow line indicating a positive correlation, with the exception of one data point that falls outside of this general pattern.

Figure 8

Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Mother Before ABI' and 'Mother After ABI' and Score on the Cognitive Impairment Scale of the PIY



*'Father before ABI' – 'Father after ABI'*

There was a small positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Cognitive Impairment Scale of the PIY ( $r= 0.286$ ,  $N=8$ ,  $p=0.246$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Cognitive Impairment Scale of the PIY ( $r= 0.310$ ,  $N=10$ ,  $p=0.192$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Cognitive Impairment Scale of the PIY ( $r= 0.476$ ,  $N=8$ ,  $p=0.116$ ).

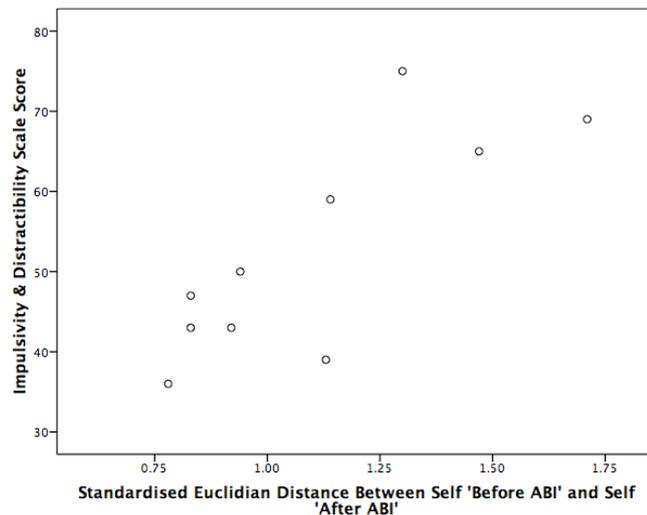
### ***Impulsivity and Distractibility Scale***

#### *'Self before ABI' – 'Self after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.814$ ,  $N=10$ ,  $p=0.002$ ). A scatterplot illustrating the data can be found in Figure 9. As can be seen in the graph, the data falls within a relatively narrow line and indicates a positive correlation between the two variables.

**Figure 9**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Self Before ABI' and 'Self After ABI' and Score on the Impulsivity and Distractibility Scale of the PIY**



#### *'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.675$ ,  $N=10$ ,  $p=0.016$ ).

#### *'Father before ABI' – 'Father after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.587$ ,  $N=8$ ,  $p=0.063$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.777$ ,  $N=10$ ,  $p=0.004$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

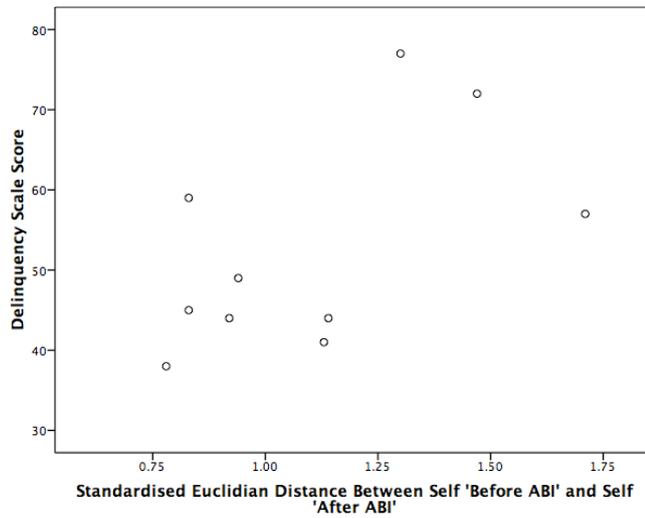
There was a medium positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.371$ ,  $N=8$ ,  $p=0.183$ ).

***Delinquency Scale****'Self before ABI' – 'Self after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Delinquency Scale of the PIY ( $r= 0.518$ ,  $N=10$ ,  $p=0.062$ ). However, when the data is examined in a scatterplot (Figure 10) it can be seen that the data appears to cluster into two groups of low standardised Euclidean distance and low score on the Delinquency Scale and of higher standardised Euclidean distance and high score on the Delinquency Scale with quite a large gap in the mid range of the scores. The data points that are present appear to indicate quite a broad spread.

**Figure 10**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Self Before ABI' and 'Self After ABI' and Score on the Delinquency Scale of the PIY**

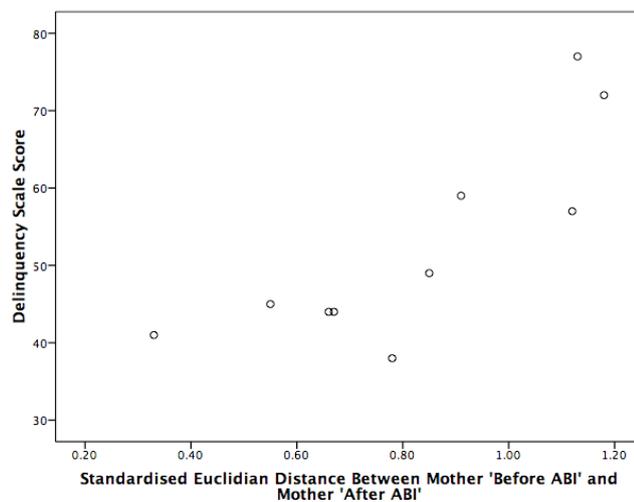


*'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Delinquency Scale of the PIY ( $r=0.815$ ,  $N=10$ ,  $p=0.002$ ). As can be seen in Figure 11, the data points form a narrow line with a flattened base. The flattening of the line occurs where the standardised Euclidean distances are very low, which may account for this effect.

**Figure 11**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Mother Before ABI' and 'Mother After ABI' and Score on the Delinquency Scale of the PIY**



*'Father before ABI' – 'Father after ABI'*

There was a small positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Delinquency Scale of the PIY ( $r= 0.216$ ,  $N=8$ ,  $p=0.304$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Delinquency Scale of the PIY ( $r= 0.524$ ,  $N=10$ ,  $p=0.060$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Delinquency Scale of the PIY ( $r= 0.515$ ,  $N=8$ ,  $p=0.096$ ).

***Family Dysfunction Scale****'Self before ABI' – 'Self after ABI'*

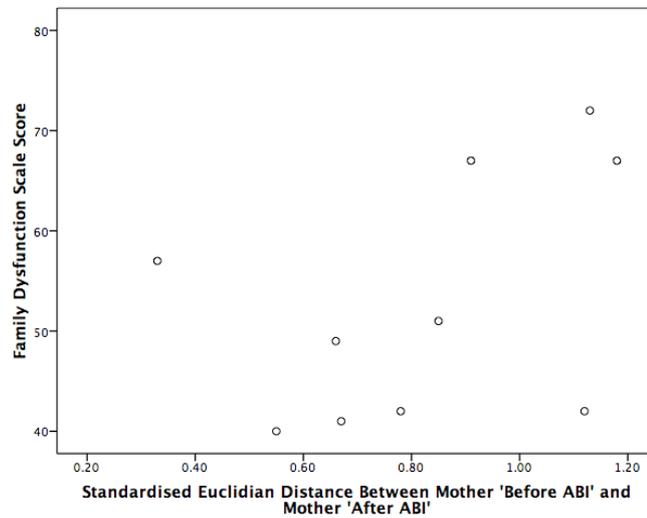
There was a small positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Family Dysfunction Scale of the PIY ( $r= 0.272$ ,  $N=10$ ,  $p=0.223$ ).

*'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Family Dysfunction Scale of the PIY ( $r= 0.555$ ,  $N=10$ ,  $p=0.048$ ). However, caution should be taken when interpreting this as when the data is examined in a scatterplot (see Figure 12) it can be seen that whilst most data points form a reasonably narrow line indicating a positive correlation, there are two data points that fall outside of this main pattern.

**Figure 12**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Mother Before ABI' and 'Mother After ABI' and Score on the Family Dysfunction Scale of the PIY**



*'Father before ABI' – 'Father after ABI'*

There was a small negative correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Family Dysfunction Scale of the PIY ( $r = -0.180$ ,  $N=8$ ,  $p=0.670$ , two tailed).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was no correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Family Dysfunction Scale of the PIY ( $r = -0.021$ ,  $N=10$ ,  $p=0.953$ , two tailed).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Family Dysfunction Scale of the PIY ( $r = 0.407$ ,  $N=8$ ,  $p=0.158$ ).

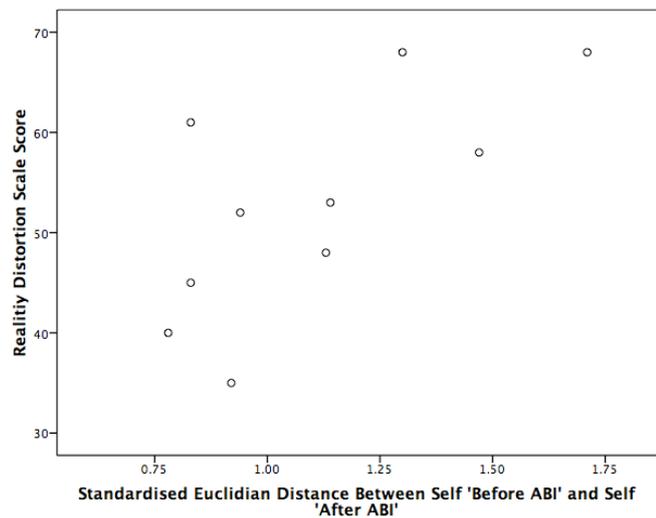
### ***Reality Distortion Scale***

#### *'Self before ABI' – 'Self after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Reality Distortion Scale of the PIY ( $r= 0.683$ ,  $N=10$ ,  $p=0.015$ ). A scatterplot illustrating the data can be found in Figure 13, which indicates a broad dispersion of data points forming a positive correlation.

**FIGURE 13**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Self Before ABI' and 'Self After ABI' and Score on the Reality Distortion Scale of the PIY**

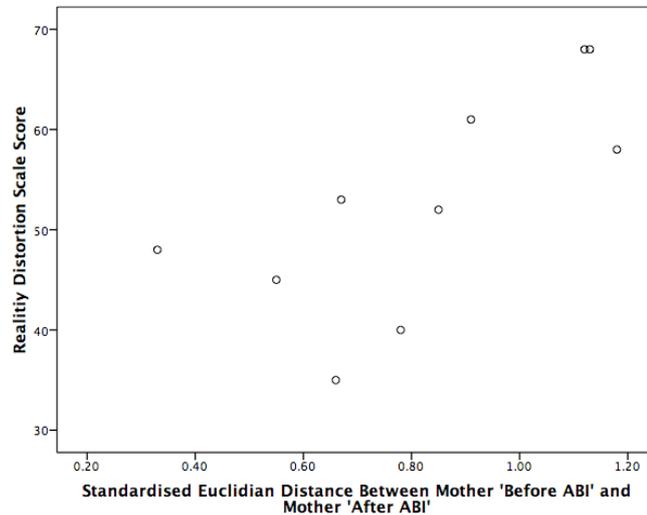


#### *'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Reality Distortion Scale of the PIY ( $r= 0.754$ ,  $N=10$ ,  $p=0.006$ ). A scatterplot illustrating the data can be found in Figure 14. As can be seen, the data points largely form a reasonably narrow dispersion along a positive correlational line, with the exception of the data point on the far left, which although it indicates a very low standardised Euclidean distance, has a Reality Distortion Scale Score that falls within the mid range of scores obtained by the sample. However, the score that was obtained by this individual still falls well below the clinical cut off point for poor adjustment, indicating that this individual showed good adjustment as measured by this scale.

FIGURE 14

Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Mother Before ABI' and 'Mother After ABI' and Score on the Reality Distortion Scale of the PIY

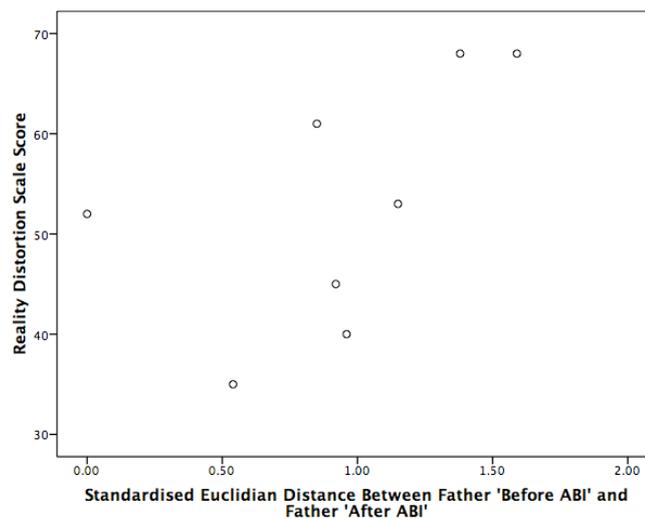


*'Father before ABI' – 'Father after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Reality Distortion Scale of the PIY ( $r=0.635$ ,  $N=8$ ,  $p=0.045$ ). A scatterplot illustrating the data can be found in Figure 15. As can be seen, the data largely form a quite narrow band showing a positive correlation, with the exception of one data point that falls outside of this main pattern and can be seen on the far left of the graph.

FIGURE 15

Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Father Before ABI' and 'Father After ABI' and Score on the Reality Distortion Scale of the PIY



*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Reality Distortion Scale of the PIY ( $r= 0.665$ ,  $N=10$ ,  $p=0.018$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Reality Distortion Scale of the PIY ( $r= 0.707$ ,  $N=8$ ,  $p=0.025$ ).

***Somatic Concern Scale***

*'Self before ABI' – 'Self after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.377$ ,  $N=10$ ,  $p= 0.142$ ).

*'Mother before ABI' – 'Mother after ABI'*

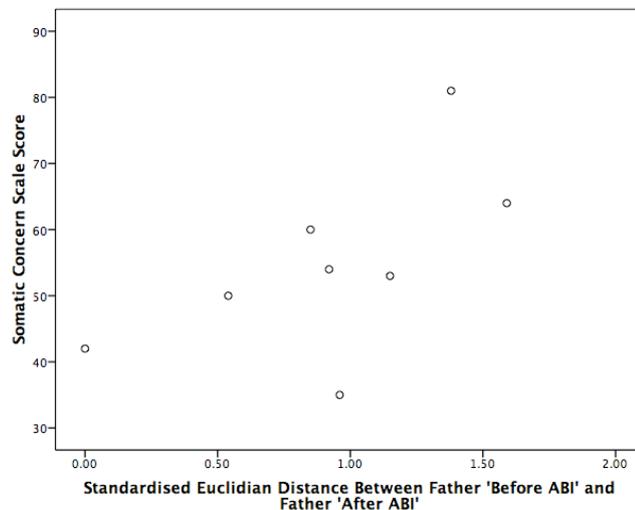
There was a small positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.212$ ,  $N=10$ ,  $p=0.278$ ).

*'Father before ABI' – 'Father after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.595$ ,  $N=8$ ,  $p=0.060$ ). A scatterplot illustrating the data can be found in Figure 16. The scatterplot shows that the data points form a clear positive relationship, with the exception of the bottom data point.

**FIGURE 16**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Father Before ABI' and 'Father After ABI' and Score on the Somatic Concern Scale of the PIY**

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.395$ ,  $N=10$ ,  $p=0.129$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI'

and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.690$ ,  $N=8$ ,  $p=0.029$ ).

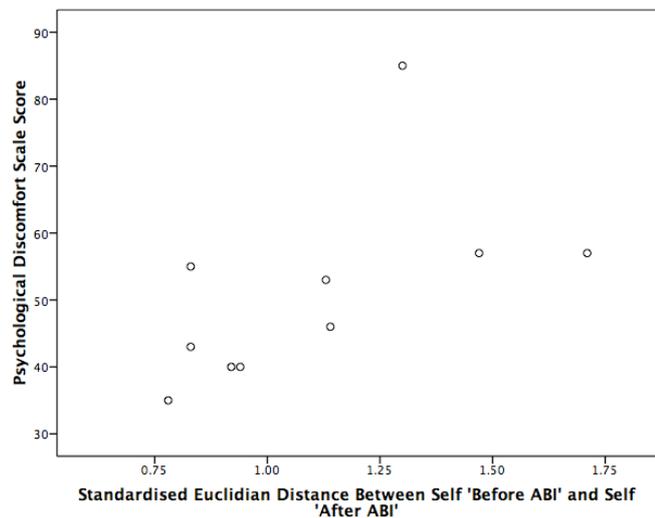
### ***Psychological Discomfort Scale***

#### *'Self before ABI' – 'Self after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.746$ ,  $N=10$ ,  $p=0.007$ ). A scatterplot illustrating the data can be found in Figure 17. Whilst the scatterplot indicates a positive correlation between the two variables, it should be noted that all but one of the scores on the Psychological Discomfort Scale are relatively low and fall below the clinical cut off point of 60. There was just one data point that scored above the cut off point, and this was an extremely high score of 85. This may have distorted the findings for this particular analysis.

**FIGURE 17**

**Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Self Before ABI' and 'Self After ABI' and Score on the Psychological Discomfort Scale of the PIY**



#### *'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.622$ ,  $N=10$ ,  $p=0.027$ ).

*'Father before ABI' – 'Father after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.635$ ,  $N=8$ ,  $p=0.045$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.560$ ,  $N=10$ ,  $p=0.046$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.719$ ,  $N=8$ ,  $p=0.022$ ).

***Social Withdrawal Scale****'Self before ABI' – 'Self after ABI'*

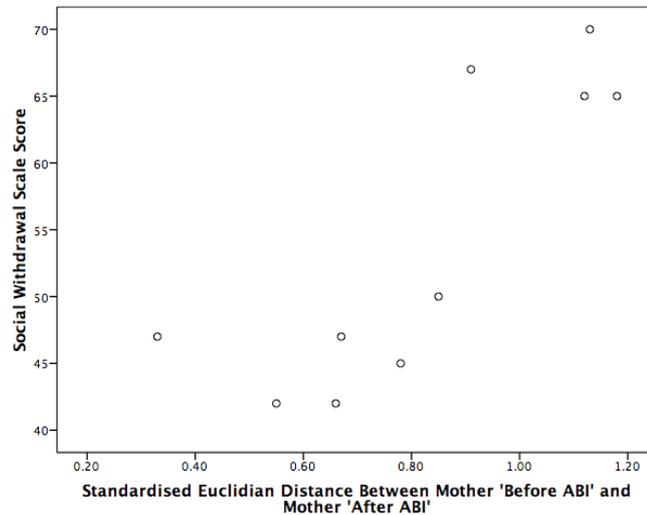
There was a large positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.537$ ,  $N=10$ ,  $p=0.055$ ).

*'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.813$ ,  $N=10$ ,  $p=0.002$ ). A scatterplot illustrating the data can be found in Figure 18. The scatterplot illustrates a positive correlation between the two variables and shows a clear distinction between those who score highly on the Social Withdrawal Scale and have comparatively large distances between how they construe their mother prior to and following parental brain injury, and those with smaller distances and low scores on the measure.

FIGURE 18

Scatterplot Illustrating the Relationship Between Standardised Euclidean Distance Between 'Mother Before ABI' and 'Mother After ABI' and Score on the Social Withdrawal Scale of the PIY



*'Father before ABI' – 'Father after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.383$ ,  $N=8$ ,  $p=0.174$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.485$ ,  $N=10$ ,  $p=0.078$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.707$ ,  $N=8$ ,  $p=0.025$ ).

### ***Social Skills Deficit Scale***

#### *'Self before ABI' – 'Self after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.402$ ,  $N=10$ ,  $p=0.125$ ).

#### *'Mother before ABI' – 'Mother after ABI'*

There was a large positive correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.502$ ,  $N=10$ ,  $p= 0.070$ ).

#### *'Father before ABI' – 'Father after ABI'*

There was a small negative correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= -0.109$ ,  $N=8$ ,  $p=0.797$ , two tailed).

#### *'Injured parent before ABI' – 'Injured parent after ABI'*

There was no correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.018$ ,  $N=10$ ,  $p=0.480$ ).

#### *'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a small positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.145$ ,  $N=8$ ,  $p=0.366$ ).

### ***Parent Rating of Child Adjustment***

It should be noted that the scoring system on the parental rating of child adjustment is the reverse of the PIY scales, in that a high score is indicative of good adjustment, and a low score is indicative of poor adjustment. Therefore, a negative correlation would indicate a relationship between smaller standardised Euclidean distances and better adjustment.

*'Self before ABI' – 'Self after ABI'*

There was a small negative correlation between the standardised Euclidean distance between 'Self before ABI' and 'Self after ABI' and the score obtained on the parental rating of child adjustment ( $r = -0.242$ ,  $N = 10$ ,  $p = 0.250$ ).

*'Mother before ABI' – 'Mother after ABI'*

There was a medium negative correlation between the standardised Euclidean distance between 'Mother before ABI' and 'Mother after ABI' and the score obtained on the parental rating of child adjustment ( $r = -0.415$ ,  $N = 10$ ,  $p = 0.117$ ).

*'Father before ABI' – 'Father after ABI'*

There was no correlation between the standardised Euclidean distance between 'Father before ABI' and 'Father after ABI' and the score obtained on the parental rating of child adjustment ( $r = 0.000$ ,  $N = 8$ ,  $p = 0.500$ ).

*'Injured parent before ABI' – 'Injured parent after ABI'*

There was a medium negative correlation between the standardised Euclidean distance between 'Injured parent before ABI' and 'Injured parent after ABI' and the score obtained on the parental rating of child adjustment ( $r = -0.410$ ,  $N = 10$ ,  $p = 0.120$ ).

*'Non-injured parent before ABI' – 'Non-injured parent after ABI'*

There was a medium positive correlation between the standardised Euclidean distance between 'Non-injured parent before ABI' and 'Non-injured parent after ABI' and the score obtained on the parental rating of child adjustment ( $r = 0.342$ ,  $N = 8$ ,  $p = 0.408$ , two-tailed).

## **4.5 TEST OF HYPOTHESIS 2**

### **4.5.1 Restatement of Hypothesis 2**

More structured 'before acquired brain injury' constructs in comparison to the structure of 'after acquired brain injury' constructs will be associated with poorer adjustment of the young person following parental brain injury.

#### **4.5.2 Testing of Hypothesis 2**

Hypothesis 2 was tested by exploring the relationship between the scale scores on the PIY and the measure of relative intensity of ‘before ABI’ constructs compared to ‘after ABI constructs’. A further exploration of the relationship between the parental rating of their child’s adjustment and the measure of relative intensity was also conducted. The relationships were investigated using Spearman’s Rank Order correlation coefficient.

##### ***Cognitive Impairment Scale***

There was a small positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Cognitive Impairment Scale of the PIY ( $r= 0.212$ ,  $N=10$ ,  $p=0.278$ ).

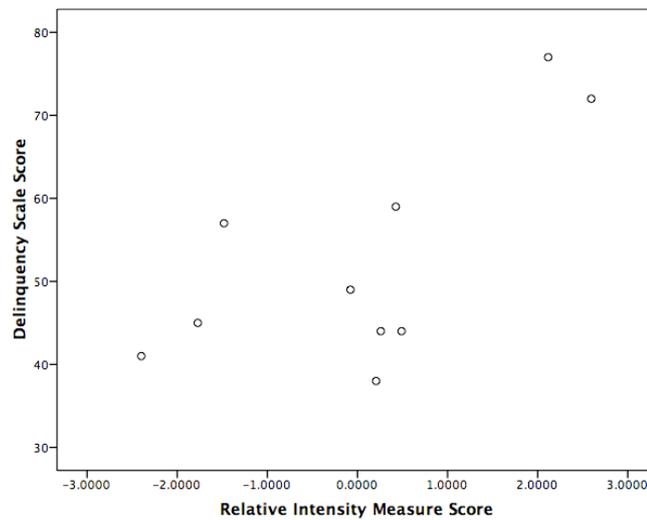
##### ***Impulsivity and Distractibility Scale***

There was a medium positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.365$ ,  $N=10$ ,  $p=0.150$ ).

##### ***Delinquency Scale***

There was a large positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Delinquency Scale of the PIY ( $r= 0.541$ ,  $N=10$ ,  $p=0.053$ ). As can be seen in Figure 19, the scatterplot illustrates a positive correlation, although the dispersion of scores is quite wide at points. Half of the data points cluster at around 0 on the measure of relative intensity, indicating that for those individuals neither ‘before ABI’ constructs nor ‘after ABI’ constructs were more intense than the other. It is interesting to note that both data points where a positive relative intensity figure is shown, thus indicating that ‘before ABI’ constructs are more intense than ‘after ABI’ constructs, show high scores on the Delinquency Scale, and those who showed a negative relative intensity score, thus illustrating that ‘after ABI’ constructs were more intense, show lower scores on the Delinquency Scale, suggesting better adjustment.

**FIGURE 19**  
**Scatterplot Illustrating the Relationship Between Score Obtained on the Measure of Relative Intensity and Score on the Delinquency Scale of the PIY**



#### ***Family Dysfunction Scale***

There was a large positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Family Dysfunction Scale of the PIY ( $r= 0.549$ ,  $N=10$ ,  $p=0.050$ ).

#### ***Reality Distortion Scale***

There was a small positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Reality Distortion Scale of the PIY ( $r= -0.261$ ,  $N=10$ ,  $p=0.233$ ).

#### ***Somatic Concern Scale***

There was no correlation between the score obtained on the measure of relative intensity and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.006$ ,  $N=10$ ,  $p=0.493$ ).

#### ***Psychological Discomfort Scale***

There was a medium positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.317$ ,  $N=10$ ,  $p=0.186$ ).

***Social Withdrawal Scale***

There was a medium positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.410$ ,  $N=10$ ,  $p=0.120$ ).

***Social Skills Deficit Scale***

There was a small positive correlation between the score obtained on the measure of relative intensity and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.220$ ,  $N=10$ ,  $p=0.271$ ).

***Parent Rating of Child Adjustment***

There was a small negative correlation between the score obtained on the measure of relative intensity and the score obtained on the parental rating of child adjustment ( $r= -0.156$ ,  $N=10$ ,  $p=0.354$ ).

**4.6 TEST OF HYPOTHESIS 3****4.6.1 Restatement of Hypothesis 3**

More superordinate ‘before acquired brain injury’ constructs in comparison to ‘after acquired brain injury’ constructs will be associated with poorer adjustment of the young person following parental brain injury.

**4.6.2 Testing of Hypothesis 3**

Hypothesis 3 was tested by exploring the relationship between the scale scores on the PIY and the measure of relative superordinancy of ‘before ABI’ constructs compared to ‘after ABI constructs’. A further exploration of the relationship between the parental rating of their child’s adjustment and the measure of relative superordinancy was also conducted. The relationships were investigated using Spearman’s Rank Order correlation coefficient. Unless otherwise stated, the analyses used 2-tailed tests of significance.

***Cognitive Impairment Scale***

There was a small positive correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Cognitive Impairment Scale of the PIY ( $r= 0.200$ ,  $N=10$ ,  $p=0.290$ , 1-tailed).

***Impulsivity and Distractibility Scale***

There was no correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= -0.061$ ,  $N=10$ ,  $p= 0.868$ ).

***Delinquency Scale***

There was no correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Delinquency Scale of the PIY ( $r= 0.006$ ,  $N=10$ ,  $p=0.493$ , 1 tailed).

***Family Dysfunction Scale***

There was a small positive correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Family Dysfunction Scale of the PIY ( $r= 0.134$ ,  $N=10$ ,  $p=0.356$ , 1 tailed).

***Reality Distortion Scale***

There was a small negative correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Reality Distortion Scale of the PIY ( $r= -0.274$ ,  $N=10$ ,  $p=0.444$ ).

***Somatic Concern Scale***

There was a medium negative correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Somatic Concern Scale of the PIY ( $r= -0.370$ ,  $N=10$ ,  $p=0.293$ ).

***Psychological Discomfort Scale***

There was a small negative correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= -0.274$ ,  $N=10$ ,  $p=0.443$ ).

***Social Withdrawal Scale***

There was a small negative correlation between the score obtained on the measure of relative superordinancy and the score obtained on the Social Withdrawal Scale of the PIY ( $r = -0.104$ ,  $N=10$ ,  $p=0.775$ ).

***Social Skills Deficit Scale***

There was a small negative correlation between the score obtained on the measure of relative superordinancy and score obtained on the Social Skills Deficit Scale of the PIY ( $r = -0.171$ ,  $N=10$ ,  $p=0.636$ ).

***Parent Rating of Child Adjustment***

There was no correlation between the score obtained on the measure of relative superordinancy and the score obtained on the parental rating of child adjustment ( $r = 0.062$ ,  $N=10$ ,  $p=0.865$ ).

**4.7 TEST OF HYPOTHESIS 4****4.7.1 Restatement of Hypothesis 4**

Tighter construing will be associated with better adjustment of the young person following parental brain injury.

**4.7.2 Testing of Hypothesis 4**

Hypothesis 4 was tested by exploring the relationship between the scale scores on the PIY and the measure of tightness of construing. A further exploration of the relationship between the parental rating of their child's adjustment and the measure of tightness of construing was also conducted. The relationships were investigated using Spearman's Rank Order correlation coefficient (two-tailed for all except parental rating of adjustment).

***Cognitive Impairment Scale***

There was a medium positive correlation between tightness of construing and the score obtained on the Cognitive Impairment Scale of the PIY ( $r = 0.479$ ,  $N=10$ ,  $p=0.162$ ).

***Impulsivity and Distractibility Scale***

There was a small positive correlation between tightness of construing and the score obtained on the Impulsivity and Distractibility Scale of the PIY ( $r= 0.267$ ,  $N=10$ ,  $p=0.455$ ).

***Delinquency Scale***

There was a small positive correlation between tightness of construing and the score obtained on the Delinquency Scale of the PIY ( $r= 0.164$ ,  $N=10$ ,  $p=0.650$ ).

***Family Dysfunction Scale***

There was a small positive correlation between tightness of construing and the score obtained on the Family Dysfunction Scale of the PIY ( $r= 0.110$ ,  $N=10$ ,  $p=0.763$ ).

***Reality Distortion Scale***

There was a small positive correlation between tightness of construing and the score obtained on the Reality Distortion Scale of the PIY ( $r= 0.274$ ,  $N=10$ ,  $p=0.444$ ).

***Somatic Concern Scale***

There was a medium positive correlation between tightness of construing and the score obtained on the Somatic Concern Scale of the PIY ( $r= 0.321$ ,  $N=10$ ,  $p=0.365$ ).

***Psychological Discomfort Scale***

There was a medium positive correlation between tightness of construing and the score obtained on the Psychological Discomfort Scale of the PIY ( $r= 0.451$ ,  $N=10$ ,  $p=0.191$ ).

***Social Withdrawal Scale***

There was a small positive correlation between tightness of construing and the score obtained on the Social Withdrawal Scale of the PIY ( $r= 0.177$ ,  $N=10$ ,  $p=0.624$ ).

### ***Social Skills Deficit Scale***

There was no correlation between tightness of construing and the score obtained on the Social Skills Deficit Scale of the PIY ( $r= 0.024$ ,  $N=10$ ,  $p=0.947$ ).

### ***Parent Rating of Child Adjustment***

There was a small positive correlation between tightness of construing and the score obtained on the parental rating of child adjustment ( $r= 0.273$ ,  $N=10$ ,  $p=0.223$ , 1-tailed).

## **4.8 CONTENT ANALYSIS OF CONSTRUCTS**

All constructs from all participants were divided into two sets, which were ‘before ABI’ constructs and ‘after ABI’ constructs. Each construct was rated using the CSPC by two raters, including the author. Where there was a discrepancy between ratings, a consensus was agreed between the raters.

The content analysis of the constructs will first examine all constructs by all children to gain a sense of the type of constructs that children use both before and following a parental brain injury. This will then be followed by a closer examination of the most pertinent constructs to be applied to the brain-injured parent.

The total ratings are reported in Table 4. Whilst there are a total of 53 categories in the CSPC, only those categories that were found in the data sets are reported. The details in bold refer to main theme titles, whereas the details beneath the main theme headings in regular font refer to the categories that together comprise each main theme. All percentage figures given refer to percentage of total ‘before ABI’ constructs or percentage of total ‘after ABI’ constructs.

As can be seen in Table 4, the most frequently occurring category for ‘before ABI’ constructs was ‘relational’, which accounted for 36% of the total ‘before ABI’ constructs. The second most frequently occurring category was ‘personal’, which accounted for 20% of the total ‘before ABI’ constructs. When the ‘after ABI’ constructs are considered, the same two categories occur the most frequently. However, constructs categorised as ‘personal’ rate more highly, accounting for 28% of the total constructs, and constructs categorised as ‘relational’ account for 26% of the total constructs. Based on this it would seem that for both before and after constructs, ‘relational’ and ‘personal’ constructs are the most frequently occurring.

Of further interest is that ‘concrete descriptors’ occurred more frequently within ‘after ABI’ constructs in comparison to ‘before ABI’ constructs. When this is examined further, these particular constructs were most frequently coded as specific behaviours. These constructs appeared to be closely related to factors associated with ABI and included constructs such as ‘slow with speech – fast with speech’, and ‘task completer – not a task completer’. There were further ‘after ABI’ constructs that appeared to be related to ABI, but were coded under different categories, for example, ‘forgetful – remembers stuff’. However, these results should be interpreted cautiously, given the overall low number of constructs in this category.

Three children chose ‘active-lazy’ as constructs, and a fourth child chose ‘active-boring’. It seemed unusual for three children to give identically phrased constructs, which were very similar to a fourth. However, these were not consistently associated with either the ‘before ABI’ or ‘after ABI’ constructs, as three children selected this as a ‘before ABI’ construct, and one as an ‘after ABI’ construct.

A further theme to emerge was that of being close to family members, versus being separate or isolated from family members. Children who chose this type of construct appeared to be referring to the quality of relationships with others, rather than physical closeness or distance. Some examples of such constructs include ‘close – separate’, ‘close – apart’, ‘close – not knowing anything about others’, ‘close – distant’, ‘attached – separate’, ‘united – rebellious’ and ‘family (defined as being as a cohesive unit rather than related) – uncooperative’.

**TABLE 4**  
**Content Analysis of ‘Before ABI’ Constructs and ‘After ABI’ Constructs**

Category	‘Before ABI’ Constructs		‘After ABI’ Constructs	
	Frequency	Percentage	Frequency	Percentage
<b>Moral</b>	<b>9</b>	<b>18%</b>	<b>6</b>	<b>12%</b>
Altruist-Egoist	7	14%	6	12%
Respectful-Judgemental	1	2%	0	0%
Responsible-Irresponsible	1	2%	0	0%
<b>Emotional</b>	<b>5</b>	<b>10%</b>	<b>7</b>	<b>14%</b>
Warm-Cold	0	0%	2	4%
Balanced-Unbalanced	1	2%	2	4%
Specific Emotions	4	8%	3	6%
<b>Relational</b>	<b>18</b>	<b>36%</b>	<b>13</b>	<b>26%</b>
Extroverted-Introverted	9	18%	4	8%
Pleasant-Unpleasant	2	4%	4	8%

Tolerant-Authoritarian	1	2%	1	2%
Conformist-Rebel	2	4%	1	2%
Peaceable-Aggressive	2	4%	2	4%
Trusting-Suspicious	1	2%	0	0%
Others	1	2%	1	2%
<b>Personal</b>	<b>10</b>	<b>20%</b>	<b>14</b>	<b>28%</b>
Strong-Weak	0	0%	2	4%
Active-Passive	4	8%	3	6%
Hard Working-Lazy	3	6%	2	4%
Organised-Disorganised	1	2%	1	2%
Thoughtful-Shallow	1	2%	0	0%
Mature-Immature	0	0%	2	4%
Self-acceptance-Self-criticism	0	0%	1	2%
Others	1	2%	3	6%
<b>Intellectual/Operational</b>	<b>6</b>	<b>12%</b>	<b>3</b>	<b>6%</b>
Intelligent-Dull	4	8%	1	2%
Focussed-Unfocussed	0	0%	1	2%
Specific Abilities	2	4%	1	2%
<b>Values and Interests</b>	<b>1</b>	<b>2%</b>	<b>1</b>	<b>2%</b>
Values and Specific Interests	1	2%	1	2%
<b>Existential</b>	<b>0</b>	<b>0%</b>	<b>1</b>	<b>2%</b>
Growth-Stagnation	0	0%	1	2%
<b>Concrete Descriptors</b>	<b>1</b>	<b>2%</b>	<b>5</b>	<b>10%</b>
Social Roles	1	2%	0	0%
Specific Behaviours	0	0%	4	8%
Others	0	0%	1	2%

The most salient constructs applied to the brain-injured parent were examined by counting any extreme ratings (those with a rating of 1 or 7) applied to the injured parent prior to and following the parental brain injury. Constructs were divided in this instance in how they were applied to the parent, rather than whether they were elicited from before or after ABI elements. A further difference in comparison to the content analysis of all constructs is that the number of constructs in each group differs, and the same category may be recorded for both before and after constructs. For this reason, percentages will not be reported. The frequency of constructs applied to the brain-injured parent 'before ABI' and 'after ABI' can be seen in Table 5.

As can be seen in Table 5, the most frequently occurring category to be applied to injured parents prior to the brain injury was moral. Interestingly, whilst the altruist-egoist categories belong to the same construct, there were an equal number of times the pole of the construct that might be perceived as positive and that perceived

as negative was applied. The same child was responsible for all three of the constructs rated as egoist. During the interview to complete the repertory grid, the child made several references to his brain injured father not being a very nice person prior to his brain injury, but that he felt that his father had changed for the better following the brain injury occurring.

The most frequently occurring category to be applied to injured parents following the brain injury was ‘relational’ (N=6). However, this was only applied on one more occasion that those constructs coded as ‘personal’ or ‘intellectual/operational’ (N=5).

Despite constructs being categorised as ‘emotional’ on five occasions when applied to the parent before their brain injury, this category is conspicuous by its absence when applied to parents after their brain injury. Four of the five constructs could be perceived as positive.

The prominence of ‘relational’ and ‘personal’ constructs seen when all constructs were examined is also absent when extreme ratings applied to the brain-injured parent are considered. Despite ‘relational’ being the most frequently occurring theme when constructs applied to the injured parent after the ABI are considered, other themes were found to occur on a similar number of occasions.

**TABLE 5**  
**Content Analysis of Constructs With Extreme Ratings Applied to Brain Injured Parent**

	<b>Constructs applied to injured parent before ABI</b>	<b>Constructs applied to injured parent after ABI</b>
<b>Category</b>	<b>Frequency</b>	<b>Frequency</b>
<b>Moral</b>	<b>8</b>	<b>3</b>
Altruist	3	0
Egoist	3	3
Respectful	1	0
Responsible	1	0
<b>Emotional</b>	<b>5</b>	<b>0</b>
Warm	1	0
Balanced	1	0
Unbalanced	1	0
Specific emotions (positive)	2	0
<b>Relational</b>	<b>4</b>	<b>6</b>
Extroverted	1	3
Introverted	2	1
Pleasant	1	0
Conformist	0	1

Suspicious	0	1
<b>Personal</b>	<b>4</b>	<b>5</b>
Active	2	1
Hard working	1	0
Organised	0	1
Mature	0	1
Others	1	2
<b>Intellectual/operational</b>	<b>5</b>	<b>5</b>
Intelligent	3	1
Unfocussed	1	0
Focussed	0	0
Specific abilities (positive)	1	3
Others	0	1
<b>Concrete Descriptors</b>	<b>2</b>	<b>2</b>
Specific behaviours (positive)	1	0
Specific behaviours (negative)	0	2
Others (positive)	1	0

## 4.9 CASE EXAMPLE 1 – EXAMPLE OF A PARTICIPANT WHO SHOWED GOOD LEVELS OF ADJUSTMENT

### 4.9.1 Background History

Sophie was a 12-year-old white British female. When she was eight years old, her father had a fall and experienced a traumatic brain injury. The family were told that it was classified as a ‘severe’ brain injury. As Sophie and her family responded to an advert placed on the Headway Facebook page, it was not possible to verify this information in clinical notes. Sophie lived with both of her parents, and was an only child. Her father was not able to work following the brain injury. The family had extended support from Sophie’s Aunt and Uncle.

### 4.9.2 Measure of Adjustment

The individual scale scores obtained on the PIY are outlined in Table 6. All of Sophie’s scale scores were below the clinical cut-off point of 60 provided by the measure, indicating that there were no identified areas of poor adjustment.

**TABLE 6**  
**Subscale Scores Obtained by Sophie on the PIY**

<b>Subscale</b>	<b>Sophie's T-score</b>
<b>Cognitive Impairment</b>	<35
<b>Impulsivity and Distractibility</b>	43
<b>Delinquency</b>	44
<b>Family Dysfunction</b>	49
<b>Reality Distortion</b>	35
<b>Somatic Concern</b>	50
<b>Psychological Discomfort</b>	40
<b>Social Withdrawal</b>	42
<b>Social Skills Deficit</b>	42

Sophie's mother was present during the interview appointment. She rated Sophie as a 9 on the subjective parent rating of child adjustment question, indicating that she felt that Sophie was well adjusted.

#### **4.9.3 Repertory Grid**

The elements chosen by Sophie were:

1. Self
2. Father
3. Mother
4. Aunt
5. Her childminder (who had known the family since before the brain injury)

Each element was rated before her father's brain injury, and following her father's brain injury.

Constructs were elicited using the triadic method and were as follows;

Constructs elicited using 'before ABI' elements

1. Confident – Shy
2. Arty – Unarty
3. Good at maths – Not good at maths
4. Logical – Unlogical
5. Animal lover – Not an animal lover

Constructs elicited using 'after ABI' elements

1. Task completer – Not a task completer
2. Organised – Unorganised

3. Sporty – Not sporty
4. Un self-centred – Self-centred
5. Active – Lazy

Sophie was helped to complete the grid by using flashcards with the names of her chosen elements written on them. She was able to understand the process of eliciting constructs well and they were elicited using the triadic method.

#### 4.9.4 Hypothesis 1

Hypothesis 1 predicted that larger changes in how young people construe themselves and significant others following parental brain injury would be related to poorer adjustment of the child.

When the standardised Element Euclidean Distances between Sophie's key 'before ABI' and 'after ABI' elements are examined, it can be seen that the distances for both her mother and her father are relatively small (father/injured parent 0.54, mother/non-injured parent 0.66). The distance between her self 'before ABI' and self 'after ABI' is 0.92, which represents neither a small nor a large difference.

This means that Sophie construes both of her parents quite similarly both before and after the brain injury, suggesting that the way she construes them has not changed significantly.

The Slater analysis allows for the relationship between elements and constructs to be plotted in a graph. Sophie's graph can be found in Figure 20. This is based upon a Principal Components Analysis, from which Principal Component 1 (PC1), represented by the horizontal axis in Figure 20, accounts for the greatest single amount of variance, whilst Principal Component 2 (PC2), represented by the vertical axis, accounts for the second greatest amount of variance. The faint lines on the graph represent Sophie's constructs. Those that are more closely aligned with the PC1 axis are more closely represented by that component, and the same is true of those whose angle is more closely related to the PC2 axis (Jankowicz, 2004). Elements are then plotted onto the graph in the position that represents how they are construed in relation to each Principal Component. Elements that are positioned closely to one another can be perceived as being construed similarly, whereas those which are positioned further away from one another can be perceived as being construed more differently. It is considered that constructs in opposing quadrants of the graph

represent the greatest dissimilarity (Winter, 1992).

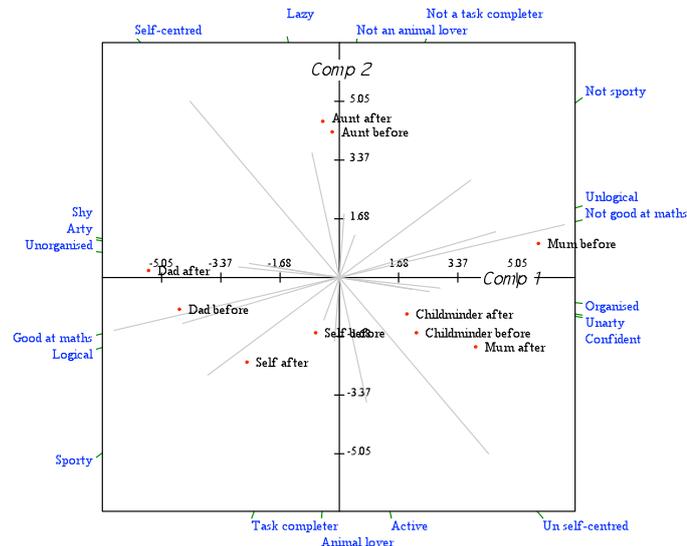
As can be seen in Figure 20, Sophie's 'before ABI' elements are situated relatively closely to their 'after ABI' counterparts. Whilst both of her parents occupy different quadrants following the brain injury, they are still positioned in close proximity to their position prior to the brain injury. Sophie's position following the brain injury is in the same quadrant as prior to her father's brain injury. This would appear to support the predictions of hypothesis 1, as Sophie obtained low scores on the PIY, which is indicative of good levels of adjustment.

**FIGURE 20**  
**Slater Analysis Graph for Sophie's Repertory Grid**

03/05/2011 (12:30:43)

*Slater Analyses for Blank Grid*

Axis Range: -0.74 to 0.74



#### 4.9.5 Hypothesis 2

Hypothesis two predicted that more structured 'before acquired brain injury' constructs in comparison to the structure of 'after acquired brain injury' constructs would be associated with poorer adjustment of the young person following parental brain injury.

Sophie's relative intensity score was 0.4898. This means that her 'before ABI' constructs were more intense than her 'after ABI' constructs. However, as her relative intensity score was low, this indicates that there was not a large difference between the relative intensity of the two sets of constructs.

#### **4.9.6 Hypothesis 3**

Hypothesis 3 predicted that larger degree of superordinancy of ‘before ABI’ constructs compared to ‘after ABI’ constructs would be related to poorer adjustment of the child.

Sophie’s relative superordinancy score was 2.27. This means that her ‘before ABI’ constructs were slightly more superordinate than ‘after ABI’ constructs. However, her score was quite low, indicating that there was not a large difference in superordinancy between the two sets of constructs.

#### **4.9.7 Hypothesis 4**

Hypothesis 4 predicted that tighter construing would be associated with better adjustment. Sophie’s tightness of construing score was 43.19. The mean tightness of construing score for all participants was 55.45 (range 30.16-83.81, std. dev. 18.18). Sophie’s score indicates that she construes relatively loosely, and her score fell in the lower range compared to other participants. Therefore, Sophie’s scores do not support hypothesis 4.

#### **4.9.8 Content Analysis of Constructs**

Three of Sophie’s ‘before ABI’ constructs were coded under the ‘intellectual/operational’ category. These were ‘arty- unarty’ and ‘good at maths- not good at maths’, which were both sub-categorised as ‘specific abilities’, and ‘logical-unlogical’ (sub-category ‘intelligent-dull’). The remaining ‘before ABI’ constructs were coded as ‘relational’ (sub category ‘extroverted-introverted’) and ‘values and interests’ (sub category ‘specific values and interests’). This is in contrast to her ‘after ABI’ constructs, two of which were coded as ‘personal’ (sub-categories ‘organised-disorganised’ and ‘hardworking-lazy’). The remaining ‘after ABI’ constructs were coded as ‘moral’ (sub-category ‘altruist-egoist’), intellectual/operational (sub category ‘specific abilities’) and ‘concrete descriptors’ (sub category ‘specific behaviours’).

When the extreme ratings applied to her father are considered, Sophie gave an extreme rating for ‘good at maths’ and ‘logical’ for before the brain injury and ‘arty’, ‘good at maths’ and ‘sporty’ after the brain injury. These were categorised as ‘intellectual/operational – intelligent’ (‘logical’) and ‘intellectual/operational – specific abilities’ (‘good at maths’, ‘arty’ and ‘sporty’).

## 4.10 CASE EXAMPLE 2 - EXAMPLE OF A PARTICIPANT WHO SHOWED POOR LEVELS OF ADJUSTMENT

### 4.10.1 Background History

Abdul was a 14-year-old British-born Bangladeshi. When he was 13 years old, his mother experienced a stroke whilst undergoing surgery. Abdul's mother stated that she had been told that she had experienced a 'mild' brain injury. Unfortunately, there was no information in the notes at the Clinical Neurorehabilitation team to verify this. Abdul lived with his mother. His parents' marriage had broken down when he was a toddler, and he had little contact with his father. He was an only child.

### 4.10.2 Measure of Adjustment

The individual scale scores obtained on the PIY are outlined in Table 7. The scores marked with an \* indicate a score above the clinical cut off point of 60 provided by the measure, and therefore indicate areas of poor adjustment.

**TABLE 7**  
**Subscale scores obtained by Abdul on the PIY**

Subscale	Abdul's T score
Cognitive Impairment	72*
Impulsivity and Distractibility	65*
Delinquency	72*
Family Dysfunction	67*
Reality Distortion	58
Somatic Concern	49
Psychological Discomfort	57
Social Withdrawal	65*
Social Skills Deficit	67*

Abdul's mother was present during the interview appointment. She rated Abdul as a 4 on the subjective parent rating of child adjustment question.

### 4.10.3 Repertory Grid

The elements chosen by Abdul were:

1. Self
2. Mother

3. Grandmother
4. Uncle
5. Aunt

Each element was rated before his mother's brain injury, and following his mother's brain injury.

Constructs were elicited using the triadic method and were as follows:

Constructs elicited using 'before ABI' elements

1. Calm – Aggressive
2. Responsible – Dependent
3. Caring – Selfish
4. Moody – Respectful
5. Can't be bothered to do anything – Does more stuff

Constructs elicited using 'after ABI' elements

1. Forgetful – Remembers stuff
2. Doesn't nag – Naggy
3. Controlling – Not controlling
4. Restless – Tired
5. Talks a lot – Quiet

#### **4.10.4 Hypothesis 1**

Hypothesis 1 predicted that larger changes in how young people construe themselves and significant others following parental brain injury compared to how they construed themselves and significant others prior to parental brain injury would be associated with poorer adjustment of the young person.

When the standardised Element Euclidean Distances between Abdul's key 'before ABI' and 'after ABI' elements are examined, it can be seen that the distance between his mother before and after injury (mother/injured parent 1.18) was one of the largest distances seen amongst all participants in how they construe their mothers, and indicates a moderate difference in how she is construed. The distance between his self 'before ABI' and self 'after ABI' was 1.47, which represents a relatively large difference.

This means that Abdul construes his mother moderately differently after the brain injury compared to prior to the brain injury, and construes himself very differently following the brain injury compared to prior to the brain injury.

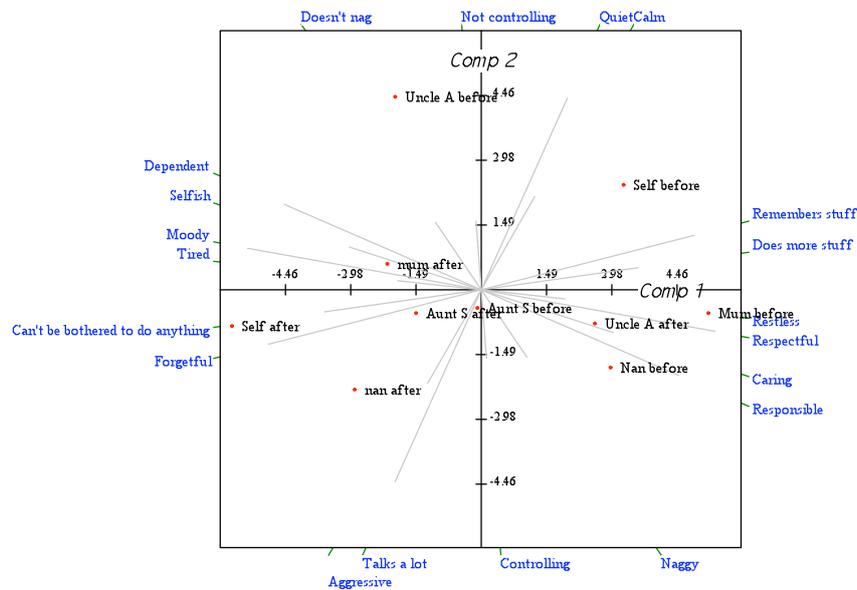
Abdul's Slater analysis graph can be found in Figure 21. As can be seen in Figure 21, Abdul's 'before ABI' elements are situated far from their 'after ABI' counterparts. It is particularly noteworthy that his self, mother and Uncle occupy opposite quadrants following the brain injury in relation to their position prior to the brain injury, which is indicative of high levels of dissimilarity (Winter, 1992). This would appear to support the predictions of hypothesis 1 as Abdul scored highly on several subtests of the PIY, indicating poorer levels of adjustment.

**FIGURE 21**  
Slater Analysis Graph for Abdul's Repertory Grid

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*Slater Analyses for Blank Grid*

Axis Range: -5.95 to 5.95



#### 4.10.5 Hypothesis 2

Hypothesis 2 predicted that more structured 'before acquired brain injury' constructs in comparison to the structure of 'after acquired brain injury' constructs would be associated with poorer adjustment of the young person following parental brain injury.

Abdul's relative intensity score was 2.5950. This means that his 'before ABI' constructs were more intense than his 'after ABI' constructs. Hypothesis 2 predicted that relative intensity scores would be positively correlated with scores on the PIY, so therefore these findings support the hypothesis.

#### **4.10.6 Hypothesis 3**

Hypothesis 3 predicted that more superordinate ‘before acquired brain injury’ constructs compared to ‘after acquired brain injury’ constructs would be related to poorer adjustment of the child.

Abdul’s relative superordinancy score was 3.11. This means that his ‘before ABI’ constructs were slightly more superordinate in relation to his ‘after ABI’ constructs. However, his score was quite low, indicating that there was not a large difference in superordinancy between the two sets of constructs.

#### **4.10.7 Hypothesis 4**

Hypothesis 4 predicted that tighter construing would be associated with better adjustment of the young person. Abdul’s tightness of construing score was 54.13. The mean tightness of construing score was 55.45 (range 30.16-83.81, std. dev. 18.18). Abdul’s score indicates that he did not construe particularly tightly or loosely, and his score fell close to the mean compared to other participants. Therefore, Abdul’s results do not support hypothesis 4.

#### **4.10.8 Content Analysis of Constructs**

Three of Abdul’s ‘before ABI’ constructs were coded under the ‘moral’ category. There were ‘responsible-dependent’ (sub category ‘responsible-irresponsible’), ‘caring-selfish’ (sub category ‘altruist-egoist’) and ‘moody-respectful’ (sub-category ‘respectful-judgemental’). The remaining ‘before ABI’ constructs were coded as ‘relational’ (sub-category ‘peaceable-aggressive’) and ‘personal’ (sub-category ‘hard working-lazy’). This is in contrast to his ‘after ABI’ constructs, two of which were coded as ‘concrete descriptors’ (sub categories ‘specific behaviours’ and ‘others’), two were coded as ‘relational’ (sub-categories ‘tolerant-authoritarian’ and ‘extroverted-introverted’) and the final ‘after ABI’ construct of ‘restless-tired’ was coded as ‘personal’ (subcategory ‘other’).

When the extreme ratings (scores of 1 or 7) applied to his mother are examined, Abdul rated his mother as ‘responsible’ (coded as ‘moral – responsible’), ‘caring’ (‘moral – altruist’), ‘respectful’ (‘moral – respectful’), ‘does more stuff’ (‘personal – hard working’) and ‘remembers stuff’ (‘concrete descriptors – others’) prior to the brain injury. Abdul did not apply any extreme ratings to his mother following the brain injury.

## 4.11 SUMMARY OF RESULTS

### 4.11.1 Hypothesis 1

**TABLE 8**  
Summary of Correlations from Testing of Hypothesis 1

ADJUSTMENT MEASURE	STANDARDISED EUCLIDEAN DISTANCE									
	Self 'Before ABI' – Self 'After ABI'		Mother 'Before ABI' – Mother 'After ABI'		Father 'Before ABI' – Father 'After ABI'		Injured Parent 'Before ABI' – Injured Parent 'After ABI'		Non-injured Parent 'Before ABI' – Non-injured parent 'After ABI'	
	Correlations (r=)	Significance (p=)	Correlations (r=)	Significance (p=)	Correlations (r=)	Significance (p=)	Correlations (r=)	Significance (p=)	Correlations (r=)	Significance (p=)
<b>Cognitive Impairment</b>	0.596 large	0.035	0.612 large	0.030	0.286 small	0.246	0.310 med	0.192	0.476 med	0.116
<b>Impulsivity &amp; Distractibility</b>	0.814 large	0.002	0.675 large	0.016	0.587 large	0.063	0.777 large	0.004	0.371 med	0.183
<b>Delinquency</b>	0.518 large	0.062	0.815 large	0.002	0.216 small	0.304	0.524 large	0.060	0.515 large	0.096
<b>Family Dysfunction</b>	0.272 small	0.223	0.555 large	0.048	- 0.180 small	0.670*	-0.021 NC	0.953*	0.407 med	0.158
<b>Reality Distortion</b>	0.683 large	0.015	0.754 large	0.006	0.635 large	0.045	0.665 large	0.018	0.707 large	0.025
<b>Somatic Concern</b>	0.377 med.	0.142	0.212 small	0.278	0.595 large	0.060	0.395 med.	0.129	0.690 large	0.029
<b>Psychological Discomfort</b>	0.746 large	0.007	0.622 large	0.027	0.635 large	0.045	0.560 large	0.046	0.719 large	0.022
<b>Social Withdrawal</b>	0.537 large	0.055	0.813 large	0.002	0.383 med.	0.174	0.485 med.	0.078	0.707 large	0.025
<b>Social Skills Deficit</b>	0.402 med	0.125	0.502 large	0.070	- 0.109 small	0.797*	0.018 NC	0.480	0.145 small	0.366
<b>Parental Rating of Adjustment</b>	-0.242 small	0.250	- 0.415 med.	0.117	0.000 NC	0.500	-0.410 med	0.120	0.342 med.	0.408*

\* Two-tailed analyses were conducted.

Table 8 shows the results of the multiple correlations conducted in the testing of Hypothesis 1. The table can be read horizontally to examine the relationships between each data type extracted from the repertory grids and the various PIY scales, or read vertically to examine the relationships between each PIY scale and the various data types extracted from the grid analysis.

When the standardised Euclidean distances between self 'before ABI' and self 'after ABI' are examined, it can be seen that there were large positive relationships with scores obtained on the Cognitive Impairment, Impulsivity and Distractibility, Delinquency, Reality Distortion, Psychological Discomfort and Social Withdrawal scales. There were medium correlations with scores obtained on the Somatic Concern and Social Skills Deficit scales. However, the reported correlations with scores obtained on the Cognitive Impairment, Somatic Concern, Social Withdrawal and Social Skills Deficit did not reach statistical significance.

When the standardised Euclidean distances between mother 'before ABI' and 'after ABI' are examined, there are large positive correlations with scores obtained on all scales with the exception of the Somatic Concern Scale, for which there was a small positive correlation. It should be noted that the correlation with the score obtained on the Social Skills Deficit scale did not reach the level of statistical significance, although this was close with an alpha value of  $p=0.070$  being achieved.

When the standardised Euclidean distances between father 'before ABI' and father 'after ABI' are examined, it can be seen that there were large positive correlations with scores obtained on the Impulsivity and Distractibility, Reality Distortion, Somatic Concern and Psychological Discomfort scales. Although the correlation obtained with the scores obtained on the Impulsivity and Distractibility and Somatic Concern scales did not reach statistical significance, the alpha values of  $p=0.063$  and  $p=0.060$  are close to achieving this.

There were large relationships between standardised Euclidean distances between injured parent 'before ABI' and 'after ABI' and scores obtained on the Impulsivity and Distractibility, Delinquency, Reality Distortion and Psychological Discomfort scales. All were statistically significant, with the exception of the analysis for the Delinquency Scale, which reached a near level of statistical significance with an alpha level of  $p=0.060$ . The analysis of the correlation with scores obtained on the Social Withdrawal scale also approached statistical significance ( $p=0.078$ ) and indicated a medium strength relationship.

There were large positive relationships between standardised Euclidean distances between non-injured parent 'before ABI' and 'after ABI' and scores obtained on the Delinquency, Reality Distortion, Somatic Concern, Psychological Discomfort and Social Withdrawal scales. All analyses reached statistical

significance with the exception of the Delinquency scale, although this analysis reached a near level of significance with an alpha value of  $p=0.096$ .

When each scale is examined individually it can be seen that there was a large relationship between scores obtained on the Cognitive Impairment scale and distance between self before and after ABI and distance between mother before and after ABI. There was a medium relationship with distances between both injured and non-injured parent before and after ABI.

There were large positive relationships between the score obtained on the Impulsivity and Distractibility scale and all standardised Euclidean distances examined with the exception of non-injured parent, for which there was a medium relationship identified.

There were large positive relationships between the score obtained on the Delinquency Scale and all distances except for father before and after ABI.

There was a large positive relationship between the score obtained on the Family Dysfunction scale and the distance between mother before ABI and after ABI and a medium positive relationship with the distance between non-injured parent before and after ABI.

There were large positive relationships between the score obtained on the Reality Distortion scale and all standardised Euclidean distances examined.

There were large positive relationships between the score obtained on the Somatic Concern scale and distances between father before and after ABI and non-injured parent before and after ABI and a medium positive relationship with distances between self before and after ABI and injured parent before and after ABI.

There were large positive relationships between the score obtained on the Psychological Discomfort scale and all examined distances.

There were large positive relationships between the score obtained on the Social Withdrawal scale and distances between self before and after ABI, mother before and after ABI and non-injured parent before and after ABI. There were medium positive relationships between the score obtained on this scale and distances between father before and after ABI and injured parent before and after ABI.

There was a large positive relationship between the score obtained on the Social Skills Deficit scale and distances between mother before and after ABI and a medium positive relationship with self before and after ABI.

#### 4.11.2 Hypothesis 2

**TABLE 9**  
**Summary of Correlations from Testing of Hypothesis 2**

Adjustment Measure	Relative Intensity	
	Correlations (r =)	Significance (p =)
<b>Cognitive Impairment</b>	0.212 small	0.278
<b>Impulsivity &amp; Distractibility</b>	0.365 medium	0.150
<b>Delinquency</b>	0.541 large	0.053
<b>Family Dysfunction</b>	0.549 large	0.050
<b>Reality Distortion</b>	0.261 small	0.233
<b>Somatic Concern</b>	0.006 NC	0.493
<b>Psychological Discomfort</b>	0.317 medium	0.186
<b>Social Withdrawal</b>	0.410 medium	0.120
<b>Social Skills Deficit</b>	0.220 small	0.271
<b>Parental Rating of Adjustment</b>	-0.136 small	0.354

As can be seen in Table 9, there was a large positive correlation between relative intensity and score obtained on the Delinquency and Family Dysfunction scales, indicating that children whose ‘before ABI’ constructs showed higher intensity than their ‘after ABI’ constructs showed greater dysfunction on these scales.

There were medium positive correlations between relative intensity and score obtained on the Impulsivity and Distractibility, Psychological Discomfort and Social Withdrawal scales. There were small, or no correlations between relative intensity and scores obtained on the Cognitive Impairment, Reality Distortion, Somatic Concern, Social Skills Deficit scales and the parental rating of adjustment.

### 4.11.3 Hypothesis 3

**TABLE 10**  
**Summary of Correlations from Testing of Hypothesis 3**

Adjustment Measure	Relative Superordinancy	
	Correlations (r =)	Significance (p =)
<b>Cognitive Impairment</b>	0.200 small	0.290
<b>Impulsivity &amp; Distractibility</b>	-0.061 NC	0.868*
<b>Delinquency</b>	0.006 NC	0.493
<b>Family Dysfunction</b>	0.134 small	0.356
<b>Reality Distortion</b>	-0.274 small	0.444*
<b>Somatic Concern</b>	-0.370 medium	0.293*
<b>Psychological Discomfort</b>	-0.274 small	0.443*
<b>Social Withdrawal</b>	-0.104 small	0.775*
<b>Social Skills Deficit</b>	-0.171 small	0.636*
<b>Parental Rating of Adjustment</b>	0.062 NC	0.865*

\* Two-tailed analyses were conducted.

As can be seen in Table 10, there was a medium negative correlation between relative superordinancy and the score obtained on the Somatic Concern scale but this did not reach statistical significance. This may indicate that there was a relationship between children whose ‘after ABI’ constructs were more superordinate in comparison to their ‘before ABI’ constructs and higher levels of somatic symptoms and health concerns. However, given that the strength of the relationship was not particularly strong, nor significant, this does not provide strong evidence to support this. There were small, or no, correlations between relative superordinancy and scores obtained on all other measures.

#### 4.11.4 Hypothesis 4

**TABLE 11**  
**Summary of Correlations from Testing of Hypothesis 4**

Adjustment Measure	Tightness of Construing	
	Correlations (r =)	Significance (p =)
<b>Cognitive Impairment</b>	0.479 medium	0.162*
<b>Impulsivity &amp; Distractibility</b>	0.267 small	0.455*
<b>Delinquency</b>	0.164 small	0.650*
<b>Family Dysfunction</b>	0.110 small	0.763*
<b>Reality Distortion</b>	0.274 small	0.444*
<b>Somatic Concern</b>	0.321 medium	0.365*
<b>Psychological Discomfort</b>	0.451 medium	0.191*
<b>Social Withdrawal</b>	0.177 small	0.624*
<b>Social Skills Deficit</b>	0.024 NC	0.947*
<b>Parental Rating of Adjustment</b>	0.273 small	0.223

\* Two-tailed analyses were conducted.

As can be seen in Table 11 there were medium positive correlations between tightness of construing and scores obtained on the Cognitive Impairment, Somatic Concern and Psychological Discomfort scales. This means that there was a relationship between tighter construing and higher levels of cognitive impairment, somatic symptoms and psychological discomfort. The remaining variables indicated that there was a small or no correlation with tightness of construing.

#### 4.11.5 Content Analysis of Constructs

When all the elicited constructs were examined together the most frequently occurring categories for 'before ABI' constructs were 'relational' (36%) and 'personal' (20%). 'Personal' (28%) and 'relational' (26%) constructs were also the most frequently occurring category for 'after ABI' constructs.

'Concrete descriptors' occurred more frequently within 'after ABI' constructs and several appeared to be closely related to factors associated with ABI. Themes to emerge were the use of 'active-lazy' as constructs and constructs regarding feeling close to family members, versus feeling separate or isolated from family members.

When the most salient constructs applied to the brain-injured parent were examined the most frequently occurring category to be applied to injured parents prior to the brain injury was 'moral'.

Whilst constructs were categorised as ‘emotional’ on five occasions when applied to the parent before their brain injury, none were categorised as such when applied to parents after their brain injury.

The prominence of ‘relational’ and ‘personal’ constructs seen when all constructs were examined was also absent when extreme ratings applied to the brain-injured parent were considered. Despite ‘relational’ being the most frequently occurring theme when constructs applied to the injured parent were considered, other themes were found to occur on a similar number of occasions.

## **CHAPTER 5**

### **DISCUSSION**

The findings of this study will be interpreted in relation to each of the four hypotheses in turn, followed by an interpretation of the main findings from the content analysis of the constructs. Implications for clinical practice, limitations of the study and implications for future research will then be considered.

#### **5.1 Interpretation of Findings for Hypothesis 1**

##### **5.1.1 Restatement of Hypothesis 1**

Larger changes in how young people construe themselves and significant others following parental brain injury compared to how they construed themselves and significant others prior to parental brain injury will be associated with poorer adjustment of the young person.

##### **5.1.2 Discussion of Findings for Hypothesis 1**

It was predicted that larger distances between how individuals construed themselves and their parents pre- compared to post-parental brain injury would be associated with poorer adjustment. Whilst not all scores on the PIY scales were strongly associated with all standardised Euclidean distances between elements analysed for the purposes of this study, several patterns emerged.

One pattern to emerge was in relation to the distances between how each parent was construed following the brain injury, in comparison to how they were construed prior to the brain injury. There were large positive correlations between the distances between mother before and after ABI and all PIY scales with the exception of the Somatic Concern Scale. Conversely, the distances between father before and after ABI were found to have large correlations with scores obtained on four of the PIY scales. This illustrates that distances relating to mothers appear to have an impact on more areas of adjustment than those relating to fathers.

Furthermore, the range of scores for the distance between how mothers were construed prior to and following the brain injury were smaller in relation to other pairs of elements, for whom a much wider range of distances were observed. As the range of scores for distances relating to mothers was small, this indicates that there were not

large changes in how mothers were construed following the parental brain injury. As there were strong relationships with many aspects of adjustment as measured by the PIY, this would appear to indicate that even small changes in how mothers are construed following parental brain injury, are associated with poor adjustment.

When the relationships between adjustment and distances concerning both injured and non-injured parents are examined, there were strong relationships between scores obtained on four and five of the PIY scales respectively. When this is considered in conjunction with the findings relating to the impact of distances relating to mothers compared to fathers, it would appear to indicate that sex of the parent appears to be more pertinent than which parent experienced the brain injury. This may be due to the tendency for the primary care giver to be mothers. However, as this information was not specifically collected in the study, it cannot be confirmed that the primary caregiver for the participants of this study was the mother. As roles of both the injured parent and their spouses are likely to change following a brain injury within the family (Gosling and Oddy, 1999; Leathem, et al., 1996), it is possible that those changes will be felt more strongly when they are present in the primary care giver.

Pessar et al. (1993) explored the impact parental brain injury had on child relatives' behaviour and explored other variables such as change in parenting performance and symptoms of psychiatric distress in both the injured and non-injured parent. The authors found that most families reported negative behavioural changes in their child following parental brain injury. They also observed that changes in the parenting performance of both parents were related to more reported difficulties in the children. There was a relationship between increased 'acting-out' behaviours and emotional difficulties when the injured parent was the father. However, there did not appear to be a relationship between severity of the brain injury or resulting disabilities and difficulties within the children. There were strong correlations between reduced parenting performance and depression in the non-injured parent and relationship problems, emotional difficulties and acting-out behaviours. This supports the findings of the current study, in that it also highlights the importance of variables associated with both the injured and non-injured parent. The authors also found that gender was an important variable, as there was a relationship between outcome for the children and gender of the injured parent, with male injured relatives being more strongly associated with poor outcome.

Scores obtained on six of the PIY scales showed large relationships with distances between self before and after the ABI. This indicates that larger differences in how children construe themselves appear to be important in relation to poor adjustment. One view might be that as part of the developmental process it is likely that as children grow and develop, they will change how they construe themselves anyway, so it may be less clear how much any observed change in how children construe themselves is due to the impact of the brain injury and how much is due to developmental processes. All of the children taking part in the study would have aged since the time of the injury, although time since the brain injury did vary. With larger numbers of participants it would have been possible to control for length of time since the injury to counter any impact that this might have had on the findings of this study.

Agnew (1985) comments that it is only possible for a child to elaborate actively if the child has continuity of self in the context of a sense of historical self, present self and future self, but that as history is rewritten from the point within which the child is currently located, aspects of that history which are particularly salient or pivotal may change. Agnew (1985) further suggests that loss is a form of disorder of continuity. Her argument is also relevant to the findings of this study in relation to how mothers are construed and the impact on the adjustment of the child. She states that

“at times we are too concretistic in our definition of what is lost such as ‘mother’. This is to make the loss too bound into an element. The question is not how to replace mother but how to restore the particular continuities held by her motherliness” (p.231).

This may be relevant to the findings of this study, as due to the consequences of the brain injury, although the child’s mother is not physically lost or absent, her ‘motherliness’ may be impacted upon by the change in her ability to function how she did previously, either due to direct changes due to the mother experiencing a brain injury, or due to more indirect changes due to a change in her role due to her spouse experiencing a brain injury.

In summary, the findings of Hypothesis 1 were largely supported. This was particularly so in relation to poor adjustment within the child and larger distances between how mothers were construed prior to and following brain injury. However, in addition to the particularly strong findings in relation to mothers, there were relationships between distances relating to fathers and both injured and non-injured parents and several aspects of adjustment. These included larger distances between

how fathers, the injured parent and non-injured parent were construed prior to and following the brain injury and reality distortion and psychological discomfort. Greater changes in how both fathers and the non-injured parent were construed following the parental brain injury were associated with increased somatic symptoms. Furthermore, greater changes in how both fathers and the injured parent were construed were associated with symptoms of impulsivity and distractibility. Also, larger changes in how both the injured and the non-injured parent were construed were related to higher levels of self-reported delinquency.

## **5.2 Interpretation of Findings for Hypothesis 2**

### **5.2.1 Restatement of Hypothesis 2**

More structured ‘before acquired brain injury’ constructs in comparison to the structure of ‘after acquired brain injury’ constructs will be associated with poorer adjustment of the young person following parental brain injury.

### **5.2.2 Discussion of Findings for Hypothesis 2**

It was predicted that there would be a positive correlation between the relative intensity score and scores obtained on the scales that comprise the PIY. It was also predicted that there would be a negative correlation between relative intensity and the score on the parental rating of adjustment. There were large positive correlations found between the relative intensity score and scores obtained on the Delinquency and Family Dysfunction scales, and medium correlations with scores obtained on the Impulsivity and Distractibility, Psychological Discomfort and Social Withdrawal scales. This means that the higher the relative intensity score, or the more intense the ‘before ABI’ constructs were in relation to the ‘after ABI’ constructs, then the poorer the adjustment in areas of delinquent behaviour and family dysfunction, and to a lesser degree in areas of impulsivity and distractibility, psychological symptoms of distress and social withdrawal. This is consistent with the prediction of hypothesis 2, which suggested that those children with higher relative intensity scores would score more highly on measures of poor adjustment.

This study found that those children whose ‘before ABI’ constructs were more intense were more likely to score highly on measures of poor adjustment whereas those children whose ‘after ABI’ constructs were more intense were likely to obtain

scores indicating good adjustment. This is likely to be due to more intense 'after ABI' constructs offering a firmer base for predicting the children's world post their parental brain injury. Children whose 'before ABI' constructs are more intense, and their 'after ABI' constructs less intense are likely to find themselves in the situation that their 'after ABI' constructs are less able to predict the world they now occupy and they are still trying to use their old construct system to predict events in their current situation. When this is unsuccessful, they are likely to find themselves in the situation where the events they experience are beyond the range of convenience of their construct systems.

This is consistent with the findings of Winter et al. (1996) who in their study looking at the success rates of clients being discharged from hospital into the community, found that those individuals whose constructs relating to life outside of the hospital were more structured in comparison to their constructions relating to life inside the hospital were more likely to be successfully resettled into the community. So, similarly to the children in this study, those whose construct system best fitted their current circumstances, found themselves better able to predict events, which results in lower levels of anxiety than might otherwise be experienced in situations where there is an awareness that events are not able to be anticipated by one's construct system.

Woodfield and Viney (1984) take a personal construct theory approach in evaluating the changes in construct systems that occur following the bereavement of a spouse. The authors describe the process of dislocation, where the construct system is unable to anticipate events that the widow is likely to encounter. They contrast this with adaptation, where the construct system is adapted or altered to enable better anticipation of events. The authors stress that these processes are not phasic, but may occur concurrently. Dislocation may manifest as anger, anxiety, sadness, guilt, despair, shock, and numbness and despair. Adaptation is described as incorporating two processes of assimilation and accommodation. Assimilation may present as denial, hostility or idealisation and is characterised by the individual's construct system remaining the same, whereas the perception of some events changes (Viney, 1990). In contrast, accommodation is described as the active elaboration of the personal construct system and manifests as defences against distress, depression and aggression. It is argued that the adaptability of the bereaved widow's construct

system is related to her adjustment following the bereavement (Viney, 1990; Woodfield and Viney, 1984).

The strongest relationships were found between relative intensity and scores obtained on the delinquency and family dysfunction scales. Pessar et al (1993) found that acting-out behaviours and relationship problems were commonly reported in children who have a parent with a brain injury. Reduced parenting performance was also commonly reported in both the injured and non-injured parent following the brain injury. These two factors map closely to the delinquency and family dysfunction scales of the PIY. The authors found no relationship between the presence of children's problems and severity of the injury or degree of disability, but found that there were close relationships between parental depression, change in parenting performance and adjustment difficulties in the child.

In contrast, a study that explored the effect of parental brain injury on both parenting and child behaviour reported mixed findings (Uysal, 1998). The study did not identify any differences in behavioural problems when children of a brain injured and non-brain injured parents were compared. However, in relation to parenting skills, there were some similarities and some differences between families with a brain injured parent and controls. Whilst there were similarities in several skills, there were identified differences in other aspects of parenting. These differences included less emphasis on rule obedience and orderliness, less nurturing and less active involvement with their children. The children's perspective on their parents' parenting was also obtained in the study, and the authors found that children did not perceive parents' skills differently, with the exception of the injured parents being viewed as not setting specific rules, allowing their children to disobey rules and ignoring misbehaviour.

In summary, the findings of this study provided partial support for Hypothesis 2. This support was in relation to poor adjustment in areas of delinquency and family dysfunction, and to a lesser degree symptoms of impulsivity and distractibility, psychological discomfort and social withdrawal being associated with 'before ABI' constructs being less intense in relation to 'after ABI' constructs. However, in other aspects of adjustment the hypothesis was not supported, including in areas of cognitive impairment, reality distortion, somatic concern, social skills and the parents' perception of their child's adjustment.

### **5.3 Interpretation of Findings for Hypothesis 3**

#### **5.3.1 Restatement of Hypothesis 3**

More superordinate ‘before acquired brain injury’ constructs in comparison to ‘after acquired brain injury’ constructs will be associated with poorer adjustment of the young person following parental brain injury.

#### **5.3.2 Discussion of Findings for Hypothesis 3**

All but one of the analyses conducted to test hypothesis 3 indicated either a small or no relationship. The one analysis that indicated a medium strength relationship (Somatic Concern) did not reach a level of statistical significance. Therefore the findings of this study did not support the predictions of hypothesis 3.

Possible reasons for this hypothesis not being supported include the question as to whether the measure used (total sum of squares) actually measures superordinancy. Bannister and Fransella (1986) observe that measurement of superordinancy is difficult “as there is no one operational definition of superordinancy” (p.70-71). Bannister and Salmon (1967; in Bannister and Fransella, 1986) compared ten measures of superordinancy where discrepancies were found between measures. It is possible that alternative measures of superordinancy may have been able to detect a relationship between relative superordinancy and scores obtained on the measures of poor adjustment.

### **5.4 Interpretation of Findings for Hypothesis 4**

#### **5.4.1 Restatement of Hypothesis 4**

Tighter construing will be associated with better adjustment of the young person following parental brain injury.

#### **5.4.2 Discussion of Findings for Hypothesis 4**

It was predicted that there would be a negative correlation between tightness of construing and scores obtained on PIY measure of poor adjustment. This means that the prediction was that tighter construing would be associated with better adjustment of the child. The results of the analysis found medium positive correlations between tightness of construing and Cognitive Impairment, Somatic Concern and

Psychological Discomfort, but in the opposite direction to that which was predicted. Therefore, tighter construing was associated with higher levels of psychological discomfort. However, caution should be taken in interpreting the data as the relationships identified were not strong, nor were they found to be statistically significant. This may be a result of the small sample size of the study, and it is possible that more significant results may have been obtained had the study not been underpowered. The remaining relationships were all small or, in one instance, no correlation was detected.

Whilst the identified relationship between tightness of construing and some aspects of poor adjustment found in this study is tentative, it contrasts to the relationship identified by Winter et al. (1997), who suggested that tight construing of family members of individuals with a brain injury may be helpful in dealing with stress.

A further factor that may contribute to the unclear findings of this study is that there can be benefits and disadvantages of either construing very loosely, or construing very tightly. Winter (1992) states that “while loose construing may allow individuals to avoid invalidation of their predictions, a very loosely organised construct system will be able to generate few, if any, coherent anticipation of events” (p.89). It is therefore also likely that whilst tight construing may allow for more coherent anticipation of events, these predictions are more likely to be subject to invalidation.

A further aspect that may be relevant is the Creativity Cycle (Kelly, 1955), which is concerned with the development of new constructions and where optimal functioning involves alternation between loose and tight construing. Constructs must be loosened to allow for realignment of the constructs, and must then be tightened again to allow for the predictive capacity of the constructs to be tested (Winter, 1992). Children engaged in reconstruing following parental brain injury could potentially be at the loose or tight construing stages of the Creativity Cycle as part of this ongoing process.

Glass (1985; cited in Florian and Katz, 1991) explored the impact of parental brain injury on child relatives and reported difficulties that closely resemble those aspects covered by the cognitive impairment and psychological discomfort scales of the PIY. These include doing poorly in school and experiencing loneliness, helplessness, disinterest, apprehension, anger and guilt. Daisley and Webster (2009)

also report that whilst not consistently investigated, child relatives have also been reported to show impaired educational functioning. They also report that a range of negative emotional responses have been reported such as crying, sadness, despair and worry.

### **5.5 Interpretation of Content Analysis of Constructs**

A frequently occurring construct to emerge on the analysis of the content of the constructs related to closeness-distance, which appeared to be referring to emotional relationships rather than physical proximity. This therefore appears to be an important theme to many of the children. McLaughlin (1992) observes that there is a potential for the home environment to seriously compromise the child's ability to develop secure relationships following parental ABI, which may relate directly to constructs relating to closeness-distance of emotional relationships being selected by the children, if this is an issue that is particularly pertinent for them. Pessar et al (1993) found that 42% of families participating in their study reported a substantial breakdown in the relationship between the injured parent and their children. The changes in the relationships observed included not wanting to spend time with their injured parent and being less loving towards them.

A further commonly occurring construct type related to levels of activity (active-lazy). It would be easy to assume that the occurrence of constructs relating to levels of activity and how close family members are to one another is a result of the negative and devastating effect that brain injury can have on the family. However, several of the children qualified their constructs by talking about how they do a lot more activities together as a family since the brain injury, or how the brain injury has brought them closer together. However, for some children, they stated that they thought that they were no longer as close to their family members since the brain injury had occurred.

The theme of constructs relating to activity levels and closeness-distance is similar to findings reported by Gracey et al. (2008). In a study that explored how individuals who have experienced a brain injury construe themselves, constructs were elicited by asking participants attending a group to think about ways in which they thought that their selves pre- and post-injury are similar and ways in which they thought that their pre- and post-injury selves were different. A thematic analysis of the constructs elicited revealed that a commonly occurring theme was 'self in the

world', which the authors described as referring to aspects of activity or social participation.

The second most commonly occurring theme identified by Gracey et al. (2008) was 'basic skills' and related to changes in cognitive, sensory, physical and social skills and abilities. This shares a similarity to this study, where it was found that 'concrete descriptors' were found more frequently amongst 'after ABI' constructs, and that these appeared to be related to symptoms associated with brain injury. Tyerman (2009) also found that following brain injury, constructs were closely related to symptoms of brain injury when examining the constructs of a brain-injured person.

The analysis also highlighted an absence of constructs categorised as 'emotional' when extreme ratings applied to the parent with the brain injury were examined. The absence of these ratings following the brain injury may perhaps be in part due to the child having an idealised view of how their parent was before the brain injury, and thus a tendency to give an extreme positive rating. Brain injury is known to have an impact upon emotion experience and regulation, so the findings here may reflect the real experienced symptoms of brain injury.

The prominence of 'relational' and 'personal' constructs seen when all constructs were examined is also absent when extreme ratings applied to the brain-injured parent are considered. This may be due to specific constructs, such as concrete descriptors, applying to the brain injured parent, but less so when applied to the child's wider system. However, when the construct system as a whole is considered, relational and personal factors may be more central, due to the impact the brain injury can have not just on the injured person, but on the family unit as a whole.

## **5.6 IMPLICATIONS FOR CLINICAL PRACTICE**

The findings of this study indicated relationships between changes in how children construe themselves and significant others and adjustment within the child. Whilst it was not possible to control for variables such as severity of brain injury, the results would appear to suggest that an important factor associated with adjustment in children is how they construe or perceive changes in both themselves and in both of their parents, which may or may not be independent of objective measures of changes or symptoms associated with acquired brain injury. Therefore, child relatives of individuals with an acquired brain injury may be at risk of developing adjustment

difficulties if the child perceives there to be changes in how they construe themselves or their parents.

Children experiencing adjustment difficulties following parental brain injury may benefit from an intervention to address their needs. Possible interventions might include group work (Diareme et al., 2007), systemic work (Gelman and Greer, 2011) or a personal construct intervention. Tyerman (2009) reported that the use of repertory grids was useful when working with issues of adjustment following brain injury, when working with the brain injured person themselves. A personal construct intervention could focus on different aspects identified by this study. This could be helping the child to find similarities in how they construe themselves or their parents both before and after the brain injury, and therefore reducing the distances between each person before and after the brain injury. Secondly, as it was identified that those children whose 'after ABI' constructs were more intense than their 'before ABI' constructs were better adjusted in some areas of adjustment, it may be beneficial if clinical work could focus on helping the child to make their new constructs more structured, and therefore better able to predict the world that they now find themselves in.

Although not specifically measured, several children and their parents stated that their children did not know any other children who had parents with a brain injury. It was reported that their peers did not appear to understand the situation that they were experiencing. This may relate to Commonality, which may be defined as "the extent that one person employs a construction of experience which is similar to that employed by another" (Fransella, 2005, p.253). As having a parent with a brain injury, or understanding the consequences of brain injury is likely to be outside of their friend's range of convenience of their construct system, the child may feel as though others are not able to relate to them, which may make the child feel isolated or not understood. Agnew (1985) likens 'disorder of commonality' to a "child marching to the beat of a different drum" (p.233), and states that such children are likely to experience isolation and be open to victimisation. In relation to the Commonality Corollary, Butler and Green (2007) observe that an aspect of group psychotherapy that young people often report as finding the most helpful was that they no longer felt alone in their thoughts and feelings and that there were others who held similar views.

This could be addressed by facilitating a forum for children who have a parent with a brain injury to meet one another and share experiences. This could be done

through a support group, or by providing an educational group for the children. When attempting to identify suitable places for recruitment purposes for this study, the author found several relatives groups or resources for adult relatives, but did not find any equivalent service for child relatives. As a result of this study and the number of children and parents expressing a desire for more support to be made available the author and her clinical supervisor will be running a group activity day for child relatives who have a parent with a brain injury. It is hoped that this will be an opportunity to provide education about the effects of brain injury, and an opportunity for them to meet other children who are going through similar experiences.

Another clinically important factor is that this study highlights the importance of considering the wider system in brain injury services. It raises the question of is the person with a brain injury the client, or is the family the client?

The study also demonstrates the value of taking a personal construct approach in the context of both brain injury settings and when working with families.

## **5.7 LIMITATIONS OF STUDY**

Unfortunately, recruitment difficulties resulted in small numbers of participants for the study. The author had felt optimistic about being able to identify potential participants based on communications with staff in local Headway centres and with the head of media for Headway. However, this did not result in large numbers of potential participants being identified. Some of the reasons for this included Headway staff members being unable to identify suitable families. Many centres reported that most of their clientele were older, and did not have children in the right age range for the study. Whilst some families initiated contact or posted comments via the Headway Facebook page, many commented that their children were too old, too young, or were born either after the brain injury occurred or that the brain injury occurred when their children were at a young age, so that they would not be able to remember life before the brain injury. A sense of dismay was evident through these comments, and appeared to highlight the frustration parents were experiencing that their children were not being supported, or that research was not being conducted with those of their own children's age or circumstance.

Recruitment through the NHS Community Neurorehabilitation team was inhibited in several ways. Again, identifying families with children of the correct age was difficult. When the NHS ethics committee reviewed the study, they stipulated

that potential families should only be contacted through routine appointments. Some families that may otherwise have been suitable did not have appointments during the period of recruitment. A large proportion of clients attending appointments in the service each week were new referrals for an assessment. Many of these new referrals had experienced their brain injury very recently. Part of the inclusion criteria for the study was that the brain injury should have occurred at least 6 months previously, so that families will have experienced a period of time living with the consequences of brain injury. Three families were approached about the study, but declined to take part. Although not directly asked the reasons for this, one family volunteered that they felt that they wished to move on from the brain injury, and not revisit it, or put their children through the experience again by taking part in the study. The remaining two families stated that although they would have liked their children to take part in the study, the children themselves were not keen to do so, although it is not known what the children's reasons for not wishing to take part were. This appeared to be difficult for the parents involved, as they stated that they felt that it would have been useful for their children to speak to an independent person about their feelings and experiences.

The small sample size may have reflected a population bias in that it may not represent the larger population of children who have a parent living with a brain injury. As the majority of the sample was recruited through the NHS Community Neurorehabilitation team, this may represent those families where the parent with the brain injury experiences more difficulties, or required a higher level of support. Although the number of families recruited through Headway was smaller, this group may also consist of people who experience a higher level of difficulty, or are more inclined to actively seek out support. It is likely that there are many children who have a parent with a brain injury who are not accessing either NHS or charitable services.

The impact of the small sample size was that the study was underpowered and reflects a serious limitation of the study. Furthermore, as the data was not normally distributed, non-parametric tests were used in the analysis. Had a larger sample size been obtained, this may have increased the likelihood of the data being normally distributed, and therefore would have enabled the use of more powerful parametric tests. Some of the large, and several of the medium sized relationships identified in

this study did not reach a level of statistical significance. It is likely that this is due to the study being significantly underpowered.

Repeated testing on the same data set increases the likelihood of a type 1 error, which is the possibility of incorrectly rejecting the null hypothesis. This is usually addressed by using post hoc tests such as a Bonferroni correction. Due to the limited amount of statistical power of this study, no correction for a familywise alpha error was undertaken. This decision was taken as such a correction would further reduce the statistical power of the study. Hypotheses were tested with an alpha level of 0.05.

Whilst the majority of participants came from different families, two participants were from the same family. This could be viewed as limiting as both children would have the same experience in terms of which parent was injured, time since injury, severity of injury, extent of resulting disability, physical environment and the elements they were rating. However, despite these tangible similarities in circumstance, the data from both siblings and the information obtained during the interview demonstrated that they had very different experiences subjectively. This is consistent with a personal construct perspective as it highlights that the internal experience and the way in which the siblings construed the same people in the same set of circumstances was very different.

A further limitation of the study is that all of the children who participated in the study lived with their parent with an ABI. Whilst this similarity leads to a more homogenous sample, it does, however, neglect to explore the impact on children where families are either separated due to the injured parent living in residential accommodation or due to the parental relationship/marriage breaking down following the brain injury. It is likely that many children are living in single parent households due to relationship breakdown. Wood and Yurdakul (1997) found that a total of 48.86% of individuals with a brain injury separated or became divorced from their long term partner following brain injury, and that 60% of couples with children were divorced following the brain injury.

It is difficult to strike the right balance between being inclusive and exploring the experiences of children in different circumstances, and having a non-homogenous sample, where many extraneous variables may account for differences between individuals. Had there been a larger sample size, it would have been possible to examine the data for gender effects, of either the child or the injured parent, time since

injury, age of the child at the time of injury, severity of the parental brain injury and the presence of extended family support for example.

The 'before ABI' and 'after ABI' constructs were elicited by asking participants to generate constructs from triads comprised of all 'before ABI' elements or all 'after ABI' elements. This technique was based on the assumption that each time period would have a distinct set of constructs associated with it, and that this method of elicitation would allow for the set of constructs associated with each time period to be generated. However, it is possible that elicited constructs may equally apply to both before and after the brain injury, particularly if the construct has continued salience for the participant.

A further methodological difficulty was having the parent present during the interview process for four of the participants. Whilst all four parents were present at the participant's request, this may have influenced the responses each participant gave. However, the subjective view of the author is that each participant appeared to be open and honest in their given responses. Equally, parents rating their children on the parental rating of child adjustment in front of participants may have influenced the ratings that were provided.

The study was also limited in that it was not possible to measure level of adjustment within the young person prior to the brain injury. Therefore, this limits the conclusions that may be drawn regarding adjustment to the parental brain injury.

## **5.8 IMPLICATIONS FOR FUTURE RESEARCH**

The largest limitation of this study was the small number of participants. It would therefore be beneficial to replicate this study in the future with a larger number of participants to verify the findings of this study. However, it is appreciated that accessing larger numbers of participants would be difficult, due to the difficulties encountered in trying to recruit for this study.

It would be beneficial to explore why it is that some children construe their parents more similarly or differently pre- and post-injury in comparison to others in a similar situation. Due to the small sample size, it was not possible to control for variables such as severity of the brain injury, sex of the injured parent, age of the child, change in economic status or other variables that may have impacted upon how the child construes. It would be interesting to explore if there are interpersonal variables that affect the degree to which construing changes. Whilst recruiting a

larger sample size to control for other variables would be the obvious way in which to do this, it is anticipated that a study of this nature may encounter similar recruitment difficulties to those that were experienced during the undertaking of this study. A possible way to explore interpersonal factors may be to investigate differences within the same family, as siblings are likely to have experienced the same environment and the same circumstances concerning the injured parent. A study of this nature would be valuable, as it would identify the difference between 'real' or tangible changes that could be objectively measured and 'perceived' changes by the individual. This may highlight the importance of how children make sense of and understand what has happened, in comparison to the 'facts' that others might consider have happened.

The main finding of this study was that greater change in how children construe themselves and their parents following parental brain injury is related to poorer adjustment. This then suggests that a therapeutic intervention to address this may be indicated. One possible intervention to explore given the theoretical orientation of this study would be a personal construct intervention. A study to evaluate the effectiveness of such an intervention would be valuable, and a possible way of evaluating the efficacy of the intervention would be to complete repertory grids and a measure of adjustment both prior to and following the intervention.

The focus of this study was to examine the constructs that children have in relation to themselves and their significant others, and how they construe themselves and their significant others. It was beyond the remit of this study to examine how the children construe the brain injury itself and whether they perceive the brain injury to have had a positive or a negative effect. During the interview process it was clear that some children felt that the brain injury had a positive effect in their lives. For example, a 12-year-old male participant stated that he thought that his father was not a very nice person prior to the brain injury, but he thought that his father was a much nicer person now. A 12-year-old female participant said that she thought her family went out together more and were much closer as a family following the brain injury.

## **5.9 CONCLUSION**

The key findings to emerge from this study were that there was a relationship between changes in how children who have a parent with a brain injury construe themselves and their parents following the ABI in comparison to how they construed

them previously and adjustment. This was particularly so for changes in how the child construed their mother, regardless of which parent experienced the brain injury.

The second finding of note was that some aspects of adjustment were related to relative intensity of the construct system, in that children whose 'after ABI' constructs were more intense than their 'before ABI' constructs were more likely to show better adjustment in areas of delinquent behaviour and family dysfunction, and to a lesser degree, symptoms of impulsivity and distractibility, psychological discomfort and social withdrawal.

The findings of the study may indicate that a PCP therapeutic intervention may be indicated for children who experience poor adjustment following their parent experiencing a brain injury. Other possible interventions that have been found to be useful for child relatives of individuals with other long-term conditions include group work and systemic work (Diareme et al., 2007; Gelman and Greer, 2011). Future research to explore the efficacy of such interventions with child relatives of individuals with an acquired brain injury would be beneficial.

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**APPENDIX A****Advertisement to be placed on Headway Facebook group****PARTICIPANTS NEEDED FOR RESEARCH PROJECT**

My name is Helen Westbury and I am a trainee Clinical Psychologist at the University of Hertfordshire. As part of my training I am completing a research project looking at the experience of children who have a parent with a brain injury.

Lots of research has been done to find out how a brain injury in the family can affect adult relatives. However, we know much less about the impact a brain injury in the family can affect children. Research may help professionals understand more about how we can help children affected by parental brain injury in the future.

I would like to interview children between the ages of 9-16 whose mother or father has had a brain injury. I would also like the children to fill in a multiple-choice questionnaire. It should take no more than 2 hours to do both the interview and the questionnaire. Children who live in the same house as their brain injured parent, or somewhere different can take part in the study.

If you are a child who would like to take part in the study, or if you are a parent and you think your child(ren) might like to take part I can provide more detailed information about what this might involve. You can contact me by sending me a private message/email on Facebook. Parental permission must be given for children to take part in the study.

Unfortunately, due to my location, I will only be able to interview people who live in the Midlands, London and some parts of the South East and East of England regions (e.g Oxford, Bucks, Beds, Cambs, Herts). If you would like to take part in the study, and aren't sure if you live in an area that I can travel to, please feel free to contact me to discuss this.

Thank you for your time in reading this  
Helen Westbury

## APPENDIX B1

## UH Parent Information Sheet

University of  
Hertfordshire



### INFORMATION SHEET FOR PARENTS

I am conducting a study looking at the experience of children who have a parent with a brain injury.

More specifically I am interested in how children view the world and significant people in their lives both before and after their parent experiences a brain injury. I am also interested in how this relates to level of adjustment in the child.

#### Who is conducting the study?

My name is Helen Westbury and I am a trainee Clinical Psychologist at the University of Hertfordshire. The study will be supervised by Professor David Winter, Programme Director and Chartered Clinical Psychologist and Dr Louise Birkett-Swan, Chartered Clinical Psychologist. I hold a current Enhanced Criminal Records Bureau (CRB) clearance certificate.

#### Why would it be helpful to take part in the study?

Lots of research has been done to look at how having a brain injury can affect adult relatives of the injured person. Not very much research has been done with child relatives of the injured person.

Sometimes, it is difficult for relatives to adjust to the impact a brain injury in the family can have. If we can learn more about what might make it easier or harder for someone to adjust to a brain injury in the family, we might be able to know more about how to help those who experience a brain injury within the family.

#### What would my child be asked to do if they take part in the study?

Your child would take part in an interview where they would be asked to think of ways in which people close to them are similar or different. The people they will be asked to think about are likely to be members of their family, such as parents or siblings.

Once they have chosen words to highlight similarities and differences between people, they would be asked to think about how well these words describe each of the people they are close to.

They will also be asked to complete a multiple-choice questionnaire about themselves. The questions are about different aspects of adjustment such as behaviour, social skills and changes in mood.

It should take approximately 2 hours to complete the interview and questionnaire

#### Where would the interviews take place?

I can visit your child in your home if you are happy for me to do this. If not, it might be possible to meet in an interview room somewhere else, for example, at your local Headway branch. However, not all Headway branches may be able to offer a room for this purpose.



**What would our rights be if we agreed to take part in the study?**

Both you and your child would need to give your permission to take part in the study.

Either you, or your child can change your mind about being in the study at any time, for any reason, even after the interview has taken place. If you change your mind after the interview has taken place, any information or questionnaires I have regarding you or your child would be destroyed.

Any information about you and your child will be anonymous and confidential. For example, names of people would not be written on the questionnaire or interview answer sheet. Each person completing the study will be given a code number, so that names will not need to be written down.

If information is shared that suggest that your child is at risk from harm, this will need to be shared with appropriate professionals/services.

**Further Information**

If you agree to take part in the study, and are interested in the results when the study is finished, a summary sheet can be provided on request.

**Who has reviewed this study?**

This study was reviewed by University of Hertfordshire Research Ethics Committee and was given ethical approval.

Registration Protocol Number: PSY/07/10/HW

Thank you for taking time to read this.

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## APPENDIX B2

## NHS Parent Information Sheet



University of  
Hertfordshire



Northamptonshire Healthcare **NHS**  
NHS Foundation Trust

## INFORMATION SHEET FOR PARENTS

**Project Title:** Children's constructions prior to and following parental brain injury

I am conducting a study looking at the experience of children who have a parent with a brain injury.

More specifically I am interested in how children view the world and significant people in their lives both before and after their parent experiences a brain injury. I am also interested in how this relates to level of adjustment in the child.

**Who is conducting the study?**

My name is Helen Westbury and I am a trainee Clinical Psychologist at the University of Hertfordshire. The study will be supervised by Professor David Winter, Programme Director and Clinical Psychologist and Dr Louise Birkett-Swan, Clinical Psychologist. I hold a current Enhanced Criminal Records Bureau (CRB) clearance certificate. The enhanced CRB check searches for details of any previous convictions (including spent convictions), cautions, warnings and reprimands, and any details that may be relevant to working with children or vulnerable adults.

**Why would it be helpful to take part in the study?**

Lots of research has been done to look at how having a brain injury can affect adult relatives of the injured person. Not very much research has been done with child relatives of the injured person.

Sometimes, it is difficult for relatives to adjust to the impact a brain injury in the family can have. If we can learn more about what might make it easier or harder for someone to adjust to a brain injury in the family, we might be able to know more about how to help those who experience a brain injury within the family.

**What would my child be asked to do if they take part in the study?**

Your child would take part in an interview where they would be asked to think of ways in which people close to them are similar or different. The people they will be asked to think about are likely to be members of their family, such as parents or siblings. Your child will be asked to think about how the people in their family were similar or different before the brain injury happened. After this, they will be asked to think about how the people in their family are similar or different after the brain injury happened. Visual aids or drawings may be used if younger children find this task difficult to understand.

After they have chosen words that show ways family members are similar or different to each other, they will be asked to think about how well these words described each family member before the brain injury happened. After this, they will be asked to think about how well the words describe each family member now.

They will also be asked to complete a multiple-choice questionnaire about themselves. The questions are about different aspects of adjustment such as behaviour, social skills and changes in mood.



It should take approximately 2 hours to complete the interview and questionnaire

**Where would the interviews take place?**

I can visit your child in your home if you are happy for me to do this. If not, it might be possible to meet in an interview room at the Isebrook Hospital, Wellingborough. Unfortunately, travel costs will not be able to be reimbursed if you choose for the interview to take place at Isebrook Hospital.

**What would our rights be if we agreed to take part in the study?**

Both you and your child would need to give your permission to take part in the study. Either parent can give consent for your child to take part in the study, provided they are able to do so.

Either you, or your child can change your mind about being in the study at any time, for any reason, even after the interview has taken place. If you change your mind after the interview has taken place, any information or questionnaires I have regarding you or your child would be destroyed.

Any information about you and your child will be anonymous and confidential. For example, names of people would not be written on the questionnaire or interview answer sheet. Each person completing the study will be given a code number, so that names will not need to be written down.

If information is shared that suggest that your child is at risk from harm, this will need to be shared with appropriate professionals/services.

**Further Information**

If you agree to take part in the study, and are interested in the results when the study is finished, a summary sheet can be provided on request.

**Who has reviewed this study?**

This study was reviewed by University of Hertfordshire Research Ethics Committee and was given ethical approval. (Registration Protocol Number: PSY/07/10/HW).

It was also reviewed by the Leicestershire , Northamptonshire & Rutland Research NHS Ethics Committee and given ethical approval (protocol number to be added subject to approval being granted)

Thank you for taking time to read this.



University of  
Hertfordshire



Northamptonshire Healthcare **NHS**  
NHS Foundation Trust

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Northants, NN8 1LP

**Complaints Procedure**

If you wish to make a complaint about the researcher, or the study, you may do so by contacting either Professor David Winter or Dr Louise Birkett-Swan, using the contact details provided above. You can ask your parent(s) to help you do this if needed.



23/12/2010 version2

## APPENDIX C1

## UH Child Information Sheet (Ages 9-11)

University of  
Hertfordshire



### INFORMATION SHEET FOR CHILDREN AGED 9-11

My name is Helen Westbury and I am a trainee Clinical Psychologist. I would like to learn more about children who have a parent with a brain injury.

As your parent has had a brain injury, I would like to learn more about how you think about things now and before your parent had their brain injury.

I would like to know about how you feel, things you might do, and how you get along with your friends and family.

#### Why would it be helpful to take part?

If we learn more about children who have a parent with a brain injury, we might be able to help other children who have a parent with a brain injury

#### What would I do?

I will ask you some questions about how people in your family are similar or different. After you have chosen some words that show how people are similar or different, you will decide how well the words describe different people in your family.

You will be asked to answer some multiple-choice questions about how you feel, things you do and how you get on with your friends and family.

It will take approximately 2 hours to complete the interview and questionnaire. You will be able to take a break during this time if needed.

#### Where would you see me?

I can see you in your home if you and your parents are happy with this. If not, I might be able to see you somewhere else that you and your parents would be able to get to easily.

#### Important things to know

Both you and your parent(s) would need to agree to take part in the study.

You can change your mind about being in the study at any time, for any reason, even after I have met you to ask you the questions.

No one else will know that any information I have is about you or your family.

If you or your parents tell me something that suggests you might be at risk from someone harming you or hurting yourself, this will have to be shared with other people.

If you would like to find out more, or to take part in the study, you can ask your parents to contact me.

If you want to find out what I learn when I have finished the study, I can give you some information about this if you ask for it.

Thank you for taking time to read this.



**Contact details of the researcher:****Helen Westbury**

Email address: h.westbury2@herts.ac.uk  
Telephone number: 01707 286 322  
Postal address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

If you would like to know the results of the study, please write your name and email address, or postal address below. Information will then be forwarded to you when the study is completed.



## APPENDIX C2

## NHS Child Information Sheet (Ages 9-11)

University of  
Hertfordshire



Northamptonshire Healthcare **NHS**  
NHS Foundation Trust

### INFORMATION SHEET FOR CHILDREN AGED 9-11

**Project Title:** Children's constructions prior to and following parental brain injury

My name is Helen Westbury and I am a trainee Clinical Psychologist. I would like to learn more about children who have a parent with a brain injury.

As your parent has had a brain injury, I would like to learn more about how you think about things now and before your parent had their brain injury. I would like to know about how you feel, things you might do, and how you get along with your friends and family.

**Why would it be helpful to take part?**

If we learn more about children who have a parent with a brain injury, we might be able to help other children who have a parent with a brain injury

**What would I do?**

I will ask you some questions about how people in your family are similar or different. You will be asked to think about how the people in your family were similar or different before the brain injury happened. After this, you will be asked to think about how the people in your family are similar or different now. After you have chosen some words that show how people are similar or different, you will decide how well the words describe different people in your family. You will be able to use pictures, drawings or flashcards to help you do this if needed.

You will be asked to answer some multiple-choice questions about how you feel, things you do and how you get on with your friends and family.

It will take approximately 2 hours to complete the interview and questionnaire. You will be able to take a break during this time if needed.

**Where would you see me?**

I can see you in your home if you and your parents are happy with this. If not, I might be able to see you at the Isebrook Hospital.

**Important things to know**

Both you and your parent(s) would need to agree to take part in the study.

You can change your mind about being in the study at any time, for any reason, even after I have met you to ask you the questions.

No one else will know that any information I have is about you or your family.

If you or your parents tell me something that suggests you might be at risk from someone harming you or hurting yourself, this will have to be shared with other people.

If you would like to find out more, or to take part in the study, you can ask your parents to contact me.

Thank you for taking time to read this.



University of  
Hertfordshire



Northamptonshire Healthcare **NHS**  
NHS Foundation Trust

**Contact details of the researchers:**

**Helen Westbury**

Email address: h.westbury2@herts.ac.uk  
Telephone number: 01707 286 322  
Postal address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

**Academic Supervisor**

**Professor David Winter**

Telephone number: 01707 286 322  
Postal Address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

**Field Supervisor**

**Dr Louise Birkett-Swan**

Telephone number: 01536 494144  
Postal Address: Community Neurorehabilitation Service  
Isebrook Hospital  
Abbey Block  
Irthlingborough road  
Wellingborough  
Northants, NN8 1LP

**Complaints Procedure**

If you wish to make a complaint about the researcher, or the study, you may do so by contacting either Professor David Winter or Dr Louise Birkett-Swan, using the contact details provided above. You can ask your parent(s) to help you do this if needed.



23/12/2010 version 2

## APPENDIX D1

## UH Young Person Information Sheet (Ages 12-16)

University of  
Hertfordshire



## INFORMATION SHEET FOR YOUNG PEOPLE AGED 12-16

My name is Helen Westbury and I am a trainee Clinical Psychologist. I would like to learn more about young people who have a parent with a brain injury.

As your parent has had a brain injury, I would like to learn more about how you view the world now, and before your parent had their brain injury. I would also like to know about things such as how you feel, things you might do, and how you get along with your friends and family.

**Why would it be helpful to take part?**

We know lots about how a brain injury can affect adult relatives of a person with a brain injury. We know much less about young people whose parent has had a brain injury.

For some young people, if your parent has had a brain injury, it may affect how you feel, the things you might do, or how you get along with your friends and family. If we learn more about this, we might be able to help other young people whose parent has a brain injury in the future.

**What would I do for the study?**

I will ask you some questions about how people close to you are similar or different. The people you will be asked to think about are likely to be members of your family, such as parents, brothers or sisters.

Once you have chosen words that show ways people are similar or different to each other, you will be asked to think about how well these words describe each of the people you are close to.

You will also be asked to fill in a multiple-choice questionnaire about yourself. The questions will include asking about how you might feel, things that you might do and how well you get along with your friends and family.

It will take approximately 2 hours to complete the interview and questionnaire.

**Where would you see me?**

I can visit you in your home if you and your parents are happy with this. If not, it might be possible to visit you somewhere else that everyone is happy with.

**Important things to know**

Both you and your parent(s) would need to agree to take part in the study.

You can change your mind about being in the study at any time, for any reason, even after I have met you to ask you the questions.

No one else will know that any information I have is about you or your family.



University of  
Hertfordshire



**Further Information and Contact Details**

**Helen Westbury**

Email address: h.westbury2@herts.ac.uk  
Telephone number: 01707 286 322  
Postal address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

If you would like to know the results of the study, please write your name and email address, or postal address below. Information will then be forwarded to you when the study is completed.



## APPENDIX D2

## NHS Young Person Information Sheet (Ages 12-18)

University of  
Hertfordshire

Northamptonshire Healthcare   
NHS Foundation Trust

## INFORMATION SHEET FOR YOUNG PEOPLE AGED 12-18

**Project Title:** Children's constructions prior to and following parental brain injury

My name is Helen Westbury and I am a trainee Clinical Psychologist. I would like to learn more about young people who have a parent with a brain injury.

As your parent has had a brain injury, I would like to learn more about how you view the world now, and before your parent had their brain injury. I would also like to know about things such as how you feel, things you might do, and how you get along with your friends and family.

**Why would it be helpful to take part?**

We know lots about how a brain injury can affect adult relatives of a person with a brain injury. We know much less about young people whose parent has had a brain injury.

For some young people, if your parent has had a brain injury, it may affect how you feel, the things you might do, or how you get along with your friends and family. If we learn more about this, we might be able to help other young people whose parent has a brain injury in the future.

**What would I do for the study?**

I will ask you some questions about how people close to you are similar or different. The people you will be asked to think about are likely to be members of your family, such as parents, brothers or sisters. You will be asked to think about how the people in your family were similar or different before the brain injury happened. After this, you will be asked to think about how the people in your family are similar or different now. You will be able to use pictures, drawings or flashcards to help you do this if needed.

Once you have chosen words that show ways people are similar or different to each other, you will be asked to think about how well these words described each of the people you are close to before the brain injury happened. After this, you will be asked to think about how well the words describe the people you are close to after the brain injury happened.

You will also be asked to fill in a multiple-choice questionnaire about yourself. The questions will include asking about how you might feel, things that you might do and how well you get along with your friends and family.

It will take approximately 2 hours to complete the interview and questionnaire.

**Where would you see me?**

I can visit you in your home if you and your parents are happy with this. If not, I might be able to see you at the Isebrook Hospital.





**Important things to know**

Both you and your parent(s) would need to agree to take part in the study.

You can change your mind about being in the study at any time, for any reason, even after I have met you to ask you the questions.

No one else will know that any information I have is about you or your family.

If you or your parents tell me something that suggests you might be at risk from someone harming you or hurting yourself, this will have to be shared with other people.

If you would like to find out more, or to take part in the study, you can ask your parents to contact me.

Thank you for taking time to read this.

**Further Information and Contact Details**

**Helen Westbury**

Email address: h.westbury2@herts.ac.uk  
Telephone number: 01707 286 322  
Postal address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

**Academic Supervisor**

**Professor David Winter**

Telephone number: 01707 286 322  
Postal Address: Doctor of Clinical Psychology Training Course  
University of Hertfordshire  
Hatfield, Herts., AL10 9AB

**Field Supervisor**

**Dr Louise Birkett-Swan**

Telephone number: 01536 494144  
Postal Address: Community Neurorehabilitation Service  
Isebrook Hospital  
Abbey Block  
Irthlingborough road  
Wellingborough  
Northants, NN8 1LP

**Complaints Procedure**

If you wish to make a complaint about the researcher, or the study, you may do so by contacting either Professor David Winter or Dr Louise Birkett-Swan, using the contact details provided above. You can ask your parent(s) to help you do this if needed.



APPENDIX E1

UH Parental Consent Form



PARENTAL CONSENT FORM

Project Title: Children’s constructions prior to and following parental brain injury and their relationship to levels of adjustment

Registration Protocol Number: PSY/07/10/HW

Name of researcher: Helen Westbury, Trainee Clinical Psychologist

- 1) I confirm that I have read and understand the information sheet dated ( ) Please initial box
2) I understand that participation is voluntary and that I can withdraw consent for my child to participate, and that my child is free to withdraw at any time, without giving any reason. I understand that if my child is withdrawn/withdraws from the study, the data that has been submitted will also be withdrawn at my mine or my child’s request.
3) I understand that the information that is submitted will be confidential and anonymised, and used only for this study. I understand that information will be filed in a locked cabinet or encrypted and stored electronically on password protected computers.

I agree/do not agree for my child to participate in the study.

Name of Parent:
Signature of Parent:
Date:
Researcher Signature:



APPENDIX E2

NHS Parental Consent Form

University of Hertfordshire



Northamptonshire Healthcare NHS Foundation Trust

PARENTAL CONSENT FORM

Project Title: Children's constructions prior to and following parental brain injury

Name of researcher: Helen Westbury, Trainee Clinical Psychologist

Please initial box

- 1) I confirm that I have read and understand the information sheet dated 23/12/2010 explaining what the research entails and what will be expected from my child. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.
2) I understand that participation is voluntary and that I can withdraw consent for my child to participate, and that my child is free to withdraw at any time, without giving any reason. I understand that if my child is withdrawn/withdraws from the study, the data that has been submitted will also be withdrawn at my mine or my child's request.
3) I understand that the information that is submitted will be confidential and anonymised, and used only for this study. I understand that information will be filed in a locked cabinet or encrypted and stored electronically on password protected computers.

I agree/do not agree for my child to participate in the study.

Name of Parent:
Signature of Parent:
Date:
Researcher Signature:

Please note that either the injured or non-injured parent can provide consent to take part in the study, providing they are able to do so.



APPENDIX F1

UH Child Consent Form (Ages 9-11)



YOUNG PERSON CONSENT FORM

Project Title: Children’s constructions prior to and following parental brain injury and their relationship to levels of adjustment

Registration Protocol Number: PSY/07/10/HW

Name of researcher: Helen Westbury, Trainee Clinical Psychologist

Please initial box

- 1) I have been given an information sheet dated ( ) explaining what the study will involve. I have been able to talk about any concerns or ask any questions about the study with my parent(s) and/or Helen Westbury.
2) I would like to take part in the study, and I know that I can change my mind about being in the study at any time and for any reason. If I change my mind about being in the study, any information about me will be destroyed.
3) I understand that the information about me won't have my name on it, and will be used only for this study. I understand that my information will be kept locked away and safe so other people can't see it. If my parents or I tell the researcher something that suggests that I might be at risk from someone harming me or hurting myself, this will need to be shared with other people.

I agree/do not agree to take part in the study.

Name of young person:
Signature of young person:
Date:
Researcher Signature:



APPENDIX F2

NHS Child Consent Form (Ages 9-11)



YOUNG PERSON CONSENT FORM (Ages 9-11)

**Project Title:** Children’s constructions prior to and following parental brain injury

**Name of researcher:** Helen Westbury, Trainee Clinical Psychologist

*Please initial box*

- 1) I have been given an information sheet dated 21/12/2010 explaining what the study will involve. I have been able to talk about any concerns or ask any questions about the study with my parent(s) and/or Helen Westbury.
- 2) I would like to take part in the study, and I know that I can change my mind about being in the study at any time and for any reason. If I change my mind about being in the study, any information about me will be destroyed.
- 3) I understand that the information about me won’t have my name on it, and will be used only for this study. I understand that my information will be kept locked away and safe so other people can’t see it. If my parents or I tell the researcher something that suggests that I might be at risk from someone harming me or hurting myself, this will need to be shared with other people.

I agree/do not agree to take part in the study.

Name of young person: -----

Signature of young person: -----

Date: -----

Researcher Signature: -----



APPENDIX G1

UH Young Person Consent Form (Ages 12-16)



YOUNG PERSON CONSENT FORM

Project Title: Children’s constructions prior to and following parental brain injury and their relationship to levels of adjustment

Registration Protocol Number: PSY/07/10/HW

Name of researcher: Helen Westbury, Trainee Clinical Psychologist

Please initial box

- 1) I have been given an information sheet dated ( ) explaining what the study will involve. I have been able to talk about any concerns or ask any questions about the study with my parent(s) and/or Helen Westbury. [ ]
2) I agree to take part in the study, and I understand that I can change my mind about being in the study at any time and for any reason. If I change my mind about being in the study, any information about me will be destroyed. [ ]
3) I understand that the information about me won't be shared with people not working on the study, won't have my name on it, and will be used only for this study. I understand that my information will be kept in a locked cabinet or stored safely on password protected computers. [ ]

I agree/do not agree to take part in the study.

Name of young person: -----
Signature of young person: -----
Date: -----
Researcher Signature: -----



APPENDIX G2

NHS Young Person Consent Form (Ages 12-18)



YOUNG PERSON CONSENT FORM (ages 12-18)

**Project Title:** Children’s constructions prior to and following parental brain injury

**Name of researcher:** Helen Westbury, Trainee Clinical Psychologist

*Please initial box*

- 1) I have been given an information sheet dated 23/12/2010 explaining what the study will involve. I have been able to talk about any concerns or ask any questions about the study with my parent(s) and/or Helen Westbury.
- 2) I agree to take part in the study, and I understand that I can change my mind about being in the study at any time and for any reason. If I change my mind about being in the study, any information about me will be destroyed.
- 3) I understand that the information about me won’t be shared with people not working on the study, won’t have my name on it, and will be used only for this study. I understand that my information will be kept in a locked cabinet or stored safely on password protected computers.

I agree/do not agree to take part in the study.

Name of young person: -----

Signature of young person: -----

Date: -----

Researcher Signature: -----



## APPENDIX H

### Debrief Information Sheet

University of  
Hertfordshire



#### DEBRIEF INFORMATION

Thank you for taking part in this study.

The study is looking at how children make sense of the world and people close to them both before and after their parent has a brain injury. The study is hoping to see if any changes in how people make sense of things are related to difficulties that people sometimes experience when someone close to them has a brain injury. This might include changes in how people feel, things they do and how they get on with other people. It is hoped that by learning more about the relationship between these things, this might help other children whose parent has a brain injury in the future.

If you need to talk to somebody about things that are difficult for you, or worries that you have about yourself or your parent, some of the information below might be useful for you.

#### **Mental health problems in children.**

Young Minds is a national charity which offers a young persons' service and parents' information & support service.

**Tel:** 0207 336 8445 Mon-Fri 9:30-17:30

**Parents' information service:** 0800 018 21 38

**E-mail:** [enquiries@youngminds.org.uk](mailto:enquiries@youngminds.org.uk)

**Web:** [www.youngminds.org.uk](http://www.youngminds.org.uk)

**Postal address:** 48-50 St John Street, London EC1M 4DG

#### **Support for child carers**

Barnados – Young carers. Barnados runs 15 projects across the UK that work to support young carers and their families.

**Web:** [http://www.barnados.org.uk/what\\_we\\_do/our\\_projects/young\\_carers.htm](http://www.barnados.org.uk/what_we_do/our_projects/young_carers.htm)

The Children's Society Include Project – includes information, web forum and contact details for local young carer support groups.

**Web:** [www.youngcarer.com](http://www.youngcarer.com)

Princess Royal Trust for carers – has a website aimed at young carers. It includes information, discussion boards, chat rooms, video links and areas for parents and professionals.

**Web:** <http://www.youngcarers.net/>

#### **Brain Injury support groups**

Headway (details of participant's local branch will be provided)

Contact details for a support group close to where the participant lives will be provided.



## APPENDIX I

## NHS National Research Ethics Service (NRES) Provisional Opinion Letter


**National Research Ethics Service**

**Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1**  
 The Old Chapel  
 Royal Standard Place  
 Nottingham  
 NG1 6FS

Telephone: 0115 8839368  
 Facsimile: 0115 8839294

15 December 2010

Miss Helen Westbury  
 Trainee Clinical Psychologist  
 Cambridgeshire and Peterborough NHS Foundation Trust  
 DClinPsy, School of Psychology  
 University of Hertfordshire  
 College Lane, Hatfield, Hertfordshire  
 AL10 9AB

Dear Miss Westbury,

**Study Title:** Young persons' constructions prior to and following  
 parental brain injury and their relationship to levels of  
 adjustment  
**REC reference number:** 10/H0406/93

The Research Ethics Committee reviewed the above application at the meeting held on 03 December 2010. Thank you for attending to discuss the study.

**Documents reviewed**

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		19 November 2010
Participant Information Sheet: Children 9-11	1	18 November 2010
Letter from Sponsor		19 November 2010
Participant Consent Form: Young People aged 12-18	1	18 November 2010
Participant Information Sheet: Parents	1	18 November 2010
Participant Consent Form: Parental	1	18 November 2010
REC application	47381/167204/1/139	19 November 2010
Participant Information Sheet: Young People aged 12-18	1	18 November 2010
Participant Consent Form: Children 9-11	1	18 November 2010
Protocol	2	18 November 2010
Evidence of insurance or indemnity		01 August 2010
School of Psychology Ethics Committee Approval		16 July 2010
Academic Supervisor CV		
Debrief Information	1	18 November 2010

This Research Ethics Committee is an advisory committee to East Midlands 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

**APPENDIX J**  
**UH Ethical Approval Letter**

Revised (September 2006)

**SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL**

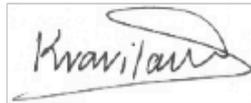
**Student Investigator:** Helen Westbury

**Title of project:** Young persons' constructions prior to and following parental brain injury and their relationship to levels of adjustment

**Supervisor:** David Winter

**Registration Protocol Number:** PSY/07/10/HW

The approval for the above research project was granted on 16 July 2010 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.



**Signed:**

**Date:** 16 July 2010

**Professor Lia Kvavilashvili**  
**Chair**  
**Psychology Ethics Committee**

-----  
**STATEMENT OF THE SUPERVISOR:**

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

**Signed (supervisor):** .....

**Date:** .....

**APPENDIX K**  
**NHS NRES Approval Letter**



**National Research Ethics Service**

**Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1**

The Old Chapel  
 Royal Standard Place  
 Nottingham  
 NG1 6FS

Telephone: 0115 8839368  
 Facsimile: 0115 8839294

06 January 2011

Miss Helen Westbury  
 58 Aynho Crescent  
 Sunnydale  
 Northampton  
 NN2 8LF

Dear Miss Westbury,

**Study Title:**                    **Young persons' constructions prior to and following parental brain injury and their relationship to levels of adjustment**  
**REC reference number:**      **10/H0406/93**

Thank you for your letter of 23 December 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the 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, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**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.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be*

*This Research Ethics Committee is an advisory committee to East Midlands 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.*

notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

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

Document	Version	Date
Protocol	2	23 December 2010
Response to Request for Further Information		23 December 2010
REC application	47381/167204/1/139	19 November 2010
Participant Consent Form: for Parents	2	23 December 2010
Academic Supervisor CV		
Debrief Information	1	18 November 2010
Evidence of insurance or indemnity		01 August 2010
Letter from Sponsor		19 November 2010
School of Psychology Ethics Committee Approval		16 July 2010
Investigator CV		19 November 2010
Participant Information Sheet: for Children aged 9-11	2	23 December 2010
Participant Information Sheet: for Young People aged 12-18	2	23 December 2010
Participant Information Sheet: for Parents	2	23 December 2010
Participant Consent Form: for Children aged 9-11	2	23 December 2010
Participant Consent Form: for Young People aged 12-18	2	23 December 2010

#### 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 Service 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
- Adding new sites and investigators
- 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.

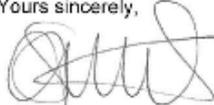
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**10/H0406/93**

**Please quote this number on all correspondence**

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

Yours sincerely,



*PE*  
**Dr Carl Edwards**  
**Chair**

Email: [susie.cornick-willis@nottspct.nhs.uk](mailto:susie.cornick-willis@nottspct.nhs.uk)

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* R&D office for NHS care organisation at lead site – Northamptonshire  
Healthcare NHS

## APPENDIX L

## R &amp; D Letter of Access to Research



**Helen Westbury,**  
 Dclin Psych Dept,  
 University of Hertfordshire,  
 Hatfield,  
 Hertfordshire.  
 AL10 9AB

**Clinical Governance Support Team**  
 Sudborough House  
 St Mary's Hospital  
 Kettering  
 Northamptonshire, NN15 7PW

Tel: 01536 494173  
 Fax: 01536 494216  
 Web: www.nht.nhs.uk

15.03.2011

Dear Helen,

**Letter of Access to Research**

As an existing NHS or University employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that such checks as are necessary have been carried out by your employer and that the research activities you undertake in this NHS organisation are commensurate with the activities you undertake for your employer. This letter confirms your right of access to undertake research activities through Northamptonshire Healthcare NHS Foundation Trust for the purpose of and on the terms and conditions set out below.

We have seen and are satisfied with the documents displayed in the table below. These will be kept in our records for the duration of your approved access to the trust.

Document Name	Valid from date	Valid to date
Signed and Dated CV	08.12.2010	30.09.2011
NHS-NHS Proforma Confirmation of Pre-Engagement Checks	10.03.2011	30.09.2011

This right of access commences on **15.03.2011** and ends on **30.09.2011** unless terminated earlier in accordance with the clauses below.

You have a right of access to support the following research project being undertaken at Northamptonshire Healthcare NHS Foundation Trust as confirmed in writing in the letter of permission for this research study from this NHS organisation.

Chairman: **John Peet**

Chief Executive: **Ron Shields**

Trust Headquarters: Sudborough House, St Mary's Hospital, London Road, Kettering NN15 7PW. Tel: 01536 410141. Fax: 01536 493147

***Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project or until we have received your signed and dated confidentiality agreement.***

You are considered to be a legal visitor to Northamptonshire Healthcare NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Northamptonshire Healthcare NHS Foundation Trust, you will remain accountable to the University of Herfordshire but you are required to follow the reasonable instructions of your nominated Manager, Louise Birkett-Swan, Clinical Psychologist within the Clinical Neuro Rehabilitation Service, in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Northamptonshire Healthcare NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Northamptonshire Healthcare NHS Foundation Trust in discharging its duties under the Health and Safety at Work Act 1974 etc. and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Northamptonshire Healthcare NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore, you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution. The right to access patient identifiable data before gaining the informed consent of the patient and their care coordinator is not permitted.

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Northamptonshire Healthcare NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, e-mail or library account, keys or protective clothing, these are returned upon termination of this agreement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your nominated manager in this NHS organisation.

Yours sincerely,



Lauren Sayers  
Research and Development Manager

cc: Dr Louise Birkett-Swan