

**The construal processes of families affected by parental
Acquired Brain Injury, and the implications for adjustment
in young people and their families.**

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Abstract

Acquired Brain Injury (ABI) has been associated with significant family disruption, yet few studies explore the experiences of child-relatives. This cross-sectional study sought to explore the experiences of young people and their families (n = 3) following parental ABI. The major aims were (1) to develop an understanding of the processes by which family members make sense of events, and (2) to explore the implications for adjustment in young people and their families. A Personal Construct Psychology (PCP) methodology was implemented and construal processes were identified through individual interviews facilitated by Perceiver Element Grids (PEG; Procter, 2002). The Family Assessment Device (FAD; Epstein et al., 1983) and the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) were used to explore aspects of adjustment. Data analysis comprised of two parts; intra-family and inter-family exploration of similarities and differences in construal. The themes identified suggest that following ABI, family members may be faced with a process of reconstrual, in which they are required to assimilate new information into their construct systems, renegotiate their roles, and come to terms with loss. The research offers an insight into some of the processes that may contribute to patterns of interpersonal relating that may negatively impact on adjustment. Psychological support following parental ABI may therefore be a crucial component of supporting young people and their families through these changes whilst reducing the impact on their own psychosocial wellbeing. This research offers an insight into the experiences of three families at one moment in time. Further exploration is recommended to better inform clinical practice, and ensure that the needs of this population are not overlooked.

Chapter 1: Introduction

This thesis sought to explore the construct systems of families affected by parental brain injury, and to determine whether similarities or differences in construal among family members had implications for the adjustment of young people and their families. This chapter begins by defining the key terms, setting the context for the research, and describing the rationale for implementing a Personal Construct Psychology (PCP) methodology. This is followed by a systematic review of the existing literature relating to the experiences of young people and their families following parental Acquired Brain Injury (ABI). Finally, the major aims of this research are stated.

1.1 Theoretical Position

The author's stance is that of a constructivist epistemology; there is an assumption that individuals actively construct meaning from their experiences (e.g. Neimeyer & Neimeyer, 1993). The author employs a post-modern position that considers individuals as active participants in making sense of events in the world around them. As such, the importance of eliciting multiple perspectives when working alongside families is considered to be of paramount importance.

It is acknowledged that through conducting qualitative research, the author's theoretical position may influence the research process. As such, reflexivity will be acknowledged throughout the research process. The theoretical position of the author and implications on the research process will be discussed in more detail throughout this thesis, in relation to any matters arising.

1.2 Definition of Key Terms

1.2.1 Acquired Brain Injury. ABI is an umbrella term used to describe an acute, non-progressive brain injury that has occurred since birth (Royal College of Physicians and British Society of Rehabilitation Medicine [RCP & BSRM], 2003). ABI encompasses a number of conditions, most notably

Traumatic Brain Injury (TBI) and stroke, but also includes brain tumours, meningitis, encephalitis, hydrocephalus and anoxia, among others (RCP & BSRM, 2003; Headway, n.d.).

Given the number of conditions that fall into the category of ABI, it is difficult to elicit exact figures with regard to prevalence. Based on hospital admissions in the United Kingdom (UK), current estimates suggest that in 2013/14, 348,934 individuals were affected by ABI, representing a 10% increase since 2005 (Headway, 2015). Table 1 describes different types of ABI and states their annual incidence (where known), alongside common causes.

Table 1. *Types of ABI*

Type of Injury	Definition	% of ABI*	Incidence (annually)	Common causes
TBI¹ <i>Blunt</i> <i>Penetrating</i>	Injury resulting from an external force. Impact without breaking skull. Impact that breaks the skull: foreign matter enters the brain tissue.	47%	UK: 162,000	Road Traffic Accident (RTA), falls, assaults, sporting Injuries
Stroke² <i>Ischaemic</i> <i>Haemorrhagic</i>	Interruption of blood flow to the brain. Blockage to a blood vessel. Bleeding in or around the brain.	37%	UK: 152,000	Lifestyle factors e.g. smoking, hypertension, obesity, high cholesterol, diabetes and alcohol abuse
Anoxia³	Interruption to the brain's oxygen supply.		Unreported.	Cardiac arrest, suffocation, choking, poisoning
Encephalitis⁴	Inflammation of the brain tissue.		Global: 1 in 250,000 to 500,000	Viral infection or autoimmune disease
Tumour⁵	Abnormal growth of cells in the brain.	16%	UK: 9,400	Medical radiation, previous cancers, family & medical history,
Meningitis⁶	Inflammation of the membranes surrounding the brain and spinal cord.		UK: 3,200	Bacterial or viral infection
Hydrocephalus⁷	Accumulation of cerebrospinal fluid (CSF) in the brain.		Unreported.	Congenital birth defects, other types of ABI

*Estimated proportion based on UK Hospital admission (Headway, 2015); ¹Headway, 2013; ²Stroke Association 2012; 2014a; ³Headway, 2013; ⁴Solomon et al., 2012; The Encephalitis Society, 2015; ⁵Cancer Research UK, n.d.; ⁶Meningitis Research Foundation, n.d.; ⁷Headway, n.d.

In this thesis, unless it is deemed fundamental to differentiate between types of injury, the encompassing term of ABI is used. ABI is typically categorised as mild, moderate, severe, or very severe. Classification systems are numerous, and different services utilise different methods of classification. Whilst structural imaging is essential for identifying localisation of damage and may aid prediction of subsequent sequelae, it can be a poor predictor of the severity of subsequent disability (RCP & BSRM, 2003). Length of Post Traumatic Amnesia (PTA; Bigler, 1990), duration of Loss of Consciousness (LoC), and level of responsiveness during coma (Glasgow Coma Scale [GCS] score; Teasdale & Jennet, 1974) are more commonly used (see Table 2).

Table 2. *Descriptions of ABI severity.*

	Severity			
	Mild	Moderate	Severe	Very Severe
Structural imaging	Normal	Normal or abnormal	Normal or abnormal	Abnormal
GCS	13-15	9-12	3-8	<3
LoC	<30 minutes	30 minutes – 6 hours	6 – 48 hours	>48 hours
PTA	0-1 day	>1 day and <7 days	>7 days	>1 month

Whilst greater ABI severity during the acute phase is often an indicator of poorer prognosis, these measures are limited regarding their prediction of longer-term outcomes (e.g. RCP & BSRM, 2003). Table 3 summarises the Glasgow Outcome Scale (GOS; Jennet & Bond, 1975), a tool used to categorise severity of functional impairment following ABI.

Table 3. *Descriptive Categories of GOS.*

	Severity			
	Mild	Moderate	Severe	Very Severe
GOS Description	Return to pre-morbid functioning. Few residual deficits.	Disabled but independent.	Dependent for daily support.	Absence of cortical functioning

1.2.2 Family systems. Definitions of family systems are culturally diverse and have undergone significant revisions in recent years. Whilst commonly accepted definitions from the Oxford English Dictionary include “a group consisting of two parents and their children living together as a unit” (n.d.) and “a group of people related by blood or marriage” (n.d.), these definitions do not privilege the diversity of family systems that exist within the current sociocultural landscape.

In this thesis, the family system refers to a social unit consisting of one or more adults, and their children. Family members need not necessarily be biologically related, nor related by marriage. As such, this definition includes non-traditional family systems, including but not limited to, single-parent families, same-sex parenting families, step-families, and adoptive families. Furthermore, it is acknowledged that an increasing number of families undergo separation. For example, recent statistics have revealed a 96% increase in the number of couples divorced in England and Wales between 1970 and 2013 (Office for National Statistics [ONS], 2015). Provided there continues to be an element of co-parenting, the family system extends to describe families that are no longer co-habiting.

1.2.3 Young People. The words ‘children’, ‘young people’, and ‘adolescents’ are often used interchangeably. In this thesis, the term ‘young people’ will refer to anyone under the age of 18 years old. Where

differentiation in age is considered important, 'child' will refer to a young person aged 12 years old or younger, whilst 'adolescent' will refer to a young person aged 13 years and older. In the context of describing interpersonal relationships, all young people will be described as the children of their parents.

1.3 Research Significance

1.3.1 Personal significance. The author has a longstanding interest in child and adolescent mental health that has been cultivated through clinical training. The importance of considering the wider family system has been highlighted considerably, particularly during clinical placements. In accordance with the author's theoretical stance, it feels imperative to consider the implications of multiple perspectives within a family system. Furthermore, the author has personal experience of supporting peers affected by parental ABI. Observing the impact of parental ABI on adult children precipitated a curiosity about the experiences of young people.

1.3.2 Social significance. This thesis sets to explore the gaps in the literature relating to young people's and families' experiences of ABI. The following sections briefly outline three key areas of social significance that were considered when developing the research proposal; the prevalence and epidemiology of ABI, the impact of ABI on family members, and Child and Adolescent Mental Health (CAMH).

1.3.2.1 Public health concerns. TBI has been identified as the leading cause of death and disability among young adults in the UK (National Institute for Health and Care Excellence [NICE], 2014a). Males are considered to be at increased risk of TBI, although hospital admissions for females have risen by 24% since 2005/6 (Headway, 2015). Risk associated with gender is considered to be a consequence of gender differences in occupational and leisure pursuits (e.g. Yates, et al., 2006).

Stroke is the fourth most common cause of death in the UK (Stroke Association, 2016), and there are thought to be in excess of 900,000 people living with the effects of stroke (NICE, 2008a; Stroke Association, 2012); 300,000 of whom will experience a moderate to severe disability (Stroke Association, 2012). Although stroke most commonly affects older adults (65+), approximately one third of stroke patients in the UK are of working age (> 65 years old) (Stroke Association, 2014b). Among working age adults, stroke is more prevalent in males (Stroke Association, 2012). Alarming, the risk factors previously described in Table 1 are all currently public health concerns in the UK (NICE, 2008b; 2012; 2013; 2014b; 2014c; 2015). It is thought that at least 50% of all stroke survivors will experience long-term disability (Stroke Association, 2012; 2016).

Whilst other types of ABI are relatively uncommon, medical advances mean that an increasing number of people are surviving ABI, and consequently living with associated disability (RCP & BSRM, 2003). ABI can result in significant behavioural, cognitive, emotional, functional, social, occupational, and personality changes, in addition to physical disability (e.g. Headway, n.d.; Meningitis Research Foundation, n.d.; RCP & BSRM, 2003; Stroke Association, 2014a; The Encephalitis Society, 2015). Deficits resulting from ABI are heterogeneous and vary dependent upon the site of injury and localisation of damage (RCP & BSRM, 2003). Given the sudden and often irreversible consequences of ABI, it is unsurprising that affected individuals may undergo a significant adjustment process (e.g. Anson & Ponsford 2006).

1.3.2.2 Impact of ABI on family members. Brooks stated 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” (1991, p. 155). The wider impact of ABI on families has been increasingly acknowledged over the past four decades, yet most research is limited to exploring the experiences of spouses, and parents (e.g. Brooks, 1991; Florian & Katz, 1991; Hall, Karzmark, Stevens, Englander, O’Hare &

Wright, 1994; Kreutzer, Gervasio & Comclair, 1994; Panting & Merry, 1972; Rivara, Fay, Jaffe, Polissar & Martin, 1992; Rivara, Jaffe, Polissar, Fay, Liao, & Martin, 1996).

Panting and Merry's (1972) seminal paper was one of the first to explore the impact of TBI on relatives of those with severe brain injury (n=31). They found that over 50% of the participants' relatives reported feeling they had insufficient information regarding their injured relative's prognosis. Furthermore, they identified that approximately two thirds of relatives had been prescribed anxiolytics. These findings have been supported over time, with a systematic review by Verhaeghe, Defloor & Grypdonck (2005) identifying that even after significant time periods (≤ 15 years), family members of patients affected by TBI reported levels of stress that warranted professional intervention.

Research has consistently identified that families report finding it harder to adjust to the personality, cognitive, and emotional sequelae of ABI than any physical disability (Brooks, 1991; Florian & Katz, 1991; Kreutzer et al., 1994; Panting & Merry, 1972; Thomsen, 1984; Urbach, Sonenklar, & Culbert, 1994). The impact of ABI on spouses is considered to be far greater than the impact of ABI on parents of brain-injured children (e.g. Hall et al., 1994; Leathem, Heath & Wooley, 1996; Panting & Merry, 1972; Kreutzer et al., 1994). It has been hypothesised that parents may be more tolerant to ABI sequelae than spouses; this is based on the hypothesis that parents are already fulfilling a caring role and consequently fewer role adaptations are required (Florian & Katz, 1991; Kreutzer et al., 1994). It has also been suggested that following ABI in children, there may be less burden if a parenting role is shared between two parents (e.g. Oddy, Humphrey & Uttley, 1978; Panting & Merry, 1972; Ponsford, 2007).

Research has identified pre-injury family functioning as a significant predictor of post-injury family functioning (e.g. Rivara et al., 1992; Rivara et al., 1996).

Specifically, cohesion, strong relationships and perceived access to coping resources are thought to have a greater influence on post-injury family functioning than injury severity (Rivara et al., 1992). Furthermore, Douglas & Spellacy (1996) found a positive correlation between family functioning and the brain-injured patient's outcome. This may highlight the invaluable role of the family system in times of adversity.

Clinical guidelines advocate the need to support families and caregivers following ABI; in particular, they note the importance of being aware of the needs of young people (RCP & BSRM, 2003). A literature review conducted by Florian and Katz (1991) highlighted the importance of supporting family members' individual psychological needs rather than solely supporting them as caregivers. They identified that psychological support fostered a reduction in the psycho-emotional sequelae experienced by the family through facilitating adjustment and reducing distress. Specifically, they identified a utility in offering guidance and education about TBI, emotional counselling, relationship counselling including sex therapy, and family therapy.

Whilst research pertaining to family experiences is becoming increasingly prevalent, there continues to be a lack of understanding of the experiences of young people affected by parental ABI. Given the aforementioned changes that may be imposed upon the family system, it is imperative to address this gap. A full systematic review of existing literature in this domain will be presented in Section 1.5.

1.3.2.3 Child and adolescent mental health. Child and adolescent mental health is currently high on the National Health Service (NHS) agenda. Children and young people make up approximately a quarter of the UK population and recent estimates suggest that one in ten young people experience mental health difficulties (Green, McGinnity, Meltzer, Ford & Goodman, 2004). Poor child and adolescent mental health has been associated with lower educational attainment and health-damaging behaviours

including alcohol abuse (Department of Health [DoH], 2015). Furthermore, recent statistics suggest that 50% of long-term mental health problems commence before a child reaches their fourteenth birthday, with 75% of mental health problems having commenced before adulthood (Kessler et al., 2007; Murphy & Fonagy, 2012). Recent policy advocates the importance of “children and young people having timely access to clinically effective mental health support when they need it” (Department of Health, 2015, p.16), yet paradoxically, less than 1% of the NHS budget currently funds child and adolescent mental health services (Law, Faulconbridge & Laffan, 2015).

Stressful life events are thought to reduce coping resources among young people, and contribute to interactional patterns between family members that perpetuate difficulties (Friedman & Chase-Lansdale, 2002; Garmezy & Masten, 1994). Stressful events in childhood and adolescence, particularly family disruption, have also been associated with increased risk of future mental health problems (e.g. Compas, 1987a; Compas, 1987b; Ge, Lorenz, Conger, Elder, & Simons, 1994; Gilman, Kawachi, Fitzmaurice & Buka, 2003).

Specifically, Armistead, Klein and Forehand (1995) examined the way in which parental chronic illness influenced functioning in young people. They identified disrupted parenting as a key variable accounting for impaired functioning in young people. Examples of disrupted parenting included reduced support, changes to routine and discipline, family reorganisation resulting in neglect, and absence of either parent. Furthermore, Korneluk and Lee (1998) found that young people’s adjustment to parental chronic illness was associated with perceived stress levels, rather than the severity of their parent’s illness. This raises the importance of understanding a young person’s perception of their parent’s difficulties, and offering support in coping with perceived stressors.

There is also an abundance of literature exploring the influence of parental mental health on young people’s psychosocial outcomes. It is estimated that

up to two thirds of young people affected by parental mental health will subsequently experience psychosocial difficulties themselves (Office of the Deputy Prime Minister, 2004). The Think Family agenda specifically encourages services to consider the wider family when working in adult mental health services in (Social Exclusion Unit Taskforce, 2008).

Since ABI can result in physical and emotional sequelae, young people affected by parental ABI may be particularly vulnerable. This further highlights the need to understand the experiences of this group of young people.

1.4 Personal Construct Psychology (PCP) Perspective

In this section, a brief overview of PCP will be given before key PCP processes will be discussed and explored in relation to familial experiences of ABI. Subsequently, the Family Construct System (FCS) will be introduced. Throughout this section, the relevance of a PCP perspective for this thesis will be explained.

1.4.1 What is PCP? PCP was developed by George Kelly in the 1950's, and is defined by the fundamental postulate and the 11 corollaries. The fundamental postulate states that "a person's processes are psychologically channelized by the ways in which he anticipates events" (Kelly, 1955, p.46). Put simply, Kelly described individuals as scientists, taking an active role in making predictions about the world. The epistemological position of PCP is one of constructivism; PCP posits that individual experience plays an essential role in how knowledge is engendered, resulting in a set of beliefs, otherwise known as the Personal Construct System. One of Kelly's defining principles of PCP is the notion of 'constructive alternativism', which suggests that events are subject to a number of different interpretations, and our interpretations are open to revision. As such, PCP suggests that it is not the event itself that influences an individual's response, but the way in which it is perceived. The corollaries are supplementary statements that support the

fundamental postulate. Full Kellian definitions can be found in Appendix A. However, for convenience they are summarised in Table 4.

Table 4. *The Eleven Corollaries (adapted from Kelly, 1955)*

Corollary	Definition
Construction	Themes in experience are identified, allowing future predictions to be made. Predictions are known as constructs.
Individuality	Individuals may construe events differently.
Organizational	Constructs are inter-related and organised hierarchically. Superordinate constructs are more important than subordinate constructs.
Dichotomy	Constructs are bi-polar and the two poles contrast one another. e.g. <i>sad</i> versus <i>happy</i> .
Choice	Constructs are selected on the basis of potential growth.
Range	Constructs can only be used to anticipate a finite range of events.
Experience	Construct systems evolve in response to new information.
Modulation	Constructs can be permeable, allowing them to be applied to new events.
Fragmentation	Subsystems of the personal construct system may be incompatible with one another.
Commonality	Individuals may construe events similarly.
Sociality	The ability to understand another's construal processes.

Kelly also described different types of constructs which have been summarised in Table 5.

Table 5. *Types of Construct (adapted from Kelly, 1955)*

Type of Construct	Definition
Constellatory	A group of constructs that are repeatedly used together.
Pre-emptive	Application of constructs in a non-flexible manner. e.g. an event that is <i>always</i> construed as 'good' and nothing else.
Propositional	A working hypothesis, or flexible construal.
Permeable	Constructs that are open to revision.

It is clear that the processes involved with anticipating events are perhaps more complex than they initially seem. Since the Experience Corollary states that construct systems are revised on the basis of experience, it could be expected that changes to construct systems will occur following ABI. The relevance of a PCP approach to this research will now be discussed.

1.4.2 Relevance of PCP. This section introduces PCP concepts, including construal processes and Kellian emotions, which are discussed in relation to familial experiences of ABI. The section concludes with an introduction to the Family Construct System (FCS).

1.4.2.1 Processes of construal. Different construal processes have different implications for the construct system. Table 6 defines six key PCP processes, which will subsequently be described in the context of this thesis, and the experience of ABI.

Table 6. *Processes of Construal (adapted from Kelly, 1955).*

Terminology	Definition
Validation	Confirmation of predictions.
Invalidation	Disconfirmation of predictions.
Tight	Use of similar predictions.
Loose	Use of different predictions.
Dilation	Expansion of construct system to accommodate alternative constructions.
Constriction	Reduction of construct system, to accommodate fewer constructions.

1.4.2.1.1 Validation versus invalidation. Confirmatory evidence sought via validation helps to strengthen the construct system. Relationship satisfaction has been associated with a higher degree of validation, whereas high levels of invalidation have been associated with relationship difficulties (Neimeyer & Hudson, 1985). Kelly (1955) described ‘disorder’ as “any personal construction which is used repeatedly in spite of consistent invalidation” (p. 831). Given the impact that ABI can have upon interpersonal relationships, and the implications that disrupted parenting can have on young people, these domains may be of particular significance. For example, a young person’s existing constructs of their parent may become invalidated following parental ABI.

1.4.2.1.2 Tight versus loose construal. Overly tight construal has been associated with anxiety disorders (e.g. Bannister & Fransella, 2013; Winter, 2013). Comparatively, loose construal has been described as a way of managing experiences of invalidation and is thought to be common among individuals experiencing interpersonal difficulties (e.g. Winter, 2013; Winter,

Shivakumar, Brown, Roitt, Drysdale, & Jones, 1987). Winter, Metcalfe and Shoeb (1997) explored the relationship between construal of significant others of brain-injured patients, and the recovery of the brain-injured person. Interestingly, they found that tighter construal among significant others was positively associated with recovery in the brain-injured individual.

1.4.2.1.3 Dilation versus constriction. Finally, dilation is in part considered an adaptive strategy, whereas constriction has been described as a defence against anxiety and a way in which to reduce threat, thus making overwhelming situations more manageable (Kelly, 1955). With regard to adjusting to the effects of ABI, both dilation and constriction could be considered functional if individuals revise their construct systems on the basis of new information. However, persistent or exclusive use of either strategy would likely lead to difficulties (e.g. Winter, 2013).

1.4.2.2 Kellian emotions. Kelly (1955) described emotions as constructs of transition, occurring when we are made aware of changes to our construct systems. Kellian emotions include anxiety, threat, hostility, aggression and guilt. In this section, Kellian emotions are described, and explored in the context of parental ABI.

Kellian anxiety describes the experience of being unable to construe a situation within which you find yourself (Kelly, 1955). Trauma is thought to result in anxiety as it may lead to an influx of new experiences (Lester, 2009). This is particularly relevant given the number of unexpected changes that can occur following ABI. Often, individuals and their families do not know of other people with ABI and therefore it is difficult to know what to expect. This may raise anxiety levels. Kellian anxiety may be particularly problematic for an individual who is a 'tight' construer, as it could be hypothesised that they will find it more difficult to adapt (e.g. Dalton & Dunnet, 1992).

Kellian threat could be considered as an 'identity crisis', or the experience within which an individual's self-concept is questioned or challenged (Kelly, 1955). Regarding ABI, this appears significant for both the injured patient and their relatives given the breadth of changes that may occur pertaining to role, identity, and ability to make sense of the world. The experience of a brain injury within the family has been likened to grief or bereavement. Neimeyer (2009) commented that "grieving is a process of reconstructing a world of meaning that has been challenged by loss" (p. 306).

Kellian hostility describes the experience of having a construct invalidated, but choosing to manipulate the event in accordance with a desired outcome, rather than make revisions to existing constructs (Kelly, 1955). Poorly adjusted families may exhibit hostility whereby they continue to use the same constructs in spite of invalidations resulting from ABI. This may have differential effects throughout the rehabilitation process, where challenges and prognosis may be variable.

Kellian aggression describes the process of actively experimenting with construal, in order to obtain validation (Kelly, 1955). For the individual with ABI, this could involve actively experimenting with doing things, in order to seek validation evidence that they are 'able' as opposed to 'disabled'. For the broader family system, this could involve actively experimenting with different ways of coping, in order to seek validation evidence that the family unit remains intact.

Finally, Kellian guilt describes the process that occurs when an individual's behaviour is inconsistent with their view of themselves (Kelly, 1955). Kellian guilt may relate to specific activities, for example, pursuing a caring role for a spouse following ABI. However, Kellian guilt may also apply to personal qualities, for example, a tolerant individual becoming impatient or annoyed at their partner. Given the different sequelae of ABI, guilt may be apparent for the injured individual as they learn to renavigate their world, and for family

members who may be required to subsume different roles, and become familiar with changes to family life.

1.4.2.3 Family Construct System. The notion of the Family Construct System (FCS; Procter, 1985) or shared construct system (e.g. Dallos, 1991) describes an extension of the personal construct system; families develop a shared set of beliefs and negotiate a common reality, which in turn informs individual construing. In accordance with the Dichotomy Corollary, Procter identified that within the FCS, family members may have contrasting perceptions of an event. Procter (1996) acknowledged that families can become polarized when faced with difficult life events, and individual viewpoints may become rigid. Sociality describes the ability to construe the construal processes of others, and it is considered that relationships are improved when individuals exhibit better sociality. Regarding family experiences of ABI, it is therefore important to consider the different perspectives that may be held by family members, in order to fully understand their experiences.

1.4.2.4 Summary. PCP offers an insight into ways in which individuals make sense of the world around them. Given the breadth of changes that families' may be confronted with following ABI, it seems likely that both individual, and family construct systems will be subject to reorganisation. Furthermore, PCP emphasises the importance of individual perceptions of events, and subsequent influence on behaviour. It therefore seems an appropriate framework to employ in order to explore whether similarities or differences in perceptions of events have implications for adjustment.

1.5 Literature Review

Research regarding the impact of brain injury on child relatives is limited. Most existing literature considers the impact of ABI on adult relatives. The impact of parental ABI on young people has historically been neglected in the literature, with research focusing upon the impact on spouses, or parents of children with ABI. The focus of this systematic review of theoretical and empirical

literature was therefore focused upon young people's experiences of parental brain injury.

Since commencing this research, Tiar and Dumas (2015) published a systematic review of the literature regarding to the impact of parental ABI. Their review examined papers through the lens of the coping competence model (Blechman, Prinz & Dumas, 1995) that describes a relationship between daily challenges, coping skills, and developmental outcomes. Specifically, they identified that young people are faced with social, affective, and achievement challenges following parental ABI, and that pro-social, asocial and anti-social coping strategies were employed by young people. They concluded that outcomes for young people following parental ABI are diverse, however, there was a consensus that affected young people are at more risk of poorer outcomes than their non-affected counterparts.

Tiar and Dumas' (2015) review strategy included papers published prior to 2010. Consequently, for the purposes of this thesis, it would have been appropriate to review literature published after this period. However, given the relative scarcity of research, and the specific lens from which papers were reviewed for their publication, it was felt that a full systematic review would support the author in developing a broader understanding of the current evidence, and ensure that additional findings were not overlooked.

1.5.1 Literature review strategy. Table 7 illustrates the search terms used to conduct a systematic review of articles from three databases: Scopus, PubMed, and psycARTICLES. As mentioned, the search parameters were extended to include all existing published literature. A detailed illustration of the literature search strategy can be found in Appendix B.

Table 7. *Systematic Review Search Terms*

AND

("brain injur*" or ABI or TBI or "head injur*" or stroke or "head trauma")

(famil* or relative or child* or parent*)

(perspective or attitude or impact or function* or adapt* or adjust* or experience or effect or outcome)

Abstracts were screened for relevance and studies were excluded if they focused predominantly on the experiences of adults (including adult children), siblings of injured children, or parents of injured children. The reference lists of remaining studies were scanned in order to identify any further relevant studies that had not been detected using the aforementioned search parameters. After removing duplicates, a total of 17 studies were identified. Two papers based on clinical experience were excluded as they were not empirical research. Additionally, two studies were excluded as their full text was not available in English.

1.5.2 Characteristics of included studies. Table 8 summarises each paper with regard to the sample population, design, measures or interview procedures, and methods of analyses. For ease of reference, studies are listed alphabetically.

Table 8. Summary of Included Studies.

Authors	Design	Young People (YP) <i>Number, age, inclusion criteria</i>	ABI <i>Parent, type, time since injury</i>	Procedure <i>Family members, measured used</i>	Analysis
Butera-Prinzi & Perlesz (2004)	Case Report	n = 4	100% fathers	YP: behaviour difficulties	Descriptive statistics
	Cross-sectional	Age: 9-12 (m = 11.25, SD = 1.5)	Haemorrhage (n = 3), tumour (n = 1) 2-4 years (m = 3.25, SD = 0.96)	Semi-structured interviews, qualitative observation during Multi Family Group Programme (MFGP)	Interpretative Phenomological Analysis (IPA)
Charles, Butera-Prinzi & Perlesz (2007)	Longitudinal	9 YP from 6 families. Age: 7-13 (m = 10.3, SD = 2.1)	67% fathers Tumour (n = 1), aneurism (n = 1), stroke (n = 1), TBI (n = 3) 2-30 years (m = 11, SD = 10.8)	Injured Parent (IP) & Uninjured Parent (UIP): emotional wellbeing, perception of marital relationship, family functioning YP: behavioural difficulties Qualitative observations during MFGP	Inferential statistics Thematic Analysis

Kieffer-Kristensen, Teasdale & Bilenberg (2011)	Cross-sectional questionnaire study, with comparison group	n = 35 with 35 matched controls. Age: 7-14 (m= 11.0 SD = 2.3)	51% fathers CVA (n = 21), TBI (n = 9), other (n = 5) < 5 years (m = 3.7, SD = 1.7)	YP: emotional wellbeing, Post Traumatic Stress Disorder (PTSD), behavioural difficulties.	Inferential statistics
Kieffer-Kristensen, Siersma & Teasdale (2013)	Cross-sectional questionnaire study	n = 35 Age: 7-14	54% fathers Stroke (n = 21), TBI (n = 9), other (n = 5) < 5 years (m = 3.7)	IP: ABI symptoms, depression UIP: parenting stress, marital satisfaction, emotional wellbeing YP: PTSD, behavioural difficulties	Inferential statistics
Kieffer-Kristensen & Johansen (2013)	Cross-sectional	n = 14 Age 7-14 (m = 10.7, SD = 2.1) Clinically significant PTSD symptoms	57% mothers CVA (n = 6), TBI (n = 4), other (n = 4) < 5 years (m = 3.5, SD = 1.6)	Semi-structured interviews	IPA

Moreno-Lopez, Holttum & Oddy (2011)	Cross-sectional	9 YP from 6 families. Age: 14-20 (m = 16, SD = 2.5)	89% fathers TBI (n = 5) Subarachnoid haemorrhage (n = 1) > 1 year < 4 years (m = 2.5)	Semi-structured interviews	Grounded Theory
Niemelä, et al., (2013)	Retrospective population-based study	Birth cohort: n = 59,476 Affected by parental ABI: n = 1,532 Age: 21	70% fathers TBI	Cohort survey	Inferential statistics
Pessar, Coad, Linn & Willer (1993)	Cross-sectional questionnaire study	52 YP from 24 families. Age: 2-23 (m = 12.6, SD = 5.6)	66.7% fathers TBI 16-84 months (m = 46, SD = 19.6)	IP & UIP: YP behaviour change, IP behaviour change, emotional wellbeing, motor and sensory disability in IP	Inferential statistics

Sieh, Meijer & Visser-Meily (2010)	Longitudinal questionnaire study	44 YP from 29 families. Age: 7-18 (m=13.2, SD = 2.5)	58.6% mothers Stroke 3 years	IP: communication, cognitive function, Activities of Daily Living (ADL) UIP: depression, perception of marital relationship YP: stress	Inferential statistics
Uysal, Hibbard, Robillard, Pappadopulos & Jaffe (1998)	Cross-sectional questionnaire study	16 families & 16 matched controls Age: 7-18 (m = 14.3, SD = 2.6)	81% mothers TBI > 2 years post injury (range = 2 - 39, m = 9.3, SD = 11.5)	IP & UIP: parenting abilities, family stress, depression YP: behavioural problems, depression, parenting abilities of both parents	Inferential statistics
van de Port, Visser-Meily, Post & Lindeman (2007)	Cross-sectional questionnaire study	44 YP from 29 families. Age: 10-21 (m = 16, SD = 3)	57% mothers Stroke 3 years	IP: depression, cognitive function, independence, mobility, life satisfaction UIP: depression, caregiving strain, life satisfaction, perception of marital relationship YP: behavioural problems, stress	Inferential statistics

Visser-Meily, Post, Meijer, Maas, Ketelaar & Lindeman (2005a)	Longitudinal questionnaire study	77 YP from 51 families. Age: 4-18 (m = 13.4, SD = 3.1)	51% mothers Stroke 2 months post-discharge	IP: disability UIP: depression & caregiver strain YP: depression, behaviour, functioning	Inferential statistics
Visser-Meily, Post, Meijer, Maas, Ketelaar & Lindeman (2005b)	Longitudinal questionnaire study.	82 YP from 55 families. Age: 4-18 (m= 13.3, SD = 3.2)	51% mothers Stroke Data collected at 3 time points between stroke and 1-year follow-up.	IP: disability UIP: depression & perception of marital relationship YP: depression, behaviour, functioning	Inferential statistics

1.5.3 Critical Review. In this section, the identified papers are discussed and critically appraised. The variety of methodologies employed and differences between sample populations makes it difficult to directly compare key findings with one another; however, some important themes arose. These were the influence of ABI sequelae on the wellbeing of young people, psychosocial outcomes in young people, the influence of systemic variables, and general experiences of ABI. The key findings will be summarised within these themes. Where suitable, the literature will be critiqued as findings are discussed. Where similarities in methodological strengths and limitations are observed, or where more general observations are made, an overall critique of the research will be summarised at the end of this section. The quality of quantitative research studies will be evaluated in accordance with the Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project [EPHPP], 1998), whilst qualitative research studies will be evaluated in accordance with Yardley’s (2000) quality framework (see Table 9).

Table 9. *Quality Criterion*

Quality Assessment Tool for Quantitative Studies	Yardley’s Quality Framework
Selection bias	Sensitivity to context
Study design	Completeness of data collection, analysis and interpretation
Confounders	Reflexivity
Blinding	Practical and theoretical utility
Data collection methods	
Withdrawals and drop-outs	
Intervention Integrity (<i>where applicable</i>)	
Analysis	

The majority of studies utilised quantitative methodologies (n= 9), whilst two were mixed-methods and two were qualitative. Most studies were cross-sectional (n= 11). Two studies used control-group comparisons.

An extensive number of measures were used to measure outcomes for young people, however, they generally measured similar domains. This included behaviour (n = 9), psychological wellbeing (n = 10) and general functioning (n = 2). All quantitative studies reported on young people's outcomes, whilst some also reported on parenting (n = 3), patient (n = 6), spouse (n = 6), and family functioning or relationship (n = 4) variables. Further information regarding the specific outcome measures used in each study is listed in Appendix C.

1.5.3.1 Sequelae. A range of severity and impairment following ABI was observed both within, and between, studies. Participant characteristics were diverse, and the quality of patient descriptions were variable. Studies included participants having experienced a range of sub-types of ABI, predominantly stroke (n = 10), TBI (n = 6), tumour (n = 2) and haemorrhage (n = 2).

Studies were varied regarding homogeneity of the sample population. For example, seven studies recruited parents with specific injuries (Niemelä et al., 2014; Pessar et al., 1993; Sieh et al., 2010; Uysal et al., 1998; van de Port et al., 2007; Visser-Meily et al., 2005a; Visser-Meily et al., 2005b), whilst six studies used broader inclusion criteria encompassing different types of ABI (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen et al., 2011; Kieffer-Kristensen & Johansen, 2013; Kieffer-Kristensen et al., 2013; Moreno-Lopez et al., 2011). Whilst a homogenous sample supports the generalisability of findings, given the heterogeneity of deficits following ABI, there may continue to be considerable variability in the clinical presentations in seemingly homogenous samples.

The majority of quantitative studies explored illness variables and ABI sequelae as determinants of psychosocial outcomes for young people. These findings are summarised with regard to cognitive, emotional, behavioural and physical sequelae. Whilst personality and relationship changes were also documented, these will be discussed in more detail in Section 1.5.3.3 with regard to systemic variables and interactional processes.

Five studies explored aspects of cognitive functioning, including memory impairment, problem-solving skills, and communication abilities (Kieffer-Kristensen et al., 2013; Pessar et al., 1993; Sieh et al., 2010; van de Port et al., 2007; Visser-Meilly et al., 2005a). No significant associations were found between cognitive disability and young people's outcomes (Kieffer-Kristensen et al., 2013; Pessar et al., 1993; Sieh et al., 2010; van de Port et al., 2007; Visser-Meilly et al., 2005a; Visser-Meilly et al., 2005b), or between cognitive disability and parenting ability (Pessar et al., 1993). Qualitative findings in one study revealed that young people reported spending considerable time supporting their parents with memory impairments (Kieffer-Kristensen & Johansen, 2013). Charles and colleagues (2007) reflected upon the difficulties that young people may have in construing invisible disabilities, including memory impairment, particularly if a parent is not physically disabled or doesn't look superficially different post-ABI.

The most commonly documented emotional sequelae were symptoms of depression (Kieffer-Kristensen et al., 2013; Sieh et al., 2010; van de Port et al., 2007). Outcomes for injured parents generally indicated sub-clinical levels of depression (Sieh et al., 2010; van de Port et al., 2007). Nevertheless, van de Port and colleagues (2007) identified positive correlations between depressive symptoms and young people's stress levels at 3-years post-stroke ($r = 0.456$, $p < 0.05$). These findings were corroborated by Sieh and colleagues (2010), who observed similar relationship at 2-months ($r = 0.51$, $p < 0.05$), 1-year ($r = 0.50$, $p < 0.01$) and 3-years post-stroke ($r = 0.53$, $p < 0.01$). Conversely, Kieffer-Kristensen and colleagues (2013) studied families

affected by parental stroke less than five years previously ($m = 3.7$ years), and did not observe a significant relationship between parental depression and young people's ratings of PTSD symptoms, or behavioural difficulties. Qualitative findings identified that some young people noticed their injured-parent had become increasingly emotional following their ABI (Kieffer-Kristensen & Johansen, 2013). However, emotional sequelae were not prominent within the literature.

Behavioural changes were discussed in four studies, particularly parental aggression and violence (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Pessar et al., 1993; Kieffer-Kristensen & Johansen, 2013). However, behavioural difficulties among young people were not significantly correlated with parental aggression (Pessar et al., 1993; Kieffer-Kristensen & Johansen, 2013). In qualitative studies, it was observed that violence was not disclosed until several months into the research (Butera-Prinzi & Perlesz; Charles et al., 2007). Furthermore, it was reported that young people were much less likely to disclose violence than their parents. In these studies, use of a longitudinal design appeared to improve the validity of findings since new themes continued to emerge a significant number of months into the study. In other qualitative studies, researchers' involvement tended to be brief and task-limited (Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2011), so participants may not have developed a trusting relationship with the researcher in which they felt comfortable discussing familial difficulties. Given the sensitive nature of the topics being discussed in interviews, and the effect of factors such as family loyalty and social desirability, information may have been withheld by participants.

Finally, seven studies explored physical disability and impaired functioning (Butera and Perlesz, 2004; Kieffer-Kristensen et al., 2013; Pessar et al., 1993; Sieh et al., 2010; van de Port et al., 2007; Visser-Meilly et al., 2005a; Visser-Meilly et al., 2005b). Butera and Perlesz (2004) highlighted that young people often felt embarrassed by their parents' physical disability, which in some

cases resulted in young people avoiding their injured parent. Nevertheless, physical disability was generally not found to be directly associated with young people's outcomes (Pessar et al., 1993; Sieh et al., 2010; van de Port et al., 2007; Visser-Meilly et al., 2005a). Conversely, van de Port and colleagues (2007) observed that parental independence in ADL was negatively correlated with increased stress in young people ($r = -0.741$, $p < 0.01$). Furthermore, Visser-Meilly and colleagues (2005b) identified that parental disability at the time of the injury was predictive of young people's depression one year post-injury, irrespective of any subsequent improvements yielded by the injured parent.

In summary, there is limited evidence to support a relationship between illness variables, and adjustment and coping in young people. This is perhaps with the exception of parental depression. The impact of parental ABI on young people's psychosocial wellbeing will now be discussed in more detail.

1.5.3.2 Young people's psychosocial wellbeing. The prevalence and severity of psychosocial difficulties among young people affected by parental ABI was variable. Emotional difficulties, including stress and depression, were commonly reported (Butera-Prinzi & Perlesz, 2004; Kieffer-Kristesen & Johansen, 2013; Kieffer-Kristensen et al., 2013; Pessar et al., 1993; Sieh et al., 2010; van de Port et al., 2007; Visser-Meily et al., 2005a; Visser-Meilly et al., 2005b), and one study identified that young people developed specific worries about their own health (Charles et al., 2007). In studies measuring symptoms of PTSD, 46% of participating young people scored above clinical cut-offs (Kieffer-Kristensen et al., 2011; Kieffer-Kristensen et al., 2013). Additionally, between 25-92% young people were reported to be experiencing behavioural difficulties (Kieffer-Kristensen et al., 2013; Pessar et al., 1993; van de Port et al., 2007; Visser-Meilly et al., 2005a; Visser-Meilly et al., 2005b).

Sub-clinical scores were also observed across a range of outcome measures (Butera & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen et al., 2011;

Uysal et al., 1998). However, where control groups were used, young people affected by parental ABI tended to obtain higher scores on standardised outcome measures than their non-affected counterparts (Uysal et al., 1998), and in comparison to young people affected by parental chronic illness (Kieffer-Kristensen et al., 2011). This suggests that young people affected by parental ABI may be at increased risk of developing psychosocial difficulties. These findings were corroborated by Niemelä and colleagues (2013), who identified that young people affected by parental ABI were more likely to access psychiatric services than their non-affected counterparts. Their retrospective population-based study based on the 1987 birth cohort, examined 21-year follow-up data for 60,069 Finnish nationals. They found that in comparison to 13% of the general population, 23% of young people affected by parental brain injury had used psychiatric services. However, the researchers were aware of confounding variables. For example, they suggested that the relationship between parental alcohol abuse and the occurrence of ABI may have placed young people at increased risk for accessing services prior to the presence of the ABI. Interestingly, it was reported that where a parent's injury was mild rather than severe, there was a higher utilisation of psychiatric services; this was hypothetically attributed to the lack of visible disability that may occur with mild brain injury, and the difficulties that may be experienced among young people trying to make sense of subsequent changes to their parent. The implementation of their methodology helps to reduce the effects of sampling bias through accessing a complete birth cohort. Nevertheless, difficulties experienced by young people are probably under-represented, as the data relies upon people accessing services.

van de Port and colleagues (2007) explored the long-term outcomes of parental stroke on young people through assessing outcomes 3-years post-stroke and concluded that the majority of young people do well. However, it was noted that the mean time elapsed since parental ABI exceeded three years in eight other studies; whilst these researchers may not have explicitly

sought to determine long-term outcomes, findings suggested that some young people may continue to have significant difficulties at 3-years post-injury (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen et al., 2011; Kieffer-Kristensen et al., 2013; Kieffer-Kristensen & Johanson, 2013; Pessar et al., 1993; Sieh et al., 2010; Uysal et al., 1998). This highlights a methodological constraint of using cross-sectional research, as inferences cannot be made about the potential trajectory of young people's difficulties.

Visser-Meilly and colleagues (2005b) measured symptoms of depression, and behavioural problems at three time points: the start of stroke rehabilitation (T1); 2-months post-discharge (T2); and one-year post-discharge. They observed a significant reduction in symptoms of depression and internalising behaviour between T1 and T2, but not between T2 and T3. Whilst the majority of young people had sub-clinical scores for depression (88%), internalising behaviour (85%) and externalising behaviour (84%) by T3, the results may highlight the importance of timely and ongoing support for young people affected by parental ABI.

There were mixed findings regarding the effect of a young person's age on their emotional wellbeing following parental ABI. Visser-Meilly and colleagues (2005a) identified age as being negatively correlated with both internalising ($r = -0.231$, $p < 0.05$) and externalising symptoms ($r = -0.230$, $p < 0.05$), but not depression or functioning. These findings suggest that younger children may be at increased risk of behavioural difficulties following parental ABI. Similarly, Visser-Meilly and colleagues (2005b) found that age at the time of injury predicted externalising behaviour one year post-stroke. Nevertheless, many studies did not find evidence of significant associations between age and outcomes (Kieffer-Kristensen et al., 2011; Kieffer-Kristensen et al., 2013; Sieh et al., 2010; van de Port et al., 2007).

Similarly, some studies identified females at increased risk of symptoms of stress (Sieh et al., 2010; van de Port et al., 2007), depression (Visser-Meilly et

al., 2005b) and internalising symptoms (Visser-Meilly et al., 2005a), whilst others did not find gender to be a significant determinant of emotional difficulties (Pessar et al., 1993; Kieffer-Kristensen et al., 2011; Kieffer-Kristensen et al., 2013; Visser-Meilly et al., 2005a). No significant associations were found between gender and behaviour (Pessar et al., 1993; Kieffer-Kristensen et al., 2013; van de Port et al., 2007; Visser-Meilly et al., 2005b).

In quantitative studies, considerable effort was made to report on the validity and reliability of selected outcome measures, contributing to the scientific rigour of their research (Butera-Prinzi & Perlesz, 2004; Charles et al., 2004; Sieh et al., 2010; Uysal et al., 1998; van de Port et al., 2007; Visser-Meily et al., 2005a; Visser-Meily et al., 2005b). The use of standardised measures in studies (n = 11) was commended, given their utility in facilitating comparisons with the general populations from which the sample populations were identified. Paradoxically, reliance on self-report measures overlooks factors such as social desirability that may limit the validity of the findings, particularly given the sensitive nature of many of the questionnaire items. For example, Charles and colleagues (2007) described 67% of young people as having conspicuously low scores on outcome measures, in comparison to the general population. They hypothesised that this may reflect denial or social desirability.

Studies using both child-report and parent-report forms of individual questionnaires (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Uysal et al., 1998) made an effort to counteract these effects. Using this approach more consistently may have improved the validity of findings across research studies, or offered a differential understanding of phenomena. For example, Uysal and colleagues (1998) noticed discrepancies between child and parent ratings. This may support the use of multiple informants to counter self-report biases, and emphasises the importance of considering different perspectives of a particular problem. Given that researchers may explore the experiences

of young people on the basis of parental reports, these findings emphasise the importance of ascertaining young people's views directly.

In summary, young people affected by parental ABI appear to be at increased risk of developing psychosocial difficulties. Whilst findings are variable, demographic and illness variables do not appear sufficient to explain the variance in data. It appears likely that these factors may be moderated by other variables resulting from changes to the family system.

1.5.3.3 Systemic Variables. Relationships between young people and their injured parents may be differentially affected. Pessar and colleagues (1993) identified relationship problems between young people and their injured parent in 42% of families. Specifically, they found a positive correlation between the age of the young person and prevalence of relationship difficulties ($r = 0.43$). Relationships appeared to be affected by personality changes in the injured parent; in two studies young people described disliking their injured parent (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007). Apathy, changed temperament, and changes in affection from the injured parent were described as being particularly challenging for young people (Butera-Prinzi & Perlesz, 2004).

Young people frequently described taking on additional responsibilities and caring roles (Kieffer-Kristensen & Johansen, 2013; van de Port et al., 2007; Visser-Meilly et al., 2005a). Of note, whilst a majority of young people were considered to be involved in caregiving activities (where documented), caregiving among young people was not significantly correlated with increased stress (Visser-Meilly et al., 2005a).

Regarding demographic variables, Pessar and colleagues (1993) identified that poorer outcomes were associated with having a brain-injured father. In contrast, Niemelä and colleagues' (2013) identified that increased use of psychiatric services occurred following maternal ABI, which was hypothesised

to be a reflection of traditional gender roles in which mothers may assume more caring responsibilities, and consequently their absence has a greater impact on young people. However, other studies did not identify significant correlations between parental gender and young people's wellbeing (Sieh et al., 2010; Visser-Meilly et al., 2005b).

Charles and colleagues' (2007) sample included young people born both before and after parental ABI. Interestingly they noted that conflict was more prevalent among families that formed pre-ABI, suggesting that the adjustment process may play a pivotal role in coping with ABI sequelae. They also identified that whilst individual distress reduced over time, marital and family dysfunction remained high.

Compromised functioning and emotional wellbeing in the uninjured parent tended to be significantly associated with poorer outcomes for young people (Kieffer-Kristensen et al., 2013; Pessar et al., 1993; Uysal et al., 1998; van de Port et al., 2007; Visser-Meilly et al., 2005a; Visser-Meilly et al., 2005b). Specifically, Visser-Meilly and colleagues (2005a) identified that depression in the uninjured parent was positively correlated with internalising symptoms ($r = 0.369$, $p < 0.01$) and depression ($r = 0.225$, $p < 0.05$) in young people, whilst being negatively correlated with young people's functioning ($r = -0.272$, $p < 0.05$). Additionally, they identified a positive correlation between caregiver strain and internalising symptoms ($r = 0.349$, $p < 0.01$), externalising symptoms ($r = 0.316$, $p < 0.01$), and depression ($r = 0.285$, $p < 0.05$), and a negative correlation with functioning ($r = -0.569$, $p < 0.01$). Similarly, Pessar and colleagues (1993) found that compromised parenting in the uninjured parent was positively associated with acting out ($r = 0.46$, $p < 0.05$), relationship difficulties ($r = 0.761$, $p < 0.01$) and emotional difficulties ($r = 0.64$, $p < 0.01$). Kieffer-Kristensen and colleagues (2013) also found that the uninjured parent's distress, dysfunctional interactions between the young person and their uninjured parent, and increased stress, were positively associated with and PTSD symptoms and behavioural difficulties in young

people. Qualitative findings revealed that young people perceived their uninjured parent as the most stressed family member, and raised concerned about contributing to family stressors or burden (Butera-Prinzi & Perlesz, 2004). Visser-Meilly and colleagues (2005b) identified that irrespective of young people's functioning at T1, depression in the uninjured parent at T1 was predictive of poorer outcomes one-year post-injury. Sieh and colleagues (2010) identified that depression in the uninjured parent was positively correlated with young people's stress at two-months ($r = 0.22, p < 0.05$) and one-year ($r = 0.34, p < 0.01$) post-rehabilitation. In contrast, van de Port and colleagues (2007) did not identify any variables relating to the uninjured parent as being predictive of stress for young people.

Uysal and colleagues (1998) specifically explored parenting in families affected by ABI and drew comparisons with a control group of families. They observed differences in parenting style in both the injured and non-injured parent of families affected by ABI, in comparison to their non-affected counterparts. Specifically, they found that parents with TBI offered less encouragement and active involvement with their children, and they reported lower levels of desired achievement and conformity in their children. Furthermore, uninjured parents of families affected by TBI reported being less nurturing and accepting of their children's behaviours than their counterparts. Interestingly, young people's own rating of their parents' behaviour did not corroborate these findings. Rather, the only significant differences between young people in families affected by TBI and their counterparts was that young people affected by parental TBI described both of their parents as less strict, particularly the uninjured parent. No significant differences were found in levels of stress relating to either household management or parenting, and no significant differences were found regarding child behaviour, as reported by both parents and young people.

Perceived quality of marital relationship was also related to poorer outcomes in young people. Kieffer-Kristensen and colleagues (2013) identified that

marital dissatisfaction in the injured parent was associated with behaviour problems in young people. Sieh and colleagues (2010) noted that marital dissatisfaction was related to stress at two months post-rehabilitation only ($r = -0.28, p < 0.10$). Lastly, Visser-Meilly and colleagues (2005b) noted a significant reduction in marital satisfaction between two months post-rehabilitation (T2) and one-year post-rehabilitation (T3), with marital satisfaction predicting health status ($\beta = 0.32, p < 0.05$) and internalising symptoms ($\beta = -0.27, p < 0.05$) in young people at T3. Comparatively, van de Port and colleagues (2007) did not find a significant relationship between marital status and young people's wellbeing. Finally, marital dissatisfaction was disclosed in qualitative studies (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007), and young people were also found to describe feeling afraid that their uninjured parent may leave the family (Butera-Prinzi & Perlesz, 2004).

Whilst findings are variable, there is evidence to suggest that the impact of ABI upon family disruption, particularly increased stress for the uninjured parent, is perhaps a better predictor of psychosocial difficulties in young people than any illness variables or baseline characteristics of young people.

1.5.3.4 Experience. Due to the predominant use of quantitative methodologies, fewer studies explicitly considered young people's subjective experience of the ABI, and their perceptions of the ABI itself. Butera-Prinzi and Perlesz (2004) identified that young people described feeling "left out and invisible" (p.88) during the acute phase of their parents' ABI, and wanting to have been more involved in the process. Additionally, they reported that even some time after their parent's injury, young people did not discuss their experiences, and they felt that professionals failed to enquire about their wellbeing.

Feelings of grief and loss were well documented (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen & Johansen, 2013). Charles and colleagues (2007) noted that young people experienced grief, distress and

confusion, with some participants even disclosing thoughts about wishing their injured parent would disappear. Furthermore, Kieffer-Kristensen and Johansen (2013) identified that such hidden losses were often neglected in an effort to protect the injured parent. Many young people described having mixed feelings towards their injured parent, which may have been a consequence of them presenting like different people (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007). These findings highlight the importance of considering hidden losses and invisible disability, particularly when a young person's developmental stage may impose limits on their ability to make sense of abstract phenomena. Interestingly, lack of understanding may simultaneously make adjustment more difficult, whilst acting as a protective factor for others.

Most young people described feeling unsupported, and unable to confide in others, yet the majority also described wanting to have opportunities to talk about their parents' injury (Butera-Prinzi & Perlesz, 2004). Visser-Meily and colleagues (2005a) identified that severity of parental disability following ABI predicted the level of support that young people received, regardless of their own psychosocial needs. Whilst it is promising that young people whose parents are more severely affected are receiving additional support, it is also concerning that young people do not appear to receive support in accordance with their own wellbeing. This may be a reflection of contact with services, since families with a more severely injured parent are likely to have more contact with healthcare professionals. However, it highlights a potential discrepancy between the needs of young people and the provision of support.

Other experiences that were described included social abandonment (Butera-Prinzi & Perlesz, 2004), and social isolation (Charles et al., 2007). Conversely, Moreno-Lopez and colleagues (2013) suggested that during the acute phase of the ABI, adolescents may reduce their peer relations as a means of coping. Moreno-Lopez and colleagues (2013) also spoke at length about the coping strategies employed by adolescents following parental ABI. They identified a

three-stage process that involved adolescents taking becoming protective of their families, endeavouring to maintain a sense of normality both within and outside of the family unit, and re-negotiating their peer relationships.

Despite potentially different functions, the notion of reduced peer relationships offers a potential insight into why the social component of studies that incorporated group programmes was particularly valued by participants (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007). However it could be anticipated that given these families sought support voluntarily, and that their experiences may differ from those of families who are unaware of support, decline support, or are unable to access it. These discrepancies are particularly pertinent cross-culturally, whereby there can be an associated stigma with accessing support, or shame associated with discussing family difficulties.

1.5.3.5 Overall Critique. Firstly, purposive sampling was used in all studies with the exception of Niemelä and colleagues' (2014) retrospective population-based study. Although purposive sampling approaches were appropriate to address the research questions, the generalisability of findings may be limited, in particular where researcher bias and subjectivity may result in the sample being unrepresentative of the target population. Furthermore, three studies recruited participants from existing research databases (van de Port et al., 2007; Visser-Meily et al., 2005a; Visser-Meily et al., 2005b); this could also implicate validity of findings since there may be systematic differences between populations agreeing to participate in research, and those who prefer not to take part. This was also relevant for studies in which there was poor uptake. For example, Kieffer-Kristensen and colleagues (2011; 2013) approached 105 young people yet yielded a sample size of 35.

Similarly, high attrition rates pose a threat to the external validity of longitudinal studies since there could be systematic differences between the participants that completed the study, and those who dropped out. For

example, Sieh and colleagues (2010) identified an initial sample of 82 young people, 44 of whom remained in the study at 3-year follow-up.

It was noted that only one study (Moreno & Lopez, 2013) was based in the UK. Whilst the remaining research occurred in Western countries, it is difficult to generalise findings given the differential rates of depression and anxiety within the general population, and the differential health care systems offering support. Furthermore, differences in social and cultural understanding of ABI, and approaches to care giving may further limit the generalisability of findings to a UK population. However, these findings offer a framework within which to understand difficulties faced by children of parents affected by ABI, and inform future research within the UK.

1.5.3.5.1 Qualitative Studies. Sample size in qualitative research varied between four and 19 young people, which seemed appropriate to the methods of analyses (e.g. Baker & Edwards, 2012). However, all researchers discussed the limitations of their sample sizes, calling for further research in the field in order to improve the generalisability of findings.

Qualitative studies varied in their descriptions of data analysis, at times making it unclear how themes within the data were derived. More information in this domain would have been valuable, in order to develop a better understanding of how significant themes were identified and whether these were corroborated or audited in any way. Moreno-Lopez and colleagues (2011) gave a detailed description of their analysis, including how they established data saturation and their processes of quality assurance and audit. Credibility of themes was cited in only four studies (Kieffer-Kristensen et al., 2013a; Moreno-Lopez et al., 2011). Whilst Moreno-Lopez and colleagues (2013) referenced supervisor audit of categories, the use of independent auditors would promote additional credibility in this domain. The use of direct participant quotations within theme descriptions added value to the findings and demonstrated candour (Butera-Prinzi & Perlesz, 2004; Charles et al.,

2007; Kieffer-Kristensen et al., 2013; Moreno-Lopez et al., 2011). It was observed that Moreno & Lopez (2011) also included service user and public consultation within their research, through giving participants the opportunity to comment on themes generated and reviewing their analyses accordingly; this approach would have been welcomed across the research studies.

Researcher reflexivity appeared relatively poor, and theoretical orientation was not stated in the majority of qualitative studies (Butera-Prinzi & Perlesz, 2004; Charles et al., 2005; Kieffer-Kristensen et al., 2013). Moreno-Lopez and colleagues (2013) considered their epistemological position and the potential individual and social influences on their data. This information helps the reader to position the research and offers a transparency that gives credit to the researchers. Their identification of specific reflexivity methods, including the use of a reflective diary, were valued. A more explicit consideration of the inherent biases that may exist, and how these effects could be counteracted would have been appreciated, for example, through disclosing either the motivations or interests that underpinned the development of the research.

1.5.3.5.2 Quantitative Studies. Many of the strengths and limitations of quantitative studies have been discussed whilst summarising findings. However, there were some more general findings. In particular, studies may have been constrained by the specific measures that were used, which may account for the high prevalence of sub-clinical outcomes identified in quantitative research, yet the substantial experiences of loss, grief and interpersonal difficulties described in qualitative studies. The quantitative measures that were selected by researchers may have failed to capture the experiences of young people and families affected by parental ABI, and thus are perhaps not sensitive to the types of difficulties experienced by this group of young people.

1.5.3.6 Conclusions. In summary, the published research in this field begins to offer insight into the significant impact of parental ABI on young

people and their families. Whilst the area warrants further attention, it seems apparent that young people are at increased risk of developing psychosocial difficulties following parental ABI, and that familial variables and implications for the uninjured parent may be more predictive of difficulties than the ABI itself. The findings highlight the need to consider the wider family system when working with ABI patients, particularly where young people are concerned.

1.6 Rationale for Current Study

Research into the area of ABI has increased steadily over the past four decades, and more recently, researchers have begun to focus specifically on the experiences of young people and families affected by parental ABI. However, there remains a notable gap in the literature, particularly regarding the experiences of young people in the UK. Findings from the systematic review suggest that parental ABI can negatively affect young people. However, the mechanisms underpinning this relationship remain unclear. Nevertheless, systemic variables and the influence of the ABI on the family system appear to have more implications for the adjustment of young people, than the ABI itself.

Furthermore, the majority of published studies in this field employ quantitative methodologies that assume a linear relationship between variables. Whilst studies have highlighted the relative influence of variables, they have failed to consider the reciprocal relationship that may exist. Consequently, it is imperative to explore the interactional processes that occur within family systems, in order to do justice to the complexities of family life. Oversimplifying the relationships between variables may risk incomplete conclusions being made, resulting in recommendations that do not reflect the realities of families affected by parental ABI. Consequently, it is appropriate to begin developing an understanding of the interactional processes occurring in family systems that may implicate adjustment following parental ABI.

1.7 Aims and Research Questions

Currently, it remains unknown whether or not families develop a shared understanding of their experiences of ABI, and whether or not a shared understanding of events supports adjustment. Consequently, the broad aims of this thesis were to explore the experiences of families affected by parental brain injury, and the implications for adjustment. Specifically, the following research questions were identified:

1. How do family members see themselves and each other? How is this similar or different from one another?
2. How do family members view the ABI? How is this similar or different from one another?
3. Do similarities or differences in construing have implications for adjustment in young people and/or their families?
4. Are there similarities or differences in the experiences of ABI between families?

Chapter 2: Methodology

This chapter outlines the research process including details of the study design, sampling strategy and recruitment process, methods of data collection, procedure, and methods of data analyses. Ethical issues were considered throughout, and are summarised thereafter. The chapter concludes by reviewing the service-user and public consultation that was sought throughout the research process.

2.1 Design

This cross-sectional study explores the experiences of families affected by parental ABI. Specifically, the research investigates the relationship between construal processes and adjustment in young people and their families. Building on existing research, a qualitative approach underpinned by the epistemological position of constructivism was considered an appropriate way in which to identify the perceptions and interpersonal processes occurring within families affected by parental ABI. The research is predominantly qualitative, however, quantitative measures were included in order to strengthen the reliability of qualitative interpretations. The study design comprised two main features; intra- and inter-family analysis. The rationale for these two aspects will now be discussed.

2.1.1 Intra-family. Intra-family analysis was implemented to answer the first three research questions:

1. How do family members see themselves and each other? How is this similar or different from one another?
2. How do family members view the ABI? How is this similar or different from one another?
3. Do similarities or differences in construing have implications for adjustment in young people and/or their families?

A PCP framework was considered an appropriate means of identifying the content and processes of individual and family sense-making in relation to parental ABI. The theoretical underpinnings of PCP summarised in Chapter 1. are congruent with the epistemological position of the research and support the identification of individual and familial meaning-making.

In order to consider the implications of construal on adjustment, quantitative measures were also used. Quantitative tools are less analogous with a constructivist epistemological position since they can be considered as reductionist; reducing a person's experience to a clinical range may fail to capture the diversity and complexity of human experience (Somekh & Lewin, 2005). However, use of quantitative tools enables triangulation of data that may subsequently enhance the credibility of qualitative interpretations. This was particularly important given the absence of existing literature exploring the relationship between processes of construal and adjustment following parental ABI. However, outcome measures were interpreted with caution and in the context of qualitative data.

2.1.2. Inter-family. Inter-family analysis was used to answer the fourth research question:

4. Are there similarities or differences in the experiences of ABI between families?

A Thematic Analysis (TA; Braun & Clarke, 2006) was identified as an appropriate method to identify similarities and differences between families' experiences. TA is a method of qualitative analysis that can be used with a number of different theoretical orientations (Braun & Clarke, 2006), and has previously been used in postmodern research (e.g Maitland & Viney, 2008; Salmon & Rapport, 2005).

Other approaches were considered, however, ruled out in favour of TA. For example, Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) has been previously used in studies informed by PCP (Denner-Stewart, Procter & Dallos, 2011; Dallos & Denford, 2008; Turpin, Dallos, Owen & Thomas, 2009). IPA explores individuals' lived experiences of particular phenomena, however, the aims of this research were to explore individual and familial patterns of sense-making in relation to the experience of parental ABI, rather than exclusively exploring families' experiences.

Discourse analysis (Starks & Brown-Trinidad, 2007) was also considered since it shares the social constructionist underpinnings of this current research. Discourse analysis explores the ways in which speech acts can shape individuals' identities and their relationships with others. Given the focus on speech and language, this methodology was ruled out in favour of a method that gives more precedence to perceptions of others, rather than interactions between them. It felt important to employ an approach that allowed individual interviews to occur, in order to elicit differences in perception of parental ABI. Consequently, the process of speech and conversing between family members was not available for analysis.

Finally, grounded theory (Glaser & Strauss, 2009) was considered. Grounded theory is a method in which the researcher aims to develop a theory that explains the findings in their data. Traditionally, it has been argued that this stance is highly positivist, however, a constructivist grounded theory approach has since been developed (Mills, Bonner & Francis, 2006). Nevertheless, the numbers required for data saturation were not in keeping with this scope of this thesis; it has been suggested that grounded theory approaches should endeavour to reach a sample of at least 20 participants (Creswell, 1998; Morse, 1994). Given the different components of the current research, it would not have been possible to do justice to that amount of data.

In summary, a range of approaches were considered but TA was selected for its suitability for answering the research question, through enabling the identification of patterns across datasets. The process of completing TA will be discussed in Section 2.5.

2.2 Sample

2.2.1. Sampling strategy. Purposive sampling was used to identify potential participants based on the inclusion and exclusion criteria (described in Section 2.2.2).

Sample size was chosen following consideration of the different elements of data analysis. The initial exploration of construal processes and evaluation of questionnaire data will be presented within families, as case studies. The subsequent TA therefore seemed the most appropriate aspect of data analysis on which to base the sample size.

Braun and Clarke (2013) suggest between 6-10 interviews for TA in 'small' projects. Whilst the overall scope of this thesis probably constitutes a 'large' project, the TA is just one aspect of data analysis. Therefore, this approximation was considered appropriate. Accordingly, a sample size of between 4-6 families was initially proposed, in order to accommodate families of different sizes. The 6-10 interviews were quickly reached with fewer families ($n = 3$). A fourth family commenced the research process, although dropped out before data collection was complete. Further recruitment was initially considered in order to reduce the effects of clustered data; when participants are recruited from the same family, variability of responses across the sample is reduced (e.g. Galbraith, Daniel, & Vissel, 2010). However, after examining the volume of data yielded from existing interviews, it was decided that a larger sample size would not have enabled the author to capture the richness of individual and familial experiences. Consequently a sample of ten individuals from three families was used. Consultation with a PCP expert supported the use of three families, and the implementation of a process akin

to Kelly's 'triadic' method of construct elicitation (e.g. Caputi & Reddy, 1999) in which the author would consider "in what way are two similar, but different from the third?".

2.2.2. Inclusion & exclusion criteria. Potential families were identified via the injured parent. This thesis sought to explore the processes by which family members make sense of events, and the implications for adjustment to parental ABI, so it was considered essential that the ABI had resulted in changes to which the family were adjusting. Consequently injured parents were required to be experiencing moderate to severe functional impairment following ABI. Whilst GOS (Jennet & Bond, 1975) scores were not necessarily available from research sites, the author used clinical judgment to determine probable scores in accordance with participant and clinician descriptions of impairment and disability.

Families were deemed suitable if the injured parent was experiencing clear functional difficulties associated with cognitive, behavioural, emotional, social or communicative difficulties, as described by themselves and clinicians at participating research sites. Nevertheless, individuals with significant unmanaged mental health problems, cognitive difficulties or behavioural disturbances were excluded as these difficulties may have made it difficult to engage in the research process, and may have placed individuals under unnecessary stress. Additionally, although participants could use communication aids, they were excluded if their communication impairment would prevent engagement in the interview. Finally, injured parents were required to have experienced ABI at least one year previously. Often ABI patients are medically, physically, and cognitively more stable than in the first 12 months and therefore in a better position to engage in research, with any subsequent changes in their presentation likely occurring less rapidly (e.g. RCP & BSRM, 2003).

To meet inclusion, families were required to comprise of at least a parent with ABI, and one child aged 8-16 years old. Limits were not imposed with regard to maximum family size. A lower age limit was imposed for young people as the research methods used involved participants considering the viewpoints of others, a skill that requires sociality and perspective taking. It has been suggested that generally children have developed a basic understanding of sociality by the age of 8 years old, which further develops during early adolescence (Selman 1976; cited in Mancuso, 2003). Additionally, an upper-age limit was imposed. Young people over the age of 16 years old were excluded. Young people under the age of 16 years old are still considered dependents, whereas young people over the age of 16 years old may have significant independence and may subsequently have had a different experience of parental ABI. Nevertheless, it was acknowledged that there would likely be marked differences in the experiences of young people at the lower age limit and upper age limit due to the relative influence of chronological age and development. These factors are reflected upon during data analysis. No age limits were implemented for parent participants.

Whilst it was desired, it was not obligatory for every member of a family to participate in order for a family to be eligible. If individual family members preferred not to participate, then a family were still eligible provided there were at least two family members, one of whom was aged between 8-16 years old, the other of whom was the parent with ABI. This composition was considered the minimum required in order to answer the research questions.

Finally, family members were required to possess good use of the English language. Whilst participants should not routinely be excluded from research on the basis of their language abilities, it was considered necessary for participants to speak fluent English in order to engage with the research interview. Given the relative importance of eliciting personal constructs, the use of interpreters in this context may have confounded results.

2.2.3 Recruitment. Recruitment took place in two phases between November 2015 and March 2016. Figure 1 summarises the recruitment procedure.

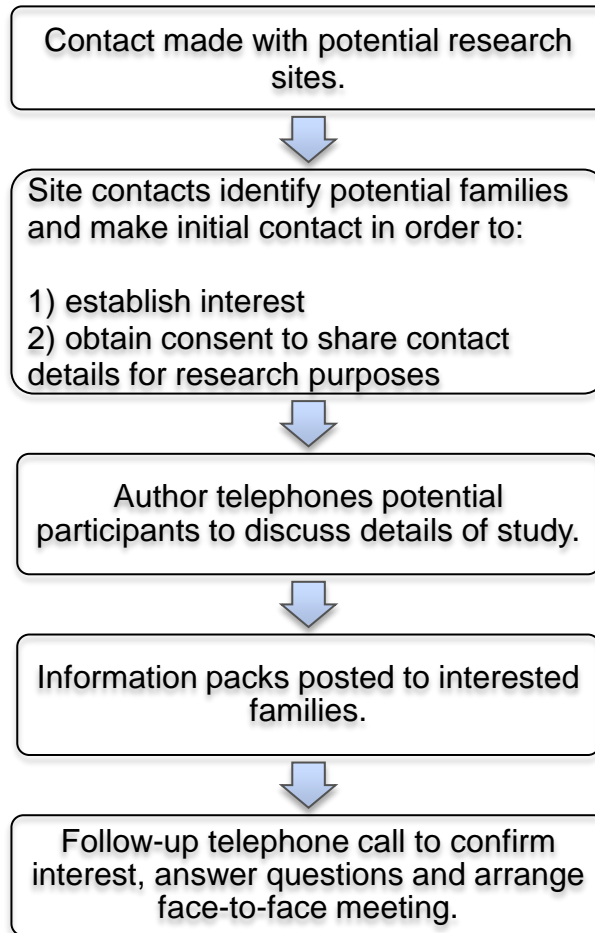


Figure 1. Recruitment procedure.

Following contact with seven potential research sites, a total of 14 families were identified and gave consent to be contacted for research purposes, three of whom took part in the research. Research sites included Headway (a national brain injury charity) branches, and an NHS ABI service. Reasons for non-participation included severity of difficulties ($n = 4$), presence of other life challenges ($n = 3$), and geographical constraints ($n = 1$). Two families opted not to take part, and preferred not to give a reason. A summary of the recruitment strategy can be found in Appendix D.

Information packs included an invitation letter (see Appendix E), and information sheets designed for different ages and levels of understanding (see Appendices F1-4), designed to support families to make an informed decision about their involvement. The process of obtaining informed consent is discussed in more detail in Section 2.6.1.

2.3 Data Collection

2.3.1 Construal. Kelly famously said “if you want to know what's wrong with someone, ask them - they may tell you!” (as cited in Bannister and Fransella, 2013). Given the principle of constructive alternativism, eliciting an individual’s constructs is of paramount importance. Whilst construct elicitation is often verbal, PCP methodology is incredibly flexible, making it widely accessible. Tools that help to elicit personal constructs are often considered superior to psychometric measures, since the latter impose the researcher’s own constructs (e.g. Jankowicz, 2005), whereas grids are considered to be uncontaminated by the researcher’s own view point. For the purposes of this research, constructs were elicited through a semi-structured interview facilitated by a Perceiver Element Grid (PEG; Procter, 2002; Procter, 2005).

The PEG is a qualitative tool that is used to elicit personal constructs and facilitate understanding of interpersonal relationships through helping individuals to explain how they see themselves and others, as well as to describe how they think other people view them. The PEG is used to elicit monadic construing; the construal of a person or event, rather than the construal of a relationship between two or more people, or events (Procter, 2014).

The PEG is a matrix in which perceivers are marked down the left hand column and elements along the top row. In this study, the names of family members were written as both perceivers and elements; on completing the matrix, participants were therefore required to identify how they perceive each

of the elements, and how they think other people in their family perceive each of the elements (see Figure 2).

		Element →		
		Child	Parent	ABI
Perceiver ↑	Child	How I see myself	How I see my parent	How I see the ABI
	Parent	How I think my parent sees me	How I think my parent sees themselves	How I think my parent sees the ABI
	ABI	How I think the ABI sees me	How I think the ABI sees my parent	How I think the ABI sees itself

Figure 2. Simplified example of a child's PEG

Whilst each row elicits monadic construal, increasingly complex cognitive processes are required with each additional row. In the first row in which the self is the perceiver, the participant was asked to construe themselves, other family members, and the ABI. This row was used to support the elicitation of the participants' views on behaviour, personality, and events. This type of construal has also been referred to as essentialist construal (Raskin, 2011), and refers to the construal of an individuals' own reactions and perceptions.

In subsequent rows in which other family members are perceivers, the participant was asked to construe the construal processes of others. Consistent with Kelly's (1955) Sociality Corollary, the PEG facilitates the identification of constructs regarding how individuals' think other people in the family make sense of events. Sociality requires the use of reflective functioning as participants consider the perspectives of others. Although

sociality considers the construal processes of two people, in this instance it continues to refer to a type of monadic construal since it reflects the perception of one person's construal by another, rather than the construal of the relationship between two people.

Finally, when the ABI was positioned as a perceiver, participants were required to engage in a process of externalisation. Externalisation encourages individuals' to separate the problem from the person, in an effort to support the maintenance of an identity separate from that of the ABI (White & Epston, 1990). Furthermore, the personification of problems is thought to help individuals to access construing about matters that are not easily verbalised (e.g. Morris & Appleby, 2012 as cited in Walker, 2016).

Within the matrix, participants can draw or write their responses, in addition to discussing their responses with the investigator. It was important to consider a construct elicitation method that was accessible to participants of different ages and abilities. Tom Ravenette (1977) pioneered the use of drawings in PCP and subsequently, drawing and play have become common methods for construct elicitation with children. Bell & Bell (2008) supposed that using drawing was a far more accurate way of developing an understanding of the construal processes of younger children, who may be less verbally competent than their older peers. Furthermore, use of non-verbal elicitation methods can help to lessen any power imbalances that may reside in the participant-researcher dyad (Procter, 2005). Interestingly, none of the participants chose to use drawings. The majority of participants (n = 7) chose to discuss their answers, whilst three participants wrote some of their responses in the PEG.

The PEG can be used clinically, and more recently has been used as a research tool (e.g. Denner-Stewart et al., 2011); PEGs have successfully facilitated the exploration of interpersonal construal. Furthermore, using a qualitative method that permits participants to share their own constructs may

improve internal validity of findings since the researchers' own constructs are not being imposed.

2.3.2 Family Adjustment. Family adjustment was measured by way of family functioning using the McMaster Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983). The FAD exhibits good reliability and validity when discriminating between healthy and unhealthy family functioning (Byles, Byrne, Boyle & Offord, 1988; Perlesz, Kinsella & Crowe, 1999), and has been frequently used in ABI studies (Charles et al., 2007; Perlesz et al., 1999).

Whilst the FAD consists of seven subscales, for the purpose of this research, only the General Functioning subscale (FAD-GF) was used (see Appendix G). The FAD-GF has been identified as an appropriate short-form measure (Byles et al., 1988; Perlesz et al., 1999; Ridenour, Daley & Reich, 1999) and has demonstrated good validity and reliability when discriminating between healthy and unhealthy family functioning following ABI (Perlesz et al., 1999). The FAD-GF defines healthy family functioning by a number of variables including acceptance, communication, and problem-solving.

The FAD-GF is comprised of twelve statements with which participants rate their agreement using a four point Likert scale from 1 "strongly disagree" to 4 "strongly agree". Higher scores indicate more significant difficulties, and the clinical cut-off is considered a mean score of above two. Recent research identified that the responses of young people aged 7-11 years old tended to corroborate responses of their parents, whereas responses for 12-17 year olds differed, suggesting the latter group have unique perceptions of family functioning (Bihum, Wamboldt, Gavin & Wamboldt, 2002). Consequently, young people below the age of 12 years old do not complete this measure.

Akister and Stevenson-Hinde (1991) explored the utility of the measure in identifying 'family disagreements'. They considered family members to be in

disagreement when their individual scores fall either side of the clinical cut-off and differ by at least two standard deviations. Given the premise of this study in identifying differential perspectives, the FAD-GF was used to identify family disagreements in addition to establishing an overall score.

2.3.3 Young People's Adjustment. The psychosocial outcomes of all participating young people were evaluated using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The SDQ is a 25-item screening tool that is divided into the following five subscales: (1) emotional symptoms, (2) conduct problems, (3) hyperactivity/ inattention, (4) peer relationship problems, and (5) pro-social behaviour. The questionnaire is scored using a 3-point Likert scale that requires respondents to express their level of agreement with each of the questionnaire items (1 = Not True, 2 = Somewhat True, 3 = Certainly True). The first four subscales are summed to yield the total difficulties score, with higher scores indicating greater difficulties. The maximum total score is 40: scores of 13 or below are considered within the normal range, scores of 14-16 are considered borderline and scores of 17 and above are considered to be consistent with a clinical population. With regard to the prosocial behaviour subscale, a higher score indicates better functioning.

The SDQ was chosen for its conciseness, ease of administration, and focus on both positive and negative aspects of wellbeing. The SDQ has been found to demonstrate good reliability and validity among young people aged between 3-16 years old (Goodman, 2001). The SDQ is available in a variety of formats, with the suitability of each dependent upon the age of the young person and the purpose of the screening. Two formats were used for the purpose of this study; the informant-rated version and the self-report version (see Appendices H1-2).

The informant-rated version (Goodman, 1997) exhibits reliability and validity when completed by parents or teachers of 4-16 year olds, and is composed of

the 25 questionnaire items discussed above. The self-report version (Goodman, Meltzer & Bailey, 1998) is suitable for young people aged between 11-16 years old and consists of the same 25 questionnaire items with the wording adapted for suitability of the participants. Information gathered from multiple informants is thought to improve reliability of findings (Young et al., 1987). As the self-report version of the SDQ is only appropriate for young people between 11-16 years (Goodman, 2001), those participants under the age of eleven did not complete the SDQs and in such cases the study relied on the SDQs from parents only.

2.4 Procedure

Following provision of the information sheets (Appendices F1-4), consent to participate was sought (see Appendices I1-4). Thereafter, a mutually convenient time and place to meet each family was arranged. All participating families chose to complete interviews in their homes, and all individual interviews within each family took place on the same day. As interviews took place in families' homes, it was ensured that a separate room was made available for privacy at the time of each individual interview.

Demographic data was collected from parents during a brief informal interview that occurred prior to the individual research interviews. Data obtained related to family composition, type and severity of ABI, time elapsed since parental ABI, and any known behavioural, educational or psychological difficulties among family members that pre-existed parental ABI. Where possible, the type and severity of ABI was verified by professionals at the relevant research site, with the consent of the ABI patient.

Next, the two questionnaire measures (FAD-GF & SDQ) were completed. Each questionnaire took between five and 10 minutes to complete.

Finally, participants completed a semi-structured interview facilitated by the PEG. Individual interviews took between 30 and 68 minutes ($m = 48.2$, $SD =$

12.2). Duration was largely dependent upon the age and ability of each participant. Each box of the PEG was introduced with a question that elaborated upon the box's title (e.g. 'How I see myself'), and was based upon Kelly's (1955) self-characterisation. For example:

“Imagine that somebody wants to get to know you, but they have never met you before. This person wants to find out the most important things about what you are like as a person. Using this piece of paper, could you draw a picture of yourself, or write something down to describe what you are like as a person?”

Adapted from Kelly (1955)

The semi-structured interview was designed to support participants to discuss their construal, and was guided by a series of prompts (see Table 10). The prompts were intended to enhance the author's understanding of participants' construct systems, for example, by using specific questions to elicit contrast poles. For each question, participants were invited to draw, write about, or discuss their responses.

Table 10. *Semi-structured interview questions.*

Perceiver	Element	Initial Question	Possible Prompts
Self	Self	Imagine that somebody wants to get to know you, but they have never met you before. This person wants to find out the most important things about what you are like as a person. How would you describe what you are like as a person?	<ul style="list-style-type: none"> - How would you describe someone who is not like that? Which one would you prefer to be? - Would you have always described yourself this way or have there been times when you would have described yourself differently?
	Other <i>Repeat for each family member</i>	Imagine that somebody wants to get to know <name family member>, but they have never met them before. This person wants to find out the most important things about what they are like as a person. How would you describe what they are like as a person?	<ul style="list-style-type: none"> - How would you describe someone who is not like that? - How are they similar/different to you? - What about other people in your family, are they similar or different to <name family member>? In what way?
	ABI	Imagine that you were trying to explain to an alien who came to earth what a brain injury is like, what do you think you would say?	<ul style="list-style-type: none"> - You described the ABI as being <insert word>, what is the opposite of that? - How is life with the brain injury similar or different to life before? - What would you change/keep the same about the brain injury?
Other	Other <i>Repeat for each family member</i>	I want you to tell me how you think <name family member> sees you. If I were to speak to them and ask them what you are like, what do you think they would say?	<ul style="list-style-type: none"> - Why do you think they would describe you in that way? - Would they have always described you like that or are there times when this would have been different? - Do you like them seeing you this way? How would you prefer them to see you?

	Self	Try and imagine how <name family member> sees themselves. If someone asked them to describe themselves, what kinds of things do you think they might say?	<ul style="list-style-type: none"> - Why do you think they might describe themselves in that way? - Do you think that they have always described themselves in that way? - Do you think it's important for them to be seen like this? - Do you think they would prefer to be seen in a different way? - Do you think he/she sees him/herself as different or similar to you?
	ABI	How would <name family member> describe the brain injury?	<ul style="list-style-type: none"> - What makes you think they might describe the brain injury in that way? - Do you think it's important to (insert name) that the brain injury is seen like this? - Do you think he/she sees the brain injury as similar or different to you? In what way?
ABI	Self & others	Now I want you to try and imagine what it would be like if the brain injury had thoughts and feelings too. What do you think the brain injury would say if it could describe the people in your family? Could you draw a picture or write down what it might say?	<ul style="list-style-type: none"> - Why do you think it would describe you/(insert name) in that way? - Would it have always described you/(insert name) like that or are there times when this would have been different? What about at different times after the brain injury came along? - Do you like it seeing you/(insert name) this way/Is it important that it sees you this way? Why? - How would you like it to see you?

ABI

Ok, like the one before, I want you to try and imagine that the brain injury could think. What do you think the brain injury would say about itself? Could you draw a picture or write down what it might say?

- Why you do think it might describe itself in that way?
 - Do you think that it has always described itself in that way?
 - Do you think it would prefer to be seen in a different way?
 - Do you think it sees itself as different or similar to you?
-

Following the completion of the interview, participants were debriefed and given the opportunity to discuss any issues arising from the interview. Further information is detailed in Section 2.6.5.

2.5 Data Analysis

Data analysis comprised of three parts: analysis of questionnaire data, analysis of construal within families, and analysis of construal between families. Each method of analysis will now be discussed.

2.5.1 Questionnaire Data. Questionnaires were scored and interpreted in relation to clinical cut-offs derived from normative data from standardised samples (from Epstein et al., 1983; Goodman et al., 2001). Due to the small sample size, only descriptive statistics were documented. Where participants were part of only three families, the assumption of statistical independence of observations would have been violated (e.g. Field, 2009), and consequently it was not an appropriate sample from which to conduct inferential statistical analyses.

Questionnaire data was explored alongside individual and familial processes of construal, where similarities and differences between questionnaire data and construal were explored in relation to a PCP framework.

2.5.2 PCP analysis. Constructs and patterns of construal were identified from analyses of PEGs and interview transcripts. Interviews were transcribed and PEGs were completed in instances that participants had preferred to discuss their answers rather than write them down. PEGs and interview transcripts were subsequently reviewed concurrently. Akin to a coding process, interview transcripts were reviewed line by line, and the preferred and contrast poles of constructs were highlighted. Processes of construal and constructs of transition, including the identification of Kellian emotions, were documented in the margin of the transcript.

Once individual PEGs and interviews had been reviewed, family data was explored together. The data was scanned in order to identify individuality and commonality within the family system. Secondly, the notion of sociality was explored and PEGs were compared to see whether family members had accurately predicted the construal processes of others.

2.5.3 Thematic Analysis. The PEG was used to elicit individual construal, and to identify similarities and differences in construal within families, whereas the TA was used to identify patterns in construal between families. The two methods complimented one another in relation to their aforementioned theoretical frameworks, and the utility of both methods in identifying patterns within data. Furthermore, both methods also support the identification of difference. For example, within TA, a theme does not simply describe commonality within the dataset but also acknowledges exceptions and differences within each theme. TA offers a way of organising data yielded from the PEGs. In this instance, the TA was used to understand similarities in experiences of ABI, and thus was predominantly used in relation to monadic construal with the self as a perceiver.

All interviews were transcribed by the author in order to facilitate familiarisation with the data. The interviews were subsequently read, and listened to, a minimum of twice. Initial thoughts were recorded alongside the transcript and a research diary was used to reflect upon observations. Following this, a coding process was initiated. Whilst the interviews included general information relating to construal (e.g. participants' likes and dislikes), only sections of the transcript that related to experiences of ABI were coded. Similar codes were clustered using a thematic map and preliminary themes were defined by the author. In order to prevent the identification of inaccurate themes due to clustered data, themes were required to be evidenced in at least two of the three families. An excerpt of a coded interview transcript can be found in Appendix J.

It is acknowledged that interpersonal processes occurring between the author and participants will have influenced data obtained, and that the author's own processes of construal may influence data interpretation. To minimise subjectivity, verbatim quotes will be used to describe findings relevant to each theme. Quality assurance was maintained by providing sections of the transcripts to be independently coded by the supervisory team. Participants were also given the opportunity to comment on the themes derived from the data; this is discussed in further detail in Section 2.7. Whilst every effort was made to minimise the effects of subjectivity, it is recognised that the themes obtained represent a subjective interpretation of the data, and alternative interpretations could be made.

2.6 Ethical Considerations

Ethical approval for the study was granted by the University of Hertfordshire Ethics Committee and the London-Central NHS Research Ethics Committee (see Appendices K-L). Research and Development (R&D) approval was also gained from the local NHS trust (see Appendix M). Recommendations from the British Psychological Society (BPS) Code of Human Research Ethics (2010) were followed throughout. The key ethical considerations are discussed below.

2.6.1 Informed Consent. Informed consent was sought from each family member participating in the study; both young people and adults were consulted. Families were sent information packs prior to meeting with the researcher, to allow sufficient time to read the information and consider any questions. As described, information packs included an invitation letter and information sheets designed for different ages and levels of understanding. These were used to ensure that all participants were made fully aware of the aims, purpose and nature of the research, so that they could make an informed decision about their involvement. Families were given the opportunity to discuss their involvement with the researcher and ask questions prior to signing written consent forms. For participants aged 16 years old or

under, informed consent was initially sought from their parents, before being sought from the young people themselves.

Capacity to give informed consent was assessed for all participants with ABI. This was assessed by the professionals involved in their care, all of whom had experience working in the field of ABI and had previously assessed capacity. Furthermore, upon discussing details of the study with the author, capacity was evaluated, following the BPS (2010) principles. Individuals who were deemed lacking in capacity to make informed decisions, for example, those with significant impairments in understanding or communication, were excluded from this study.

2.6.2 Research with vulnerable participants. Both young people and individuals affected by ABI are deemed vulnerable participants. In order to support participants of different ages and abilities, the interview methods were used flexibly, and shorter research interviews tended to occur for young people, and injured parents.

Whilst the interviews were conducted in a location of the participant's choice, the author ensured there was another responsible adult present at all times. Furthermore, participants were given the choice as to whether a family member joined them for the interview. It was acknowledged that the presence of another family member may have influenced participant responses; however, it was deemed an important option to be made available to participants, to ensure that they felt safe and comfortable at all times. However, none of the participants requested to have a family member present at the time of their interview.

2.6.3 Confidentiality. Confidentiality was maintained at all times. Families were assigned a numerical code, and data was stored correspondingly in electronic files. All PEGs and questionnaires were scanned onto an encrypted USB device, and hard copies were subsequently

destroyed. All data was stored electronically on encrypted USB devices; anonymised transcripts of audio recordings were stored separately to the audio recordings themselves. Furthermore, audio recordings were erased from the audio recorder as soon as the files had been uploaded and stored securely. A database of participant details was again stored on a separate encrypted device, to ensure that in the event of unauthorised access to either device, confidentiality was still maintained. Finally, encrypted USB devices were stored securely and separately from one another.

2.6.4 Anonymity. All participants had the right to anonymity.

Pseudonyms were assigned to all participants, and identifying information was removed from transcripts and PEGs. Participants gave consent for quotations to be used when the research was written up, subject to them being fully anonymised. One participant gave consent for a section of their transcript to be made available in the appendices. Whilst the researcher considered submitting a full transcript, an excerpt was chosen. The excerpt was considered an appropriate length to allow an audit trail of data analysis to be conducted, whilst reducing the risk of the family being identified.

2.6.5 Potential distress to participants. Participants were given the opportunity to choose when, and where, the interviews were held. Regular breaks were offered to participants in order to reduce fatigue and increase comfort.

It was possible that participants may have become distressed when talking about the impact of the ABI. Every measure was taken to ensure the risk of distress was minimised. Participants were told in writing via the information sheet, and verbally prior to starting the interview, that they could take a break at any time. Participants did not have to answer any questions that they preferred not to. The author has experience of supporting people who are highly distressed and conducted the interview in a sensitive manner, drawing upon clinical skills where appropriate. The interviews were paused if

participants became distressed and only resumed once the participant reported feeling comfortable to do so.

Following the interviews, time was protected in order to debrief participants and signpost them to sources of support, if required. Families were given contact details of support services in the local area, including their local Headway branch and local counselling services.

If concerns had been raised about ongoing psychosocial difficulties, families would have been encouraged to contact their G.P. Furthermore, the author would have contacted the G.P. or the local safeguarding team if any risk to self or others had emerged.

2.7 Consultation

Service users and the general public were consulted throughout the research process. Consultations took place with adults and young people known to the author, and through approaching families affected by ABI via an online forum. Initially, consultation was sought regarding the wording and design of information sheets and consent forms. A summary of feedback is presented in Table 11.

Table 11. *Summary of feedback following consultation.*

Characteristics e.g. age, gender, ability	Key Points
10, male	Reduce length of information sheet.
14, female	Change font, use sans serif.
54, female	Consider wording and ensure consistency of explanations.
57, male	Requested clarification of points, suggested re-wording to be more 'user-friendly'
Unknown, adult with experience of ABI	Ask individual families for their preferred term to describe ABI & personalise information sheets accordingly.

Adaptations were also made in accordance with feedback obtained during the researcher's clinical role. For example, the use of PhotoSymbols™ and a minimum font size of Point 14 have been recommended by adults with cognitive difficulties as ways of making information more accessible. Furthermore, feedback from previous work with young people indicated the use of pictures to compliment written prose.

Following each research interview, feedback was requested regarding the process of completing a PEG, in addition to the associated semi-structured interview. Some young people described the experience as 'unusual' and spoke about their anxieties prior to the interview, however, specific recommendations were not made. Fortunately, the process of completing the PEG and asking about the participant allows the researcher and participant to build a rapport before sensitive questions are asked. Particularly for the youngest participant (aged nine years old), longer time was given to build rapport and find out about their hobbies and interests.

Finally, participating families were given the opportunity to comment on the themes generated in the research. Two of the three families opted to take part in this stage of the research process. After being given a written summary of the themes, families were asked: 1) whether the themes appeared to encapsulate their family's experience; 2) whether there were any experiences that were overlooked by the themes; and 3) whether they had any additional comments. Both families agreed that the themes reflected their experiences and no points of disagreement were highlighted. Whilst this was promising, it remained important to reflect upon the potential power imbalance between the researcher and participating families. Consequently, participant voice is demonstrated through the use of quotations, to support the researcher in staying close to the data. This is reflected throughout the presentation of results in Chapter 3.

Chapter 3: Results

This chapter will describe the findings from the 10 research interviews completed with individuals from three families. Part one introduces the participants¹ in order to orientate the reader to their familial context. Afterwards, questionnaire data and construal processes will be explored for each family. Part two details findings from the Thematic Analysis and explores the similarities and differences between families' experiences of parental ABI.

3.1 Construal and Questionnaire Data

The primary aim of this research was to investigate whether or not similarities and differences in construal between family members were related to young people's and families' adjustment to parental ABI. In this section, each family will be introduced by way of a genogram, description of demographic variables, and an overview of the ABI. Next, data from the FAD-GF and SDQ will be presented and interpreted in accordance with normative data from standardised samples. For the SDQ, both the total score and subscale scores will be documented. Whilst clinical ranges are noted, differences between parent-report and self-report scores will be examined, as it is acknowledged that there can be marked differences between scores even if they fall within the same range. Next, individuals' processes of construal will be examined using data from the PEG and associated semi-structured interview. Finally, familial construal will be explored. In particular, individuality, commonality, and sociality within the family will be described. Construal will be discussed alongside questionnaire data from the SDQ and FAD-GF.

For clarity of data presentation, PEG data has been summarised for each participant. However, all constructs that are presented have been elicited within research interviews, and are presented verbatim.

¹ Families are presented in order of interviews. All identifying information has been changed in order to protect participant confidentiality.

3.1.1 Family 1: The Rossis. Figure 3 illustrates a simplified family genogram for The Rossis.

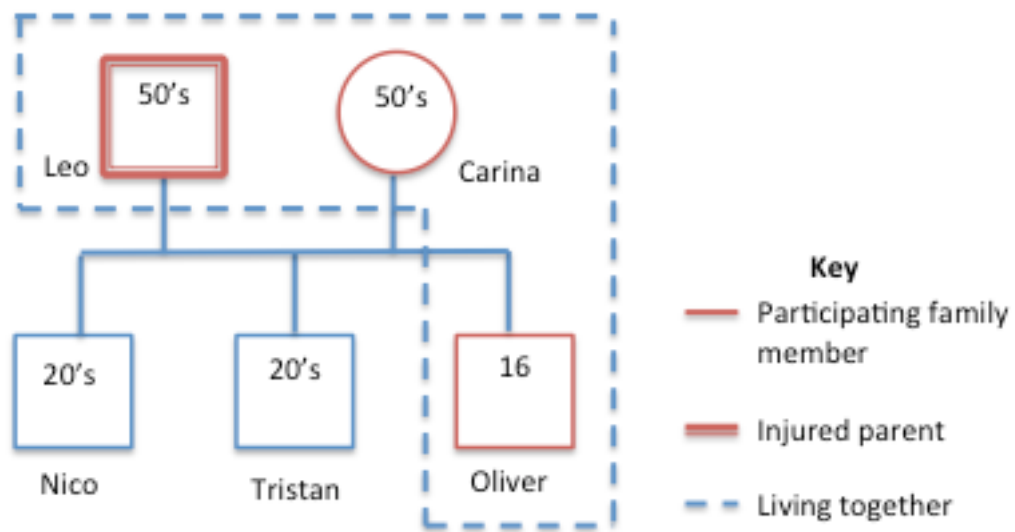


Figure 3. The Rossis' genogram

Leo, Carina and Oliver participated in the research, however, Nico and Tristan declined due to living away from home whilst studying at university. Leo and Carina describe their ethnicity as White European. However, the children identify themselves as White British.

Leo experienced an acute ischaemic left hemispheric stroke in February 2012 (46 months previously), following two myocardial infarctions. Leo was admitted to an Intensive Care Unit (ICU) for three weeks, after which he accessed inpatient rehabilitation for approximately eight weeks before being discharged and returning to the family home. At the time of the research interview, Leo presented with muscle weakness on his right side, aphasia and apraxia. He also described difficulties with his short-term memory and fine motor skills. Leo attends his local Headway centre on a weekly basis, where he accesses physiotherapy and cognitive rehabilitation, in addition to receiving social support.

3.1.1.1 Questionnaire data. Table 12 summarises the data elicited from the FAD-GF. The family mean fell below the 2.00 cut-off, suggesting that the Rossis do not perceive themselves to be experiencing significant difficulties with family functioning. Since each family member's score fell on the same side of the clinical cut-off, it is not considered that they are experiencing any family disagreements.

Table 12. *Rossi Family FAD-GF Data.*

	Family Member			Descriptive Statistics	
	<i>Leo</i>	<i>Carina</i>	<i>Oliver</i>	<i>Mean</i>	<i>SD</i>
FAD-GF	1.75	1.33	1.58	1.55	0.21

Table 13 summarises the questionnaire data from the SDQ. Carina and Leo completed the parent-report questionnaire together, and their scores are compared to Oliver's self-report.

Table 13. *Comparison of self-report and parent-report SDQ for Oliver.*

Subscale	Parents		Oliver	
	Score	Range	Score	Range
<i>Emotional</i>	3	Non-clinical	4	Clinical
<i>Behavioural</i>	0	Non-clinical	6	Clinical
<i>Hyperactivity</i>	4	Non-clinical	4	Non-clinical
<i>Peer relations</i>	1	Non-clinical	1	Non-clinical
<i>Prosocial Behaviour</i>	10	Non-clinical	10	Non-clinical
<i>Impact</i>	0	Non-clinical	1	Clinical
<i>Overall</i>	8	Non-clinical	15	Clinical

3.1.1.2 PEG data.

3.1.1.2.1 Individual engagement and processes of construal. Oliver engaged well with the research interview and spent a considerable amount of time writing his responses in the PEG, which can be seen in Figure 4. Oliver appeared preoccupied with ensuring that he had described his mother and father equally, amending his PEG accordingly as he identified additional constructs. Oliver's process of construal appeared to exemplify tight construal as he used similar constructs to describe the different people within his family, and found it difficult to identify times when he would describe himself or others differently. Oliver described himself and others as being at the preferred pole of each of his elicited constructs, and there were times when he struggled to identify contrast poles.

		Elements →			
		Me	Mum	Dad	ABI
↑ Perceivers	Me	Funny, caring, sporty, love music, people can trust me, always there for friends and family.	Amazing, lovely, the best, caring, funny, good chef, amazing family she has.	Cool, very very funny, always there to talk, likes football and rugby, supports Liverpool, caring, the best, lovable.	You can lose your speech and movement, it's a horrible feeling, always pray to God if things aren't going well.
	Mum	Funny, caring, loves football, getting annoyed if someone blames me for something that I haven't done, loves music and drama, loves going out with mates.	Very worried, caring, loves to talk, loves to help people, loves her family and friends and loves my reggae music.	The best, amazing, always knows what's best, he loves to talk to people, one of the best things in her life.	Very hard, hard work, it hurts to see someone she loves with a brain injury, frustrated.
	Dad	Doesn't like school, loves football, likes playing the piano and acting, always watching TV or playing the PS4, funny, caring, always there for friends and family.	Good cook, always there for him, best thing ever, she's beautiful, always nice and helpful, hardworking.	Loveable, strong, caring, always talking, meeting new people.	Frustrated, very sad, sometimes he gives up quite easily.
	ABI	Getting me worried, getting a bit more frustrated, changed the way I think.	More worried, it hurts her a lot emotionally.	Changed his life.	Can hurt people, can change someone's life, could kill, dangerous.

Figure 4. Oliver's PEG

Carina's PEG data can be seen in Figure 5. Carina quickly discussed the ABI, often sharing constructs in relation to the ABI regardless of the questions asked. This was illustrated when she described Oliver as wanting to be "macho" and how he "[grew] up quickly". Carina appeared looser in her construal, however, ascribing different constructs to different people, and seeming flexible within her application of constructs across different points in time. As such, many of Carina's constructs appeared permeable and open to revision on the basis of experience.

		Elements →			
		Me	Oliver	Leo	ABI
↑ Perceivers	Me	Very friendly, I like people, I'm there if they need help.	The baby of the family, he wanted to be macho, he put [on] a mask, he would grow up quickly.	Friendly with everybody, helping people if they need something, always smiling, there for everybody, very calm, big heart.	Devastating.
	Oliver	Good mum, caring, loving, unconditionally there.	Lovely boy, caring, there for his friends, he will help you, good friend, good with the family.	He always look up on him [sic].	A very bad experience for him, it was the worst experience he had.
	Leo	Lovely, always there for anybody.	The baby of the house, the mad one, the cheeky one, always wants to play, loves to talk about football, the young one.	He's a good person, good husband and father, always provides for the family, be there for the family.	Devastating. It was the worst thing that's happened.
	ABI	He can rely to me [sic].	Talks all the time, makes jokes, makes him laugh.	A fighter.	Very clever because he can put down the path, the most important thing that's in the person.

Figure 5. Carina's PEG

Finally, Leo's PEG data can be seen in Figure 6. The research interview appeared most difficult for Leo as a consequence of both his verbal communication difficulties, and the emotion that arose across the course of the interview. However, he was keen to persevere and respond to each of the questions that were asked of him. This may have been indicative of Kellian hostility, whereby Leo was attempting to extort validation evidence of being able to engage in conversation, in spite of his communication difficulties. Leo's patterns of construal were very similar to Oliver's, in that he often used similar words to describe different family members, or would simply respond stating they were "all the same" (e.g. line 68). Again, this appears indicative of tight construal; however, may also be a reflection of Leo's language difficulties. Leo

was able to map some changes over time and consider differences pre- and post-ABI.



		Elements 			
		Me	Oliver	Carina	ABI
Perceivers 	Me	I like antiques, Church, outward going [sic]	Beautiful.	Beautiful.	It's hard, I can't speak, every day is better.
	Oliver	Don't know. The same [likes antiques and Church], Liverpool	Nice man, good, independent.	Can talk to her, listens very carefully to her.	Carry on.
	Carina	We're both the same, sit down, eat together, talk.	He's changed a little bit. Likes football and women. Does the piano and drama.	Bubbly, alive, talking.	We don't know [what will happen]
	ABI	Pray, 'cause that's all I can do.	Pray.	Pray.	It's hard, which way are you gonna go? You can't do it anymore.

Figure 6. Leo's PEG

3.1.1.2.2 *Individuality and commonality.* The Rossis demonstrated commonality in their construal of one another, which is consistent with Carina's description of the family being "five people but like one person" (lines 620-621). This was consistent with their FAD-GF scores, that all fell below the clinical cut-off, and were not indicative of family disagreements.

Additionally, the Rossis generally perceived themselves as being similar to one another. Specifically, both Oliver and Leo described seeing everyone in the family as similar to one another, although acknowledged that different

dyads within the family were similar in different ways. Carina also acknowledged similarities between family members, notably between Oliver and Leo, yet stated “I think I’m different, we’re all different I think, we aren’t all the same” (lines 330-331) and was able to speak at length about individual differences. This pattern appeared consistent with individual family members’ patterns of construal in that Carina’s construct system appeared more permeable than both Oliver’s and Leo’s.

A number of constructs were associated with familial roles, particularly in relation to gender. Both Carina and Oliver appeared to engage in constellatory construing. For example, Carina explained that “I’m the only woman in the family, you know. I’m the mum and the wife” (lines 327-328) and described her role in the house as being to “look after the kids and [Leo] and cooking” (lines 69-70). She also explained how her role changed following Leo’s ABI, when she “became man and woman” (line 74). Furthermore, when asked to describe a mother different to his own, Oliver stated:

“It’d be weird how they would have a son ‘cause obviously you’ve gotta be caring, er like, let’s say you’ve gotta be like lovely to your son, ‘cause if you’re not then it’s a- like the son won’t like their own Mum so it’d be a bit strange relationship between the son and the Mum” (lines 187-192)

Oliver’s description may imply that it was difficult for him to imagine how someone could be a mother if they weren’t both caring and lovely. Carina also expressed that Leo would describe himself as a “good husband and father, you know, and he always provides for the family” (lines 343-345), further reinforcing the traditional gender roles that appear to exist within their family system.

Regarding religion, Oliver described how he would “always pray to God if things aren’t going well” (line 316), Carina expressed that “the only thing to

help us, it was our faith” (lines 293-294) and Leo spoke about the need “to pray, you know, ‘cause that’s all I can do” (lines 478-479). Their construal of religion appeared tighter than some of their other construing. Where tight construal can serve a function of reducing anxiety through enabling predictability, religion appeared to offer a coping strategy at a time when many factors pertaining to the ABI and subsequent impact lay outside their individual and familial ranges of convenience.

When discussing the ABI, Leo and Oliver appeared to consider the ABI as the acute event and subsequent impact, whereas Carina appeared to consider the ABI as Leo’s remaining cognitive functioning. This offers explanation to Oliver and Carina’s seemingly polarized positions of “could kill” (Oliver) versus “the most important thing that’s in the person” (Carina). Further discussion revealed that they both held positions more akin to Leo’s in that he stated “it’s hard” but also that “every day is better”. Having a looser construal of the ABI may result in fewer invalidations and thus a greater propensity to coping.

3.1.1.2.3 Sociality. The Rossis exhibited good sociality as they were generally able to accurately predict how they are perceived by different family members. This is congruent with descriptions of their family system, for example, “we are this open family, everything we share together, we never have the secret” (Carina, lines 166-167), “he talks to her, so I think he listens very carefully to her” (Leo describing Oliver’s relationship with Carina, lines 368-369), and “always there for one another” (Oliver, line 226).

However, in contrast to Oliver’s description of himself as “I’m always worried” (line 369), neither Leo nor Carina described him in this manner. Although Carina acknowledged that Oliver “put [on] a mask” (line 142), this appeared to be time-bound to the acute phase of the ABI.

These differences in the current perception of Oliver’s wellbeing were reflected in the self-report and parent-report versions of the SDQ. Carina’s

ratings of Oliver’s wellbeing were similar to those of the general population and not indicative of clinically significant difficulties, yet Oliver’s own scores suggested that he may be at risk of developing clinical difficulties, particularly regarding his behaviour. Figure 7 uses the ‘bow-tie’ diagram (Procter, 1987) to illustrate how the relationship between Carina and Oliver’s construing and subsequent actions may have been perpetuated.



Figure 7. Perpetuation of parental assumption that Oliver is coping.

Whilst Oliver’s strategy of “keeping it in” appears effective in allowing him to “be strong” for his family, it simultaneously leads Carina to believe that he is coping, particularly given her confidence that Oliver would turn to her if he needed to.

Given the aforementioned gender roles that appeared prominent for the Rossis, Oliver may have felt it necessary to fulfil the role of the dominant male within the family. Particularly as he had described the implications of the ABI on Leo’s abilities, and since his two older brothers were away at University. This is also consistent with Carina’s reports that Oliver “wanted to macho” (line 141) and “grow [sic] up quickly” (line 144).

Carina and Leo's assurance that Oliver was coping may also have been perpetuated by Oliver's behaviour varying in different contexts. Regarding school, Oliver reported that "I kinda like getting in trouble...it's kinda like funny 'cause sometimes I get into trouble for no reason. I just laugh about it" (lines 539-542) and he spoke about having a "reputation" (line 520), yet he also raised concern over the impact of his behaviour stating that "if I keep getting phone calls my Mum thinks I'm not doing well" (lines 502-503), later stating that he would prefer if Carina didn't see him as "getting annoyed". The resulting incompatibility between "doing well" and "like getting in trouble" appears to exemplify Kelly's (1955) Fragmentation Corollary, suggesting that Oliver may construe differently depending upon his situational context.

3.1.1.3 Summary. The Rossis' patterns of construal appeared to account for consistencies between the content of their interviews and outcomes on both the FAD-GF and SDQ. Generally, it appears as though their shared commonality and sociality has supported their functioning as a family following the ABI. Whilst Oliver has successfully engaged in a strategy of being strong for his family, this has resulted in discrepancies in how he is construed by his parents with relation to his wellbeing.

3.1.2 Family 2: The Smiths. Figure 8 illustrates a simplified family genogram for the Smiths.

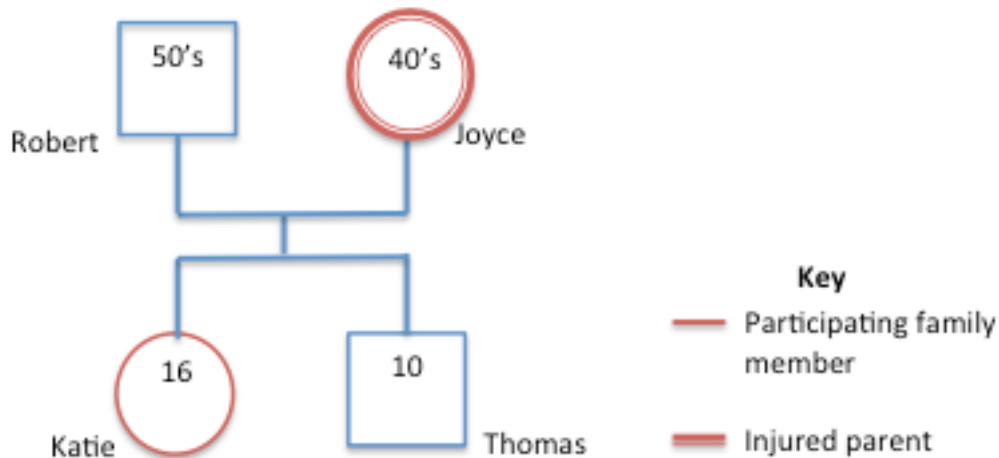


Figure 8. The Smiths' genogram.

Joyce and Katie participated in the research. Joyce expressed that she felt Thomas was too young, and she preferred that he did not participate, whilst Robert declined due to work commitments. Robert is White British and Joyce is of South Asian origin. Katie and Thomas identify as Asian British.

Joyce experienced a right hemispheric stroke in June 2014 (18 months previously). She was admitted to an ICU for two and a half weeks, after which she accessed inpatient rehabilitation for two weeks, before being discharged home. At the time of the research interview, Joyce presented with muscle weakness on her left side. Joyce attends her local Headway centre on a weekly basis, where she accesses physiotherapy, and receives social support.

3.1.2.1 Questionnaire data. Table 14 summarises the data elicited from the FAD-GF. The family mean fell above the 2.00 cut-off, suggesting that Joyce and Katie perceive the family to be experiencing significant difficulties with family functioning. However, since both family members' scores fell on the same side of the clinical cut-off, it is not considered that they are experiencing any family disagreements.

Table 14. *Smith Family FAD-GF Data.*

	Family Member		Descriptives	
	Joyce	Katie	Mean	SD
FAD-GF	2	2.21	2.11	0.15

Table 15 summarises the questionnaire data from the SDQ as completed by Joyce and Katie.

Table 15. *Comparison of self-report and parent-report SDQ for Katie.*

Subscale	Joyce		Katie	
	Score	Range	Score	Range
<i>Emotional</i>	5	Clinical	4	Clinical
<i>Behavioural</i>	4	Clinical	5	Clinical
<i>Hyperactivity</i>	5	Clinical	9	Clinical
<i>Peer relations</i>	4	Clinical	1	Non-clinical
<i>Prosocial Behaviour</i>	6	Clinical	4	Clinical
<i>Impact</i>	0	Non-clinical	2	Clinical
<i>Overall</i>	18	Clinical	19	Clinical

3.1.2.2 PEG data.

3.1.2.2.1 Individual engagement and processes of construal. Katie initially appeared somewhat uncertain about taking part, which was evidenced through her short, unelaborated responses. However, throughout the interview, Katie was gradually able to elaborate her construal when prompted. Katie's PEG data can be seen in Figure 9. Katie used both tight and loose construal processes when describing herself; she used constructs flexibly to make varying predictions about herself in different contexts and at different points in time. Her construal processes appeared tighter when considering

other family members. For example, she employed unvarying constructs to describe Joyce, even in the context of the ABI, stating that “it hasn’t changed her” (line 515).

		Elements →		
		Me	Mum	ABI
Perceivers ↑	Me	Sporty, funny, outgoing, really hyper, I make everyone happy, relaxed.	She can be nice but you don't wanna get on the wrong side of her.	It's hard at first but you get used to it, you have to be patient with them and you can't stress them out a lot.
	Mum	Likes football, lazy.	Nice, laid back.	A pain cause she has to deal with it.
	ABI	I help out a lot.	Weak cause she can't do much.	It loves himself. It can control itself but we can't control it.

Figure 9. Katie’s PEG

Joyce’s PEG data can be seen in Figure 10. Joyce’s construal processes were initially indicative of tight construal whereby she made statements such as “when I don’t like it, I don’t like it” (lines 30-31) whilst referring to her perceptions of other people’s behaviour. This suggests that once she has construed something in a particular manner, she may be reluctant to revise her construct system following disconfirmation. During the interview, there appeared to be some contradictions between Joyce’s verbal and non-verbal communication, which may have been indicative of a double-bind (Bateson, 1972). For example, she described herself as “I’m friendly, easy to get on with” (line 10), whilst her tone was flat, she appeared disinterested and her speech was punctuated with sighs. Whilst not necessarily problematic, and potentially indicative of the contrived nature of the interview, double-binds can

lead to interpersonal difficulties since other people may have difficulty construing the interpersonal relationship.

		Elements →		
		Me	Katie	ABI
↑ Perceivers	Me	Friendly, easy to get on with, easy to talk to.	The same as me, easy to get on with, smiley face, friendly, she's got my character, loads of friends, outgoing, spoiled brat	Part of my brain is gone, is dead, this [side] is weak, I have to start like a baby, I have to train myself, it's hard, trying to be strong. Building up instead of rushing things.
	Katie	Chatty woman, talkative, very strict.	Friendly. Doing okay, or struggling, I dunno [sic]	Hard because she see me having the stroke [sic]. Have to work hard, helping me.
	ABI	Hardworking.	Friendly, easy-going.	Wants to be alive again.

Figure 10. Joyce's PEG

3.1.2.2.2 *Individuality and commonality.* Joyce and Katie tended to exhibit commonality when construing at a superficial level, for example, the physical implications of the ABI. However, at a more psychological level, there were a number of observed differences in both the content of their constructs, and their patterns of construal. For example, Katie expressed that Joyce would be perceived by the ABI as “weak ‘cause she can’t do much” (lines 639-640), whereas Joyce described thinking that she would be perceived as “hardworking” (line 661). These differences in construal could be indicative of contrast poles, and appear consistent with Joyce’s reports that other people maybe describe her as struggling, yet her own admission that “for me it’s not struggle, I’m trying my best” (lines 253-254).

Joyce perceived herself to be similar to other family members, only noting differences with regard to her cultural upbringing. In contrast, Katie was quick to describe herself as different to Joyce. Interestingly, when Katie was asked to elaborate the differences, she began talking about similarities. Perceived similarities tended to relate to superficial constructs, such as a shared interest in cooking, rather than construal of events, or psychological processes.

Joyce and Katie's differences in construal of psychological processes was made apparent by their scores on the SDQ. Whilst their overall scores were similar, there was a marked difference in their raw scores on the 'hyperactivity' subscale. These differences are consistent with Katie's description of being "really hyper at school" (line 63) in comparison to being "moody" (line 95) whilst at home. This exemplifies the Fragmentation Corollary, whereby Katie construes herself differently in different contexts, and the differing constructs are somewhat incompatible with one another. There were also notable differences on the 'peer relations' subscale, with Joyce's ratings indicating that Katie may have difficulties within this domain. However, Joyce's ratings should perhaps be interpreted with caution as they were incongruent with her later description of Katie as "easy to get on with" (line 70), and reports that "she's got so many friends" (line 460).

Another notable discrepancy related to their construal of Joyce's temperament. Whilst Katie had acknowledged that "you don't wanna get on the wrong side of her" (lines 139-140), she also reported that Joyce had always been this way, and whilst referencing the ABI expressed that "the stroke hasn't changed her, it's just changed like her movements and stuff" (lines 516-517). In contrast, Joyce described a significant change in her temperament post-ABI, stating that "I get fed up so easily now" (line 345) and she explained that she has received psychological support for anger management. Joyce expressed that, "I start screaming sometimes, I get angry, I nearly throw everything on the floor" (lines 595-597). Whilst sources of familial disagreement were mentioned, the extent of Joyce's temper was not

discussed by Katie. This may signify a difference in construal; however, it may also have denote a sense of family loyalty and potential concerns about the implications of disclosing her mother's anger.

Katie and Joyce were, however, similar in their construal of sources of conflict. This was consistent with their FAD-GF data that indicated a shared construal of family dysfunction. Additionally, they both appeared to hold egocentric positions regarding their interpersonal relationships, which may contribute to the perpetuation of conflict. This is illustrated using the 'bow-tie' diagram (Procter, 1987) in Figure 11.

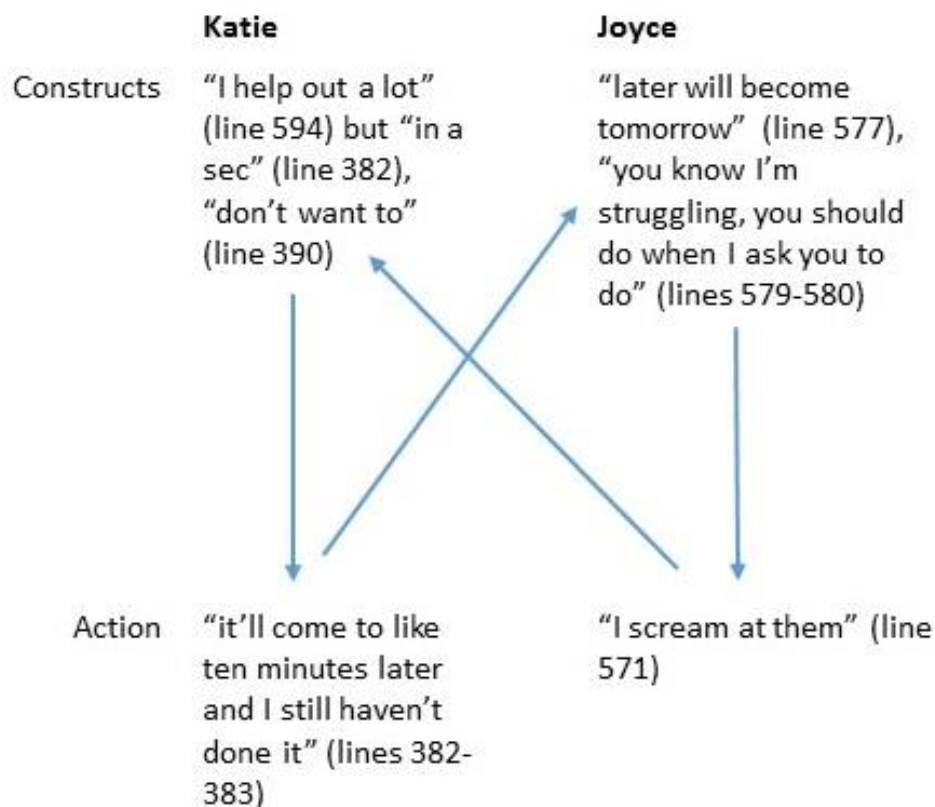


Figure 11. Bow-tie diagram illustrating perpetuation of conflict.

In this instance, Joyce expecting her needs to be prioritised, and Katie wanting her own needs to be prioritised, appears to result in the screaming behaviour from Joyce. It was noted that when Joyce is not getting her needs

met, she takes the position of struggling. Kelly (1955) described 'slot-rattling' as the re-construal of oneself at the contrast pole of an existing construct. This example may indicate that Joyce was slot-rattling between "trying my best" and "struggling", both of which may be functional in different contexts. It was also interesting to consider the trans-cultural scripts that may have been influencing this dynamic, particularly regarding hierarchy and power, with regard to familial roles and expectations. This type of interaction was concordant with Joyce's description of Katie as, "[Katie]'s spoiled brat. She's very spoiled brat. I mean both of them really. We never had what they have now as a kid" (lines 130-132).

3.1.2.2.3 Sociality. Sociality between Joyce and Katie was variable. They were both able to accurately predict how one another would describe themselves and the ABI, yet exhibited relatively poor sociality when it came to predicting how they were perceived by each other. For example, Katie anticipated that her mother would describe her as "lazy" (line 373), whereas Joyce acknowledged that Katie has to "work hard, helping us, helping me" (lines 550-551). Similarly, Joyce anticipated that Katie would describe her as "very strict", whereas Katie actually stated that, "she's not like really strict" (line 497). Whilst both Joyce and Katie perceived that the other would perceive them at the contrast pole of the differing constructs, there appeared an ambivalence around this. Despite having described being lazy as a negative, Katie expressed that she did not mind being construed this way by Joyce. Similarly, Joyce explained that:

She probably would describe me as strict because I always tell her off or tell her not to do this or I tell her something, so many things, so I dunno, either she thinks that's strict with just being caring but it's up to her (lines 372-375).

Joyce's difficulty construing Katie's construal processes reflects the aforementioned differences on between the self-report and parent-report versions of the SDQ.

3.1.2.3 Summary. The Smiths' patterns of construal appeared to account for consistencies between the content of their interviews and outcomes on both the FAD-GF and SDQ. Their fluctuating sociality and perceived individuality may have resulted in some difficulties in family functioning, whilst a sense of ambivalence may be preventing the family from attempting to apply solutions to these difficulties.

3.1.3 Family 3: The Joneses. Figure 12 illustrates a simplified family genogram for the Joneses.

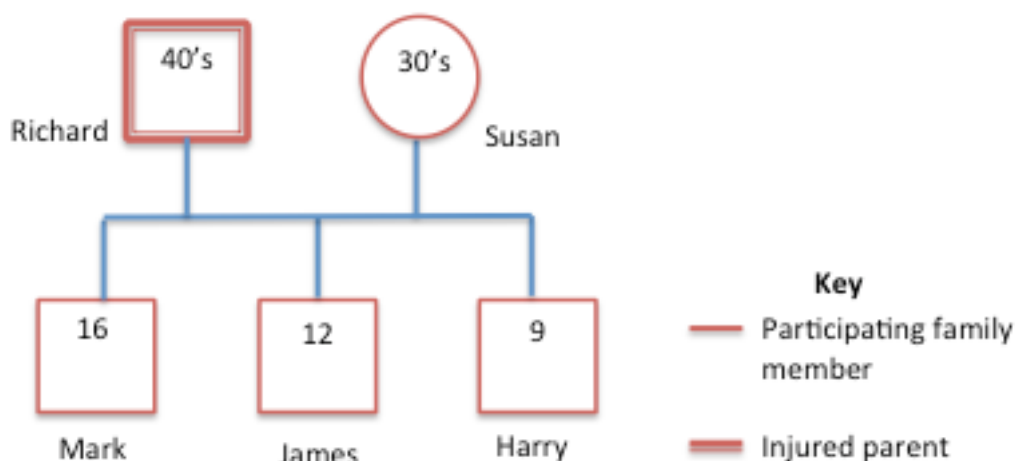


Figure 12. The Joneses' genogram

The Joneses are a White British family. Richard experienced a subarachnoid haemorrhage following a myocardial infarction in June 2013 (42 months previously). He was admitted to a neurological centre for acute inpatient rehabilitation for five weeks, then a general rehabilitation unit for approximately seven months, before being discharged and returning to the family home. The haemorrhage predominantly affected Richard's left cerebral hemisphere, notably his occipital lobe. At the time of the research interview,

Richard presented with hemianopia, poor balance, and cognitive difficulties including poor short-term memory, poor concentration and aphasia. He receives support three times weekly from a support worker who assists Richard in accessing the community.

3.1.3.1 Questionnaire data. Table 16 summarises the data elicited from the FAD-GF. The FAD-GF was completed by all family members except Harry, due to his age at the time of the research interview.

Table 16. *Jones Family FAD-GF Data.*

	Family Member				Descriptives	
	<i>Richard</i>	<i>Susan</i>	<i>Mark</i>	<i>James</i>	<i>Mean</i>	<i>SD</i>
FAD-GF	2.50	2.75	2.08	1.92	2.31	0.38

The family mean fell above the 2.00 cut-off, suggesting the Joneses perceive themselves to have significant difficulties with family functioning. James' rating fell below the clinical cut-off, and was more than two standard deviations below Susan's score; this difference is indicative of a family disagreement. No other family disagreements were observed.

Tables 17, 18, and 19 summarise the questionnaire data from the parent-report and self-report SDQ. Harry did not complete a self-report version of the SDQ due to his age at the time of the research interview.

Table 17. Comparison of self-report and parent-report SDQ for Mark.

Subscale	Parents		Mark	
	Score	Range	Score	Range
<i>Emotional</i>	4	Clinical	4	Clinical
<i>Behavioural</i>	4	Clinical	4	Clinical
<i>Hyperactivity</i>	5	Clinical	6	Clinical
<i>Peer relations</i>	5	Clinical	0	Non-clinical
<i>Prosocial Behaviour</i>	7	Non-clinical	8	Non-clinical
<i>Impact</i>	0	Non-clinical	0	Non-clinical
<i>Overall</i>	18	Clinical	14	Clinical

Table 18. Comparison of self-report and parent-report SDQ for James.

Subscale	Parents		James	
	Score	Range	Score	Range
<i>Emotional</i>	1	Non-clinical	0	Non-clinical
<i>Behavioural</i>	0	Non-clinical	3	Clinical
<i>Hyperactivity</i>	5	Clinical	6	Clinical
<i>Peer relations</i>	1	Non-clinical	0	Non-clinical
<i>Prosocial Behaviour</i>	10	Non-clinical	7	Non-clinical
<i>Impact</i>	0	Non-clinical	0	Non-clinical
<i>Overall</i>	7	Non-clinical	9	Non-clinical

Table 19. *Parent-report SDQ for Harry.*

Subscale	Score	Range
<i>Emotional</i>	7	Clinical
<i>Behavioural</i>	2	Non-clinical
<i>Hyperactivity</i>	5	Clinical
<i>Peer relations</i>	4	Clinical
<i>Prosocial Behaviour</i>	9	Non-clinical
<i>Impact</i>	0	Non-clinical
<i>Overall</i>	18	Clinical

3.1.3.2 PEG Data. For the Joneses, the structure of individual interviews varied. Due to size of the family and time it would have taken to complete a full PEG, interviews were tailored for individuals. For example, young people were not asked to complete grids with their siblings as perceivers or elements. This appeared to suit James and Harry in particular, who were observed to become restless towards the end of their respective interviews. Susan and Richard were asked to consider all three of their children as perceivers and elements, given the importance of understanding their construal of their children as part of the research question. However, this was primarily conducted in relation to themselves and the ABI. Where time permitted, perceived construal of siblings was also considered.

3.1.3.2.1 Individual engagement & patterns of construal. Harry engaged well with the research interview, but was easily distracted at times. Harry's PEG data can be seen in Figure 13. Harry's construal tended to be superficial, for example, describing other people in terms of their hobbies or physical attributes, rather than considering more psychological constructs involving an individual's thoughts and feelings. This is common in younger children, who learn to elaborate their construal as they get older, and their own cognitive processes become more sophisticated (Dallos, 1991; Selman 1976; cited in

Mancuso, 2003). Harry also found it difficult to construe the construal processes of others and thus could be seen as exhibiting poor sociality. Harry's construal processes were generally tight; he made unvarying predictions about events. A notable exception was with regard to the ABI, whereby Harry was clearly able to consider its impact and subsequent changes to the family system.

		Elements →			
		Me	Mum	Dad	ABI
↑ Perceivers	Me	Get bored, sometimes play xBox, I play out, sometimes with my older brother and the motorbike. I like making, cooking & camping, fun, bit tired sometimes.	She does like going to bed, lazy, she has to do lots of stuff.	Loves going on jet skis and motorbikes, likes driving, likes doing lots of stuff.	Not very good because [Dad] wasn't as fun since [sic]. He didn't get much to do and lots we couldn't do, very hard.
	Mum	I don't know.	Nice, bit fun.	I don't know.	I don't know.
	Dad	Don't know.	Don't know.	Don't know.	Don't know.
	ABI	Don't know.	Don't know.	Don't know.	Can't do as much stuff.

Figure 13. Harry's PEG

James responded readily to questions within the research interview, but was observed to become fatigued, at which stage his responses were less elaborated. James' PEG data can be seen in Figure 14. James appeared to employ a variety of construal processes, enabling him to apply his constructs flexibly. At times, he was observed to utilise superficial constructs, but he was also able to consider psychological processes, for example, explaining that

Susan “doesn’t wanna hurt anyone” (lines 118-119) and that Richard “worries about if he gets told off” (line 568).

		Elements →			
		Me	Mum	Dad	ABI
↑ Perceivers	Me	Friendly, helpful, don't wanna hurt anyone, go on the motorbikes, play xBox	Very kind, helpful, loving, she's like me, she doesn't wanna hurt anyone.	He loves us, he doesn't want to go away from us for a long time because he gets really upset, loving like my Mum, cares a lot about people, friends with disabled [people]	It wasn't well, it had something bad happen to it, it's got hurt [sic]
	Mum	Nice, fixed to the xBox,	Kind, likes cleaning.	Caring, sometimes he gets a bit over reactive with stuff – he worries about if he gets told off.	It was a really bad accident. She prefers not to talk about it.
	Dad	Caring, always playing games.	Beautiful, nice, caring.	I don't know.	A terrible thing. It's ruined his life.
	ABI	Mean because I didn't want Dad to have [it]	Mean because my Mum didn't want it there either.	Mean 'cause he doesn't want it there.	It didn't want to harm anything but he did.

Figure 14. James' PEG

The research interview appeared most difficult for Mark, who became tearful and requested a break. Mark agreed to continue the interview but preferred not to answer certain questions about the ABI and the impact on his father. Mark's PEG data can be seen in Figure 15. Mark demonstrated both tight and loose construal processes in relation to different events, and was able to map differences in his construal over time.

		Elements →			
		Me	Mum	Dad	ABI
↑ Perceivers	Me	I like doing stuff with my brothers and my Dad like 'cause we've got a couple of motorbikes, sometimes I have a bad temper, generally happy sometimes, happy with life, it's going alright.	Interested in gardening, usually just wants to relax and chill, she's got a temper,	He's still a Dad, he cares for me but he's like a friend now. He's there, he's funny to talk to, he's a funny guy sometimes, he acts like a bit of a child sometimes, bit immature, got a big temper, can get angry easily.	It's been crap, terrible really, it's ruined us, don't like it.
	Mum	Got a temper, proud of me.	Stressful but happy sometimes and happy with life except for the brain injury	A child but still her husband, caring, always there for each other.	Preferred not to answer.
	Dad	Preferred not to answer.	Preferred not to answer.	Active child, always out there, happy to do [things], short temper, funny person.	Trapped.
	ABI	Someone whose try'na stop the brain injury from try'na break the family even more [sic]	Someone who's trying to stop it, trying to make [Dad] happy.	A source: "if I affect him, I affect the whole family", easy to take control of.	Hateful person, murderer, ruins families, breaks everything apart.

Figure 15. Mark's PEG

Susan's PEG is shown in Figure 16. Susan appeared to go 'off-topic' at times, which could be indicative of loose construal. Whilst Susan did not respond to all interview questions, as evidenced by gaps in her PEG, the tangents gave additional information about her personal construct system. Susan applied constructs flexibly, whilst acknowledging familial, and individual, differences. At times, there was evidence of pre-emptive construal, for example, describing her relationship with Mark as, "we either get on really well or not at all" (line 183).

Susan spoke about her difficulties following the ABI and described experiences akin to agoraphobia. Kelly (1955) described agoraphobia as a process of constriction whereby an individual narrows their perceptual field to reduce the risk of having their constructs invalidated. It appeared as though Susan had reduced her world as a means of coping with the ABI.

		Elements →					
		Me	Richard	Mark	James	Harry	ABI
↑ Perceivers	Me	Love to be out, walking, just get on with it, love the outdoors, love nature, bit of a temper.	Loves everything with engines, Mr Angry, very loving, always wanted to do better.	Bit of a temper, we get on really well or not at all, likes the bikes	Happy go lucky, gets on with it, lovely kid, loving, practical.	Likes music, similar to me, I get on well with [him]	Not all of it you can explain properly, spend a week in the house and see what it's like.
	Richard	In control.	Pretty useless now. I can't really do much, [Susan] does everything.	He thinks I'm a vegetable or spastic.	On the xBox all the time.	I don't know what he'd say.	Life's rubbish, I wish I was the way I was.
	James	-	-	-	-	-	Didn't show emotion, just stayed on the Xbox
	Harry	-	-	-	-	-	Spent more time needing Mummy.
	Mark	Can sympathise with me.	Protector, there to look after us all.	-	-	-	Hardest for him, he was used to Dad doing things with him.
	ABI	Don't know.	Trying to take a hold of him, trying to keep [Richard] as backwards as it can.	Don't know.	Don't know.	Don't know.	I don't think it'd like itself, an illness, almost like a cancer, not a very nice thing.

Figure 16. Susan's PEG

Finally Richard's PEG data can be seen in Figure 17. Similarly to Susan, there were occasions that the research interview went off on tangents. This may have related to executive dysfunction and difficulty holding the question in mind. When discussing his experience of the ABI, Richard was able to elaborate his construct system regarding the acute event and whilst

considering changes to his abilities. He spoke at length about his interest in motorbikes, recalling stories from the past. This may have been indicative of Kellian hostility, wherein he was seeking evidence to support construal of himself as a motorbike enthusiast, despite not currently being able to ride them. At times Richard used tight construal, for example, he used the same constructs to describe each of his sons. He also demonstrated pre-emptive construal, particularly when considering familial roles and gender roles, for example, referring to Susan as being “a bit of a man” (line 89).

		Elements →					
		Me	Susan	James (J)	Harry	Mark (M)	ABI
↑ Perceivers	Me	Hard to get along with because I'm shy, nervous because of my dyslexia.	Heart of gold, bit of a dinosaur, likes to be a bit of a man, lovely girl.	xBox. Good old boys.	Forgetful like me, likes motorbikes.	Likes smoking, motorbikes, trying to get a job.	It ain't life. I've met some real nice people through it.
	Susan	A pain in the arse, turned into a kid, someone good.	Too fat, could be quite critical.	-	-	-	It's hurt [Susan] a lot but she'd be overcome it [sic]. She's managing but it's been tough.
	J	I'm still his Dad.	-	-	-	-	Hates it.
	Harry	-	-	-	-	-	Don't think he really understands.
	M	Used to call me "spastic".	-	-	-	-	Winds him up.
	ABI	Brilliant, perfect, because it's already destroyed me.	Wouldn't like her.	In the way, annoying			

Figure 17. Richard's PEG

3.1.3.2.2 *Individuality and commonality.* The Jones' demonstrated commonality in their construal of the ABI, each other, and their shared interests. This was evidenced as similar topics came up across research

interviews. Harry and James generally described similarities and differences between family members in terms of physical attributes, whereas Mark, Richard and Susan spoke about psychological constructs, such as temperament.

Perceived similarity was generally reciprocated. For example, both Susan and Mark perceived themselves as similar with regard to their temperament, whilst both Susan and Harry saw themselves as similar with regard to their interests. There was even commonality in perceived differences, whereby both Susan and Richard described themselves as being the most different individuals within the family.

Consistent with suggestions that commonality is central to the development and maintenance of relationships (e.g. Duck, 1975 as cited in Dallos, 1991), commonality appeared important for the Joneses. Mark described Harry as “like a twin brother but a smaller version” (line 341) and Mark’s construal of Richard and James was, “they’re almost like the same person” (line 357). Harry spoke about the importance of being similar to other family members, stating that being similar means, “you just don’t feel like really lonely” (line 244).

Interestingly, whilst James perceived himself as similar to others, and other people perceived James as similar to different family members, nobody explicitly described themselves as similar to James. In fact, both Mark and Harry described themselves as most different to him. Interestingly, Mark construed his close relationship with Harry as being a consequence of their shared interest in motocross, yet this is a hobby that James also pursues.

The Jones’ descriptions of family life were somewhat incongruent with outcomes on the FAD-GF, which were indicative of family dysfunction. Concordant with James’ individuality, he was the only family member whose score fell below the clinical cut-off, suggesting that he perceived the family to

be functioning well. Furthermore, given Mark's description that "he's always there to just keep you happy" (line 166-167), and James' own admission that he "don't [sic] wanna hurt anyone" (line 11), he may be also have felt uncomfortable discussing familial difficulties. The difference between Susan's and James' ratings was indicative of a family disagreement. Where Susan was described as being the most stressed member of the family, and James was described as "happy-go-lucky" (Susan, line 383), the differences in their emotional states may have influenced their construal of events.

3.1.3.2.3 Sociality. As discussed, Harry and James had more difficulty with sociality, as would be expected given their ages. Harry's sociality was poor, whereas James' was variable. For example, James perceived his mother to be fond of cleaning, stating, "I hate cleaning up. It seems like she loves it or something 'cause she always does it" (lines 149-150). This may suggest that he has difficulties identifying other people's internal states when they are incongruent with their behaviour.

Mark exhibited good sociality, accurately construing his parents' perceptions of each other and the ABI. Mark appeared very sensitive to the needs of other family members, and for example, when discussing his mother's worries stated that it "makes me think what she is thinking about, like how she's coping with it" (lines 593-594).

Susan's sociality was relatively poor and she only appeared able to construe the construal processes of others in the context of more superficial constructs. She explained that "In certain circumstances, I could sit there and say "oh yeah [Richard] would say this in this situation" but it's not something we've spoken about" (lines 753-755). This response was similar to that of James and Harry, who described difficulty imagining what other people would think when an explicit conversation about the topic had not occurred.

Finally, Richard appeared able to consider how other people in the family may construe family members and the ABI, although his predictions were somewhat limited to during the acute phase of the ABI, and he didn't articulate any changes in other people's perceptions over time. This may have reflected his cognitive difficulties following the ABI and lack of insight, or fear of getting the wrong answer in the context of the research interview.

Despite variability in sociality, parent- and self-report versions of the SDQ generally yielded similar scores, suggesting that Susan and Richard were able to construe the psychological processes of their children with reasonable accuracy. There was a notable difference between Mark's score on the 'peer relations' subscale, with his parents perceiving Mark to have significant difficulties within this domain. Given the observation of tight construal of Mark, it may be that they lack flexibility to consider varying predictions of Mark in different contexts. By his own admission Mark reported that he can have mood swings and prefer to take time away from the family home; his parents may therefore believe that he behaves similarly amongst friends.

The primary difference on James' SDQ scores was his perception that he has difficulties with behaviour, which was not corroborated by his parents. During the interview, James expressed that "I do get quite angry, I just go upstairs into my bedroom and play with my phone or something" (lines 192-193). He described this as being different to other family members who "get really angry and start like stompin' and shouting" (line 197-198) and explained that "I prefer I can take myself away because if I stomp and shout it'll just get me in more trouble" (lines 202-203). It may be more difficult for family members to construe James' anger, since it manifests internally and he responds differently to them. Their low scores were also concordant with Susan's construal of James as "happy-go-lucky" (line 383).

Whilst Harry did not complete the SDQ due to his age, outcomes from the parent-report version can be compared to qualitative interview data. In

contrast to the high score on the 'emotional' subscale, Harry reported that he does not often get upset. Richard and Susan also rated him high on hyperactivity; whilst this was not reported by Harry per se, he explained that "most the time I just get bored" (lines 9-10) and was observed to be easily distracted during the research interview. Finally, Harry was perceived by his parents to have difficulties with peer relations, however, this was neither corroborated nor contradicted during Harry's interview.

3.1.3.3 Summary. The Joneses' patterns of construal appeared concordant with their questionnaire data. Interestingly, the family member perceived as most different, also had the most different perception of the family system. This suggests that for the Joneses, perceptions of difference may be accurately reflect differences in their personal construct systems.

3.1.4 Overall summary. Families generally construed the ABI similarly, identifying it as something unwanted, particularly given the subsequent changes within their family systems. Additionally, there was generally shared commonality of construal of family functioning, regardless of whether this was perceived as healthy or unhealthy.

Of note, parents affected by ABI appeared to find the grids the most challenging. As described in Chapter 2, the PEGs increased in complexity over the course of the interview by which time participants may also have become fatigued. Processes such as sociality and externalisation require higher order executive functioning skills, including cognitive flexibility and insight. Seemingly tight construal should therefore be interpreted with caution; unvarying predictions may also be a consequence of difficulty managing the cognitive demands of the questions. Furthermore, difficulties with emotional regulation and ability to empathise may impact an individuals construal of others and ability to consider different perspectives.

Parents exhibited sociality with regard to their children’s construal processes, and were likely to rate aspects of the SDQ similarly. An exception was the construal of contextual differences, perhaps indicating tight construal of their children. Notably, the majority of young people perceived themselves to be, and were perceived by others, as experiencing significant difficulties. Table 20 illustrates the mean parent-report and self-report SDQ outcomes from participating families, in relation to those of the general population (obtained from Goodman et al., 2001).

Table 20. Comparison of parental and young person (YP) means with normative data.

Subscale	Parent	Parent Norms*	YP	YP Norms*
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<i>Emotional</i>	4.0 (2.2)	1.9 (2.0)	3.0 (2.0)	2.8 (2.1)
<i>Behavioural</i>	2.0 (2.0)	1.6 (1.7)	4.5 (1.3)	2.2 (1.7)
<i>Hyperactivity</i>	4.8 (0.5)	3.5 (2.6)	6.3 (2.1)	3.8 (2.2)
<i>Peer relations</i>	3.0 (1.9)	1.5 (1.7)	0.5 (0.6)	1.5 (1.4)
<i>Prosocial Behaviour</i>	8.4 (1.8)	8.6 (1.6)	7.3 (2.5)	8.0 (1.7)
<i>Impact</i>	0.0 (0.0)	0.4 (1.1)	0.8 (1.0)	0.2 (0.8)
<i>Overall</i>	13.8 (5.8)	8.4 (5.8)	14.3 (4.1)	10.3 (5.2)

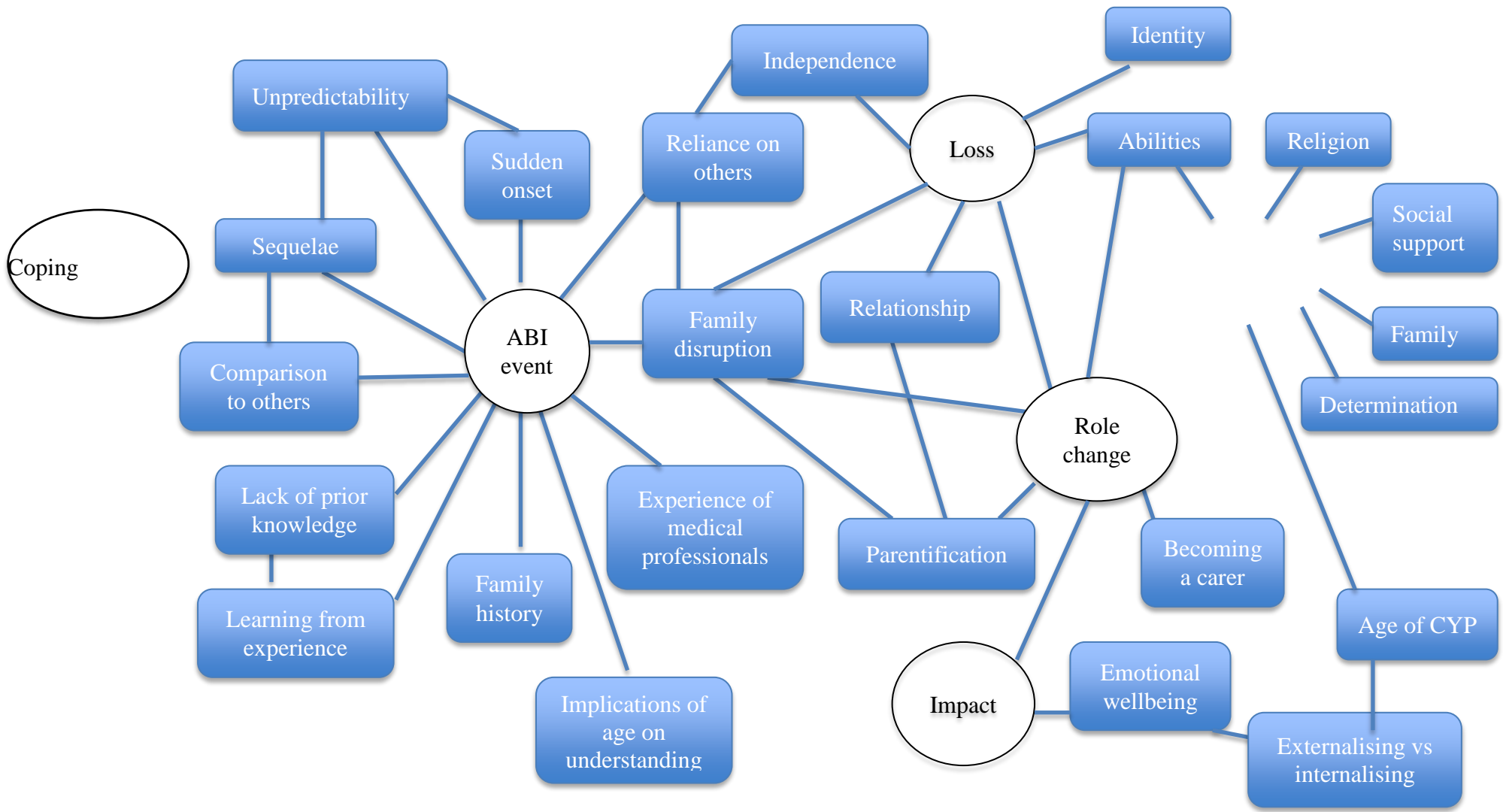
Mean scores were higher on the emotional, behavioural, and hyperactivity subscales, and lower on the prosocial behavior subscale, for both parents and young people in the current sample in comparison to those obtained from the normative sample. In contrast, young people’s rating of peer relationship difficulties was lower in the current sample (m = 0.5, SD = 0.6) than the normative sample (m = 1.5, SD = 1.4), however, parent ratings on this

subscale exceeded those of parents in the normative sample. This data suggests that young people in these families affected by ABI may be at more risk of experiencing psychosocial difficulties than their non-affected counterparts according to available norms.

3.2 Thematic Analysis (TA)

The TA was conducted in order to identify similarities and differences in families' experiences of ABI. The thematic map in Figure 19 summarises the initial clusters of codes that were generated from the data. Lines were used to illustrate relationships between codes, and clusters of similar codes contributed to the acquisition of themes. Initial groupings were identified on the basis of different aspects of the experience of ABI that were prevalent within the data: the ABI event, impact, role change, loss and coping.

Figure 19. Thematic Map



These groupings were further explored to identify the most significant aspects that contributed to understanding of the data. Following analysis of grouping and similarities and differences between codes, themes were defined and named. Table 21 summarises the superordinate and subordinate themes that were identified. Each theme will subsequently be discussed in relation to PCP processes and the implications for young people’s and families’ adjustment.

Table 21. *Summary of Themes*

Superordinate Themes	Subordinate Themes
“it’s nothing you could ever prepare anyone for”	“In one night, everything changed”
	“I haven’t got a clue”
	“Oh my gosh, I am dying”
“I need to do things I’ve never done before”	“I can’t do anything”
	“It’s almost like having a child”
“I’ve been more stressed”	“I didn’t tell anyone”
	“They all suffer differently”
“that person wasn’t there anymore”	“It just feels like I’ve lost a bit of my Dad”
	“I would hate to see you gone”
“fight if there is a chance to fight”	“I will show it to you”
	“I had good friends”

3.2.1 “It’s nothing you could ever prepare anyone for”. Families spoke about their lack of preparedness for the ABI, regarding onset, epidemiology, and future risk. When events fall outside of the range of convenience for an individual, their previous experiences are not sufficient to enable them to anticipate the events with which they are faced. This may result in Kellian anxiety, which appeared present for all participating families. For example, “it’s nothing you could ever prepare anyone for” (Susan, lines 962-963), “in one night, everything changed” (Carina, line 623), and “I didn’t know it was gonna come to me” (Joyce, lines 681-683).

3.2.1.1 “In one night everything changed”. Families spoke about the lack of warning, and the stark contrast between the days preceding the ABI, and the events that followed. For example, “the night before they were playing boxing and laughing and everything, and the next morning [Leo] was in hospital” (Carina, lines 613-615), and “three years ago I had a stroke. Monday and Tuesday I was fine, I was, I was coming out, and suddenly I collapsed again” (Leo, lines 100-102). Consequently, Kellian anxiety may have been coupled with Kellian threat, as individuals and families were confronted with an awareness that their existing construct systems could undergo major changes.

3.2.1.2 “I haven’t got a clue”. Participants also described a lack of knowledge regarding the epidemiology of ABI, for example, “when my Dad had the stroke and heart attack, I didn’t really know about heart attack and strokes” (Oliver, lines 320-321), “I don’t really know until they explain it to me, that part of my brain is gone, is dead” (Joyce, lines 178-180), “so the brain injury, I haven’t got a clue. I only find out now, I haven’t got a clue before” (Joyce, lines 186-188) and:

I knew it was like a life risk but I didn’t know how it can be caused, I didn’t know what the consequences could be, I didn’t know like you have to have all these tablets to like keep- but I didn’t know all- I knew it was like life threatening but I didn’t know what that meant (Oliver, lines 613-615).

It was observed that following the ABI, some parents attempted to protect their children. For example, “for me it was protection, to not tell everything that was going on” (Carina, lines 96-97). Paradoxically, this may have perpetuated young people’s lack of understanding and consequent Kellian anxiety. Figure 18 uses a ‘bow-tie’ diagram (Procter, 1987) to illustrate these interdependencies between construal and action.

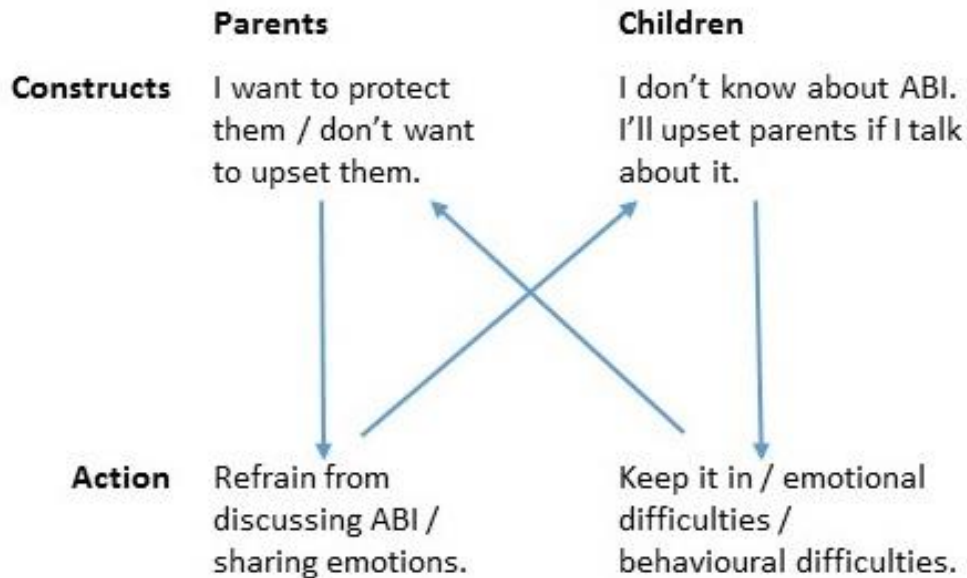


Figure 18. Perpetuation of anxiety following ABI.

Kellian Anxiety also appeared present with regard to participants' construal of the rehabilitation journey. For example, "my husband, he thought within six months I'd, you know, I'll be okay" (Joyce, lines 246-247). When predictions are disconfirmed, constructs can become invalidated. Consequently, individuals may be required to alter their construal and failure to do so may result in Kellian hostility.

Upon discharge from inpatient rehabilitation services, all injured parents received support from the charitable sector, through organisations that provide opportunities to meet other individuals with experience of ABI. Whilst this may help to alleviate anxiety through enabling individuals to share their experiences thus supporting the elaboration and revision of personal construct systems, it was also observed that attendance could maintain anxiety. For example:

I didn't realise the stroke, there's so many things, so many types, and you can see it's like nothing wrong with her, she can move her hand,

she can move, she can walk properly, but she attends the brain- er Headway (Joyce, lines 226-230).

Joyce's experience of comparing herself to others highlights the importance of not assuming that anxiety would be reduced once an individual has access to support, particularly given the differential impact of ABI and breadth of sequelae. Joyce's comments also highlight the concept of invisible disability; where ABI sequelae may not always be obvious, it may be more difficult for other people to construe the impact of ABI and predict the course of rehabilitation.

3.2.1.3 "oh my gosh, I am dying". The unfamiliar nature of ABI may have invalidated previously held constructs regarding health and longevity. There was commonality for some participants in their misconstrual of physical sensations as signs of ill health. For example, "sometimes I care about my health but then not as much as I care about more other people's health" (Oliver, lines 404-406) and:

I've been more like stressed, like not stressed like scared of like, say if I get like a mole or something, I'd be scared like "oh no, I'm getting, say like cancer or something like that" and I just worry about it for like three or four weeks and then it's like an ongoing cycle, my heart races, I feel ill (Mark, lines 417-422).

Similarly:

I used to have like panic attacks but it was almost like having a continual panic attack all the time. Erm the only time I ever do now, 'cause obviously it's health anxiety erm was if I get- everyone gets a pain and goes "oh I'm a little bit worried" but at the time it was like "oh my gosh, I am dying" (Susan, lines 155-161).

Following a process of reconstrual, it seems likely that participants may have loosened their constructs regarding health, subsequently interpreting a greater number of occurrences as signs of ill-health. Lack of knowledge about the epidemiology of ABI may also have resulted in family members' overestimating their risk of ABI or other health problems.

3.2.2 "I need to do things I've never done before". Within all families, individuals were required to adapt their usual roles and responsibilities following the ABI. Kelly (1955) described guilt as the experience of behaving in a manner that is incongruent with one's sense of self. Kelly discussed guilt in the contexts of individuals' roles; these can be practical roles, or more abstract phenomena such as preferred personal characteristics.

3.2.2.1 "I can't do anything". Injured parents spoke at length about the differences in their lives following the ABI, with comments including, "it ain't life" (Richard, line 327), and "I have to do more, start like a baby, so I have to train myself, my left side to do things because of my part of my brain it can't do it anymore" (Joyce, lines 183-185). All three injured parents had been in employment, maintained social relationships, and pursued hobbies prior to their ABI. Families spoke about injured parents' abilities to complete these activities being compromised. For example, "always used to do something and she never liked to be lazy. And like with our shop, *she* worked there but now she can't and she's like basically on the sofa all the time" (Katie describing Joyce, lines 537-540). In this instance, it appears as though Joyce became dislodged from her role as someone who likes to 'do something', and was thrust into a position where her reduced functioning is akin to being 'lazy'. This experience was corroborated by Joyce, who explained that, "it changed everything because I get frustrated, I can't do anything. I have to ask my kids to do it for me (lines 613-615). This experience was similar for the other two families, where comments included, "he can't work and he doesn't really have his own money" (Susan, lines 267-268), "he can't take care of the family like

before” (Carina, line 406), and “now all he can really do is just walk around, talk to his mates” (Mark, lines 563-564).

It was observed that injured parents were perhaps able to lessen their guilt by focusing on areas in which they were still consistent with their previous roles, or in which improvements were occurring, for example, “at least I still walk” (Joyce, 630-631) and “every day is better” (Leo, line 45).

3.2.2.2 “it’s almost like having a child”. Uninjured family members were required to take up additional roles and responsibilities to support their injured parent. Participants explained that “it’s almost like having erm a child. They’ve had the brain injury and you’ve got to try and re-teach them to the best that you can” (Susan, lines 483-485), “he need help for everything he do” (Carina, line 402). Uninjured parents described taking on additional responsibilities. For example, “I became man and woman now because I need to do things I’ve never done before, I’ve never take finances and everything else” (Carina, lines 74-76). In addition to completing responsibilities usually upheld by injured parents, additional caring responsibilities were necessary. For example, “she’s like the carer now for him, so like if he goes to shower she’s always got to clean him, change him” (Oliver describing Carina, lines 1015-1021) and “now it’s like looking after four children now instead of like three” (Mark describing Susan, lines 189-190). Whilst the uninjured parent in the Smith household (Richard) did not participate in the research, his role change was still acknowledged, notably through his absence and responsibilities managing the family business, “he’s never home, not because he’s never here, because he’s looking after the shop” (lines 552-553).

In addition to Kellian guilt, uninjured parents may also have been experiencing further Kellian anxiety as they faced tasks with which they were unfamiliar. Kellian guilt and Kellian anxiety are more likely to occur within families that use tight construal of individual roles. In these instances, fulfilling other roles

may have been more difficult than if a family construe individual roles in a more flexible manner.

Young people were also required to adapt their usual roles in order to provide support. Whilst physical abilities and sensory perception were differentially affected in injured parents, young people in all families spoke about the challenges that they faced within these domains. Notably, there were difficulties adjusting to these sequelae as injured parents had become dependent upon others as a result. For example, “when he goes out he’s gotta be with someone. He *can* go on his own but sometimes obviously it’s easier to go with someone just in case he doesn’t [sic] fall over” (Oliver, lines 913-920) and “you put your arm out, she can like use you as a walking stick, yeah and like [Thomas] helps hold her hand, her bad hand, so it doesn’t like curl up” (Katie, lines 612-614).

Although young people described taking up additional responsibilities, none of the participating young people described fulfilling roles of young carers. Regardless, newfound concerns about their parents’ vulnerabilities suggested an additional role shift analogous with parentification whereby young people demonstrated parenting traits towards their parents. For example, worries included, “like if anything bad’s gonna happen or like if he’s gonna get hit or robbed because he’s, erm hasn’t got that good eyesight” (James, lines 270-271), “you have to be patient with them and you can’t like, stress them out a lot (Katie, lines 253-254), and “he felt unprotected because, you know [Leo] was in hospital, I was there with [Leo], you know he felt, I think at the beginning it was, he felt alone, he felt ‘I need to grow up’”(Carina describing Oliver, lines 170-173).

3.2.3 “I’ve been more stressed”. The impact of the ABI on emotional wellbeing was apparent for almost all participating family members, with a differential impact being observed between young people, uninjured parents, and injured parents.

3.2.3.1 “I didn’t tell anyone”. For uninjured family members, there was commonality in the way that emotions were managed, namely through keeping them hidden from others. For example, “I didn’t want to upset them and I thought if I was crying then they would worry” (Susan, lines 410-411), “what I normally do is just go upstairs” (Harry, lines 439-440), and:

I’m kind of a guy that doesn’t show his emotions to people, I’m always keeping it in, like when my Dad had the heart attack and stuff, I didn’t tell none of my friends. I didn’t tell anyone like kind of how I felt, I kinda like kept it in and obviously be strong for my other, like my Mum, my brothers (Oliver, lines 689-695).

And:

I kept a lot of stuff in like at the time and erm I didn’t tell anyone or anything and then like I ended up in hospital, like my face like half of it like blew up like I’d got a massive swollen face, and then like I couldn’t move my right side either and then like they knew it wasn’t [stroke] so they thought I was allergic to something and so I had my allergy tests and they said it wasn’t anything and it, they said well it’s stress” (Katie, lines 276-283).

By not talking about emotions or other experiences that are more difficult to construe, family members may be attempting to reduce other people’s anxiety through constricting their perceptual fields. Furthermore, young people may have learned to internalise their emotions through construing their parents’ responses to difficult events. These processes are likely influenced by dominant societal discourses and the stigma that continues to exist within the domain of mental health.

3.2.3.2 “They all suffer differently”. Despite attempts to keep emotions hidden, family members were still able to exhibit sociality and

construe some of each other's psychological processes. Uninjured parents in particular were able to construe the differential responses of their children. For example, Carina stated "they all suffer differently" (lines 148-149) and later explained that:

[Nico] was more cry, express himself, talk about what's happened.
[Tristan] was the one, he never talked, he never involved in anybody, he was close, closing down himself. [Oliver], he become, you know, a little er "oh I'm big now, I can do things" (Carina, lines 837-843).

Similarly, Susan expressed, "I think it was hardest for [Mark] in some respects because he was er used to Dad doing things with him" (lines 343-345), "because [Harry] was a lot younger erm he spent a lot more time with me and sort of needing Mummy" (lines 398-399), and:

It's not like [James] ever cried about it or, and he'd just sit and play his computer and that's about it. Get on with whatever he was doing, erm so I was a bit concerned about that really cause it was kind of like well he's not showing any signs of anything (lines 387-391).

An exception was Joyce who struggled to construe the emotional wellbeing of Katie, stating, "she's doing okay, I think. I dunno. Or she's struggling, I haven't got a clue" (lines 455-456).

Mark was able to construe Susan's emotional experiences, stating that, "she's been really stressed since Dad's injury and I think it's affected her more than any of us" (Mark describing Susan, lines 185-187), and "you can see that stress has like actually hit her because in a picture of her about five, six years ago she's all thin, she hasn't got any spots on her face, she's- she's good but now..." (Mark describing Susan, lines 237-239). Younger participants were less able to construe the psychological impact of the ABI on others, but this appeared concordant with their developmental stage.

3.2.4 “that person isn’t there anymore”. Individuals and families spoke of experiences akin to loss. Neimeyer (1997) described the processes within which individual construct systems are challenged following loss, often resulting in a process of reconstrual. As such, loss can disrupt the ways in which we construe ourselves and others.

3.2.4.1 “It just feels like I’ve lost a bit of my Dad”. Participating families described the loss of their relationships with the injured parent. For example, “he’s still a Dad like he cares for me and all that, but most of him now, he’s like a friend now.” (Mark, lines 278-280), “it feels like you’ve lost something and it just feels like I’ve lost a bit of my Dad” (Mark, lines 289-291), and “he felt he lost his Dad, you know, he felt unprotected” (Carina describing Oliver, lines 183-184).

Younger participants noticed the loss of injured parents in terms of the types of activities that they would do together, which is concordant with their ages and greater use of superficial constructs. For example, “not very good because [Dad] wasn’t as fun since then and he didn’t get much to do and lots of stuff we couldn’t do” (Harry, lines 256-258), and:

We can’t go on holidays as much and we can’t go- well my Dad used to go with me on a jetski and go to this place to get us pancakes and that, which we can’t do anymore (Harry, lines 275-278) .

Similarly, James expressed that:

My Dad used to be able to like ride the jetskis and have me on the jetskis and boats and that but now he can’t because of his brain injury and he can’t erm go stuff that will wobble him around (lines 427-430). Uninjured parents responded similarly. For example, “he’s not the person he was, erm he’ll never be the person he was, so in that respect it has completely changed life erm and we’ve just gotta get used to it really” (Susan, lines 477-

479), “this is [Leo] but it’s not [Leo] was before, he’s the same [Leo], but with different needs and different things” (Carina, lines 845-853), and “he’s there for the kids but he can’t do the things he can before for them” (Carina, lines 851-852). This was corroborated by Oliver who stated:

Before he had the heart attack he used to always be talkative, like always talk like he’d never shut up [laughs] well like he never like—he’d always start talking and loved it and obviously take me to places in the car but obviously now he can’t really drive and when he talks he gets frustrated because he can’t say what he wants to say and obviously he’s talking to his son so like it’s frustrating for him but yeah its definitely been difficult (lines 397-405).

Kelly (1955) described two contrasting types of dependency: dispersed and undispersed. He explained that an individual with dispersed dependency may turn to different significant others for different types of support, whereas individuals with undispersed dependency may rely on a specific person for every type of support. Loss appeared more significant for individuals who presented with undispersed dependency. For example:

Dad had been the protector as it were, y’know, he was there to look after us all, you know, and even I missed that cause he’s- he’d always be that person if something was going on, I’d talk to him, and y’know talk through it properly more and if I was upset and, he’d try and y’know give me cuddles and that, and that person wasn’t there anymore (Susan, lines 375-381).

Nevertheless, family members also spoke about characteristics of the injured parent that had remained the same. For example, “his like kindness and all that’s been the same (James, line 380) and when asked if there was anything he would keep the same about the brain injury, James expressed, “how much he cares for, cares for us” (line 460). Other comments included, “it’s still son,

er Dad and son relationship” (Oliver, line 417), “we’ve bonded like altogether all the same, we always react the same, it’s like nothing’s changed between, there’s nothing really changed between us” (Oliver, lines 926-929).

The experience of loss had been less noticeable for the Smiths. Katie commented that “the stroke hasn’t changed her, it’s just changed like her movements and stuff (lines 516-517). This may have reflected a difference in their premorbid relationship or the different sequelae experienced.

Furthermore, if the Smiths have dispersed dependencies, the impact of the ABI may be less pronounced.

3.2.4.2 “I would hate to see you gone”. Participants appeared to have a heightened anxiety about further loss. For example, “he doesn’t want to go away from us really long like for a whole day or something because he gets really upset” (James describing Richard, lines 243-245) and “it makes me happy and my Dad happy and my brothers, cause well, without, without my Mum, we’re kinda stuck really” (Mark discussing Susan’s smoking cessation, lines 387-389).

Mark also spoke about Susan’s fear of losing others, reporting that she states:

‘Cause I always lost- I almost lost your Dad and I’ve lost half of your Dad really cause he’s not the same as before and I don’t wanna lose like you and [Harry] and [James] cause it would just make me worse and I would hate to see you gone (lines 586-591).

Akin to aforementioned Kellian anxiety, these sentiments appear to reflect a recognition of the fragility of life.

3.2.5 “fight if there is a chance to fight”. It was encouraging to observe the strength and resilience of injured participants and their families. Whilst individual families had their own coping mechanisms and protective

factors, there were also commonalities between family systems, namely by way of Kellian hostility and Kellian aggression, and social support.

3.2.5.1 “I will show it to you”. Participants discussed their experiences of the injured parent being informed that they may not regain their premorbid functioning. It was striking to observe that participants spoke of their determination to prove professionals wrong. For example, Joyce described being “determined to walk again” (line 314) after initially having been told:

The consultant there, he said to me “I can’t say that you will be able to walk again, I don’t wanna say that because of your, you know, you had a stroke” and I said “look, you, you can’t say that because yeah I know I had a stroke but I will show it to you, I can walk again” (lines 294-298).

Somewhat similarly, Carina explained that, “[Leo’s] situation was very bad, three times they said they can do nothing” (lines 700-703), and:

The specialist in hospital said “oh we can do nothing for [Leo], he can’t understand nothing, he can’t do nothing for himself, he can’t get up from the bed and everything” and they said “you need to put him in the care home”. I said “Never” [laughs]. I married him” (lines 708-712).

These experiences appear indicative of Kellian hostility, whereby injured parents and their families continued to extort validation evidence for constructs described as failures by medical professionals. Additionally, participants exhibited Kellian aggression as they actively experimented with different ways of doing things. For example, Leo explained that:

The thing is, this way or that way, which way are you gonna go? You’re gonna go that way, you know you like that [points to arm], you can’t do it anymore or you do that way or that way (lines 515-519).

Joyce also spoke about doing things differently and described using mobility aids to allow her to retain as much of her independence as possible, for example, “when I go shopping, I can’t walk so far, I have to use wheelchair” (lines 309-310). In these instances, both hostility and aggression appear to have been functional for injured parents as they have offered a determination to continue working towards their rehabilitation goals.

However, Kellian hostility and Kellian aggression also have the potential to be detrimental. For example, Richard spoke about his desire to return to driving. Whilst goal-setting may facilitate his commitment to rehabilitation, Susan expressed that she was not sure it would be possible given the severity of his difficulties. In this sense, Richard may be confronted with repeated invalidations as he endeavours to achieve this goal.

3.2.5.2 “I had good friends”. The practical and emotional support offered by extended family members and friends appeared central for the continued functioning of all participating families. Carina explained that, “it was very difficult at the beginning but I had good friends (Carina, lines 115-116) and “my brother, my sister came straight away from [Europe]” (Carina lines 120-121). Similarly, Susan described how she would have struggled without the support of her mother-in-law in running the family business, explaining that:

I guess she’s taken over most of the running of it because- I was very lucky in that respect that while [Richard] was in hospital and things, I was able to spend so much time with him because she was keeping that going and erm that even money and things like that, you know, without that we would have been very, very stuck. (lines 66-72).

Even within family systems, support from one another appeared of paramount importance. It was interesting to observe that the threat of family breakdown appeared a possibility. For example, Carina explained that “I heard, and I

knew, loads of people left, the marriage broke down” (lines 755-756), whilst Mark also acknowledged that, “at any point my Mum could have just said ‘no’ but- ‘no, I can’t take anymore’ but no she’s stuck with her- stuck with my Dad through this” (lines 463-465). However, for these families, it appeared as though their determination prevented this from becoming a reality. Carina expressed that, “love the person when he had the stroke, to be there for them because love can cure people, can, can give hope” (lines 865-867), whilst Mark acknowledged the role of familial support stating that:

We’re all supportive and I think if we keep being supportive, it will help and it’ll just keep on helping even more but if we keep it to ourselves, it’s just gonna break us more, we’re gonna become more lonely and won’t be able to talk about it (lines 707-711).

These ideas reflect the notion of dispersed dependency and the utility in being able to rely on significant others for different types of support.

3.2.6 Summary. These themes offer insight into the changes in individuals’ and families’ construal processes following parental ABI. Chapter 4 explores the key findings in relation to existing literature and explores their clinical implications.

Chapter 4: Discussion

The findings of this study offer a unique perspective into the processes underpinning individual and familial adjustment following parental ABI. This chapter presents a summary of the main findings, and discusses their clinical relevance. Thereafter, methodological considerations of the current research are explored, before potential areas for future research are considered. The chapter concludes with the author's personal reflections on the research process.

4.1 Summary of Findings

The key findings will now be summarised and discussed in relation to existing literature. First, the construal processes of individuals and families affected by parental ABI will be explored. Subsequently, themes pertaining to common experiences of parental ABI will be discussed.

4.1.1 Processes of construal and implications for adjustment. The principal aim of this study was to explore the construal processes of families affected by parental ABI, and to consider the implications for adjustment in young people and their families.

4.1.1.1 Individuals. The results identified that generally, injured parents were more likely than other family members to demonstrate tighter construal. Moreover, it was evidenced that injured parents demonstrated Kellian hostility through continuing to use constructs despite invalidation, and to extort evidence for invalidated constructs. In contrast, young people and uninjured parents tended to apply constructs more flexibly, and revise their construct systems in light of new information. Whilst the direct experience of ABI in injured parents may implicate the adjustment process, these differences could also be explained by ABI sequelae. For example, executive functioning difficulties can negatively affect domains such as cognitive flexibility, insight, problem-solving and concentration. Difficulties in these

areas may result in it being more difficult to revise construct systems on the basis of experience. Whilst cognitive functioning was not directly tested during this study, it may be a helpful adjunct to future research, in order to better understand the differences between family members' construal, and the implications of the ABI on injured parents' ability to anticipate events.

Whilst it was anticipated that patterns of construal would be associated with adjustment in young people, this was not evidenced in the current sample. Given the varied construal processes, it is difficult to infer a relationship between construal and adjustment. However, this appears to reflect the complexity of processes involved with adjustment, which are likely also influenced by systemic variables, some which are discussed in subsequent sections.

Nevertheless, the majority of young people (75%) yielded clinically significant scores on the SDQ, which supports existing research that has identified young people affected by parental ABI to be at risk of developing psychosocial difficulties (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen et al., 2011; Niemelä et al., 2013). Generally, parents were able to accurately construe their children's emotional wellbeing. Notable exceptions related to contextual differences, or when young people employed specific strategies to prevent their parents from accurately construing their experiences. This relationship appeared to account for the limitations of parents' sociality, and differences between the self-report and parent-report versions of the SDQ which showed parents tending to underestimate young people's difficulties. This suggests that where possible, having multiple perspectives improves the validity of findings. Parents in all participating families completed the parent-report SDQ together. Future research exploring similarities and differences between parents' construal of their children may offer further insight into familial processes. Furthermore, a teacher-report version of the SDQ is also available and may offer a richer understanding of young people's psychosocial wellbeing with regard to contextual differences.

4.1.1.2 Families. Commonality was observed within all families, even between family members who perceived themselves as different to one another. Notably, there was significant commonality between how family members construed the ABI. These findings support the notion of the FCS, and the suggestion that personal construct systems are influenced by the wider systems within which we exist (Procter, 1996). Two of the three families yielded scores indicative of unhealthy family functioning. Nevertheless, individual's tended to construe their family's functioning similarly, regardless of whether it was categorised as healthy or unhealthy by the FAD-GF. Mutual identification of family dysfunction could be construed as a positive characteristic, suggesting that family members share an acknowledgement of their difficulties. However, families may lack the knowledge or resources to overcome these difficulties in the absence of professional support. Overall, these findings suggests that the perpetuation of unhealthy patterns of family interaction are complex, and support in understanding each family's unique patterns of interaction at different times during their rehabilitation journey may be beneficial in order to support familial adjustment.

Finally, parents in two families disclosed anger. Anger is common following ABI (Headway, 2009). Cummins (2003) described anger as "an emotional experience of invalidation" (p. 84), and considered anger to serve a function of allowing the individual to stay in control. This may be relevant for participating injured parents given that ABI results in numerous changes that the individual does not have control over. It was noted that these disclosures were not corroborated by young people; this may reflect family loyalty and fears around disclosure. In previous research, disclosures of violence did not occur until several months into the study once trust had developed (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007). This may highlight a methodological limitation of using one-off research interviews.

4.1.1.3 Summary. These findings offer insight into the complexities of these family systems following parental ABI. Whilst construal may not be

linked directly to adjustment, the combination of construal, ABI sequelae and interpersonal interactions may affect the adjustment of young people and their families.

4.1.2 Themes. The Thematic Analysis sought to explore similarities and differences in familial experiences of parental ABI. Findings will be summarised within themes, and discussed in relation to existing literature.

4.1.2.1 “It’s nothing you could ever prepare anyone for”. It was striking that although ABI occurred between 18 and 46 months previously in the current sample, the ABI event appeared significantly more present in research interviews than discussions around the subsequent impact (as illustrated by the thematic map in Figure 19 on page 106). The data indicated that the sudden changes brought about by ABI coupled with lack of prior knowledge, may have resulted in Kellian anxiety for individuals and families. These findings complement existing research that suggests that lack of information contributes to distress following ABI (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen & Johansen, 2013; Panting & Merry, 1972; Visser-Meily et al., 2005a). Furthermore, the present study identified that lack of information about the epidemiology of ABI can result in adults and young people having increased concerns about their own health and vulnerability to ABI, which was similar to experiences described by previous researchers (Charles et al., 2007); Kieffer-Kristensen & Johansen, 2013). Difficulty construing ABI due to lack of prior knowledge, and construing loosely, may result in the misinterpretation of physiological changes as signs of ABI. Additionally, individuals may misconstrue their own vulnerabilities to experiencing ABI and perceive themselves to be at greater risk than they actually are. Furthermore, difficulty recalling information given during the acute phase due to distress or cognitive impairment, may affect construal.

Current findings have begun to illustrate the interpersonal processes that can inadvertently perpetuate difficulties within family systems, as illustrated using

the bow-tie diagram (Procter, 1987) that highlights the relative impact of individual construal and subsequent action, on the construal and actions of other people (see Figure 18, page 109), and may subsequently reinforce Kellian anxiety. At a time of significant challenges, it seems unsurprising that family members would endeavour to protect one another. During the acute phase of the ABI, it seems possible that parents may wish to have a clearer idea of prognosis before sharing details with their children. Whilst it may feel counterintuitive, offering information at this stage could be more helpful. These findings mirror existing findings that suggest young people are often protected from learning about their parents' injury, despite preferring to be kept informed (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Kieffer-Kristensen & Johansen, 2013). These findings indicate the importance of supporting families to have a shared construal of events, albeit tailoring information to the age and developmental level of a young person.

4.1.2.2 “I need to do things I’ve never done before”. Role change and the presence of Kellian guilt was demonstrated for the majority of participating family members. Role changes among spouses have been extensively explored (e.g. Hall et al., 1994; Kreutzer et al., 1994 ; Panting & Merry, 1972; Uysal et al., 1998; Viesser-Meily et al., 2005a), and changes to the uninjured parents' role and compromised ability to parent have been found to moderate the relationship between parental ABI and young people's adjustment (Pessar et al., 1993; Kieffer-Kristensen et al., 2013; Sieh et al., 2010; van de Port et al., 2007; Uysal et al., 1998; Viesser-Meily et al., 2005a).

In the current research, the majority of role changes described by injured parents related to impaired social and occupational functioning, whereas compromised parenting ability was rarely discussed. These differences could perhaps be explained by the particular sequelae experienced by parents in the current sample. For example, parents with a higher degree of personality change or executive dysfunction may have more difficulties in this domain. However, given that parents in this sample also demonstrated Kellian hostility,

it would also be important to interpret these differences with caution, as objective reports of role change may differ from the subjective accounts given in interviews. Furthermore, avoidance of disclosing such changes may be a coping strategy implemented by parents with an awareness of any loss of role, whereas for other parents, they may lack insight into the objective changes that have occurred within the family system.

Young people in the current study described taking on extra chores and responsibilities, and pursuing some additional tasks in order to support their injured parents. These experiences reflected those identified in earlier research (e.g. Kieffer-Kristensen & Johansen, 2013; Moreno-Lopez et al., 2013; van de Port et al., 2007). In the current sample, two adolescents had younger siblings, but neither of them described taking on any additional caring responsibilities for them. This may relate to both the particular sequelae experienced by their parents, and the degree of role change for both the injured and uninjured parents.

The thematic map (Figure 19, page 106) identified a relationship between family disruption as a consequence individual and familial role changes, and subsequent feelings of loss that are described in Section 4.1.2.4. This suggests that whilst family reorganisation can be adaptive, it may also be associated with difficult feelings. Loss may be associated with changes in an individuals' own roles, as well as being a consequence of the challenges faced when expectations of other family members' roles are not met. For example, a parent being less able to care for their child.

4.1.2.3 "I've been more stressed". Family members' preference to refrain from talking about difficult experiences mirrors findings from previous studies (Butera-Prinzi & Perlesz, 2004; Kieffer-Kristensen & Johansen, 2005; Moreno-Lopez et al., 2013). In this study, uninjured parents were described as being under significant pressures resulting from caregiving and from assuming different responsibilities. Young people may therefore refrain from sharing

their own experiences as they do not wish to further burden their uninjured parent. This was illustrated in the thematic map (Figure 19, page 106), whereby an association between emotional responses, the age of young people, and coping was illustrated. As highlighted in Chapter 3, young people may be constricting others' perceptual fields in an effort to reduce Kellian anxiety. Furthermore, Moreno-Lopez and colleagues (2013) identified that young people strived to retain normality, which may also have been present for young people in the current sample.

4.1.2.4 “that person wasn’t there anymore”. Participating young people described differences in their parent following the ABI, and expressed preference for the ‘old’ parent, which reflects existing findings (Butera-Prinzi & Perlesz 2004; Charles et al., 2007; Kieffer-Kristensen & Johansen 2013). However, participating families also appeared to have been able to retain a sense of normality within their interpersonal relationships, which was encouraging and contrary to previous findings in which young people have gone as far as to say they dislike their injured parent (Charles et al., 2007). Again, these differential responses may relate to particular ABI sequelae experienced by parents in different studies. Alternatively, this may be related to premorbid family functioning, which has been recognised to influence family functioning post-ABI (e.g. Rivara et al., 1992; Rivara et al., 1996).

Similarly to the processes underpinning Kellian anxiety, it appears as though individual construct systems have undergone a process of revision whereby they have dilated, yet failed to constrict following receipt of new information, resulting in fears of further loss. Fears of further losses have been previously documented (e.g. Kieffer-Kristensen & Johansen, 2013).

4.1.2.4 “fight if there is a chance to fight”. Coping is also cited relatively scarcely in existing research, which appears to be a reflection of the methodologies used, and the relative frequency of quantitative designs utilising specific outcome measures. It was promising to observe how the role

of coping and protective factors was mentioned across research interviews, and featured distinctly when initial codes were clustered.

The data indicated that Kellian hostility and Kellian aggression may support families through the rehabilitation process. This offers a unique perspective into the experiences of injured parents that are often quantified on the basis of negative emotions and experiences. Charles and colleagues (2007) identified one participant who spoke favourably about surpassing the expectations of others, which mirrors the experiences of injured parents within the current sample. Sieh and colleagues (2010) observed that higher levels of depression for the injured parent were associated with increased stress for young people, so Kellian hostility and Kellian aggression could pose a protective factor if injured parents are actively experimenting with different experiences, or exhibiting determination to make progress with their rehabilitation.

Finally, the role of social support was particularly relevant given the age of these young people at the time of their parents' ABI, and the need for childcare. It was noted that none of the young people in this study referred to support networks themselves, although their parents described a reliance on others during the acute phase of the ABI. Butera-Prinzi and Perlesz (2004) noted that all participating young people were cared for by others, which was also pertinent in the current sample. Whilst social support in these instances allowed uninjured parents to attend to injured parents, it may have had significant implications for young people, especially during longer inpatient admissions. Whilst significant differences weren't observed among the three participating families, there may also be differential responses to the impact of social support on the basis of culture. Specifically, it has been identified that Asians benefit more from implicit support, for example, belonging to valued social groups (Taylor, Welch, Kim & Sherman, 2007). Comparatively, Europeans have been found to benefit from explicit support, for example, seeking advice and emotional support (Taylor et al., 2007).

4.2. Clinical Relevance and Implications for Practice

This research is clinically relevant for a range of reasons. The main areas of clinical relevance and key implications for practice will be explored in relation to the adjustment of young people and their families following parental ABI.

4.2.1 Information. The potential relationship between lack of information and Kellian anxiety highlights the importance of information-giving. Information should be tailored to reflect the age and cognitive abilities of different family members. As construal changes with experience, different information could be offered as construct systems are revised, accommodating new experiences and subsequently lessening the anxiety that may be present. Furthermore, it is acknowledged that during the acute phase of ABI it may be difficult for family members to absorb what they are being told. Use of written materials to support understanding would therefore be beneficial. Books such as 'My Parent has Brain Injury' by Jo Johnson (2011) can be used for this purpose. Information should be re-visited during the acute-phase and throughout the rehabilitation process.

4.2.2 Psychological intervention. The findings of this study suggest that there is a utility in offering psychological support to both young people and their families following ABI. Intervention could help address Kellian guilt, Kellian anxiety, loss, and other psychosocial difficulties. Separate recommendations for young people and families will now be discussed.

4.2.2.1 Young people. The majority of young people demonstrated clinically significant difficulties on the SDQ, emphasising the need for psychological support following parental ABI. Many young people described keeping their difficulties hidden from others, so whilst they may benefit from having a space to discuss their experiences, professionals may find it difficult to engage young people. Utilising approaches informed by PCP may therefore be particularly beneficial. Butler and Green (2007) explored the applications of PCP with young people and discussed the utility of self-portraits, drawings and

repertory grids to allow young people to express themselves in a less threatening manner than talking. Moreover, Procter (2007) refers to the use of toys and objects in supporting the engagement of young people, and to enact situations.

Young people noted contextual differences to their behaviour, with some describing differences to their behavioural presentations whilst at school. These differences were more difficult for parents to construe which may suggest that parents are not always best placed to identify psychosocial difficulties in their children. Education providers may be better equipped to support the early identification of difficulties in young people following parental ABI. Consultation to schools when a family is affected by parental ABI could be particularly beneficial. The Targeted Mental Health in Schools (TaMHS) is an initiative informed by government policy intended to support the psychosocial needs of young people through utilising external practitioners to work alongside, and support, school staff in promoting emotional wellbeing in young people. TaMHS provision has been associated with a reduction of behaviour problems among children in primary schools, increased inter-agency working and social care provision across primary and secondary schools, and improved relationships with local CAMHS services (Department for Education [DfE], 2011). Working alongside TaMHS providers to offer consultation or direct intervention may be a crucial way of supporting this group of young people. Given the frequency of young people's contact with teachers and pastoral staff, it seems commonsense to draw upon these resources. Integrating psychology services within schools has been identified as an effective way to support the identification and early intervention of psychosocial difficulties among young people (e.g. McConnellogue, Hickey, Patel & Picciotto, 2015). Additionally, services available through schools may support young people to overcome some of the barriers to accessing CAMHS, for example, accessibility (e.g. Faulconbridge, Law & Laffan, 2015).

4.2.2.2 Families. Two of the three participating families were identified as having unhealthy patterns of functioning according to the FAD-GF, yet interpersonal processes that could be seen to perpetuate familial difficulties were evidenced in all families. Consequently, these findings support the use of a systemic approach to support familial adjustment to parental ABI. In particular, personal construct family therapy (Procter, 2005) may be advantageous. The use of a PCP methodology readily highlighted similarities and differences in family members' construal, and began to identify ways in which family difficulties were perpetuated, without the researcher directly asking about family functioning during the research interviews. As such, this supports the utility of a PCP approach in early intervention, where specific problems may not yet have been identified by the family themselves. Personal construct family therapy can highlight patterns of interpersonal construal and dilemmas. Figure 18 (page 109) illustrated how parental construal may have implicated their actions whilst simultaneously contributing to young people's construal and associated actions. In this instance, parents efforts to protect their children contributed to lack of information and difficulty coping. Sharing these hypotheses in a therapeutic context may support families to understand their interpersonal processes whilst reducing the apportion of blame.

Procter (2002) discussed the use of qualitative grids in family therapy and identified that sharing individual PEGs can open up conversations and facilitate the development of sociality within the family. Using tools like the PEG as an adjunct to talking therapy may promote accessibility, whilst supporting the negation of any power imbalances within the family, or that may exist between families and clinicians. In particular, the PEG is a tool that can be used clinically to promote mutual understanding. Through identifying unique perspectives, the PEG can support families to recognise that individual viewpoints are subjective, and that events can be interpreted differently. Comparing perceived construal with actual construal can promote sociality and understanding of one another's views. Moreover, clinicians can use the PEG to identify interpersonal dilemmas or family alliances that may be

inadvertently perpetuating family difficulties. Finally, responses on the PEG could be used as an outcome tool to monitor change over the course of a therapeutic intervention.

Finally, the disclosures of aggression highlights the importance of healthcare professionals remaining mindful of the potential for violent behaviour following ABI. Supporting families to develop strategies to cope with emotional regulation may be particularly helpful. Emotional regulation requires an executive functioning process that may be impaired following ABI. A non-pathologising approach is needed to develop awareness and coping around this from the system as a whole. Offering resources to all families as standard practice may help to normalise the increased risk of violence following ABI, breaking down some of the barriers to seeking support that may occur if families fear judgment. Cummins (2003) proposed that psychological intervention to improve sociality may support individuals in overcoming anger through enabling them to better understand different points of view.

4.2.3 Social & practical support. During the acute phase, familial and social support was heavily relied upon to support parents in caring for their children. Enquiring about social support will enable clinicians to identify young people and families that may be more at risk. Inter-agency working and liaison with social care is central to ensuring that all young people receive adequate support whilst their parent is in hospital, particularly if there is no-one who can fulfil the parenting role in their absence.

During the rehabilitation phase, families spoke favourably about support received from organisations such as Headway. However, it was noted that less support was available for uninjured parents and young people. Whilst accessing support groups may also assist in the reduction of Kellian anxiety through learning more about experiences of ABI (e.g. Butera-Prinzi & Perlesz, 2004; Charles et al., 2007), a less direct approach may also be useful. Where existing literature suggests that young people like to retain a sense of

normality (Moreno-Lopez et al., 2013), offering increased support for their injured and uninjured parents may free up time to pursue preferred social and leisure activities, and fulfil their roles as young people, thus reducing Kellian guilt. Consultation with young people would offer a more accurate insight into their needs and preferences, and may inform different types of support at different stages of the adjustment process.

4.3 Methodological Considerations

4.3.1 Strengths. This research study offered an exploration of the experiences of a population that are under-represented within existing literature. Furthermore, it contributes to the sparse research conducted within the United Kingdom, and offers a unique insight into the experiences of young people and families who have experienced an ABI within the UK. Given the increasing prevalence of ABI, and increased number of individuals living with the effects of ABI, the research offers a valuable contribution to the understanding of this field.

Following recommendations of previous research, this study endeavoured to explore multiple perspectives on the experience of parental ABI, and privilege the complexity of family systems during the exploration of individual and familial construal. Often, the experiences of families are explored through individuals, or constrained by a reliance on quantitative measures.

Consequently, this research attempted to overcome some of these barriers to identifying familial experiences, through valuing each family member's perspective equally.

Using a PCP methodology allowed the researcher to begin to consider the processes underlying individual and family functioning, in response to the ABI. Whereas previous research has revealed themes and experiences of this population, the methodology used allowed the researcher to go beyond the semantic themes and offer an insight to some of the processes which may

contribute to patterns of interpersonal relating that may negatively impact upon adjustment.

Furthermore, the methods used were accessible, and sensitive to the different ages and abilities of participants; this was a novel way of attempting to reduce the inherent power discrepancy that resides in the relationship between researchers and their participants.

Finally, incorporating the ABI as a perceiver and element allowed it to be externalised from the injured parent, which offered some unique perspectives that were not otherwise raised when discussing the ABI and its effect on the families. For all participating families, the most negative aspects of the ABI were elicited in response to positioning the ABI as both a perceiver and an element, thus enriching the research interviews.

4.3.2 Limitations. This study has a number of limitations. Firstly, the study was restricted by the small sample size that was warranted given the design of the study. Whilst smaller samples offer the opportunity for more in-depth analysis of data in qualitative research, any subsequent findings are consequently more difficult to generalise to the wider population. Replicating this study would be an important step in confirming the findings. Additionally, following up the findings using alternative methodologies that would necessitate a larger sample size may be beneficial. For example, the use of quantitative grids may be advantageous.

Secondly, recruitment was a significant difficulty in conducting this research. Of the potential families that were identified, only 21% participated in the research. It is acknowledged that since the majority of reasons for non-participation included the presence of other life stressors, and geographical constraints following familial separation, the current findings perhaps underestimate the type and severity of difficulties encountered by families affected by parental ABI. For example, all participating families had remained

a family unit in spite of the difficulties faced, whereas at least two families approached had separated following the ABI. Consequently, data from the current sample may be underestimating some of the difficulties faced by families following parental ABI.

In order to address recruitment difficulties, the inclusion and exclusion criteria remained broad, contributing to a heterogeneous sample. On this basis, it is likely that individual and systemic factors contribute to variability within the data. Whilst the data obtained permitted insight into the interpersonal construal of three families affected by ABI, it was more difficult to consider the general implications for adjustment. Additionally, while a relative strength of the research was the elicitation of multiple perspectives from within a family system, it is acknowledged that of the three participating families, only one family participated in full. Particularly for the Smith family, of which only two family members participated, it is difficult to infer an accurate perception of systemic processes. For example, any evidence of family coalitions, disagreements, or patterns of interpersonal construal have potentially been undetected yet present in the wider family system. This raises a difficult dilemma, since making the inclusion criteria stricter, to include complete families only, would have further contributed to recruitment difficulties. Results should therefore be interpreted with caution.

A fourth limitation of the research was the method of data collection itself. Researchers have previously argued against the use of interviews for data collection, suggesting that participants are not being observed in a natural setting, and consequently, data is biased (e.g. Miczo, 2003; Schegloff, 1997; Sandelowski, 2002). This was supported by one participant who stated, "*spend a week in the house and see what it's like*" (Susan, lines 438-439), when asked to describe the ABI. Whilst it is recognised that the process of conducting interviews may have resulted in biases in findings due to factors such as social desirability, they allowed a richness of data that would not otherwise have been generated. Finally, where all participating families

preferred to complete interviews in their family homes, this may also have influenced the data. Situational influences such as an awareness of other family members being present in the family home may have affected the validity of participants' responses, especially around sensitive topics such as familial conflict.

4.4 Possibilities for Future Research

Whilst there are many possible extensions of this research, a few key ideas will be discussed. Firstly, it is essential to replicate this study, in order to improve the generalisability of findings. Replication on a larger scale would help to address many of the aforementioned limitations, for example, heterogeneity of the sample, and presence of confounding variables. Not only would replication allow researchers to discover more about the construal processes of families affected by ABI, but with sufficient data it would be possible to draw more inferences regarding the potential relationship between patterns of construal and adjustment in young people and their families.

Secondly, it would be interesting to further explore the effect of age on both construal and adjustment. Obtaining a more in-depth understanding of differential experiences may consequently inform different clinical recommendations. Furthermore, it would be useful to employ a control group design in order to identify similarities and differences in the experiences described by young people in terms of their emotional wellbeing and patterns of interpersonal interaction following parental ABI, in comparison to the experiences of young people in the general population, or following other sources of familial disruption, such as parental divorce or parental chronic illness. Similarly to the research conducted by Niemelä and colleagues (2013), a cohort study would allow researchers to estimate the number of young people affected by parental ABI within the UK, and identify whether or not young people in the UK affected by parental ABI are more at risk of psychological difficulties than their unaffected peers, at the population level.

Thirdly, families alluded to changes that had occurred over time, noting differences in their experiences at the time of the ABI in comparison to at the time of the research interviews. Whilst this research offers a snapshot into the experiences of families affected by parental ABI, employing a longitudinal design would allow researchers to investigate changes over time, and may reveal differences in how individuals and families respond during different stages of the rehabilitation journey. This may allow for a more accurate analysis of families' adjustment processes.

Fourthly, whilst the inclusion criteria extended to include families affected by any type of parental ABI, all injured parents had suffered a stroke. Given the likely differences between the implications of stroke, versus TBI, for example, it would be interesting to explore these differences. Trauma may also play a more significant role following TBI, given the circumstances in which it can occur, for example, RTA's and assaults. These variables may also result in greater differences in construal between family members. Furthermore, specifically exploring the impact of families affected by high levels of executive dysfunction may reveal further difficulties in injured parents' ability to construe their experiences and those of others.

Finally, whilst individual interviews were conducted in order to establish unique perspectives and patterns of construal, conducting family interviews would offer researchers the opportunity to observe construing in action (Procter, 2008). This approach was initially proposed to take place following individual interviews; however, given the time restraints and limits imposed for the purpose of this thesis, it would not have been possible to do justice to the data.

4.5 Personal Reflections

Within qualitative research it is important to consider how the researcher may influence the research process. A reflective diary was kept throughout the research process, and the most pertinent points will now be discussed. For

clarity, the researcher will adopt the first person for the remainder of this section.

Firstly, owing to my professional background as a clinician, it is important to consider my limitations as a researcher, and the ways in which these limitations may have affected the content and process of research interviews. Akin to Kelly's Fragmentation Corollary, researchers and clinicians can possess conflicting skill sets. Johnson and Clarke (2003) discussed role conflict in relation to clinicians undertaking research roles, and identified that they may feel inclined to intervene, particularly when sensitive topics are being discussed. I noticed this occurring on a number of occasions, most notably when participants were discussing aspects of their emotional wellbeing, and dissatisfaction with services received from healthcare providers. The impact of this was somewhat buffered through the preparation of resource packs, allowing me to signpost participants who may have benefitted from discussing any concerns further.

I was aware of role conflict pervading through the research process, for example, through my propensity to look for difficulties experienced by individuals and their families. Potter and Hepburn (2005) describe the 'psychological agenda', wherein qualitative researchers in social sciences may be influenced by the phenomena that they are exploring. During interviews, I noticed this when I perceived participants to be discussing tangential issues, and I felt myself feeling frustrated that interviews had gone 'off course'. Perhaps unduly influenced by an awareness of time, there were occasions when it became difficult to maintain a balance between listening to participants, and ensuring that the interviews were completed in a timely manner. Having an awareness of this dilemma enabled me to remind myself that my own preconceived ideas of what would make a successful interview would likely limit the themes that arose, and following the participants' leads in these instances may allow new ideas to become illuminated. Furthermore, I was able to reflect upon the times during which these tangents arose, and

consider whether there was perhaps a protective mechanism, whereby the participant could talk at length about a topic that felt safer, or more familiar. During data analysis, I again found myself drawn to looking for difficulties. I endeavoured to resolve this bias through sticking close to data and ensuring that any interpretations were corroborated by excerpts from participant interviews.

Finally, I found myself wanting to offer reassurance to participants at times of distress, and I noticed that I may quickly remind participants that we could terminate the research interview at any time. Although motivated by my desire to uphold ethical guidelines and reduce distress to participants, I became aware that participants may have perceived me to be uncomfortable. Nevertheless, I experienced participants as generally feeling comfortable to discuss sensitive issues.

4.6 Conclusion

This thesis sought to explore the interpersonal construing of families affected by parental ABI and consider the implications for adjustment. The findings complement existing literature, whilst offering a unique insight into the processes that may underpin difficulties. Parental ABI appears to have considerable implications for young people and their families. Nevertheless, the findings emphasise the complexities of family systems, and associated difficulties in predicting adjustment and informing support. The varied experiences of participating families highlights the need for patient-centered care with individual families at the heart of all clinical decision making. Using this awareness to offer support may give young people and their families the opportunity to overcome the obstacles with which they are faced.

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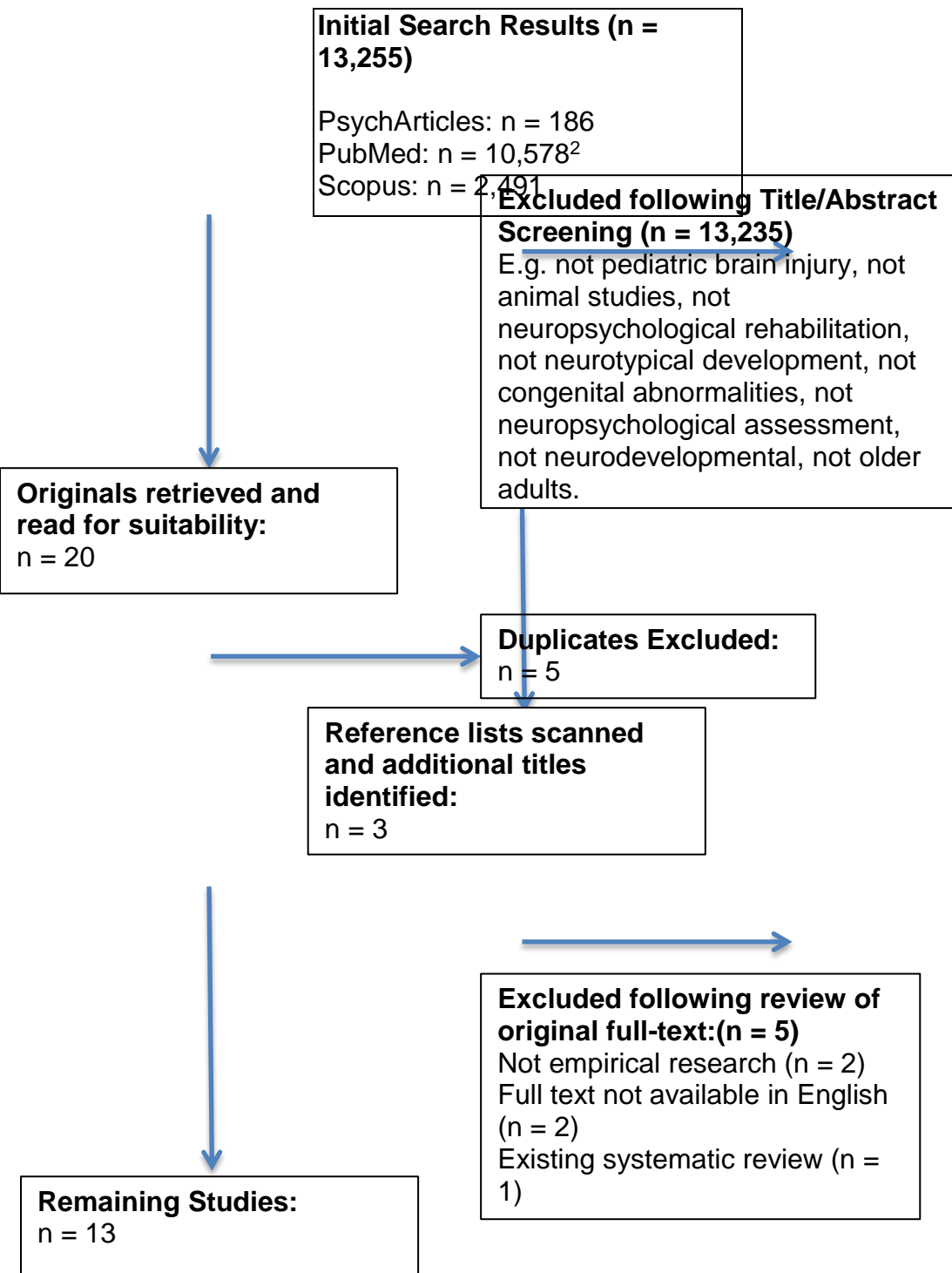
Appendices

Appendix A: Corollary Definitions

Table 1. Descriptions of Corollaries (Kelly, 1955)

Corollary	Definition
Construction	A person anticipates events by construing their replication.
Individuality	Persons differ from each other in their construction of events.
Organizational	Each person characteristically evolves, for his convenience in anticipating events, a construction system embracing ordinal relationships between constructs.
Dichotomy	A person's construction system is composed of a finite number of dichotomous constructs.
Choice	A person chooses for himself that alternative in a dichotomized construct through which he anticipates the greater possibility for elaboration of his system.
Range	A construct is convenient for anticipation of a finite range of events only.
Experience	A person's construction system varies as he successively construes the replication of events.
Modulation	The variation in a person's construction system is limited by the permeability of the constructs within whose ranges of convenience the variants lie.
Fragmentation	A person may successively employ a variety of construction subsystems which are inferentially incompatible with each other.
Commonality	To the extent that one person employs a construction of experience which is similar to that employed by another, his processes are psychologically similar to those of the other person.
Sociality	To the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person.

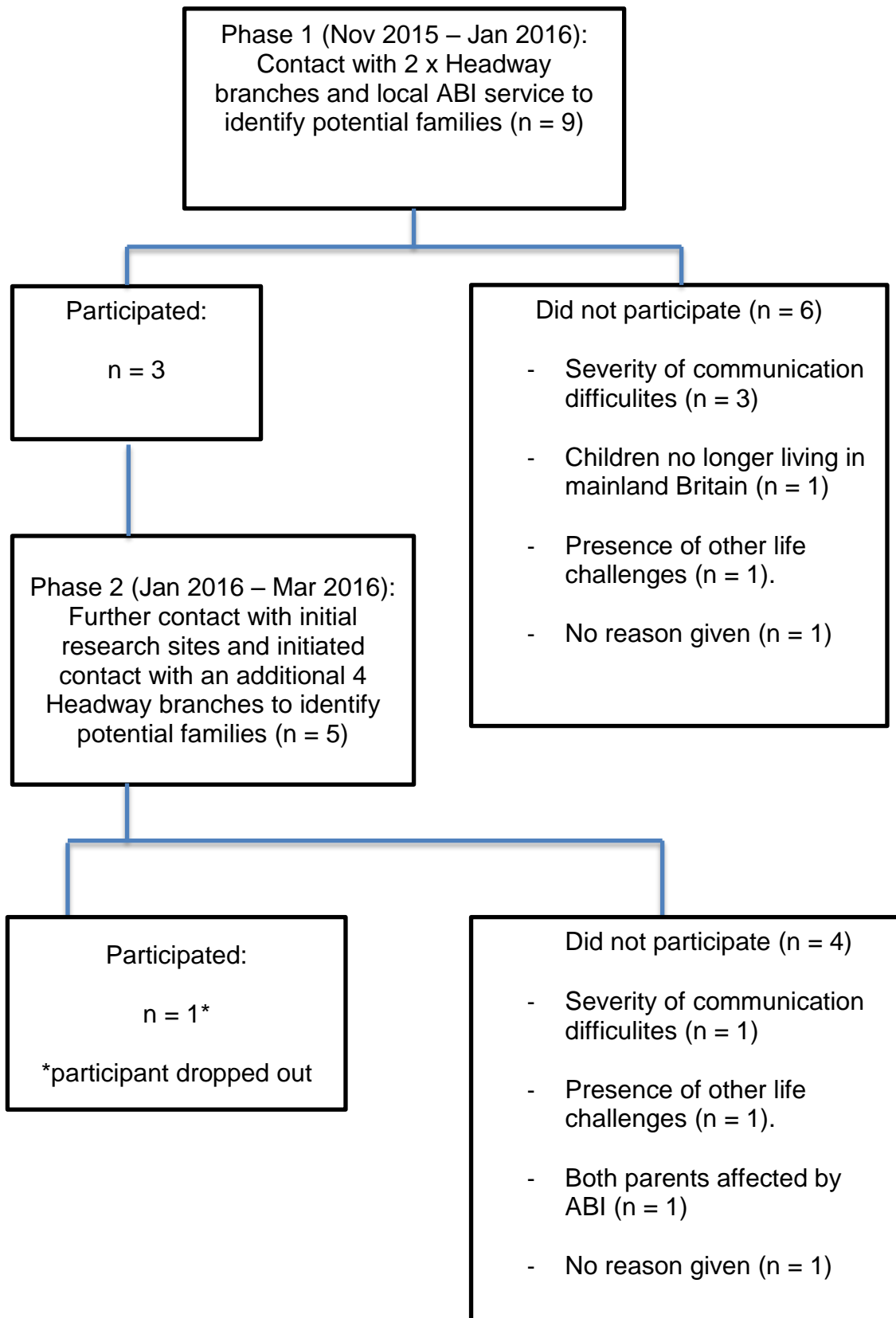
Appendix B: Literature Search Strategy



Appendix C: Summary of Outcome Measures

Author(s)	Measure(s)
Butera-Prinzi & Perlesz (2004)	Behaviour Assessment System for Children (BASC)
Charles et al., (2007)	BASC; Dyadic Adjustment Scale (DAS); Family Assessment Device (FAD); General Health Questionnaire (GHQ)
Kieffer-Kristensen et al., (2011)	Beck Youth Inventory (BYI); Child Behaviour Checklist (CBCL); Children's Revised Impact of Events Scale (CRIES-13)
Kieffer-Kristensen et al., (2013)	CBCL; CRIES-13; DAS; European Brain Injury Questionnaire (EBIQ); Parenting Stress Index-Short Form (PSI-SF); Symptom Checklist-90-Revised (SCL-90-R)
Pessar et al., (1993)	Child Information Form (CIF); Behaviour Rating sCALE (BRS), SCL-90-R; Health and Activity Limitation Survey (HALS)
Sieh et al., (2010)	Barthel Index (BI); Centre for Epidemiological Studies-Depression Scale (CES-D); Dutch Stress Questionnaire for Children (SVK); Goldberg Depression Scale (GDS); Interactional Problem Solving Index (IPSI); Mini Mental State Examination (MMSE); Utrecht Communication Observation (UCO)
Usyal et al., (1998)	Beck Depression Inventory (BDI); Behaviour Rating Profile, 2 nd edition (BRP-2); Child Depression Inventory (CDI); Children's Problem Checklist (CPC); Parenting Dimensions Inventory (PDI); Parenting Behaviour Form (PBF); Parenting Practices Questionnaire (PPQ); Sources of Family Annoyance (SOFA)
van de Port et al., 2007	BI; CES-D; CBCL; Caregiver Strain Index (CSI); Extended ADL (EADL); Frenchay Activities Index (FAI); GDS; Life Satisfaction Questionnaire (Li-Sat-9); MMSE; Rivermead Mobility Index (RMI); SVK; Youth Self Report (YSR)
Visser-Meily et al., (2005a)	CSI; CBCL; GDS; Functional Status (FS-II)
Visser-Meily et al., (2005b)	CBCL; CDI; GDS; FS-II; IPSI

Appendix D: Recruitment Strategy



Appendix E: Invitation Letter

Doctorate in Clinical Psychology Training Course
Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

8th December 2015

Dear ,

Thank-you for speaking to me yesterday. As I explained, I am a Trainee Clinical Psychologist at the University of Hertfordshire. As part of my training, I am required to undertake a doctoral research project.

For my research, I am interested in exploring the experiences of children and families when a parent has an Acquired Brain Injury. I am interested in how each family member's views may be similar or different, and whether this affects children's and family's adjustment.

I would like to interview children aged between 8-16 years old, and the other people in their family. I would also like each family member to complete two quick questionnaires. Although I am hoping to speak to whole families, as long as at least one child, and the parent who has experienced a brain injury wish to take part, then your family may be eligible.

If you think that your family would be interested in taking part, please read the enclosed information. I have enclosed four information sheets: (1) information for young people aged 8-12 years old, (2) information for young people aged 13-16 years old, (3) information for adults, and (4) information for adults, easy read version.

As discussed, I will make telephone contact with you in approximately 7-10 days in order to discuss whether or not you wish to participate, and answer any questions that you may have. Please note that requesting this information has in no way committed you to taking part and you are free to change your mind at any time.

If you have any questions in the meantime, or have decided that you no longer wish to take part then you can contact me using the address above, or <details removed>

I look forward to hearing from you.

Clare Coppock
Trainee Clinical Psychologist

Appendix F1: Information Sheet (Adult)

Your family have been invited to take part in a research study exploring how family members view themselves and each other, after a parent has experienced an Acquired Brain Injury.

Before you decide whether you would like to take part, please take the time to read the following information that has been written to help you understand why the research is being carried out and what it will involve.

Provisional title of research study:

Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.

Who is conducting the study?

The study is part of a Clinical Psychology Doctorate led by Clare Coppock (Trainee Clinical Psychologist). It is being supervised by Professor David Winter (Chartered Clinical Psychologist) at the University of Hertfordshire and by Dr Scott Ferguson and Anna Green (Clinical Psychologists) at <details removed>

Purpose of the Study

We are hoping to find out more about the experiences of families in which one parent has experienced a brain injury. We are particularly interested in finding out whether differences and similarities in how people make sense of things could have implications for how children, and families, adjust.

Who can take part?

As you (or your partner) have recently received support from Headway, your family may find this study of interest. I am looking to interview families with at least one child aged between 8-16 years old.

Whilst we would like to speak to everyone in the family, if there are some family members who would prefer not to take part, they don't have to. As long as the parent who has experienced an Acquired Brain Injury, and at least one child aged between 8-16 years old wish to take part, then your family will be eligible, providing that parental consent has been given. In the case of a two-parent family, both parents will need to consent to their child(ren) taking part.

What would taking part involve?

1. I will speak to any adults in the family, to get a brief outline of the history and nature of the brain injury, and to collect demographic information.
2. I will interview you on your own and ask questions relating to how you would describe yourself and the other people in the family, in addition to how you think they might describe themselves and you. Then I will ask you to describe the brain injury. I will also ask you to imagine what the brain injury might think about each of the people in your family. You will be invited to draw or write down any of your responses, if you prefer.
3. Anyone else in your family that has agreed to take part will also have an individual interview in which they will be asked similar questions. Each individual interview will last no longer than one hour, and there will be the opportunity to take a break at any time. Individual interviews can take place on different days, if preferred.
4. I will also ask you to complete two short questionnaires. This will be to find out a bit more about your family and about how you think your child(ren) are doing at the moment. Any children aged 12 years and older will also be asked to complete copies of the questionnaires about your family, and about their own wellbeing.
5. Following your participation, your family will be given the opportunity to have a debrief. Please note that feedback regarding the content of individual interviews will not be given.

Please note: All interviews will be audio recorded. This will allow me to be clear about who has said what. The recordings will be used for the purposes of data collection ONLY. Following the interviews, all recordings will be transcribed and the transcripts will be anonymised. The recordings will then be stored securely, and separately from the transcripts. A professional transcription service recommended by the University of Hertfordshire may be used; in this instance they will be required to sign a confidentiality agreement.

Risks & Benefits

Whilst we cannot guarantee any direct benefits from taking part, we anticipate that it many participants will find it valuable to have the time and space to reflect upon their experiences. In learning about family experiences, this might help us to better support families following a brain injury.

As the study will involve both you and your family member(s) discussing your experience of brain injury, it might cause some distress. For this reason, there will be the opportunity after the interviews for anyone to talk to the researcher about some of the issues that might have been raised. If necessary, a management plan to address these concerns will also be considered (e.g. by providing you with information about local organisations or services that may be able to offer you support).

Anyone can change his or her mind about being in the study at any time, for any reason. If you change your mind after the interview has taken place, any information I have regarding your family will be destroyed. If you decide not to take part in the study, or change your mind, this will not affect the support that you might receive from other services.

Will taking part be confidential?

- Any information about your family will be kept confidential.
- All written data will be anonymised.
- All information will be stored securely for up to five years after the research is submitted for examination (until approximately June 2021), and will be stored according to the University of Hertfordshire's 'Good practice in research' guidelines. Following this, all data (including audio recordings) will be destroyed.

There is a possibility that quotations, drawings or written words from your interviews might be used when the findings of this research are written up. Using quotations does mean that there is always a slight possibility that a person or family could be identified. However, in an effort to avoid this, all quotations will be anonymised and any personally identifying information (e.g. names, dates, locations) will be removed.

Please note: If anyone discloses information that raises concerns about their safety or that of others, then this will be discussed within the research team, in order to establish an appropriate course of action. This may involve sharing information with other people (e.g. professionals or authorities), if necessary.

What will happen to the results of this research study?

The results will be reported in a thesis for the purpose of gaining a qualification in Clinical Psychology. The thesis will be held in the University of Hertfordshire Learning Resource Centre and will be

accessible to interested parties. Further to this, a summary of the main findings will be submitted for publication in a research paper. If you agree to take part in the study, and are interested in the results, a summary sheet can be provided on request.

Further Information

Your family will be given the opportunity to comment on the themes that are generated when the interview data is analysed. This will be entirely voluntary and is done to check whether the themes accurately reflect your views and beliefs.

Who has reviewed this study?

This study was reviewed by the University of Hertfordshire and the London-Central Research Ethics Committee, and was given ethical approval.

What happens if I want to make a complaint?

If at any time you are unhappy about the way that either you or someone in your family has been treated whilst taking part in the research project, please do not hesitate to contact me to discuss this directly. If I am unable to resolve your concerns or if you do not feel comfortable talking to me, you can contact:

<details removed>

Please be reassured that any subsequent care received will not be adversely affected due to any concerns raised.

What do I do now?

Please discuss the information provided with your family. If you are interested in taking part, or would like to find out more about the study, please contact me using the details below. Enquiring about the study will not commit you in anyway.

Contact Details

<details removed>

Thank-you for taking the time to read this.



INFORMATION SHEET (ADULT – EASY READ)



Hello, my name is Clare Coppock. I am a Trainee Clinical Psychologist.

You are invited to take part in my research project. I would like to tell you about what I will be doing, and why.



You can talk through this with the other people in your family. They have all been given some information too. Please ask if there is anything that you do not understand.



I want to find out:

- What people think about themselves, the other people in their family, and the brain injury.
- Whether different family members think about things in the same way, or a different way.
- Whether this affects how families adjust to the brain injury.



Do I have to take part in this research?
NO, you do not have to take part in this research. If you say YES, you can change it to NO later on.



If I say YES, what will I have to do?
I will ask you a little bit about the brain injury, and what happened. If you agree, we may look at your medical records but we will always ask you about this first. I will also ask for some background information about your family (e.g. ethnicity, ages).

I will meet with you by yourself. I will ask you some questions about yourself, the other people in your family, and the brain injury. You will be able to draw or write some of your answers down.



One by one, I will meet with each person in your family and ask them the same questions that I have asked you. I won't tell everyone what each person has said. **Each meeting will take about one hour. We can take a break whenever you like.**



Could bad things happen if I do the research?
Talking about the brain injury might be upsetting. If anything upsets you, we can stop, and you can talk to me, or you can talk to someone else. You don't have to answer any questions that you don't want to.



Could good things happen if I do the research?

We can't promise that there will be any direct benefits for you. But by saying YES you might help us to understand how families adjust to a brain injury. You might also help us to understand how it could be helpful to support families after a brain injury.



Will information about me be kept private? YES, but:

- We might need to tell someone else if you tell us things that mean you or someone else is at risk. This is to protect you and other people.



- People who are in charge of making sure that the researchers are following the rules may also look at your records and the information they collect about you.



- We will record the interviews so that we can listen back and review what you have said.



What happens at the end?

I will write about the things that I find out. Everyone's names will be changed, so if someone reads it, they won't know it's about you. If you would like to see the results then you can ask me about them.



We will keep the information collected in the study for up to five years at the University of Hertfordshire. After this, any written data or recordings will be destroyed.



Has the research been checked?

People have looked at the study to check it is safe.

People have also checked to make sure that everyone gets good information before they start.



What if you are unhappy about the research?

- You can talk to me if you have any questions or worries.
- You can make a complaint to the University of Hertfordshire or the NHS.
- We will give you information about how to complain.
- You can ask someone to help you make a complaint.



Contacts:

If you have any questions, you can contact me at:



<details removed>

THANK-YOU FOR READING



Appendix F3: Information Sheet (Young Person, 8-12)



Hello, my name is Clare Coppock. I am a Trainee Clinical Psychologist. That means that I am learning about how other people think and feel about different things.

You are invited to take part in my research project. Before you decide, I would like to tell you why this research is being done and what it will involve.

What's it all about?

I am really interested in learning about what it's like to have a parent with a brain injury.

I hope to find out about what helps families and children to cope. I hope that what we find out from this project will also be helpful for other families, so we can think about how best to help them.



What will I have to do?

1

I will ask you to fill out a quick questionnaire. This will ask some questions about how you are feeling and how things are going at the moment.





I will meet with you on your own and ask you some questions about yourself, the other people in your family, and about your parent's brain injury. You will be able to write some of your answers down, or you can draw pictures to let me know what you think.

I am really interested in what you have to say, so there are no right or wrong answers. It will last up to 1 hour. If this feels like a long time and you would like a break, that's OK. If you would prefer, I can come back another day.



One by one, I will meet with the other people in your family and I will ask them the same questions that I have asked you. I am interested to learn about how their answers might be the same or different to yours. I won't tell everyone what each person has said.

When and where will it happen?

If you and your family would like to take part then we will find a time when you are free. I can see you in your home, or somewhere else, like a quiet room in a library, or at the clinic that your parent(s) go to.

What are the good and bad things about taking part?



We can't promise that good things will happen, but some children find the chance to talk about themselves and their families can be helpful and enjoyable.



Talking about a brain injury can be upsetting. If anything upsets you, we can stop at any time. You don't have to answer any questions that you don't want to.



- It's up to you to decide whether you would like to take part or not. Both you and your parent(s) will need to agree to take part in the project.
- You can change your mind about being in the project at any time and you won't need to tell me why.
- All of the things you have said or written or drawn will be kept private.
- Our meeting will be voice recorded so that I remember everything that you have told me. Nobody else will listen to the tape.
- If I was really worried about you, I might need to speak to another adult, so that they can help you. This might be if you talk about something bad which might be happening to you or if you (or someone else) might be in danger.

- When I write up the results, I might share some of the things that you have said, written or drawn. If I do this, I will change your name, so that nobody will know it was you.
- All the information that I collect in the study will be kept at the University of Hertfordshire for up to five years after the study has finished. After this any information about you (including the voice recordings) will be deleted.

What happens if I want to make a complaint?

A complaint is telling somebody when you are unhappy about something. If you are angry or upset about the way that you have been treated when you take part in the project, you should tell someone. You can talk to me, or you can talk to someone that you trust, like a parent or a teacher. Please remember that if you do make a complaint, this will not affect the help that you get from other people. You could also ask your parent(s) to make the complaint for you.

You can write to this address:

<details removed>

What if I have questions about this project?

If you have any questions, please contact me by email or post. You could also ask your parent(s) to get in touch with me for you.

Thank-you for reading.

Appendix F4: Information Sheet (Young person, 13-16)



Hello, my name is Clare Coppock. I am a Trainee Clinical Psychologist. You are invited to take part in my research project. Before you decide, I would like to tell you why this research is being done and what it will involve.

What's it all about?

I am really interested in learning about what it's like to have a parent with a brain injury. I hope to find out about what helps families to adjust to a brain injury. I hope that what we find out from this project will also be helpful for other families, so we can think about how best to help them.

What will I have to do?

1. I will ask you to fill out some questionnaires. The first one will have questions about how you have been feeling, and the second will be asking about your family.
2. I will meet with you on your own and ask you some questions. I will ask you to describe yourself and the other people in your family. I will also ask you about how you think the other people in your family might describe you, and each other. Then I will also ask you some questions about your parent's brain injury. You will be able to write some of your answers down. If you want, you can draw pictures.

I am really interested in what you have to say, so there are no right or wrong answers. It will last about 1 hour. If you need a break, we can pause at any time.
3. One by one, I will meet with the other people in your family and I will ask them the same questions that I have asked you.

I am interested to learn about how their answers might be similar or different to yours. I won't tell everyone what each person has said.

What are the risks and benefits of taking part?

We can't promise that there will be any direct benefits, but some young people find the chance to talk about themselves and their families can be helpful and enjoyable.

There is a chance that talking about your parent's brain injury could be upsetting. We can stop the interview at any time, and you don't have to answer any questions that you don't want to.



- It's up to you whether or not you would like to take part. Both you and your parents will need to agree to take part in the study.
- You can change your mind about being in the study at any time and you won't need to explain your decision.
- Everything will be confidential. No-one else will be able to get hold of the information that you have given, unless you agree that it can be shared.
- This will be audio recorded so that I remember everything that everyone has told me. The audio recording will be kept confidential too.
- When I write up the results, it can be helpful to use quotes and share some of the things that have been written or drawn. If I

use any of yours, I will change your name, and any personal details, so that nobody will know it was you.

- The only time I would need to speak to someone else about what have told me would be if I were concerned about your safety, or the safety of somebody else. If this happened, it would be to make sure that you can get the right support.
- Once the study has finished, any information collected will be stored securely at the University of Hertfordshire for up to five years. After this time, all information (including audio recordings) will be destroyed.

What happens if I want to make a complaint?

If you are unhappy about the way that you have been treated when you take part in the project, you can make a complaint. Please remember that if you do make a complaint, this will not affect the help that you get from other people. You could also ask your parent(s) to make the complaint on your behalf.

You can write to:
<details removed>

What if I have questions about this research?

If you have any questions please get in touch by email or post. You can ask a family member to get in touch with me, if you would prefer.

Thank-you for taking the time to read this.

Appendix G: McMaster Family Assessment Device (General Functioning Subscale)

1. Planning family activities is difficult because we misunderstand each other.

__SA __A __D __SD __

2. In times of crisis we can turn to each other for support.

__SA __A __D __SD __

3. We cannot talk to each other about the sadness we feel.

__SA __A __D __SD __

4. Individuals are accepted for what they are.

__SA __A __D __SD __

5. We avoid discussing our fears and concerns.

__SA __A __D __SD __

6. We can express feelings to each other.

__SA __A __D __SD __

7. There are lots of bad feelings in the family.

__SA __A __D __SD __

8. We feel accepted for what we are.

__SA __A __D __SD __

9. Making decisions is a problem for our family.

__SA __A __D __SD __

10. We are able to make decisions about how to solve problems.

__SA __A __D __SD __

11. We don't get along well together.

__SA __A __D __SD __

12. We confide in each other.

__SA __A __D __SD __

From:

Epstein, N. B., Baldwin, L. M. & Bishop, D. S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9(2), 171-180.

Appendix H1: Strengths and Difficulties Questionnaire (self-report)

Strengths and Difficulties Questionnaire

S 11-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that you have difficulties in one or more of the following areas:
emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes", please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties make it harder for those around you (family, friends, teachers, etc.)?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your Signature

Today's Date

Thank you very much for your help

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Appendix H2: Strengths and Difficulties Questionnaire (parent-report)

Strengths and Difficulties Questionnaire

P 4-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes", please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature

Date

Mother/Father/Other (please specify:)

Thank you very much for your help

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Appendix I1: Consent Form Adult

INFORMED CONSENT FORM (ADULT)

Title: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.

Researcher: Clare Coppock, Trainee Clinical Psychologist.

Please read this sheet **AFTER** you have read the information sheet and discussed it with your family. You can ask me any questions you might have before you sign this sheet. Please tick each box if you are in agreement with the statements.

1. I have read the information sheet. I have had the opportunity to ask questions and discuss any concerns that I may have.
2. I understand that participation is voluntary and that I am free to withdraw at any time. I understand that if I, or a family member, choose to withdraw, our individual data will be deleted. This will not affect the support that we receive from other services.
3. I understand that the interviews will be audio recorded. I understand that this information will be stored securely. I understand that a professional transcription service may be used to transcribe both my interview and that of my family. In this instance, the recording will be given a code (e.g. Interview A) to maintain anonymity. Furthermore, the service will have signed a confidentiality agreement. All data, including audio recordings, will be destroyed after five years.
4. I agree that any anonymised drawings, written words or quotes from my interviews may be used in any future publications. I understand that the nature of using of direct quotations means that there may be a slight possibility of identification, however, the researchers will remove any personally identifying information, for example, names.
5. I understand that everything will be kept confidential. I understand that if any information is shared which suggests that I am (or somebody else is) at risk of harm, this may need to be shared with other professionals.
6. I understand that individuals from the University of Hertfordshire or regulatory authorities may review anonymised sections of data collected during the study.

Appendix I2: Consent Form Adult Easy Read



INFORMED CONSENT FORM (ADULT – EASY READ)

Title: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.



Researcher:
Clare Coppock, Trainee Clinical Psychologist.

Please read this sheet **AFTER** you have read the information sheet. You can ask me any questions you might have before you sign this sheet. Please tick the boxes if you agree.



I have read the information sheet. I have been able to talk about any worries or questions that I have with Clare.



If I say YES, I can change it to a NO later on. If I say NO, my information will be deleted. This won't affect any other help that I get.



I understand that anything I talk about will be kept private. I understand that if Clare is worried about me, or someone else, she might need to speak to someone else.



I know that the conversation will be voice recorded.



I understand that individuals from the University of Hertfordshire and regulatory authorities may look at some of data collected during the study. If this happens, they won't be given any of my personal details.



I understand that it may be helpful for members of the research team to look at my medical records. I give permission for these individuals to have access to my records.



I understand that Clare may use my drawings or write about the things that I have described to put into the project. I understand that everybody's names will be changed so people can't tell it's me, or my family.



I understand that information collected about me may be kept for up to five years at the University of Hertfordshire. After this time, any written information or audio recordings will be destroyed.



I would like to say YES, and take part in this project.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature



Appendix I3: Assent Form 8-12

INFORMED ASSENT FORM (8-12)

Title: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.

Researcher: Clare Coppock, Trainee Clinical Psychologist.

Please read this sheet **AFTER** you have read the information sheet with an adult, like your parent(s). You can ask me any questions you might have before you sign this sheet. Please tick each box if you are happy with what it says.

1. I have read the information sheet. I have been able to talk about any worries or questions that I have with my parent(s) and/or Clare.
2. I know that I can change my mind at any time. If I decide that I don't want to take part in the project anymore, my information will be deleted. This won't affect any other help that I get from other people.
3. I know that the conversation will be voice recorded. I understand that my information will be kept locked away so other people can't see it, and it will only be used for this project. It will be destroyed five years after the study has finished.
4. I understand that Clare may use my drawings or write about the things that I have described to put into the project. I understand that everybody's names will be changed so people can't tell it's me, or my family.
5. I understand that anything I talk about will be kept private. I understand that if Clare is worried about me, or someone else, she might need to speak to another adult.
6. I would like to take part in this project.

Name of Young Person

Date

Signature

Name of Parent

Date

Signature

Name of Researcher

Date

Signature

Appendix I4: Assent Form 13-16

INFORMED ASSENT FORM (13-16)

Title: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.

Researcher: Clare Coppock, Trainee Clinical Psychologist.

Please read this sheet **AFTER** you have read the information sheet and discussed it with your family. You can ask me any questions you might have before you sign this sheet. Please tick each box if you agree with the statements.

1. I have read the information sheet. I have been able to ask questions and discuss any concerns with my parent(s) and/or Clare.
2. I know that I can change my mind at any time. If I decide that I don't want to take part in the project anymore, my information will be deleted. This won't affect any other help that I get from other people.
3. I know that the conversation will be audio recorded. I understand that this, and any other information about me, will be stored securely, and it will only be used for this project. I understand that all information will be destroyed after five years.
4. I understand that Clare may use quotations and/or drawings when writing up the research. I understand that if any of mine are used, names will be anonymised and personal information will be removed.
5. I understand that everything will be kept confidential. I understand that if I share any information that could mean that I am (or someone else is) at risk of harm, this information may need to be passed on to other professionals.
6. I would like to take part in this project.

Name of Young Person

Date

Signature

Name of Parent

Date

Signature

Name of Researcher

Date

Signature

Appendix J: Transcript

Participant identifier: Family 1, UIP

Interview Date: 21/12/2015

Key:

... = Pre-injury roles

... = ABI sequelae

... = Protective factors/coping strategies

... = Consequence of ABI

Initial Thoughts & Hypotheses	Line #	Original Transcript	Codes
<p>Kellian guilt (role change)</p> <p>Constellatory construal</p> <p>Kellian guilt.</p> <p>Kellian anxiety</p> <p>Outside of range of convenience.</p>	<p>65</p> <p>66</p> <p>67</p> <p>68</p> <p>69</p> <p>70</p> <p>71</p> <p>72</p> <p>73</p> <p>74</p> <p>75</p> <p>76</p> <p>77</p> <p>78</p> <p>79</p> <p>80</p> <p>81</p>	<p>P: And then now as well, if—you know, sometimes it's more worry for some letter arriving, he can't understand what it (I: mhm) says [imitates panicked voice, words unclear] (I: yeah, that must be difficult) and you know because he always dealt with everything (I: right), my—my role in this house was look after them, the kids (I: mhm), him and cooking—you know, be the—the—the mum.</p> <p>I: So how—</p> <p>P: But after [names husband], after [names husband] had all that, my role changed. I became man and woman (I: mhm) now because I need to do things I've never done before (I: mhm), I've never take finances and everything else (I: mhm) do you understand, it was ...</p> <p>I: So how was that (P: yeah) taking on all the new responsibilities?</p> <p>P: At beginning it was hard (I: mhm) because I thought "I can't do it, I can't do it" (I: mhm), I'm anxious not good enough, "I</p>	<p>Anxiety, loss of abilities.</p> <p>Change in family roles.</p> <p>Traditional gender roles.</p> <p>Change in family roles. Lack of previous experience.</p> <p>New responsibilities.</p> <p>Lack of faith in own abilities.</p>

Kellian guilt for YP.	82 83 84 85 86 87 88	can't (I: mhm) do it, I can't do it." But erm thank God—you know, I er—I had you know ... I: So you felt—you felt that you might not be good enough (P: yeah) at it but now you feel (P: yeah yeah) that things are going okay? P: Yeah, yeah. I: Brilliant.	Anxieties reduced with time & experience.
Potential perpetuation of children's anxieties?	89 90 91 92 93 94 95 96 97 98 99 100 101 102 103 104 105 106 107 108 109 110 111	P: And after as well, I—I need for me my older son because he become like my rock because (I: mhm) I think the only thing I think went wrong when [names husband] had the stroke and the heart attack and everything, it was share so much with er, with my older son, with [names eldest son] (I: mhm) because I felt he was more mature (I: okay, yeah he was the older one) but not because I wanted to left out the other two, I want to protect them, for me it was protection (I: mhm) to not tell everything that was going on (I: yeah) but my second one, he react very—you know, he was very upset (I: okay) because he felt left out (I: okay) at the beginning—you know, but when he explained to me, and after, I opened to him and after we—you know. I: So it was important for you to try and protect them (P: yeah, yeah) but then they felt a little bit (P: yeah, yeah) left out. P: Yeah because it was only me and [names eldest son] “ ssh ssh ssh” you know and that “it's okay, it's okay, it's okay” (I: mhm)—you know but it was only for to help them-you know to .., I: Okay, so when you realised (P: yeah) actually what might be helpful (P: yeah) for them (P: yeah, yeah), you were able to adapt (P: yeah, yeah) that. Okay— P: Yeah it was—because sometimes you can't be like—your focus when this is happened, it was—for me it was—my	Change in children's roles e.g. parentification? Reflection/hindsight. Implications of age of YP. Protection vs. keeping secrets. Differences between YP reactions. Feeling excluded. Change in approach following YP expression of emotion. Family secrets. Trying to do what is best for children. Need to focus on the ABI patient.

<p>Dispersed dependency: cultural experiences of family e.g. collectivist versus individualistic</p> <p>Slot-rattle?</p>	<p>112 113 114 115 116 117 118 119 120 121 122 123 124 125 126 127 128 129 130 131 132 133 134 135 136 137 138 139 140 141</p>	<p>concentration it was [names husband] erm you know (I: mhm) and how to manage all of the other things round, it was everything—seems at the beginning everything comes in one (I: mhm), in one go. It was very difficult at the beginning but I had good friends (I: mhm), good—you know.</p> <p>I: So people to turn to?</p> <p>P: Yeah. (I: okay)-you know it was very difficult.</p> <p>I: It sounds like you've got a good support (P: yeah) network.</p> <p>P: And after, my Mum as well. My brother, my sister came straight away from <removed>-you know (I: mhm) it was—you know, something you know erm we went—we were [names hospital] we were—every day I went [names hospital] with er ..., with [names eldest son] you know (I: mhm), the friends take—I got one friend every day took us to [names hospital], they take him back and the kids go to school, come back and stay alone until I was around but ...</p> <p>I: Right, okay, so you couldn't be there for them as much as you had been before.</p> <p>P: Yeah this is (I: okay) this is—was the beginning (I: yeah) – you know (I: mhm). After, when [names husband] comes back from—in [names local town], it was more easier-you know?</p> <p>I: Mhm it was easier when he was here and (P: yeah) you could be together.</p> <p>P: Yeah, yeah.</p> <p>I: Okay. So how would you describe [names youngest son]?</p> <p>P: Ahh [names youngest son], [names youngest son]'s the—the the baby of the family (I: mhm)—all three of them are my baby. Erm I think when [names husband] had the stroke it had a big impact on him (I: mhm), and erm he began a little bit er—you know, he wanted to be macho, you know (I: okay), I think</p>	<p>Conflicting demands.</p> <p>Sudden changes. Lack of warning.</p> <p>Social support.</p> <p>Family support.</p> <p>Disruption to daily routine. Social support. Disruption to family routine.</p> <p>Temporary loss of both parents.</p> <p>Differences between acute phase and rehabilitation. Hospital out-of-area.</p> <p>Family hierarchy.</p> <p>Impact on sense of self.</p>
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<p>Kellian guilt: Taking on Dad's role? Maintaining</p>	<p>142 143 144 145 146 147 148 149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165 166 167 168 169 170 171</p>	<p>he ..., he [pause], he put a mask (I: yeah, okay), this is—it was a mask, not because he was—it was so hard but he put the—like you know, like he would grow up quickly—sorry, I need a tissue. I: That's okay. P: Erm, after that he grow up (I: mhm) from the little boy ... I: So he matured? P: Yeah, matured (I: okay) and I think he— ..., they all suffer differently [crying]. I: Take your time. P: [crying- 8.40 to 8.52]. For the older one it was—you know [sob] ..., he take out emotion—you know, cry—you know whereas my second one, he was—stopped talking—you know he was (I: mhm) very ..., [names youngest son], he was talking back—you know, he was very quickly—you know, it was like he was—I told you, like he put a mask to (I: yeah) to—to— ..., I: So he was hiding how he felt? P: Yeah. (inaudible- 9.26) but I think after- after when [names husband] comes back home and it seems the family come back to normal again, he—he— real- (+really) ... I: So when you were all together (P: yeah, yeah), it's been a lot easier (P: yeah) for everyone. P: Yeah, yeah. I: Would you say that [names youngest son] has always hidden how he feels, or was he different before? P: ..., no, we always—we are this open family. Everything we share together, we never (I: mhm) have the secret—you know, if something happens we [deep breath]— but I think after [names husband] had the—the stroke, he felt he lost his Dad (I: mm)— you know, he felt unprotected (I: mhm) because—you know [names husband] was in hospital, I was there with [names</p>	<p>Hiding emotional response. From 'baby' to 'macho'. Loss of childhood? Differential responses. Externalising Internalising Externalising – new behaviour Hiding emotional response. Importance of having family unit together. Family support, importance of relationships and openness. Loss of parent. Loss of safety and change in parental roles.</p>
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family homeostasis	172 173 174 175 176 177	husband] –you know he felt (I: mhm)– I think at the beginning it was–he felt alone–he felt “I need to grow up, I need to..” (I: okay, yeah), you understand? You know ..,	Role change.
Kellian hostility	178 179 180 181 182 183 184	I: To become (P: yeah) more adult (P: yeah). Okay, and so when–when you say he did mature and he did grow up, what differences did you notice in him? P: .., [audible exhale] .., in what way er he like–er he grow up to be like “oh, I’m okay, I can do this, I can do that”–you know, <u>he felt he can do things he wasn’t able to do it</u> (I: mhm) –you know, do you understand me (I: yes) he wanted to (I: so wanting to be able to do things for himself?) yes, for himself but erm yeah but as well–you know erm .., I think sometimes	Independence? Behaviour change.
Kellian anxiety – confronted with events outside of range of convenience.	185 186 187 188 189 190 191 192 193 194 195 196 197	(inaudible- 11.06) at school he had some w- (+with) with the teachers say something and he never done it before, he replied back (I: right) but I think it was a reaction because he was upset with what happened at home (I: okay), he never told the teacher what’s happened at home (I: mhm) and erm and when the teacher phoned he said “ oh I’m very surprised about how [names youngest son] reply to me”, I don’t know what it might be–I can’t remember what it was but he said to go out and he said “I don’t want to go out” (I: mm)–you know something, he said “I’m very surprised” but I explained to him it was–his dad had (I: mhm) a stroke, he said “oh, I never knew that” (I: mm)– you know it was that, it was for the teachers and it was a surprise.	Justification: Response to ABI. Not disclosing ABI. Atypical behaviour at school. Teacher’s shock. Lack of school’s awareness.

Appendix K: UH Ethics



Professor David Winter &
Miss Clare Coppock
Department of Psychology and Sports Science
School of Life and Medical Sciences

University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

27 October 2015

Dear Professor Winter and Miss Coppock,

Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:
RESEARCH STUDY TITLE: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment
NAME OF CHIEF INVESTIGATOR (Supervisor): Professor David Winter
NAME OF INVESTIGATOR (Student): Miss Clare Coppock
UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER: LMS/PG/NHS/00417

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements. It is also essential that evidence of NHS Trust Management Permissions (formerly known as R&D Approval) is sent as soon as they are received.

Permission to seek changes as outlined above should be requested from myself before submission to an NRES (NHS) Research Ethics Committee (REC) and notification to the relevant University of Hertfordshire Ethics Committee with Delegated Authority (ECDA), and I must also be notified of the outcome. It is also essential that evidence of any further relevant NHS management permissions (formerly known as R&D approval) is provided as it is received. Please do this via email to research-sponsorship@herts.ac.uk

Please note that University Sponsorship of your study is invalidated if this process is not followed.

In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely

Professor J M Senior
Pro Vice-Chancellor (Research and International)



A Charity Exempt from Registration under the
Second Schedule of the Charities Act 1993

Appendix L: NHS Ethics

London - Central Research Ethics Committee

3rd Floor, Barlow House

4 Minshull Street

Manchester

M1 3DZ

Telephone: 0161 625 7820

22 October 2015

Professor David Winter
University of Hertfordshire
Doctorate in Clinical Psychology Training Course
Health Research Building, University of Hertfordshire
College Lane, Hatfield, Hertfordshire
AL10 9AB

Dear Professor Winter

Study title: Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment.
REC reference: 15/LO/1634
Protocol number: LMS/PG/NHS/00417
IRAS project ID: 177167

Thank you for your letter of 21 October 2015, 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, Frances Goodhart and Sophie Forsyth. We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Elaine Hutchings, NRESCCommittee.London-Central@nhs.net.

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.

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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 a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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).

Ethical review of research sites

NHS 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).

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Invitation/Cover Letter]	1	10 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance/Indemnity Certificate]	1	04 August 2015
Interview schedules or topic guides for participants [Interview Schedule - Version 2 - 10/08/2015]	2	10 August 2015
IRAS Checklist XML [Checklist_04092015]		04 September 2015
IRAS Checklist XML [Checklist_21102015]		21 October 2015
Letter from sponsor [Letter from Sponsor]	1	28 July 2015
Letters of invitation to participant [Invitation Letter - Version 1 – 10/08/2015]	1	10 August 2015
Letters of invitation to participant	1	10 August 2015
Other [Email with additional information]		22 September 2015
Participant consent form [Consent: Adult Easy Read Version 3 – 14/10/2015]	3	14 October 2015
Participant consent form [Consent Adult - Version 3 - 14/10/2015]	3	14 October 2015
Participant consent form [Assent: 8-12 - Version 3 - 14/10/2015]	3	14 October 2015
Participant consent form [Assent: 13-16 - Version 3 - 14/10/2015]	3	14 October 2015
Participant information sheet (PIS) [Information Sheet: Adult - Version 5 - 14/10/2015]	5	14 October 2015
Participant information sheet (PIS) [Information Sheet: 8-12 – Version 3 - 14/10/2015]	3	14 October 2015
Participant information sheet (PIS) [Information Sheet: 13-16 - Version 3 - 14/10/2015]	3	14 October 2015
Participant information sheet (PIS) [Information Sheet: Adult Easy Read - Version	4	14 October 2015

4 - 14/10/2015]		
REC Application Form [REC_Form_04092015]		04 September 2015
Referee's report or other scientific critique report [Proposal Feedback (University of Hertfordshire)]	1	01 February 2014
Research protocol or project proposal [Project Proposal - Version 2 - 10/08/2015]	2	10 August 2015
Summary CV for Chief Investigator (CI) [David Winter CV - Version 1 - 30/03/2015]	1	30 March 2015
Summary CV for student [Student CV - Version 1 - 10/08/2015]	1	10 August 2015
Summary CV for supervisor (student research) [David Winter CV - Version 1 - 30/03/2015]	1	30 March 2015
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Summary of Protocol Version 1 – 10/08/2015]	1	10 August 2015
Validated questionnaire [SDQ - Parent Version]		08 April 2015
Validated questionnaire [SDQ - Child Version]		08 April 2015
Validated questionnaire [FAD]	1	07 April 2015

Statement of compliance

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

After ethical review

Reporting requirements

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
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

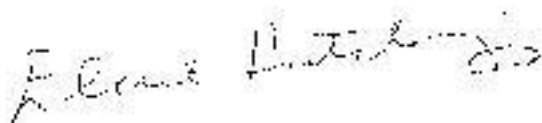
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/LO/1634	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Dr Andrew Hilson
Chair

Email: NRESCommittee.London-Central@nhs.net

Enclosure: "After ethical review – guidance for researchers"

Copy to: <details removed>

Appendix M: R&D Approval

<header removed>
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4th November 2015

Miss Clare Coppock
health Research Building
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB

Dear Clare,

Research Study	Exploring the interpersonal construing of families affected by Acquired Brain Injury and the implications for familial and childhood adjustment
NRES ref	15/LO/1634
NIHR ID number	N/A (not portfolio adopted)
IRAS ref.	177167

I am pleased to confirm that your research study was discussed by the Research Governance Group (RGG) at their meeting on 29th October 2015 and was given approval on the condition that all participant documentation must include the <trust details removed> logo in the header alongside the University of Hertfordshire logo to ensure transparency and define collaborative links with the Trust.

The Trust has to meet rigorous standards set by the Department of Health for research governance so your research must be carried out subject to the following conditions:

- The research must be carried out in strict accordance with the protocol submitted and any changes to that protocol must be approved by the RGG and receive a favourable ethics opinion from a Research Ethics Committee before the research is undertaken or continues.
- Please see Appendix 1 for the list of documents that have been approved. If you make any changes to the approved documents relating to the study please inform the RGG.
- A financial or any other agreement relating to your research that is binding upon this Trust must be notified to me and thereafter approved and signed by <details removed>, the Executive Director of Clinical Governance and Quality on behalf of the Trust.

- You must report any adverse events/serious untoward incidents relating to this research to me as soon as practicable. I can be contacted by telephone on <details removed>. In my absence, incidents should be reported to <details removed>, the Associate Director of Clinical Governance & Quality on <details removed>. In addition, you must complete one of the Trust's adverse incident forms and follow the requirements as set out in the Trust's adverse incident reporting policy. A copy of this form must be submitted to **me** as soon as possible. A copy of the Trust's adverse incident reporting policy can be located on the Trust's intranet or alternatively, please contact me and I will be happy to supply you with a copy.
- In cases where the research will take place over a period of more than 12 months, you are required to send to me a copy of the report on your research which will be required by the Research Ethics Committee. You will be notified when this report is due by the Research Ethics Committee that issued the favourable opinion to proceed with the study.
- Any research terminated prematurely must be notified to me immediately.
- The full final report from the study should be sent to me within 3 months of final report completion so that the RGG can consider it. You are also required to supply a summary or abstract of the study that would be suitable for dissemination.
- As a result of the Research Governance Framework for Health and Social Care, the Trust now has an obligation to monitor research being undertaken within the Trust. You might be required to complete a short questionnaire although this will be no more than once a year. The questionnaire will be completed for you with as much information already known in order to reduce the amount of your time that you have to spend on this. In addition, the Trust is required to randomly select 10% of research studies to be audited. If your study is selected as part of this audit process, you will be notified to ensure your availability.

The RGG, on behalf of the Trust, will revoke or suspend its approval to any research that does not comply with these conditions, is in breach of Research Ethics Committee approval or where there is any misconduct or fraud.

I would like to reassure you that these conditions are applied simply to ensure that the Trust meets its obligations under the Research Governance Framework for Health and Social Care. Please contact me if I can help with any issues that might arise for you as a result.

I would also like to remind you that should members of the research team from University of Hertfordshire be required to attend the <details removed> site for any study related purposes they will need to be issued with an appropriate Letter of Access (LoA) by my colleague <details removed> prior to them attending on site and commencing any study related procedures.

I wish you every success with your research and look forward to receiving a copy of the study report in due course.

Kind regards

Yours sincerely

<details removed>

Chief Psychologist

& Chair of the Research Governance Group