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Doctoral Thesis

Family experience after paediatric acquired brain injury

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Word Count

	Text	Appendices (including tables, figures and references)	Total
Abstract	299	0	297
Literature Review	7986	5885	13736
Research Paper	7998	5738	13,725
Critical Appraisal	3999	125	4,124
Ethics section	5825	9067	14,892
Total	25567	20,690	46,257

Declaration

This thesis records research activity completed between September 2014 and August 2015 for the Doctorate in Clinical Psychology course at Lancaster University. The work presented in this thesis is my own work, except where reference to other authors is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Emma Tyerman

Date: 24th August 2015

Signed:

Acknowledgements

I am extremely grateful to my supervisors for all their efforts to support me. To Fiona thank you in particular for the many drafts reads and your always calm and containing support. Vicky, thank you for your continued efforts to support difficult recruitment and the passion and knowledge for the subject and our findings. Craig, thank you for all your knowledge and wisdom of IPA and guiding me through analysis to completion. And Natalie, thank you for your patience, time and understanding.

I particularly want to thank the five siblings and their families who participated in this research. I felt privileged to hear your stories and moved by the power of your experience. I hope that our findings will be helpful in increasing understanding about your experiences and making things better in the future.

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To all my wonderful friends and family, I could not have done this without you all. Thank you for sharing the fun and laughter and tears along the way and the many encouraging messages. To my mum and dad for you constant and unwavering love and support throughout the long journey to get here; the phone calls, the cards, the wonderful gifts and text messages were incredible. And to Jamie, for being you and being with me every day, for understanding, for never complaining, for accepting and loving me always.

Thesis Abstract

This thesis explores family experiences after paediatric Acquired Brain Injury (ABI). ABI can result in physical, cognitive and psychological difficulties (Royal College of Physicians & British Society of Rehabilitation Medicine, 2003). Given its wide-ranging impact, ABI is likely to have an effect on the family. However, there is limited qualitative research exploring the lived experiences of siblings of children with ABI, and none that focuses specifically on sibling relationships. There is more research exploring parents' experience of this same phenomenon but a lack of synthesis of this knowledge. My thesis seeks to address this gap by conducting a systematic review of parents' experiences and qualitative research on sibling experience.

In the literature review, I systematically searched three databases and identified fourteen qualitative papers that met the inclusion criteria. These were synthesised in line with Noblit and Hare's (1988) guidelines. Three themes emerged, representing the challenges that parents experience with a child with ABI: (1) Disconnection: Cut off from internal emotions and isolated from society; (2) Seeking understanding and support to manage in an insecure world; (3) New parent to a different child. In the research project, I used semi-structured interviews with five siblings (aged between 9-12) and Interpretative Phenomenological Analysis to understand their experience of the sibling relationship after ABI. This resulted in four themes: (1)Coping with "a nightmare that you live"; (2)Disconnection from family relationships; (3)My sibling is different but "still the same underneath all this thing"; and (4)Changing togetherness. These themes showed high levels of distress alongside attempts to adjust to a changed sibling and sibling relationship.

In the third section of this thesis, I critically appraise the above papers and consider strengths and weakness, challenges and recommendations for future research. I hope that this paper will inform future researchers interviewing children, particularly within ABI.

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Section one: Literature Review

Section 1: Literature Review

Parents' experience of parenting a child with an acquired brain injury:

A metasynthesis of the qualitative literature

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Parents' experience of parenting a child with an acquired brain injury: A metasynthesis of the qualitative literature

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Statement of contribution

What is already known on this subject?

- Parents experience substantial psychological, social and physical health difficulties as a consequence of having a child with acquired brain injury (ABI).
- Qualitative research has been conducted to explore parents' experience in-depth.

What does this study add?

- The study adds to current understanding of parents' experience as it synthesises all the current literature to offer new and deeper understanding.
- This metasynthesis highlights how the suddenness of change due to an ABI disrupts the parent-child relationship and leaves parents feeling emotionally overwhelmed.
- It details how parents struggle to manage extreme levels of uncertainty while feeling disconnected from the support networks and relationships around them and suggests ways in which services can respond to these challenges.

Abstract

Purpose. This paper presents a metasynthesis of the qualitative literature on parents' experiences of having a child with an acquired brain injury (ABI). Although the quantitative literature suggests significant psychological, social and physical health consequences for parents of children with ABI, a qualitative synthesis permits deeper exploration of these experiences.

Methods. A systematic search of the literature was conducted in three databases: PsycINFO, PubMed and Web of Science. A total number of 3880 papers were retrieved. Fourteen qualitative papers met the inclusion criteria and were synthesised according to Noblit and Hare's (1988) guidelines.

Results. Three themes were identified from analysis: (1) Disconnection: Cut off from internal emotions and isolated from others; (2) Seeking understanding and support to manage in an insecure world; (3) New parent to a different child.

Conclusion. The findings show that parents experience major challenges of having a child with an ABI. This includes feeling isolation from others, insecure in the situation and struggling to adapt to the different roles required to parent their different child. Clinical implications highlight the need for specialist support that is ongoing after discharge, including specialist knowledge and understanding of ABI and the need for opportunities for peer support.

Keywords: Child Acquired Brain Injury, Parents, Experience, Metasynthesis

An acquired brain injury (ABI) is caused either by an external force or by internal damage. External causes include road traffic accidents, falls and assaults leading to a traumatic brain injury (TBI). Internal causes include stroke, infection, lack of oxygen to the brain and treatment such as surgery (Middleton, 2001). A significant proportion of those who experience ABI are children. For example, within the UK the Neurological Alliance (2003) estimate that as many as 200,000 children have an ABI every year and 30% of attendances at accident and emergency departments for a head injury are children. At least 35,000 children are admitted to hospital in England each year with a TBI (NHS England 2013/2014). Internationally between 280-1,373 per 100,000 children a year suffer a TBI depending on the inclusion of hospital and GP visits or just hospital admissions (McKinlay & Hawley, 2013). Hence, ABI in children is of international concern.

It is widely recognised that ABI can have considerable consequences for the child, resulting in impairments in physical, cognitive, emotional and social functioning. For example, children with an ABI are more likely to exhibit behavioural problems including aggression (Cole et al., 2008; Hawley, 2003; Schwartz et al., 2003) and are at increased risk of mental health difficulties such as depression, anxiety and obsessive-compulsive behaviours (Grados et al., 2008; Green, Foster, Morris, Muir, & Morris, 1998; Hawley, 2003; Max et al., 2013; Max et al., 1997; Vasa et al., 2002). They can also have problems with schoolwork, learning and with friendships (Hawley, 2003). These have been attributed to reduced neurocognitive skills such as executive functioning and pragmatic skills and social problem soving (Yeates et al., 2004). Coupled with physical impairments this leads to restricted social participation (Bedell & Dumas, 2004). Additionally ABI in younger children is associated with worse long-term neurocognitive and psychosocial outcomes (Donders & Warschausky, 2007; Karver et al., 2012), perhaps due to the impact of the ABI on a child's

developmental trajectory (Donders & Warschausky, 2007). Hence ABI has significant implications for children both immediately but also for future development.

Parents of children with an ABI provide important support in managing the resulting difficulties (Savage, DePompei, Tyler, & Lash, 2005). However, given the impact that ABI has on children, it is not surprising that it also affects parents' lives. This review focuses specifically on parents of younger offspring as parental stress after paediatric TBI is reported to be greater when children are living at home than when grown up and living elsewhere (Verhaeghe, Defloor, & Grypdonck, 2005). Therefore, parents of offspring living at home may be at higher risk of experiencing difficulties. Whilst moving out of home occurs at different ages, the transition to adulthood is often defined as age 18 in line with common cultural and legal norms. Consequently, this review will consider 'children' as under age 18.

The quantitative literature on parents with a child with an ABI demonstrates significant impact. For example, parents experience high levels of psychological distress (Rivara et al., 1992), anxiety and depression (Wade, Taylor, Drotar, Stancin, & Yeates, 1998) and worsened physical health (Shudy et al., 2006). The paediatric literature also suggests that parents of children who are critically ill or injured experience a high level of stress, anguish, helplessness and aggravation due to role alteration and loss of control, creating a sense of helplessness (Shudy et al., 2006). This pattern of high stress is similar for parents of children with TBI (Hawley, Ward, Magnay, & Long, 2003; Wade, Taylor, Drotar, Stancin, & Yeates, 1996), which persists over time (Hawley, Ward, Magney & Long, 2003) and can be caused in part by reactions of other family members including partners (Wade et al., 2001) . Additionally parents of younger children can experience guilt for not protecting their child after a TBI (Savage, Depompei, Tyler & Lash, 2005).

This higher risk of psychological and physical health difficulties may in part be due to the high level of injury-related burden that parents experience (Rivara et al., 1996; Wade et

al., 2006). For example, one study found that in 31% of families at least one working parent gave up their job to take up caring responsibilities for the child, many had to buy additional aids, and fund travel to and from hospital (Hawley et al., 2003).

Not only do parents have to manage these additional burdens, but also their social implications. For example, in one study parents reduced their social activities by 79.3% (severe TBI group), 73.7% (moderate TBI) and 51% (mild TBI) (Hawley et al., 2003). This limits social contact and is likely to reduce emotional wellbeing (Caunt, Franklin, Brodaty, & Brodaty, 2013; Wang & Wong, 2014). Given that social relationships are helpful in managing difficult emotional experiences (Benn & McColl, 2004), parents are at risk of being left without key coping mechanisms at a time of high psychological distress.

Despite all of these difficulties, parents have an important role in their child's recovery, for example in facilitating coping (Marsac, Donlon, Winston, & Kassam-Adams, 2013). However, parents' ability to cope with what is a very challenging experience may be compromised. This may influence their ability to parent not only the child with ABI, but also any siblings. There is evidence that high parental stress can have detrimental effects on parental and child wellbeing as well as parent-child relationships (Crnic, Gaze, & Hoffman, 2005). Additionally other mental health difficulties can affect child outcomes such as psychological wellbeing (Oyserman, Mowbray, Meares, & Firminger, 2000), behavioural and social difficulties and problems at school (Fletcher, Ewingcobbs, Miner, Levin, & Eisenberg, 1990). Therefore, there is evidence of increased risk for children of parents experiencing difficulties. As such, it is important to understand the impact of having a child with an ABI on parents, not only to support their wellbeing but also to support the rehabilitation of the child with ABI and the psychological wellbeing of any other children in the immediate family.

In summary, the quantitative literature shows that paediatric ABI has significant implications for parents, which has the potential to affect the psychological wellbeing and coping of children in the family. It is therefore crucial that the experience of parents is understood in order to provide appropriate support. A body of qualitative research has explored parents' experience in depth but it is yet to be synthesised to inform development of appropriate support. Thus, this review will be completed in the form of a metasynthesis, which aims to enrich knowledge through synthesising the findings of research studies and producing additional interpretations (Noblit, 1988). Synthesising qualitative research is important as it provides a fuller and greater understanding of the phenomenon in question (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004) and has the potential to generate helpful results for informing practice. It moves beyond describing qualitative research in a narrative review to the reinterpretation of data in published studies (Britten et al., 2002). Metasynthesis also provides a way to systematically review the qualitative literature, as meta-analysis does the quantitative (Campbell et al., 2003). The aim of this metasynthesis is to increase understanding about the experiences of parents with a child with an ABI, from their own perspective.

Method

Design

This review uses a metasynthesis approach to answer the research question: What are the experiences of parents of children with an ABI? In order to find relevant papers the following eligibility criteria were developed and applied: (1) The paper described a research study using a qualitative approach; (2) The study focused on the experiences of parents of an individual with an ABI between 0 and 18 years of age[1]; (3) The study was published in

[1] One paper included two grandparents (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015)

English due to financial restrictions for translation; (4) The study was published in a peer-reviewed journal, thus offering quality assurance.

Studies were excluded when: (1) The views of parents could not be separated from the views of others (for example, partners); (2) The information was a thesis, dissertation or a book due to access restrictions and lack of quality control via peer review; (3) Papers included children with ABI acquired at the time of birth because the parents had no experience of their child prior to injury; (4) The focus of the research was just on the experience of an intervention rather than the general phenomenon of having a child with an ABI; (5) The paper did not specify the age of participants or included participants over 18.

Literature Search and Selection of Papers

After consultation with a specialist librarian, relevant literature was searched in three databases (PsycINFO, PubMed and Web of Science) on 17 March 2015. Search terms were identified by consulting relevant literature, specialists in neuropsychology and relevant organisation websites (e.g. The Child Brain Injury Trust, The Children's Trust and The UK Acquired Brain Injury Forum).

Searching covered combinations and variations of the terms: "qualitative", "parents" and "Acquired Brain Injury" (ABI). For example, to find qualitative papers, general terms such as qualitative or interview were utilised as well as specific approaches such as "narrative analysis" or "thematic analysis". To find papers related to parents, terms such as mother and father were included. For ABI terms included brain injury, stroke, brain haemorrhage and brain tumour. Appendix 1-C gives a full list of free text search terms. As well as free text searching, medical subject headings (MeSH in PubMed) or the thesaurus feature (PsycINFO) were used (see Appendix 1-D). Limiters were placed in databases when this was available such as "peer reviewed", "human subjects", or "English language" (Appendix 1-B).

The following number of papers were identified in each database: PsycINFO, 600; PubMed, 736; and Web of Science, 2544. Of a total of 3880 papers 815 were duplicates across databases. Therefore, the titles of 3065 papers were reviewed against the eligibility criteria and 2478 were excluded. The abstracts of 587 papers were then examined against the criteria, resulting in the exclusion of a further 370 papers. The full texts of the remaining 217 were read and 13 papers identified that met the inclusion/exclusion criteria. Further searching on google scholar and through references of relevant papers resulted in one further paper that met the criteria. Thus, 14 papers were included in the review. The systematic process of identifying papers is summarised in Figure 1.

INSERT FIGURE 1 ABOUT HERE

Characteristics of Included Studies

The 14 studies were published between 1997 and 2015 from five countries: Australia (n=4), UK (n=4), Sweden (n=3), USA (n=20) and Canada (n=1). Three studies included a range of ABI aetiology (Guerriere & McKeever, 1997; Menezes & Shinebourne, 1998; Ramritu & Croft, 1999), seven studies focused solely on TBI (Brown, Whittingham, Sofronoff, & Boyd, 2013; Clark, Stedmon, & Margison, 2008; Falk, von Wendt, & Klange, 2008; Kirk et al., 2015; Robson, Ziviani, & Spina, 2005; Roscigno & Swanson, 2011), four were focused on brain tumour (Forinder & Norberg, 2010; Jackson et al., 2007; Norberg & Steneby, 2009; Shortman et al., 2013), one study looked at hemiparesis (Meehan, 2005). When papers met the inclusion criteria but not all findings were relevant to the research question the data of interest were extracted. For example, information regarding parents' reactions was extracted from studies about brain tumours, but themes about managing cancer treatment were excluded.

Ten studies included both mothers and fathers although two did not specify respective numbers. Four studies looked only at mothers, one included two grandmothers (Kirk et al.,

2015). (Given that grandmothers made up less than 7% of participants this study was included.) The ages of children with ABI ranged from one month to 18 years; both genders were represented. Parents were interviewed up to 12 years post-injury but only one study included parents of children over 6 years post injury (Brown et al., 2013). Two papers used the same data to answer two different research questions. Given that these had a very different focus, both were included but caution was taken to avoid undue influence of these participants on the metasynthesis, as recommended by (Sandelowski, 2007).

In terms of data collection methods eleven studies used interviews, one a focus group and two open-ended questions in a questionnaire. All papers met the requirements for qualitative analysis as described by (Sandelowski & Barroso, 2015), which meant they used analysis that produced themes that were interpreted. The analysis process varied in the level of interpretation and data transformation from content analysis to phenomenological analysis. The aims of the papers included general exploration of experience and emotional responses, informational and/or support needs, coping and adjustment, challenges, experiences of post-trauma and existential issues. The papers varied in reporting of epistemological position but, from reading the papers, they all seemed to adhere to a broadly critical realist position and were judged similar enough to be synthesised. Table 1 summarises the demographic and methodological details of the papers.

INSERT TABLE 1 ABOUT HERE

Quality appraisal of papers

Only peer reviewed studies were included to ensure they met a minimum quality. However, in addition, the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2006) tool was used to assess quality (see Table 2 for CASP ratings). The

CASP is a 10 point assessment criteria for qualitative research which includes two screening questions and a further eight questions. For example: 'Was the recruitment strategy appropriate for the aims of the research?'; and 'Have ethical issues been taken into consideration?' The papers were rated out of three for each criterion giving a maximum score of 24. None of the themes were solely supported by relatively weak quality papers.

The synthesis process

The analysis was completed systematically according to Noblit and Hare's (1988) guidelines for a metaethnographic approach. This was chosen to allow for further interpretation of the concepts that other papers have identified in order to create additional insight and understanding. Every effort was made to preserve the meanings and concepts of the original studies (Silva, Cruz, Gouveia, & Capretz, 2013). The papers were read repeatedly to gain familiarity with the main concepts and metaphors. A summary of key concepts in each paper was produced along with details of study design. The relationship between studies was then considered, looking for recurring common concepts. Following that, the studies were translated into one another by checking the concepts and themes in each paper against each other to develop further understanding (see Appendix 1-E for an example of initial concepts/metaphors and contribution to final themes). (Britten et al., 2002) suggest using first and second order constructs (Schutz, 1964) as a way of distinguishing between everyday understandings that are participants' own reports (first-order) and constructs used by social scientists that interpret the participant data (second-order). Finally, the translations were synthesised to create new understanding or reinterpretations (i.e. third-order constructs). The process of interpretation of the third-order themes was discussed with my supervisors to ensure the themes are credible and coherent.

Results

Three themes emerged from the analysis: (1) Disconnection: Cut off from internal emotions and isolated from others; (2) Seeking understanding and support to manage in an insecure world; (3) New parent to a different child. Quotes from the original studies are used to evidence each theme.

Theme 1. Disconnection: Cut off from internal emotions and isolated from others

Disconnection was evident both in the way many parents managed their intense emotions and in their relationships with partners and other children. Parents were also left feeling socially isolated as others were unable to understand their experience.

Parents experienced intense and prolonged emotional reactions to their child's injury both immediately and years afterwards. This included depression (Kirk et al., 2015), anxiety (Guerriere & McKeever, 1997; Robson et al., 2005), stress (Roscigno & Swanson, 2011), anger (Brown et al., 2013; Meehan, 2005) and post-traumatic responses (Clark et al., 2008; Kirk et al., 2015) to such intensity that parents were left feeling emotionally exhausted. As one participant described: "at times the hurt can come on so instantaneously it takes my breath away...I sometimes wonder when I'm not going to be sad" (Meehan, 2005, p. 269). These emotions were so intense that parents often ignored or avoided them in order to cope (Brown et al., 2013; Forinder & Norberg, 2010; Roscigno & Swanson, 2011; Menezes & Shinebourne, 1998; Robson et al., 2005). Other coping strategies included alcohol or drug use (Ramritu & Croft, 1999). While such strategies were recognised as helpful in the short-term by some parents (Menezes & Shinebourne, 1998), as being disconnected from emotions meant they could manage the practical burden, they became detrimental in the long-term (Menezes & Shinebourne, 1998; Roscigno & Swanson, 2011).

Although some studies found that the couple relationship was crucial to coping and adjustment, for others the theme of disconnection was observed within family relationships. As the needs of the child with an ABI were prioritised (Norberg & Steneby, 2009), parents struggled to invest in other family relationships (Menezes & Shinebourne, 1998; Roscigno & Swanson, 2011). As a result, some reported conflicts in their couple relationship such as disagreements over parenting and behaviour management given their child's changed needs (Brown et al., 2013; Norberg & Steneby, 2009) or frustration at the couples' lack of reciprocal support or appreciation (Brown et al., 2013; Robson et al., 2005). This was exacerbated by different coping styles and reactions (Forinder & Norberg, 2010; Robson et al., 2005; Shortman et al., 2013).

Alongside the couple relationship, parents noticed the impact on their relationship with other children (Forinder & Norberg, 2010; Menezes & Shinebourne, 1998; Norberg & Steneby, 2009). Some recognised that they were forced to neglect siblings' needs at times (Forinder & Norberg, 2010) despite recognising their own distress at their sibling's ABI (Forinder & Norberg, 2010; Norberg & Steneby, 2009; Robson et al., 2005): "Everything revolved around Josh [affected child] and Josh's wellbeing, so for Andy [sibling] he was starting to get a bit cheesed off with it" (Shortman et al., 2013, p. 746). Even years post-injury, some parents felt they were more attentive to the child with ABI with a more intensive relationship, in contrast to emotional distance with the sibling (Forinder & Norberg, 2010; Norberg & Steneby, 2009), despite efforts to counteract this (Norberg & Steneby, 2009; Robson et al., 2005).

In contrast other parents talked about feeling more connected and closer as a family unit (Clark et al., 2008; Menezes & Shinebourne, 1998; Norberg & Steneby, 2009) because of their shared experience. For example, "now it's more like us, it feels like we are more we"

(Norberg & Steneby, 2009, p. 375). However, this intra-familiar closeness contrasted with wider disconnection, as parents felt isolated and detached from society (Clark et al., 2008; Kirk et al., 2015; Menezes & Shinebourne, 1998; Norberg & Steneby, 2009). They felt misunderstood or judged by friends, family and professionals who could not truly understand what it was like to be a parent of a child with an ABI (Brown et al., 2013; Forinder & Norberg, 2010; Guerriere & McKeever, 1997; Kirk et al., 2015; Menezes & Shinebourne, 1998; Robson et al., 2005; Roscigno & Swanson, 2011). For example, one parent explained that: The pain and loss we experienced …. was made so much worse by having no one to talk to who we felt understood (Menezes & Shinebourne, 1998. p. 287).

Some parents felt their child's difficulties were not recognised by family and friends because they were not obvious (Brown, Whittingham, Boyd, McKinlay, & Sofronoff, 2014; Kirk et al., 2015). Specific judgements about their child as manipulative or intentionally lazy were particularly difficult (Brown et al., 2013; Roscigno & Swanson, 2011). The resultant barriers to their child's full social participation made parents feel disillusioned, frustrated, dismissed and sometimes avoided by others (Brown et al., 2014; Clark et al., 2008; Roscigno & Swanson, 2011).

This lack of recognition was not limited to the impact on the child with ABI, as parents also experienced a lack of society's understanding of the impact of ABI on all the family (Kirk et al., 2015). As a result, many parents felt they did not fit or belong with parents without a child with ABI (Brown et al., 2013; Meehan, 2005). This meant that, although family and friends were important in helping some parents cope (Clark et al., 2008; Roscigno & Swanson, 2011; Shortman et al., 2013), for others, they were not able to provide emotional support as they could not connect with parents' experiences. For this reason, some parents wanted to connect with others in similar situations (Meehan, 2005; Menezes &

Shinebourne, 1998; Roscigno & Swanson, 2011). For example, talking to other parents on the ward was helpful for some (Robson et al., 2005) although not for others (Jackson et al., 2007), such as when survival and recovery was uncertain (Kirk et al., 2015). A lack of peer support opportunities within the community was noted (Brown et al., 2013; Roscigno & Swanson, 2011).

Sharing the emotional burden with professionals offered an outlet (Falk et al., 2008; Robson et al., 2005), and could be helpful in validating their experience (Clark et al., 2008; Falk et al., 2008; Ramritu & Croft, 1999). However, some parents felt that professionals did not understand the social and cultural factors that affect families and their unique perspectives as they focused on a narrow medical approach rather than a holistic view (Clark et al., 2008; Roscigno & Swanson, 2011). This meant that professionals often missed what was important to families. Some parents sought counselling but opinions varied on its necessity and provision for this also varied (Ramritu & Croft, 1999).

Theme 2. Seeking understanding to manage in an insecure world

This theme reflects parents' need to obtain stability and security in an unstable and frightening situation. They sought to understand the situation and ensure their child received appropriate care.

Having a child with ABI resulted in fear and anxiety, initially due to uncertainty of the child's survival (Brown et al., 2013; Falk et al., 2008; Kirk et al., 2015). This was often followed by immense relief and gratitude on realising their child was alive, for example on regaining consciousness (Brown et al., 2013; Guerriere & McKeever, 1997; Ramritu & Croft, 1999). However, this was often mixed with shock, confusion, and devastation upon realising the extent of the ABI (Guerriere & McKeever, 1997; Menezes & Shinebourne, 1998; Ramritu

& Croft, 1999; Shortman et al., 2013). This realisation happened over time as parents came to recognise the extent of and permanence of ABI (Clark et al., 2008; Roscigno & Swanson, 2011). Additionally parents expressed fears about the future for their child (Brown et al., 2013; Falk et al., 2008; Meehan, 2005): how the ABI would affect them (e.g. academically, Shortman et al. 2013) and how society would accept them (Meehan, 2005; Menezes & Shinebourne, 1998).

Parents' fears and uncertainty were experienced in the context of re-evaluating core values, views, priorities and fundamental assumptions about life (Forinder & Norberg, 2010; Guerriere & McKeever, 1997; Norberg & Steneby, 2009; Robson et al., 2005). Parents were confronted with ideas that life is unpredictable, unstable and dominated by fate (Forinder & Norberg, 2010; Guerriere & McKeever, 1997; Menezes & Shinebourne, 1998). For example,

> I think until something horrible happens to you, you kind of go through life thinking you have a bit of control and you think, if I am a good person and I try hard, and I work hard and I look after everybody and I try to be a good mother, things will go pretty well. But it doesn't work like that. Your stability goes out the window and what you've always based your life on you can't do it anymore because it's not there anymore (Guerriere & McKeever, 1997)

Parents attempted to manage their anxieties, uncertainties and changes in life perspective by considering themselves lucky that their child survived (Brown et al., 2013) or by breaking down rehabilitation into small manageable milestones (Menezes & Shinebourne, 1998; Robson et al., 2005). This likely provided some containment to their anxiety and uncertainty. Parents were also assisted in managing uncertainty by consistency in staff caring for their child (Jackson et al., 2007; Kirk et al., 2015; Menezes & Shinebourne, 1998), which was important in building relationships (Ramritu & Croft, 1999; Robson et al., 2005). Trust

and a feeling that staff cared were important elements of this for some parents (Jackson et al., 2007; Kirk et al., 2015; Menezes & Shinebourne, 1998; Roscigno & Swanson, 2011). This linked to parents' need to ensure that their child was receiving quality care. There seemed to be particular anxiety and criticism of care at times of increased uncertainty, such as transition from higher staffed intensive care wards to less intensive and difficult to access community services (Clark et al., 2008; Kirk et al., 2015; Menezes & Shinebourne, 1998; Robson et al., 2005; Roscigno & Swanson, 2011).

As part of quality of care, many parents stressed the need for information and understanding (Falk et al., 2008; Kirk et al., 2015; Meehan, 2005; Menezes & Shinebourne, 1998; Robson et al., 2005; Roscigno & Swanson, 2011). This included information about ABI (Falk et al., 2008), medical procedures (Clark, Stedmon, & Margison, 2008; Falk et al., 2008), prognosis (Brown et al., 2013), support available (Brown et al., 2013; Falk et al., 2008; Menezes & Shinebourne, 1998; Shortman et al., 2013), behaviour management (Brown et al., 2013), as well as practical issues such as car parking (Jackson et al. 2007). However, parents in Jackson et al's study (2007) recognised a conflict between receiving and not receiving information, as both could cause exasperation and fear. For example, "You want all the information. But you don't want to know either" (Jackson et al., 2007, p. 100). Knowing typical emotional responses was also seen as helpful: "well it's like, your feelings change all the time, from day to day, even from minute to minute at the beginning. It would have helped to know that what we felt was 'normal' not 'madness" (Menezes & Shinebourne, 1998, p. 288). These information needs were particularly important as many parents had little or no prior knowledge of ABI beyond television shows, which led to confusion (Kirk et al., 2015). When information needs were met, parents reported feeling relief and reassurance and

were less frustrated, fearful and apprehensive (Jackson et al., 2007; Ramritu & Croft, 1999; Shortman et al., 2013).

It was essential that information was accessible so parents could understand the language and have the opportunity to ask questions (Kirk et al., 2015). Unfortunately, many felt that the information provided was insufficient (Kirk et al., 2015; Meehan, 2005; Roscigno & Swanson, 2011) and some believed staff felt they would not understand or did not require the information (Ramritu & Croft, 1999). The parents in Roscigno & Swanson's (2011) study increasingly accessed independent sources of information including books, the internet and talking to other parents.

Parents also stressed the importance of when and how information is delivered as heightened emotions made it difficult for parents to absorb information (Jackson et al., 2007; Kirk et al., 2015; Shortman et al., 2013) Written information was helpful for this reason and telephone access to ask questions once information had been processed (Brown et al., 2013; Shortman et al., 2013). Many parents responded positively when information was given honestly, sensitively but frankly with empathy and compassion (Jackson et al., 2007; Kirk et al., 2015; Menezes & Shinebourne, 1998). Uncertainty about prognosis or when professionals were proved incorrect led to increased stress (Clark et al., 2008; Robson et al., 2005; Roscigno & Swanson, 2011). On the other hand, parents wanted acknowledgement of the uncertainty and respect for their parents' need to maintain hope and positive thinking (Guerriere & McKeever, 1997; Norberg & Steneby, 2009; Robson et al., 2005; Roscigno & Swanson, 2011). Information tailored to parents' needs seemed important in facilitating understanding and reducing uncertainty.

Theme 3. New parent to a different child

Most of the papers discussed the need to adjust to being parents to a changed child. Along with grieving for the 'lost' child, parents tried to understand their new child and changed relationship.

A common finding was parents' pain and grief of the loss of the past child due to changes in cognitive ability, behaviour, personality and temperament. For example, "This is not the same kid that went into the coma. Where is that…that used to be mine? He's not there, he's gone. And the bottom line is you almost treat it like a death. That child is no more… You have to go through a grieving process. You have to let go of what you had because he'd not the same child. His name is the same, he may look the same, he may not look the same. That's what really happens, is this huge sense of loss, just sometimes overwhelming sense of loss' (Guerriere & McKeever, 1997, p.109).

At first parents in Ramritu and Croft's study (1999) were aiming for maximum if not complete recovery. However, many parents realised that the changes were most likely to be permanent (Roscigno & Swanson, 2011) and that their child was profoundly different from the pre-injury child (Guerriere & McKever, 1997). The pain of this realisation was only ever partially or temporarily relieved (Menezes & Shinebourne, 1998). The impact of ABI often became apparent on arrival home (Kirk et al., 2015). At this point, parents had to begin to adapt to a new and different child (Clark et al., 2008; Kirk et al., 2015; Menezes & Shinebourne, 1998) and adjust their expectations of their child's future (Meehan, 2005; Roscigno & Swanson, 2011). A parent in Meehan's study (2005) described realising that "This isn't going to go away. This is going to be a lifetime. There is nothing that is going to fix this" (p. 267). As a result, some parents felt robbed of the child's potential and idealised the pre-injury, "perfect child" (Brown et al., 2013; Menezes & Shinebourne, 1998; Roscigno

& Swanson, 2011). However, other parents reported their child's recovery met their expectations, which supported the grieving process (Roscigno & Swanson, 2011).

Given the changes in the child, some parents reported the need to reconstruct another view of their child (Guerriere & McKeever, 1997; Kirk et al., 2015). For example, they sought to understand the reason for behaviour, whether it could be attributed to the ABI, associated trauma, developmental stage or other life stresses (Brown et al., 2013). In response parents altered their own behaviour and communication to try and compensate for their child's deficits (Guerriere & McKeever, 1997). Some felt that if they could not understand their child it was stressful and confusing (Brown et al., 2013) and greater emotional support was needed (Kirk et al., 2015).

Many parents also reported a changed relationship with their child (Clark et al., 2008; Guerriere & McKeever, 1997; Norberg & Steneby, 2009; Robson et al., 2005). For some this meant a rupture and insecurity in their relationship, feeling like strangers to each other. However, others felt they had become closer to their child due to the time spent together and enhanced mutual appreciation.

Parents had to adjust to a new way of relating to their child, for example, by finding behaviour management strategies for unpredictable behaviour (Brown et al., 2013; Forinder & Norberg, 2010). Coping with behavioural changes was reported in Kirk et al.'s (2015) study as the most concerning in which parents felt unsupported. Parents also recognised that their own fatigue and emotional experiences (see theme 1) made it harder to be consistent, provide structure and have time to teach their child new skills (Brown et al. 2013). Parents reported a level of over-protectiveness, particularly if told by professionals to be extra careful or watchful early in recovery (Kirk et al., 2015; Robson et al., 2005). Parents often felt

uncertain about promoting independence versus protecting from discomfort or pain (Brown et al., 2013; Kirk et al., 2015).

The new parent-child relationship involved many new roles while maintaining their parental role. Brown et al.'s (2013) study identified a loss of their parenting role within the hospital environment. Being involved in care and decision-making reinforced the parent role and contributed to increasing confidence and ability to cope and reduced stress and anxiety. (Falk et al., 2008; Jackson et al., 2007; Kirk et al., 2015; Ramritu & Croft, 1999; Robson et al., 2005). However, some parents preferred not to be involved in specific care provision, for example bathing a child with intravenous therapy, or in specific decision-making, deferring to clinicians' expertise (Kirk et al. 2015; Ramritu & Croft (1999).

As the child progressed, parents took on increasing responsibility (Kirk et al., 2015), sometimes in quasi-professionals roles (Clark et al., 2008; Norberg & Steneby, 2009; Roscigno & Swanson, 2011). This included acting as trainers to coach new skills and teachers to support with homework, taking on social work and advocacy roles by reorganising and networking services and managing legal proceedings and benefits (Brown et al., 2013; Meehan, 2005; Menezes & Shinebourne, 1998; Roscigno & Swanson, 2011) and acting as medical assistants in observing symptoms and administering medication. They were also therapists, handling difficult questions and children's responses as well as interpreters for the wider family, friends and community. Some parents reported feeling inadequate in these unfamiliar roles due to uncertainty about techniques (Norberg & Steneby, 2009) or a fear of injuring the child (Menezes & Shinebourne, 2015). The mothers in Shortman et al.'s study (2013) described drawing on their sense of responsibility of being a mother to give them the strength to cope.

Discharge was an important time in adapting to being a different parent but one that came with conflicting emotions (Robson et al., 2005):

> You feel so alone and you feel, like I say, you're dealing with all this stuff that you've not got a clue really what you do, you know what I mean…it's like have you got a manual for this child? Because I don't know who he is and I'm trying to look after him and, as far as they was concerned, they'd sent him home…you just feel so alone and you're with this child that you don't really know what you're dealing with' (Kirk et al., 2015, p. 308).

For some parents this meant giving up work and becoming a full-time carer (Brown et al., 2013; Guerriere & McKeever, 1997). To help adopt these daunting roles, parents reported a number of helpful interventions. For example, trial periods at home before complete discharge and staff providing appropriate information, which decreased anxiety and increased confidence (Kirk et al., 2015; Ramritu & Croft, 1999; Robson et al., 2005).

Discussion

This review highlights the challenging nature of parents' experience of having a child with ABI including social isolation, the insecurity of the situation and the challenges of adjusting to different roles required in parenting a changed child. The use of metasynthesis has enabled the experience of a larger number of parents to be brought together and highlighted unmet needs. It may offer greater depth and understanding to the quantitative literature. For example, we know that these parents experience anxiety and depression but this review offers some understanding as to why this might be, such as the high levels of uncertainty, isolation and difficulties with social relationships. It also identifies shared experience over different types of ABI. The findings of the themes will be discussed in the context of relevant literature.

In the theme of disconnection: cut off from emotions and isolated from society, it was clear that parents had to find a way to manage their intense emotional experiences, with some disconnection in order to cope. This has some parallels with the emotional numbing that can occur after a trauma (Ehlers & Clark, 2000). Use of distancing and avoidance as a defence against overwhelming emotional experiences has been found to be more likely when parents are experiencing high levels of stress (Mednick, Gargollo, Oliva, Grant, & Borer, 2009).

Parents reported feeling isolated and different from others which was compounded by the lack of society's understanding. Social support is importance for resilience (Christie & Khatun, 2012) and the quantitative literature suggests that parents' social activity is reduced (Hawley et al., 2003). This may be due to burden, but the current findings also suggest that parents have difficulty connecting with others who do not understand and feel alone. While high levels of distress and trauma echo experiences of having a child with any chronic illness (for example, Norberg, Lindblad, & Boman, 2005) the high levels of disconnection from others does seem more salient for these parents. This occurred, even when attending community groups for parents of children with a developmental disorder, which suggests there is something distinct about the ABI experience.

The second theme of seeking understanding to manage in an insecure world, reflects quantitative findings of parents of children with chronic illness needing normality and certainty (Fisher, 2001). This suggests common themes across paediatric chronic health conditions. In this review parents' need for information contrasted with the reality experienced by many parents. This is reflected in the quantitative literature where one study found 42% of parents of moderate and 34.5% of parents of severe TBI reported they did not receive enough information and of those that did receive information only around half found it helpful (Hawley et al., 2003). This might reflect parents' views in this metasynthesis of the

need for information to be accessible in how and when delivered. In addition, memory for medical information is generally poor; patients forget 40-80% of medical information immediately (Kessels, 2003). When combining this with parent's extreme distress, it is not surprising that they have difficulty absorbing information. The quantitative literature demonstrates the information needs of parents (for example, Hawley et al. 2003), but the current findings demonstrate how delivery interacts with parents' coping mechanisms, such as the need to maintain hope. The current findings add understanding to the current literature about parents' informational needs with paediatric chronic illness (e.g. Hummelinck & Pollock, 2006) as it demonstrates why these needs are so significant in the context of extreme uncertainty. Information assisted parents in anchoring themselves throughout the uncertainty.

As in other paediatric illnesses (e.g. leukaemia; Patistea & Babatsikou, 2003) parents reported that professionals were often too focused on physical health and neglected psychosocial implications. This suggests a predominant biomedical model and there might be benefit from application of bio-psycho-social models which encompass more holistic understanding of a family. For example, the three resilience models for paediatric chronic illness discussed by Mullins and colleagues (2015), include Wallander and colleagues, Disability-stress-coping model (Wallander, Varni, Babani, Banis, & Wilcox, 1989), Thompson and collegues Transactional Stress and coping model (Gustafson, Gil, Kinney, & Spock, 1999) and Kazak et al.'s social ecological model (Kazak, 2006). All of these adopt a wider systemic understanding of the child's coping to include interpersonal, in addition to intrapersonal, variables. The findings of this review support these approaches as all the themes highlight the importance of family's interactions with each other, professionals and wider society

The experiences described in the final theme of adjusting to being a parent to a different child and the loss of the child they knew, seemed more prominent for parents of children with ABI than other chronic illnesses. The experiences of loss of the child as they once were seemed to be consistent with the concept of episodic sorrow (otherwise known as chronic sorrow; Hewson, 1997; Roos, 2013) , which has been developed to understand an individual's repeated, long term distress when an family member has lost significant cognitive ability (Hewson, 1997). This study adds to the understanding of this concept as it highlights the experiences of parents of children with a wide range of acquired difficulties. The quantitative literature highlighted the significant burden that parents experience in their caring role after paediatric ABI (Hawley et al. 2003). However, this review highlights the wide range of these new roles and associated burden. Many parents of other chronic conditions may identify with increased roles and adaptation to parenting styles and in some cases, a changed child in their emotional wellbeing and physical health. However, after ABI there are additional cognitive and neuro-behavioural changes, associated relationship changes, and greater loss of the child's previous identity.

Limitations

There are a number of limitations of this metasynthesis. First, although the results were drawn from participants from five countries, this only included economically developed counties with arguably similar socio-cultural backgrounds. This may be in part due to the restrictive inclusion criteria of English language articles. Even when studies reported the cultural background, the ethnic origin was predominantly white, for example four white women and one from an Asian background (Meehan, 2005). The results may not therefore apply to parents from different cultural backgrounds. Second, the predominance of mothers might bias the results towards maternal experiences. This requires further research

specifically looking at fathers' experiences, especially given some parents highlighted differences in coping styles between mothers and fathers.

Thirdly, there was variety in the breadth of studies such as the age range of children, time since injury and ABI aetiology. The age of children at onset ranged from early infancy up to 18 years old, which will have different implications. However, all of these parents are still parenting a child who, in the western cultural framework, is usually dependent on them, although in different ways. Time since injury also varied, and it is recognised that parents interviewed early post-onset might have different reflections to those years post-injury. However, to understand parents' experience it is important to gain their perspectives along the entire journey and this research has added to the depth of the analysis and themes. The range of types of ABI has also added to the richness of the analysis, however half the studies focused on TBI, so may be biased towards this sub-group.

Clinical Implications

This research emphasises the need to support parents through this traumatic and overwhelming experience, not only initially and during acute care but through discharge and in the community. There is a clear need for professionals to recognise the emotional journey of parents. This includes the need for time and space to grieve which was not always supported by professionals (Ramritu & Croft, 1999). This suggests that parents' grief needs to be acknowledged and validated to support this process and reduce feelings of guilt. There is also an argument for suitably trained professionals to provide emotional containment as some parents thought nurses were either too busy or not appropriately trained to respond to their needs. This could involve training nurses directly or other professionals groups such as clinical psychology providing direct support or supervision to ward staff.

This review suggests that interventions for parents might be beneficial. Interventions are being provided and evaluated, both generally in paediatric chronic illness and specific to ABI. However, both Anderson and Davis (2011) and Mororawski and colleagues (2012) highlight the limited choice of evidence-based interventions for parents caring for a child with a chronic illness, particularly psychosocial interventions. The findings of this research support Anderson and Davis's (2011) argument for the need for more research and development of interventions.

On reviewing the chronic illness literature, Mororawski, Calam and Fraser (2012) recommend that parenting interventions should include linking the illness with a child's behavioural and emotional adjustment, as well as with parenting strategies. They also emphasise the importance of addressing parents' information needs. Both of these recommendations are supported by the findings of this review. However, it is important to recognise that parents of children with ABI have distinct needs, as discussed previously, which may require specifically tailored interventions. Such interventions have showed significant benefits for children and parents (for example, Brown et al., 2014; Wade, Wolfe, & Pestian, 2004).

An important outcome from this metasynthesis was that not all parents had the same needs, for example information content and when and how delivered. Additionally, the needs of parents changes over time. It is therefore important that clinicians recognise these differences and respond to parents' individual needs. This includes the provision of information specific to ABI. Given that parents report feeling not understood as an isolating experience, access to professionals that understand ABI is important, especially in the community. It also suggests greater training in the wider professional community about the implications of ABI (for example, in schools). Not only did parents report the need for

services to understand them, they also sought connection with other parents, which suggests there is an unmet need for specialist peer support groups.

Future research

The studies in this metasynthesis only included papers where all participants were less than 18 years old. However, during the searching process, it was noted that a number of papers focused on children and young adults up to 35 years old (Gebhardt, McGehee, Grindel, & Testani-Dufour, 2011; Jordan & Linden, 2013). Given that western cultures are changing and young people live with parents for longer (Office of National statistics, 2014), it would be interesting to compare the findings with parents of young adults. Additionally, given the lack of fathers involved in the current research, it is also important to develop the literature specifically focusing on their experience.

Most importantly, this review has highlighted significant unmet need for parents, and provides further evidence of the need to explore effective ways of supporting these parents and evaluating existing interventions. It appears from these findings that these interventions are not widely provided, although it is recognised that circumstances may have changed since these research projects.

Conclusion

This review paper adds important understanding to the experience of parents of children with ABI. More specifically the findings add to the quantitative literature by demonstrating why this experience is so challenging as it requires significant adaptations to parents' relationships with themselves, their child, and their family and wider society. Parents' perspective that others did not understand their experience has the potential to leave parents feeling isolated and unsupported throughout managing this overwhelming experience.

The findings therefore suggest that there is significant unmet need for support, and indicate a need for more research and evaluation of interventions for these parents.

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Tables and Figures

Figure 1. Flow diagram showing process of determining eligibility of papers

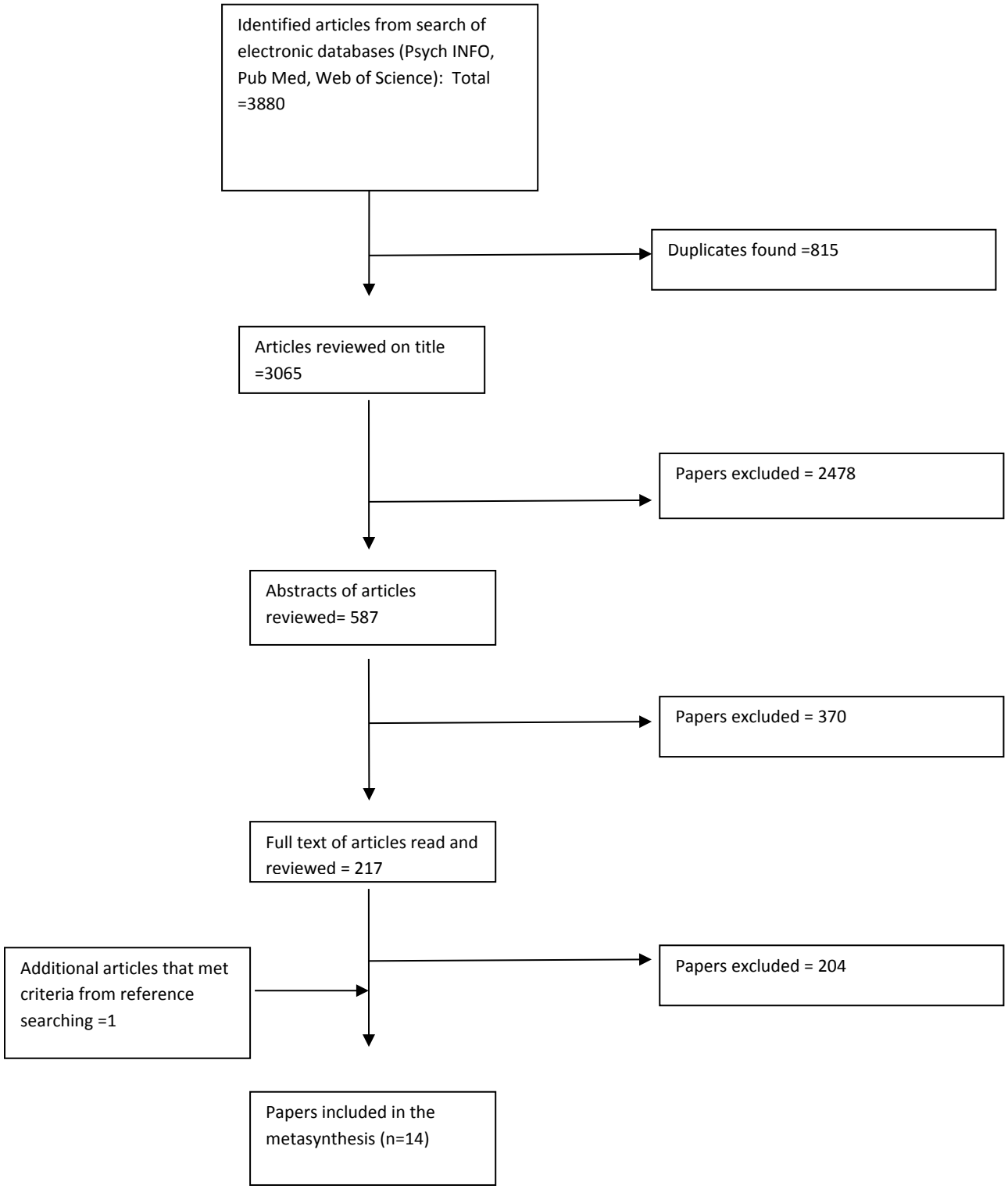

Table 1: Overview of included studies

Author/ Year	Aim of study	Method of data collection	Method of analysis	Current age / sex of child	ABI type	Time since onset	Mothers / Fathers	Country
Guerriere & McKeever (1997)	To explore how mothers come to terms with the multiple changes that occur in children who sustain sudden brain injuries	Open-ended interview	Descriptive analysis (symbolic interactionism)	3-13 years : 2 female, 5 male	Mixed ABI	1-2 years	Mothers 7	Canada
Menezes & Shine-bourne (1998)	To identify the short and longer term needs of parents whose children sustain severe brain injury after cardiac surgery and to determine what further measures could be of use to the family after such a catastrophe	Semi-structured interviews	Analysed using techniques from (Coffey, 1996)	Does not specify age but specifies 'children'	Mixed ABI	Not reported	Mothers 8 Father 3	UK

Author/ Year	Aim of study	Method of data collection	Method of analysis	Current age / sex of child	ABI type	Time since onset	Mothers / Fathers	Country
Ramritu & Croft (1999)	To identify needs of parents of children with ABD, admitted to a metropolitan tertiary referral paediatric hospital throughout the continuum of care	Semi-structure interviews	Content analysis	6 wks-14 yrs 5 female 23 male	Mixed ABI	1.5 years-3.5 years Mean=2 years	27mothers 7 fathers	Australia
Robson, Ziviana & Spina (2005)	To explore the experiences and perceptions of parents of children with TBIU in the transition from hospital to home	Semi-structured interview	Thematic content analysis	4.5-10.5 yrs	TBI	Approx. 6months	Parents: 5 females 1 male	Australia
Meehan (2005)	To describe the experience of mothering 3 to 6-year-old children with hemiparesis	Unstructured interviews	Colaizzi's method-phenomenology	3 to 6yrs	Hemi-paresis	Not specified	Five mothers	US

Author/ Year	Aim of study	Method of data collection	Method of analysis	Current age / sex of child	ABI type	Time since onset	Mothers / Fathers	Country
Jackson et al. (2007)	To explore coping adaptation and adjustment in families of a child with a brain tumour.	2 open ended questions in questionnaire	Thematic analysis (Creswell, 1994)	Under 18 yrs	Brain tumour	4 time points (dx to 2yrs post)	53 parents Genders unknown	Australia
Clark, Stedmon & Margison (2008)	To explore the nature and quality of family members emotional responses and any change in the family and clinical relevance of different psychological theories.	Semi-structured interview	Interpretive phenomenology cal analysis	11- 16 years 10 male	TBI: 7 Moderate / severe 7, Unclear 3	2-6 years	Mothers 10	UK
Roscigno &Swanson (2011)	To describe the common experiences of English speaking parents of children with TBI.	Two semi-structured interviews	Descriptive phenomenology cal framework	8-20 years Gender un specified	TBI: Moderate 13. Severe	4 months – 3 years.	34mothers 8 fathers	USA

Author/ Year	Aim of study	Method of data collection	Method of analysis	Current age / sex of child	ABI type	Time since onset	Mothers / Fathers	Country
Falk, Wandt & Kiang (2008)	To characterise the informational needs of parents & compare these to previously determined needs of parents whose children have suffered more serious injury	Questionnaire with one open ended question	Content analysis (Krippendorff, 2012; Weber, 1990)	1mth-15 yrs 24 female 33 male	Mild head injury	3 months after the injury	57 parents Does not specify gender	Sweden
Norberg & Steneby (2009)	To capture a panorama of parents experiences of post-traumatic influence	In-depth interviews	Inductive thematic analysis	7-14 years	Brain tumour	Off treatment for 20-38 months	7 mothers 7 fathers	Sweden
Brown, WhittinghamSofronoff & Boyd (2013).	To add to the current understanding by further exploring the experiences, challenges and needs of parents of children with ABI.	Small focus group discussions of structured questions.	Transcribed > inductive thematic analysis	5-17 years 2 female,6 male	TBI : moderate, 4, severe 4	2-12 years	Mothers 7 (mother 1) Fathers / step-father 2	Australia

Author/ Year	Aim of study	Method of data collection	Method of analysis	Current age / sex: child / YA	ABI: Type (& severity)	Time since onset	Mothers / Fathers	Country
(Shortman et al., 2013)	(1) To explore the impact of having a child with a brain tumour on the main caregiver: (2) to describe their experiences of coping with the child's illness: (3) to identify causes of stress and sources of support	Semi-structured interviews	Type of analysis not specified but coded into themes	8-13	Brain tumour	27 months from diagnosis	All mothers	UK
Kirk, Fallon, Fraser, Robinson &Vasallo, (2014)	To examine parents experiences & support needs following a childhood TBI boost during the initial stages of recovery in hospital the following discharge home	Semi-structured interviews	Semistructured interviews Framework approach (Ritchie et al. 2003)	3-18 years Female=13 Male =6	TBI	6 months to 72 months Mean= 33	29 Parents 18mothers 9 fathers 2 grand-mothers	UK

Table 2. Assessment of Study Quality Using the CASP Qualitative Appraisal Tool

Study	Research design	Sampling	Data Collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total score
Guerriere & McKeever (1997)	3	3	3	2	3	3	3	3	23
Menezes & Shineboune, (1998)	3	3	3	2	2	3	3	2	21
Ramritu & Croft (1999)	3	3	3	2	2	1	3	3	20
Robson, Ziviana & Spina (2005)	3	3	3	3	3	3	3	3	27
Meehan (2005)	3	3	3	2	2	2	3	3	21
Jackson et al. (2007)	3	2	3	2	3	3	3	2	21
Clark, Stedmon & Margison (2008)	3	3	3	3	3	3	3	3	27
Falk, Wandt & Kiang (2008)	3	3	3	2	2	3	3	3	22
Norberg & Steneby (2009)	3	3	3	2	3	3	3	3	23
Kirk, Fallon, Fraser, Robinson and Vasallo, (2014)	3	3	3	2	3	3	3	3	23

Forinder & Norberg (2010)	3	3	3	2	3	3	2	3	22
Roscigno & Swanson (2011)	3	3	3	3	2	3	3	3	23
Brown, Whittingham, Sofronoff & Boyd (2013).	3	3	3	2	3	3	3	3	23
Shortman et al., (2013)	3	3	3	2	3	2	3	3	22

(1) = weak, (2) = moderate, (3) = strong evidence

Appendix 1-A. **British Journal of Health Psychology**

Instructions for authors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

• papers reporting original empirical investigations, using either quantitative or qualitative methods;

• theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;

• review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and

• methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

• the content of the paper falls within the scope of the Journal

• the methods and/or sample size are appropriate for the questions being addressed

• research with student populations is appropriately justified

• the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

• Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

• The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book.* City, Country: Publisher.
Author, A. (2013). Title of journal article. *Name of journal, 1,* 1-16. doi: 10.1111/bjep.12031

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

• Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

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10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour

in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe's web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights.* Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper?

Appendix 1-B. Additional Limiters in each database

Database	Limiter
Psyc Info	Peer reviewed
	Human Subjects
	English
Pub Med	Human Subjects
	English
Web of science	English

Appendix 1- C. Free Text Search Terms

Free text Search Terms
Qualitative OR "Grounded Theory" OR “Narrative Analysis” OR “Thematic Analysis” OR Experience OR "content analysis" OR ethnog* OR "Interpretative Phenomenological Analysis" OR "Discourse Analysis" OR "Framework Analysis" OR "Conversational analysis"
AND
“Acquired Brain Injury” OR "Brain Damage" OR "Traumatic Brain Injury" OR Meningitis OR Encephalitis OR "Hypoxic brain injury" OR "Anoxic Brain Injury" OR "Brain Injury" OR Stroke OR "Arteriovenous Malformation" OR Aneurysm OR "Brain Haemorrhage" OR "Cerebral Haemorrhage" OR Asphyxiation OR Suffocation OR "Brain Tumo*" OR "Cerebral Tumo*" OR “Brain Neoplasm” OR Neurosurgery OR “Head Injur*” NOT Alzheimer OR “Cerebral Palsy” OR Parkinson OR Dementia OR “Multiple Sclerosis” OR “Neurodegenerative Disorder” OR “Amyotrophic Lateral Sclerosis”
AND
Parent* OR Mother* OR Father* OR Mum OR Dad OR Caregiver* OR Family OR Families

Appendix 1-D. Additional thesaurus terms and MeSH headings

Database	Area of searching	Thesaurus term/ MeSH heading
Psych INFO	ABI	Brain damage Brain neoplasms Encephalitis Hydrocephalitus Aphasia Cerebrovascular accidents Meningitis Anoxia Respiratory distress Neurosurgery
	Parent	DE "Parent Child Relations" OR DE "Family Relations" OR DE "Parenting" OR DE "Father Child Relations" OR DE "Mother Child Relations" OR DE "Parental Involvement" OR DE "Parental Role" OR (DE "Parents")
	Qualitative	Qualitative research
Pub med	ABI	Brain Diseases

		Brain Injuries Brain Injury, Chronic Head Injuries, Penetrating Brain Damage, Chronic Hypoxia, Brain Stroke Encephalitis Brain Neoplasms Asphyxia Head Injuries, Closed Neurosurgery Brain Hemorrhage, Traumatic Cerebral Hemorrhage, Traumatic
	Parent	Qualitative research
	Qualitative	Parents

Appendix 1-E. **The synthesis process: Example of initial notations/ metaphors for one paper and how they fit into each overall theme**

Author	Theme 1. Disconnection: Cut off from internal emotions and isolated from others	Theme 2. Seeking understanding and support to manage in an insecure world	Theme 3.New parent to a different child
Roscigno & Swanson (2011)	Experiences of trauma; full of worry, confusion, chaos and state of shock Emotionally difficult to the extent of entertaining suicidal thoughts Everything centred around injured child therefore unable to meet their own needs and needs of others Difficult to maintain level of care for sibling and forced to neglect some of	The way diagnosis conveyed is crucial to coping Doubts about future independence- possibility need tangible and emotional support for many years to come Basic sense of security had been disrupted as now worry that anything can happen to anyone at any time. Seeking support from professionals is	Feeling empty and sad in conflict with their child being alive The child is a shadow of their former self- Experiencing loss of child before illness Childs situation demanded a lot of parenting skills Increasing roles with include comforting and supporting injured child's anxiety

	their needs including increased emotional needs due to the injury leading to emotional distance experienced with siblings	important to Need for crisis intervention and information early including a sense of what to expect feelings	and dep. Changed child leads to worry about the future – prospects of growing up to be a fully independent adult (educational and vocational issues- romantic relationships/ having children and being a parent).

Section 2: Research Paper

Exploring the lived experiences of the sibling relationship after a paediatric acquired brain injury

Emma Tyerman

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

2012 Intake

Word count: 7998 (excluding title pages, references, tables and figures and appendix)

Prepared for submission in the British Journal of Health Psychology (See Appendix 2-A for journal guidelines)

Exploring the lived experiences of the sibling relationship after a paediatric acquired brain injury

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[1]Lancaster University

Word count (exc. figures/tables): 7998

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Acknowledgements

Statement of contribution

What is already known on this subject?

- Evidence suggests that siblings of children with an ABI experience a range of difficulties such as emotional and behavioural problems, increased obsessive-compulsive thinking and lowered self-esteem.
- Sibling relationships are important for social and emotional development.
- The literature indicates a need to support parents of children with ABI and the potential impact such trauma may have on parent-sibling relationships.

What does this study add?

- These findings expand understanding about the unique lived experience of younger siblings (aged 9-12) of children with ABI.
- The findings demonstrate siblings' significant challenges and trauma and their perspective on needing to adapt to a changing sibling relationship while also feeling disconnected from their family. This raises concern that siblings are vulnerable without the full support of family which has the potential for long-lasting impact.
- The findings suggest a need for service support for siblings, providing interventions to involve them in their brother/sister's care and rehabilitation, cope with trauma and provide information to validate and understand their experience.

Abstract

Purpose. Acquired brain injury (ABI) is internal or external injury to the brain, which often results in considerable physical, cognitive and psychosocial difficulties. Child ABI has significant impact on the family including siblings. This study aimed to explore siblings' experiences of their relationship with their brother or sister with ABI.

Method. Semi-structured interviews were conducted with five siblings of children with ABI aged between nine and twelve and analysed through Interpretative phenomenological analysis.

Results. The analysis resulted in four themes: (1) Coping with "a nightmare that you live"; (2) Disconnection from family relationships; (3) My sibling is different but "still the same underneath all this thing"; and (4) Changing togetherness.

Conclusion. The siblings in this study experienced a high level of distress with the near loss of their brother or sister. This is followed by difficulty in adjusting to the physical and psychological changes in their injured sibling and the impact on their sibling role and relationship. The changes were experienced alongside disruption to family relationships. Important clinical implications include the inclusion of siblings in their injured sibling's care and the provision of information and support for this group.

Key words: ABI, Acquired Brain Injury, Siblings, Experience, Qualitative, IPA

Acquired brain injury (ABI) is acute damage to the brain. This can include trauma due to a head injury (known as traumatic brain injury; TBI), surgery or a stroke, cerebral anoxia (lack of oxygen supply to the brain), infection or inflammation (Royal College of Physicians & British Society of Rehabilitation Medicine [RCP, BSRM], 2003). A significant number of children experience ABI annually, for example the number of children experiencing a TBI alone is estimated to vary between 280 to 1,373 per 100,000 internationally, depending on the inclusion of hospital and GP visits or just hospital admissions (McKinlay & Hawley, 2015). In the UK, approximately 35,000 children have a brain injury annually (NHS, 2013/2014).

Resulting difficulties include physical problems, cognitive impairments and behavioural difficulties (Cole et al., 2008; Hawley, 2003; RCP, BSRM, 2003; Schwartz et al., 2003). Children with ABI are at high risk of anxiety, depression, obsessive-compulsive behaviours and social difficulties (Grados et al., 2008; Green, Foster, Morris, Muir, & Morris, 1998; Hawley, 2003; Max et al., 2013; Max et al., 1997; Vasa et al., 2002). The individual effects of ABI vary due to differences in type, severity, age, pre-morbid functioning and social and family circumstances (Middleton, 2005; Teeter, 1986). However, there is often significant impact on families (for example, Rivara et al., 1996). The literature review (section 1) highlights the significant needs of parents of children with ABI. Many parents in this review reported experiencing distance from other uninjured children in the family despite recognising the increased emotional need of siblings. This raises concern that siblings of the child with ABI may be unsupported at a time of major change and challenge.

Sibling relationship

Siblings play an important role in many individuals' lives, as they are often our longest relationships (Bank & Khan, 1997). The sibling relationship affects how children develop, particularly socially and emotionally (Sander, 2004, p1), and is described as

"distinctive in its power and intimacy, its qualities of competitiveness, ambivalence and of emotional understanding" Dunn, 1998, p119). The sibling relationship is likely to experience significant consequences when one sibling has ABI.

Quantitative research using parents' reports has evidenced that siblings of children with ABI can experience emotional and behavioural difficulties, which impact on school and home life (Fay & Barker-Callo, 2003) increased obsessive compulsive thinking (Orsillo, McCaffrey, & Fisher, 1993) and lowered self-esteem (McMahon, Noll, Michaud, & Johnson, 2001). However, these difficulties may not be universal, as other research has found no difference to controls in sibling behaviour (McMahon et al., 2001; Swift et al., 2003).

Quantitative literature examining the sibling relationship has found a more negative sibling relationship in families of children with a TBI in mixed gender dyads (Swift et al. 2003), when compared with orthopaedic injury with the behaviour of the young person with TBI predicting the sibling relationship. However, this quantitative study did not provide in-depth exploration of how the relationship was experienced by siblings.

In-depth qualitative research exploring experiences of having a sibling with ABI is limited. Bugel (2011, 2014) reported the experience of seven siblings (8-12 years) after traumatic injury, defined as an "acute, serious, damaging injury threatening the previously healthy child's physical well-being" (Bugel, 2011, p.34). These siblings experienced compassion, sadness, empathy and altruism for their injured sibling. Seeing their injured sibling was painful but they also felt emotionally closer. Although this research included children with TBI, it also included orthopaedic and spinal-cord injuries. Therefore, many of the injured siblings will not have the cognitive and psychosocial changes common in ABI.

More specific to ABI, Gill and Well (2000) interviewed eight siblings (aged 14-30) and found that siblings' lives were now very different because of change in their injured

brother or sister. For example, the uninjured sibling described differences in their emotional reactions and their daily life. In addition, siblings were acutely aware of parental distress, offering support to parents or taking on more responsibility. The sibling relationship featured as part of these findings but it appears no research has explored this in depth. In addition, Gill and Wells only considered teenage and adult siblings.

A review of the literature of siblings' experiences after ABI (Sambuco, Brookes, & Lah, 2008) raised the need for further research specifically looking at the younger primary school aged group. This age group may be at particular risk of difficulties in adjusting to a changing sibling relationship because of their more limited independence and reduced ability (when compared to adolescents) to access peer support. This may leave younger children more dependent on parents to meet emotional needs. Given that parents themselves are under increased stress (Hawley, Ward, Magnay, & Long, 2003; Wade, Taylor, Drotar, Stancin, & Yeates, 1996) and experiencing high levels of ABI-related burden, (Rivara et al., 1996; Wade et al., 2006), this may leave siblings of this age more vulnerable.

In summary, quantitative research has highlighted that siblings can experience a range of difficulties after their brother or sister's ABI although specific findings have not always been consistent. The limited qualitative research available adds depth to quantitative findings. However, the impact of having a sibling with ABI on the sibling relationship specifically has not been explored through qualitative research. Additionally there is a lack of research addressing the experiences of younger aged siblings despite research showing that young children can report on their experience (for example, Alex & Ritchie, 1992). Consequently, this study aimed to use a qualitative methodology to explore the lived experience of children (aged 4-12) of their sibling relationship after ABI.

Method

Research Design

This study used a qualitative methodology by means of interpretative phenomenological analysis (IPA) using face-to-face semi-structured interviews to allow for the collection of rich, detailed data required for IPA (see Reid, Flowers & Larkin, 2003). Developed from a philosophical phenomenological approach, IPA focuses on understanding how people make sense of their life experience (Smith, Flowers, & Larkin, 2009). IPA takes a double hermeneutic position recognising that the researcher interprets the participants' interpretation of their experience and is therefore a double layer of interpretation (Smith, Flowers & Larkin, 2009). It also takes an idiographic approach, understanding the experience of an individual and maintaining this when seeking commonalities with others. The focus and aim therefore of IPA is to "say something in detail about the perceptions and understandings of [a] particular group rather than prematurely make more general claims" (Smith & Osborn, 203, p. 55).

Sampling and participants

The recruitment process included three services: an NHS paediatric psychology service and two specialist child ABI charities. Recruitment occurred over a period of eight months. Purposive sampling was used to identify participants, that is siblings were selected because they had experienced the phenomenon of interest (Smith, Flowers and Larkin, 2009).

Inclusion criteria were developed to identify potential participants. The sibling had to have a brother or sister with a sudden onset ABI and live with them or have lived with them prior to the ABI to ensure they had a continuous relationship. The sibling had to be between four and twelve years old both at the time of injury and at interview. No interpreters were available so siblings were required to speak English and tolerate up to an hour of interview. The child with an ABI had to have been between four and eighteen at the time of onset and

injured between six months and five years ago. This allowed siblings time to have a sense of their relationship with their brother or sister now, but also not too long to have difficulty accessing memories pre-injury. The child with the ABI had to have spent a week or more in hospital to focus on more significant ABI.

Exclusion criteria were as follows: bereavement of a family member in the same incident or a brother or sister with a life-limiting health condition. These were excluded due to the potential effect on the sibling relationship to maintain a homogenous sample as necessary for IPA (Smith, Flowers, & Larkin, 2009).

The exact numbers of families invited to participate is unknown, as many research packs and leaflets were offered to families by staff at recruitment sites but not always taken. This information was not passed on to the researcher. One of the charities also placed a summary on their facebook page and the numbers of families who accessed this nationally is unknown.

Five siblings were recruited for this research and demographic information was collected (See Table 1). They were relatively homogenous (as required for IPA; Smith, Flowers & Larkin, 2009) in that they were all white British, aged between nine and 12 and had a sibling with ABI. There were four females and one male[1]. Two injured siblings experienced a stroke, two had hypoxic brain injury from cardiac arrest and drowning and one experienced damage after surgery to remove a tumour. The small number of five participants in this study allows for thorough detailed analysis of individual experience, while also permitting examination of shared or contrasting experiences across this group (see Hefferon & Gil-Rodriguez, 2011).

Data Collection

[1] Gender neutral names have been used to prevent identification of participants.

Families that met the inclusion criteria were given an information pack by each service. The pack included the participant information sheets (see section 4;ethics, Appendix 4-B,p.90-100). Interested families were invited to contact the researcher for more information.

A semi-structured interview guide was developed (see section 4;ethics Appendix 4-B, p.106) using a range of question types (e.g. Descriptive, Narrative and Structural). The questions were designed to be open and expansive to facilitate in-depth reflections (Smith, Flower and Larkin, 2009). The guide included prompts to further discussion and was used flexibly (including language and phrasing) allowing for siblings' varying ages and ability. The guide was reviewed after initial interviews but considered appropriate.

The duration of interviews was between 35 and 60 minutes. Every effort was made to explain and check that participants understood the information sheets/forms. Siblings and parents were reminded of the limits of confidentiality and their rights to withdraw. In order to increase engagement and reduce anxiety, the research used two introductory activities. The first involved completing a picture which shared important things about them, such as likes and dislikes. In the second activity, siblings completed a timeline of their important life events providing a visual tool for structuring conversation.

The families had a choice of interview location: four siblings were interviewed at home and one at the hospital where her sister was treated. Four siblings were interviewed alone but one sibling chose for her parents to remain. In this case, the parents signed consent for their contributions to be included, but were reminded that the focus was on the child's perspective. The interviews were audio recorded to be transcribed.

Ethics

The project was approved by an NHS research ethics committee, the local NHS Research and Development office and the charities involved (see Section 4). To ensure the children's materials were accessible, two primary school teachers were consulted regarding the wording of the information sheets. As the topic of a sibling's ABI could potentially cause distress, the researcher approached this with sensitivity and offered breaks and avenues to access support if required. The anonymity of participants was maintained as much as possible; all names are pseudonyms.

Analysis

The interviews were transcribed and analysed systematically according to Smith and colleagues (Smith, Flowers and Larkin, 2009; Smith & Osborn, 2008). Each transcript was initially considered separately and repeatedly read by the researcher to familiarise herself with the data and complete initial notes of significant comments. This included considering the language used and descriptive and conceptual comments. The transcripts were then re-read "in order to identify themes that best capture the essential qualities of the interview" with more concise phrases (Biggerstaff & Thompson, 2008 p.10). These emergent themes were noted in the right margin (see Appendix 2-B for an example). Each theme was recorded alongside supportive evidence of times observed in the transcript in order to ensure that there was a trail to the participants' own words. The themes were then clustered into groups to produce a set of super-ordinate themes (see Appendix 2-C for an example of super-ordinate theme). This process was repeated for each participant until the researcher had a set of super-ordinate themes for each sibling.

Finally, the researcher explored connections over all the super-ordinate themes for every sibling and merged these to create four themes that represented all five participants. The researcher was looking for patterns across the cases, interested both in convergence and

divergence and maintaining individual experience (Smith, 2008). At each stage of the process, the researcher referred back to the transcripts to ensure themes were reflective of individual experiences and were inductive rather than imposed from previous theory, knowledge and preconceptions.

IPA recognises the influence of individual interpretations of researchers on the research process and analysis given their own views and prior experiences (Larkin, Watts, & Clifton, 2008). Given this double hermeneutic position, the researcher reflected on her prior preconceptions and attempted to reduce the influence of this as much as possible in order to focus on the presented data (Biggerstaff & Thompson, 2008, p.9). For example, the researcher attempted to distance herself from her own sibling experiences in interpreting siblings' experiences. In general, the researcher approached the data from the standpoint of a 27 year old trainee clinical psychologist who has an interest in children's experiences and family relationships and who was concurrently on a paediatric psychology placement. Her perspective is that children have important voices that need to be heard but that this does not always happen in research and clinical work. To support this process of reflexivity, the researcher kept a diary of thoughts and reflections. For example, she noticed that her prior experience of ABI was generally with very severe ABI resulting in profound difficulties. She recognised that this may not be reflective of the wider ABI population.

Validity

The principles proposed by (Yardley, 2008) for assessing the quality of qualitative research were followed to maximize validity (sensitivity to context, commitment and rigour, transparency and coherence and impact and importance). The researcher grounded the research in current literature in order to be sensitive to the context. As such a thorough literature review was conducted using available databases, as well as consultation with the clinical field supervisor. The researcher was also sensitive to the socio-cultural context of

participants from design to the analysis, for example, considering the influence of the adult-child power dynamics and how to minimise its impact. As this research focused on in-depth exploration of a small number, it was important that the analysis was of high standard, provided detailed insights and maintained individual experience to achieve commitment and rigour. To ensure this was the case, frequent supervision with an IPA consultant took place and amendments to process were made accordingly. For example, after the first interview the researcher adapted some elements of her interview style to bring out more in-depth reflections and limit her reflective responses that might risk reinforcing specific elements of the sibling's experience. The researcher grounded the design and analysis in IPA to ensure the research was coherent and consistent with the method and aims. The analysis was conducted thoroughly and systematically, which for IPA means having sufficient idiographic engagement (Smith, Flowers & Larkin, 2009). A clear audit trail for the analysis process was retained to increase transparency (see Appendix 2-B & 2-C). This includes grounding the write-up in illustrative quotes (Elliott, Fischer, & Rennie, 1999). Impact and importance was ensured by considering the clinical importance of the research both for practitioners in supporting families of ABI and directly for the community.

Results

The analysis resulted in four interrelated themes, presented below: (1) Coping with "a nightmare that you live"; (2) Disconnected from family relationships; (3) My sibling is different but "still the same underneath all this thing"; and (4) Changing togetherness.

Theme 1: Coping with "a nightmare that you live": nearly losing a sibling

Siblings recounted their traumatic experience of the ABI due to the potential loss of the injured sibling. All but Charlie chose to put their sibling's injury on their life timeline, as one of the most important events. Charlie chose not to include this "because it's sad" and too

painful. Andy, Charlie and Chris, who had witnessed their sibling's ABI, recounted the incident in detail. Andy summed this up as "a nightmare that you live". Jessie, who did not witness the incident, gave a detailed account of her mother's experience, as though she was experiencing the trauma through her mother's re-telling:

> she started like, apparently like crawling up her bed, like you know vomiting and stuff, and umm my Mum had obviously, like she panicked […] then they ended up calling the doctors and she collapsed in Mum's arms and they had to, they took a while to resuscitate her, like 30 minutes, I think.

Jamie did not describe her sister's illness in as much detail as she appeared avoidant of difficult questions throughout. This may reflect emotional difficulties associated with thinking about the event. Andy in particular seemed to struggle with why this has happened to her family, "why George? Why not someone else? Why not some horrible kid that was like dead bratty, like horrible kid, why our George?"

All of the ABIs included a significant risk to life and siblings referred to injured sibling as being seriously unwell and/or dying. For Jamie this was expressed by her serial use of the word sick, "it started off actually quite simple she was just sick and then it just like got sick sick sick sick sick sick" (Jamie). Jessie was shocked by the serious nature of her sister's condition when she saw her in hospital:

> Mum eventually said when she, when she knew that she was going to survive at least and she was quite stable, that she said "you can come and visit her now" and because, although she hadn't told me, I literally did not know what to expect. I thought that she would be absolutely fine, that she would be sat up talking to me. Turned out she couldn't talk, she could literally just lie in a bed (Jessie).

Andy's fear that her brother was dying was more immediate:

> George was like dying in there [the ambulance] …….he was 10 minutes away from death. If you haven't got him here quicker than he wouldn't have survived and my dad rang me up and he said "you don't mind if I, I just wanted to tell you that George might be going up to play with my nan". (Andy).

Chris even described his brother as dead for a time and was almost detached and dehumanised by describing his brother as a body. "Cos I saw a dead body. Cos he was dead while he was under there. Umm….And err they got him out, then they brought him back to life". These experiences of trauma and fear of loss continued long after the sibling was stable. For example, Chris described having "scary" flashbacks nearly one year on, when reminded of what happened. Andy said, "when I go to sleep I wake up sometimes and I think that he's screaming again for some reason like it's weird… I don't like it".

Given this near total loss, siblings expressed how grateful they were to still have their brother or sister with them. However, this experience resulted in a realisation of the fragility of their sibling, how important they were to them and anxiety and fear for potential loss: "It's different because like you realise how dangerous, how close you can get to losing him sometimes, like protective, special they are to you" (Chris).

The realisation of the potential to lose their sibling tested resilience and coping skills. The siblings tried to manage this in different ways, such as seeing friends or talking to professionals. Siblings focused on a need to talk about their feelings, for example, Andy said "a problem shared is a problem halved and it did help me". Some siblings had accessed professional psychology or counselling support but were at different stages of processing. For example, Jessie described her experience:

> I went to counselling and I think that that helped quite a lot if you are quite stressed, so I would probably say go to counselling or talk to someone about it if all your emotions are sort of building up … I found it quite helpful or getting like writing in your diary or using like a stress ball.

Jamie described herself as having "recovered now" from the trauma but also said "I sometimes talk about it with Kate [friend] who lost her dad". This suggests that Jamie found it helpful to talk to this particular friend as she identified with the experience of loss.

In summary, the siblings experienced trauma due to the fear of losing their brother or sister entirely. This changed their perspective of the security of the sibling relationship, creating fear and uncertainty. At the time of the interview, some participants had talked to others and begun to process their distress. However, this was an ongoing process, particularly given that Chris, for example, only recently had his brother back at home.

Theme 2. Disconnection from family relationships

Sibling relationships were intricately woven through and contextualised by wider family relationships. Therefore, the relationship with their injured siblings reverberated through relationships with other family members.

During hospital admission all the siblings experienced physical separation from their brother or sister which was difficult when they were used to being together. For example, Jessie described "I hadn't seen my little sister so I didn't play or anything or be able to play with her or do anything really like go and do fun things out like everyone else". For Jessie, a pet partly filled the void, whereas Andy felt that no-one could fill that void but her brother because of their unique relationship.

Not only was the connection to their sibling disrupted, but ABI disrupted their connections with other family members. For example, all experienced separation from their parents who were often at the hospital: “it was sort of quite depressing really ‘cos, of course, I hadn’t seen my Mum in, I didn’t see my Mum much and so I didn’t get to spend time with her” (Jessie).

The loss of parent interaction was not only due to temporary physical separation whilst at the hospital but also to the demands of caring, for example, “we were like one happy family and now we’re like one tired paperwork family” (Andy), to the extent that Andy felt peripheral to her family:

> “I asked them [Mum and Dad] to go to the park... ‘I’m too tired, I’m too tired.’ That was their answer for everything like in the first months… I just felt like I was un-important like I just felt like my mum and dad didn’t care that much about me but I didn’t know like that they had to keep like doin-, I didn’t really think that they were that tired not to like play with me like, it was weird.

Although Andy was frustrated at the lack of attention, she did not seem to feel resentful towards her injured brother. In contrast, Jamie did experience resentment towards her sister (Sam) because she (Jamie) “doesn’t get much attention anymore”. This extended to the attention Sam got from Jamie’s friends as she felt that she had less attention from “quite a few people cause my friends sort of fuss over Sam as well”. Jamie also perceived Sam to receive preferential treatment: “she still pretends she’s ill ‘cause she doesn’t have to go to school” and “I sort of miss out on watching the television. I only get to watch it on Thursdays ‘cause I go to my nan’s”.

Additionally Charlie felt the loss and impact on both her sibling group and the whole family system. She explained:

> ...we used to always do this thing at night time, we used to play this little game…. we had this way we said goodnight to each other. She always said it first, then me, then my little sister, my little brother ….he goes to bed earlier than us, we always say it together and we just giggle. That's the thing I miss most of all.
>
> It wasn't the same without Robin at home. It's really not the same because we don't see them every day, it's not the same without them. So it's just me, my little brother, my dad and my little sister (Charlie).

For these siblings, their brother or sister's ABI affected the whole family system. Not only did the siblings feel disconnected from their brother or sister with the ABI, but they also felt disconnected from their parents as well as well as experiencing a disruption to the family group as a whole. These experiences left them feeling lonely and isolated.

Theme 3: My sibling is different but "still the same underneath all this thing"

Changes in appearance and behaviour post-ABI resulted in siblings attempting to make sense of the degree to which their brother or sister remained the same person. Siblings described the initial shock at the physical transformation of their injured sibling and their body's loss of function:

> It was like, she, she, she had no hair and she had a tube going up the right nostril….And, and the annoying thing was she could hardly move cause she had she had to carry this food thing round with her….She also had a pipe coming out of her belly button and the thing was it was a big difference when she got her hair back..... (Jamie)

These physical differences were sometimes emotionally challenging to observe, for example, "I didn't really want to look at Robin, it was too upsetting to see her" (Charlie). Even once

the brother or sister had left hospital, physical changes acted as reminders of difference. For example, Andy described changes in her brother's voice:

> it's been weird because he sounds like a middle aged man when he should sound a bit like this [*mimics high pitched voice*]. He used to, he used to be like a mouse and now he's like, errr, dead like my dad.

In addition to the physical changes, siblings also commented that their brother or sister's had changed in personality had changed, such as becoming more shy, assertive, noisy or aggressive. This created differences in interactions, which could be positive or negative. Jessie reported having to be more "wary" of her sister, as though she was more unpredictable. However, at the same time Jessie felt her sister talked more and therefore they actually got on better since the ABI: "we didn't used to be really amazingly good friends, we didn't usually spend that, lots of…It feels like we know each other a bit better now, 'cause she has changed personality quite a lot".

Despite describing changes, when asked, the siblings said that their brother or sister was "exactly the same" (Charlie). For example, Andy argued passionately that George was the same and still her brother, "he's just mine, like he is no one else's brother, he's my brother" (Andy). However she then said that it was "like someone's just gone and swapped him for somebody that looks like him" (Andy), suggesting a marked change of identity. Andy later tried to make sense of this incongruence by suggesting that the "spark" of her brother was not lost, which suggests there is a core part of her brother that means he is still that person. She explained, "our George is still the same boy, just underneath all this thing". She was obviously relieved when reminded of this: "he'll start laughing at them jokes and all that. It's ...It's nice to know that he still there".

Participants clearly held onto their belief that a core part of their brother or sister's identity was maintained, even when familiar aspects of sibling identity were absent. Chris, for instance, commented, "we have got him mostly back", indicating a continuing loss of some part of his brother that he never got back when the doctors resuscitated him. Despite these changes, Andy strongly argued that she would still rather have her changed brother than not at all: "it's weird not having him by me again in school like I'd rather George be like my shadow then like not have him there at all".

The consequences of the changes was particularly felt by Jessie when comparing to other families. For example, she made frequent reference to her sister and therefore their family being different from others. This included a sense of loss of shared sibling activity which she observed in other families.

> it was a bit upsetting 'cause you see everyone go out on the bike with the family and ride along but of course I can't do the same because sort of a walk is the only option really. She can scoot and stuff but it's still not the same (Jessie).

In summary, the siblings experienced challenging and distressing changes to their brother or sister with an ABI, both in terms of physical appearance, behaviour and personality. Processing these changes was challenging, particularly when considering to what extent their brother or sister's post-injury identity was consistent and continuous with that before injury.

Theme 4: Changing togetherness

All of the siblings talked about the changes in their brother or sister's physical ability, communication skills and temperament impacting on their sibling interactions, including their reciprocal roles.

The ABI and resulting impairments meant that the siblings' shared experience was now restricted. The hospital environment limited opportunities for shared activity and play, but restrictions also remained at home due to medical needs and physical disability. For example, some injured siblings could not access different areas of the house (upstairs or the garden) or play games that were physically demanding. Charlie had enjoyed practising gymnastics in the garden with her sister, but Robin (her sister) was no longer able to join in due to her physical disability. Additionally she was restricted to certain areas in the house if she wanted to include Robin:

> play hide and seek upstairs because that is where most of the hiding spots are, but when we play that now Robin can't really play so she has to be the one that saying 'you can't go upstairs' (Charlie)

Similarly, Andy described one of her experiences of restricted play with George,

> he used to want me to always like lift him up in the air, throw him around quick cos George liked being fast, he liked going fast and everything. Now I have to take him like if I wanted to pick him up I'd have to pick him up and then walk like a tortoise cos he gets dizzy, he's like…if you move too quick you get disoriented.

Siblings commented on the striking difference in their injured siblings' speech, particularly early after ABI, and how they adapted to this in order to communicate. Chris observed that the biggest change was his brother's "talking" as he was unable to understand him to start with as he just "made noise". He described becoming accustomed to his brother's communication so he could begin to understand him again. Nearly all the injured brothers and sisters could not speak initially which siblings found shocking at first but learnt to use visual ways of communicating. All of the siblings seemed to adjust to this, although Jamie still expressed a wish that her sister be able to talk better. "Cause her talking's not as

good, I want her to get better cause she was young when it happened, her talking's not as good" (Jamie).

These changes in sibling interactions influenced their reciprocal roles. Siblings talked about the need to adopt other roles, many of which included caring for and protecting their brother or sister to meet needs which they were no longer able to fulfil themselves. For example, Chris said that he "has to do everything for him when me Mum's busy". The siblings talked about a range of ways they provided for their sibling, such as making things for them and giving them gifts. For some siblings being the person who made their brother or sister laugh and lifted their mood was really important. Providing comfort and reassurance was important for Andy who explained her attempts to share her brother's pain:

> when he goes dizzy he feels better if you put your head against his head like so he feels like you're going through it as well as him…So it's like I'll share it with you and then we won't feel as bad.

Another key role for siblings was re-teaching skills, "Just the fact that I had to push him around, all that, and his wheelchair, you get used to him not talking and not playing the same and having to teach him everything again" (Chris). Rehabilitation was not just focused on practical skills but also social skills as part of Andy's role was "to bring him [George] out of his shell a bit to get him to be…the same boy [that] he used to be" before the ABI. Andy particularly seemed to facilitate social engagements with friends and stressed the importance of persevering with her efforts. While experiencing relief, as expressed by Chris when his brother made progress, siblings also expressed frustration at the lack of knowledge about their brother or sister's condition which they felt would have supported their efforts in the rehabilitation process.

For all but one of the siblings (Charlie), adoption of caring and teaching roles seemed an extension of their familiar older sibling roles. For example, Andy described her brother always seeing her as a role model and his problem-solver when things were difficult. However, for Charlie, the only younger sibling, the change seemed more marked as she used to follow her sister round prior to the ABI, whereas now she had to adopt new caring roles. This was not just in relation to her sister, but also to her younger siblings, for example, "I make the breakfast now and pack lunches now as she [sister with ABI] is obviously here [at the hospital]. Even when she is at home we go to school, she still can't do it because she's really only got one hand" (Charlie).

In summary, after their brother or sister's ABI, these siblings had to adjust to a changing togetherness which meant that their opportunities to engage in shared interactions, such as play, were restricted. These changes in interactions also altered reciprocal roles, as siblings took on increasing rehabilitation and caring roles with their sibling.

Discussion

The findings of this research expand current knowledge and understanding about sibling's experience of their sibling relationship after ABI. The four themes interpret the experience of five siblings whose brother or sister had ABI. Siblings initially experienced a traumatic near loss of their brother or sister, followed by difficulty in adjusting to the impact of physical and psychological changes, both in terms of the affected sibling's identity and their sibling role and relationship. These changes were all experienced within the context of disruption to the network of family relationships.

The siblings' experience of the trauma of the event that caused the ABI and the ongoing traumatic hospital experience were linked with fear of loss of their injured brother or sister. Siblings recounted significant anxiety about the potential loss of their sibling which is

consistent with the experiences of adolescent and young adult siblings of children with TBI (Gill & Wells, 2000). Gill and Wells also found that siblings experienced "emotional turmoil" (p. 50) and numerous, conflicting emotions while living with their sibling with TBI. This research illustrates the extent of the traumatic experience for siblings in witnessing (or vicariously experiencing) the traumatic incident, their brother or sister in a desperately ill or lifeless state and resuscitation and/or other life-saving procedures. As such, the findings unpick sibling's trauma and add additional understanding to what about the experience is so traumatic in that it relates specifically to the sibling relationship.

The siblings in this research experienced physical separation leading to disconnection between siblings. The access siblings have to each other is important for the development and maintenance of the emotional sibling bond (Bank & Kahn, 1997). The sibling bond also becomes more intense and influential when parental influence is reduced (Bank & Kahn, 1997). Given that siblings in this study also reported disconnection in parental relationships, the need for the sibling bond may be more important but access was not available, at least during the acute hospital admission. The timeframe post-injury was relatively short to medium-term for these siblings, ranging from five months to 2 ½ years, and therefore the development of the sibling relationship after ABI might change over time.

Intrinsic to the changing sibling relationship was the disconnection and exclusion from the family experienced by the non-injured sibling, particularly while the injured sibling remained in hospital. This was consistent with similar aged siblings of traumatic injury and older siblings of TBI (Bugel, 2014; Gill & Wells, 2000). Minuchin's family systems model (Minuchin, 1974) highlights the interactive nature of the spousal, parental and sibling subsystems. The interconnectedness of these subsystems was particularly salient in the findings here, as the altered sibling relationship appeared to be both partially as a result of,

and experienced in the context of, changes in the functioning of these subsystems. All but one of the siblings were still living with both parents, however Jessie's parents had separated since her sister's ABI. The separation and loss of her father in the family home seemed important for Jessie as she talked about this for a significant part of the interview. The findings both from the literature review of parents' experience and of siblings in this study strongly suggest siblings are vulnerable to breakdown in their attachment relationships with their main caregivers. This is concerning given the negative impact that this can have on the siblings' immediate wellbeing and future trajectory, which could have long-lasting impact.

The theme that the brother or sister with ABI is "still the same underneath all this thing" recognises the challenge of processing the changes in their injured sibling. This mirrors the literature of adolescents and young adults with a sibling with TBI, where the changes in their brother or sister were really difficult to accept and changed their lives (Gill & Wells, 2000). Both the siblings in this study and those in Gill's and Well's highlighted the changes in the injured siblings' cognition, behaviours and interpersonal skill. However, the siblings in this research seemed more struck by the physical changes and associated restrictions on play than those in Gill and Well's. This difference may be a result of their developmental stage and ability to process change given that the siblings in Gill and Well's study were on average 14 at the time of the injury and 21 at the time of interview.

The siblings in this research experienced significant changes in their sibling interactions, such as shared activity and roles. Bugel (2011) found inconsistent changes in sibling relationships after traumatic injury. Some siblings reported more meaningful relationships with increased affection, while others experienced increased resentment which was also evident in this research. However, all siblings experienced frustration and loss because of the changes. Additionally, the role changes that siblings adopted reflects Degeneffe and Olney's (2010) findings of an increased need for adult siblings to adopt caring

roles after their sibling's TBI. However, the adopted roles in this study are different, as they seem more focused on improving mood and supporting rehabilitation. It is interesting that, despite the young age of the present participants, they still took on these roles, in effect supporting their parents as young carers.

Clinical implications

This research indicates that siblings experience trauma in relation to the near loss of their sibling with ABI. Some siblings talked about the importance of sharing their experiences and revealed that they had accessed helpful professional support. A resulting recommendation therefore is that psychological support be made routinely available.

There are very few interventions specifically available for siblings of children with ABI (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007). However, there are some interventions for siblings of children with chronic health conditions which might be helpful to consider, for example, Lobato and Kao (2002) increased knowledge and connectiveness after a sibling-parent group intervention for paediatric chronic illness. Given the themes of disconnection in both this research and the literature review, it may be worth exploring similar interventions for families and siblings with ABI. However, it is important to remember the unique nature of parents' and siblings' experience given the sudden change and the organic cognitive and emotional changes in the injured child, which might require specialist interventions.

Additionally this study indicates a need for siblings to be involved in their brother or sister's care and rehabilitation both for their own wellbeing, and the maintenance of the family system. Siblings are central members in their family but care systems within the UK frequently do not involve them as standard. Given both siblings' and some parents' (section 1) experience of family disconnection, family therapy would offer families the opportunity to

approach the ABI together, for example, narrative family therapy allowed siblings of adults with ABI, to share each other's pain as well as promoting resilience and bringing together family members (Butera-Prinzi & Perlesz, 2004).

The findings increase understanding about sibling's important roles in rehabilitation but these five siblings appeared to receive limited support to manage this. This implies that services should be teaching siblings about ABI as well as the potential roles and rehabilitation needs, as recommended by Klonoff, (2014) for child and adult siblings. She advocates providing information about the health of the injured sibling through psycho-education, strategy training, and stress management techniques.

This study suggests that it is important that relevant information is communicated to siblings in an age-appropriate way that they can understand. There are some resources available for families that provide opportunities to access this information, for example factsheets, informational videos, online blogs, links to support groups both online and group meetings and short books. However, these are predominately aimed at parents rather than siblings. Only one fact sheet that was specific to siblings was found online in the UK (The Children's Trust, 2015) highlighting a need for further development, access and regular distribution of resources.

Helping parents to recognise the difficulties that siblings experience may also be helpful, particularly when considering siblings' loss of the parent-child connection. This is particularly important as parents experience high injury-related burden (Rivara et al., 1996; Wade et al., 2006) and significant emotional demands (Rivara et al., 1992), which may make it difficult to fulfil sibling's needs. Additionally, the finding that siblings feel a loss of shared sibling time suggests they may also benefit from increased opportunities for this at the hospital.

Strengths and limitations

This research has captured the perspectives of five young children, whose voices are not often heard in research. Although smaller sample sizes are often seen as a limitation, following IPA's idiographic emphasis (Smith, Flowers & Larkin, 2009), the small sample size here permitted an in-depth exploration of each participant's rich experience. Due to the detailed, exploratory nature of this research with a small sample, the findings cannot be generalised to all siblings who have a brother or sister with ABI. However, IPA's aim is not to provide "empirical generalisability" (Smith and Osborn, 2008, p56) and therefore it could be argued that this limitation is less relevant in this study (Chamberlain, 2000).

Due to the difficulties in recruitment and lack of response nationally from the facebook and email recruitment, the families who participated were all from the same area and attended the same hospital for treatment which may have influenced siblings' experience and the representative nature of the findings. In addition, all but one of the participants were older siblings and some small differences were evident in the younger sibling's experience in one theme. Therefore, some aspects of the themes may be more reflective of older siblings. The gender dyads are also relevant to consider as there was only one mixed-gender dyad in the participant group and this can influence the nature of a sibling relationship (Bank & Kahn, 1997) although there were no marked differences noted in the themes.

Future research

For the participants in this research, their injured siblings had experienced an ABI within the previous three years. Given that paediatric ABI can impact on future development (Middleton, 2001) other difficulties may arise over time. Therefore, future research could explore the trajectory of the sibling relationships ideally in a longitudinal study. There is also a lack of literature focusing specifically on the sibling relationship in adolescents and young

adults which may differ from the experience of younger children explored here. Given the inevitable limitations of this research in terms of the diversity of the sample, future research could focus on other groups such as different gender mix of sibling dyads, sibling order and socio-cultural backgrounds.

Conclusion

The findings of this research add to the understanding of siblings' lived experiences after a paediatric ABI. More specifically, it provides an insight into the perspectives of younger siblings and a more in-depth focus on the sibling relationship. There is a clear need to recognise the siblings as an important part of the immediate family unit and therefore involve them in the process of care and rehabilitation. However, the experience of these siblings was that they experienced a high level of trauma and find themselves thrust into a situation of managing significant changes not only in their sibling relationship, but also their child-parent relationship and general life stability. This highlights the need for providing individual support to this group if required, to help them manage the trauma and adjustment process.

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Table 1. Participant Demographics

Table 1. redacted to protect participant anonymity

Appendix 2-A. British Journal of Health Psychology

Instructions for authors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

• papers reporting original empirical investigations, using either quantitative or qualitative methods;

• theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;

• review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and

• methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

• the content of the paper falls within the scope of the Journal

• the methods and/or sample size are appropriate for the questions being addressed

• research with student populations is appropriately justified

• the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

• Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

• The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book.* City, Country: Publisher.

Author, A. (2013). Title of journal article. *Name of journal, 1,* 1-16. doi: 10.1111/bjep.12031

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

• Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the

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10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe's web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred.

Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights.* Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper?

Appendix 2-B. Example of initial notations and emerging themes for one participant

Key:

P=Participant

I=Interviewer

Italics: Descriptive notations

Underlined: Linguistic notations

Bold: Conceptual notations

Initial notations	Line		Transcript	Emergent themes
Changes in child's voice – from child	435	P	No not really is just weird like I tell a joke and I'm expecting like	
high pitched voice to a tiger	436		((high-pitched laughter)) and he goes ((low grunt)) like that it sounds	Trying to adjust
Changes are weird *and unexpected*	437		like a tiger ((grunt))	and make sense of
Her brother doesn't sound like her	438	I	mmm	changed brother
brother anymore – **trying to make**	439	P	he doesn't sound like George he sounds like someone else	
sense of change	440		like someone else,	
	441	I	mhmmm	
Feeling like brother been taken	442	I	mhmmm…	Experiencing loss

away/swopped	443	P	like someone's just gone and swapped him for somebody that looks	of brother before
Her brother not the same person	444		like him	
	445	I	yeah	
	446		…..((silence))	
	447	I	you are able to tell me about what happened when he did go into	
	448		hospital?	
	449	P	on the day?	Shared activity
Painful to talk about the ABI	450	I	yeah	part of sibling
	451	P	yeah, if go quiet but that means and a bit ufff	interaction
Sharing activity	452	I	okay that's fine	
	453	P	like we were playing all day on the bouncy castle and then we got too	Sibling role in
Sibling giving comfort when upset at	454		hot and we went in and then we had our tea and halfway through the tea	comfort and care
time – sat on knee and started	455		he started crying so I went over and I sat him on my knee and I started	
rocking him	456		rocking them and he was going "my head my head my head" and he	
Sibling crying- **distressing at trauma**	457		was screaming and everything and then my mum ran in and then like he	Experinces are
at time of injury	458		just passed out like on mum's knee and I was there and I was crying	

‘Dead hectic’**- feeling overwhelmed at time of injury**	459	and they called the ambulance and then it wasn’t there and it was like…	distressing,
	460	dead hectic so it was like one minute he was like our bouncy boy and	traumatic and
Making sense of sudden change in her sibling- *one minute a bouncy boy and then not able to breath*	461	then he was like on suite like like he was- he wasn’t breathing properly	overwhelming
	462	((gasping noise)), like that, on my mum’s knee and he was like crying	
	463	and then my dad told me that I had to go down the road to stay with my	Trying to adjust
Sibling protected by parents – sent away from the incident	464	dad’s mate for a bit and then the ambulance came and they took into	and make sense of
	465	****((name of hospital)) while I was at my dad’s mates and then my	changed brother
Separated from sibling- two weeks stayed with nan while child in ICU	466	nan came to pick me up and I stayed at my nan’s for two weeks while	
	467	he was in intensive care and and when he went in they just said to my	Disconnection
Very close to death **–nearly lost her brother**	468	mum like a while ago that he was 10 minutes away from death if you	from ABI
	469	haven’t got him here quicker than he wouldn’t have survived and my	
Fear of loss of brother – going up to heaven to be with his grandmother – horrible	470	dad rang me up and he said you don’t mind if I I just wanted to tell you	Separation from
	471	that George might be going up to play with my nan so it was… horrible	sibling
	472	and then like this is an important but it really annoyed me, there was	
	473	this man and he pulled up outside the ambulance while George was like	
	474	getting pumped with oxygen and started shouting at the ambulance and	

	475		swearing at it and I was like out and my nan was taking me down by	
Feeling annoyed and angry at	476		this time and he'd stopped and he was like swearing his head off and	Fear of loss of
others not giving respect/ concern	477		me, he, my uncle stock my uncle's like dead hard and he stuck his head	brother entirely
that is warranted	478		out of the window and said "shut up there's a boy in there and he's	
	479		dying" and he went "I don't care, I've got to get my kids down here"	
	480		like and my uncle said "go down the other way then", he went "it	
Feeling fear of loss of brother	481		hasn't got it's lights on so it's not an emergency". it was like its parked	
	482		in front of our house, the doors are open, you can hear screams and he's	
	483		not bothered like it really annoyed me that my dad, my dad kept saying,	
	484		"let's go down the road and have a look at the house that he went into	
	485		like see if he's in". My mum seen through the window that he was	
Fear of loss of brother- *he's dying*	486		complaining and she couldn't put her head down round because she	
	487		was holding our George's hand and it just annoys me that he did it	
	488		because like George was like dying in there and they just didn't care,	
	489		they just wanted to get home so really annoyed me	
Questioning why this happened to her	490	I	yeah, really annoyed you	

brother why not someone else who deserved it more?	491 492	P	yeah it made me want to go and like bash his head in like get something out the ambulance and make him go in the ambulance it's like why	Questioning life's
Sense of the injury not being <u>deserved-</u> by George or family	493 494		George? Why not someone else? Why not someone horrible kid that was like dead bratty like horrible kid why our George	
	495	I	is that something you think a lot?	
Feeling guilty about wishing it on others- <u>not nice</u> feeling	496 497	P I	yeah a lot of the time yeah what's it like having those thoughts?	
	498		not nice because I don't want to think about any kid having to go	
Sense of George 's experience difficult- <u>"gone through"</u>	499 500		through that but like its…..((silence)) it's I don't want any kid to go through what George's gone through but	
Questioning why us as a family	501		why did I have to be us	
	502	I	yeah	
Noticing change in her family- comparing before to after	503 504	P	why not some other family because we were like one happy family and now we're like one tired paperwork family	
<u>Now 'tired' family who needs to do a lot of 'paperwork'</u>				

Appendix 2-C. Example of development of superordinate themes for one participant.

Initial notations	**Emerging themes**	**Narrative of super-ordinate themes**	**Examples of supporting quotes**
Superordinate theme 1: "Weird": My brother is different but still the same			
• Sense of sibling feeling conflicted: contradiction between brother "exactly the same" but some things are different • Sudden change in her sibling- one minute a bouncy boy and then not able to breath • Sibling perceiving child meets in hospital not as her brother • Brother replaced by a different	Sense of conflict- brother is same but different Experiencing changed brother (physical/behaviour/personality etc.) Trying to adjust and make sense of changed brother Experiencing loss of brother before Brother replaced by someone	This theme reflects Andy's juxtaposing positions that her brother is different than he was before the ABI but that he still remains the same brother. She reflects on the immediate sudden traumatic changes at the time of the injury of George being a 'bouncy boy' to struggling to breath and still and limp. She talks at first as though her brother had been taken away and replaced or swopped	"He was the cutest little boy in the world and he had the squeakyish voice and he used to be dead funny and we when like when he was in school he always used to shout, he always used to see me come out the door to go out on the playground he always used to run up to me and cuddle me and it feels weird without him

figure of him • Brother been taken away/swopped and someone else in his place who looks like him but not him • Sib. adapting to change that brother can't close eye anymore • Sibling noticing physical changes, paralysis down one side • Sibling noticing smile is different and it's 'weird' • Changes in child's voice – from child high pitched voice to a mans voice • Weird: sounds like a man and	else Seeking the brother that used to be What makes him him is still there Relief that have him despite the changes Changing perspectives on difference	with someone else. This seemed particularly evident on first visiting her brother in hospital. Andy seemed to find the changes she noticed as difficult to comprehend and 'weird'. For example, the physical changes, such as paralysis, his smile looking different, becoming left handed, and more personality and behaviour changes such as becoming shy and no longer ticklish. Andy particularly appeared to have more difficulty with the change in his voice, from a child's voice to a man's voice. This was in contrast to the way	on the playground" "like someone's just gone and swapped him for somebody that looks like him" "it like it affected him a bit like before he was like he used to laugh like dead high-pitched like *((imitates high pitched laugh))* like that and now he goes like *((grunt))* he sounds like a man whose just he sounds (*grrr)* he sounds like that so it affected his voice a bit"

'should' sound like before • Her brother doesn't sound like her brother anymore. Change between mouse to like dad – strange • Using past tense to describe sibling indicating change - used to be dead funny. • Sibling explaining difference in using right handed to left handed • Sib noticing changes in his behaviour around others- becoming more shy. • Change in his behaviour- used to be ticklish now not: changes		she seems to view her brother, i.e. a 'cute' little boy. Changes to personality and behaviour are also noted, such as becoming shyer around others. Andy talked about a need to find times when her brother was more like the brother he used to be. She experienced reassurance and enjoyed times when he responded in a way that met her expectations prior to the injury but that this did not always happen. She carried round a photo on her phone of him prior to the injury and reminisced about memories that	"it's been weird because he sounds like a middle aged man when he should sound a bit like this ((really high voice 'this')) he used to, he used to be like a mouse and now he's like errr dead like my dad he talks like my dad now" "like the first time I went to see him he had liked tubes everywhere and I just thought, that's not my brother you must be mistaken, my brother does not look like that, he looks like, he was just paralysed it was

in play together • Changes are weird for sibling • Not understanding why a change happened • Favourite things/memories about him (hair colour and voice • Not expected- jarring/ reminders of the change • Sib seeking brother to respond like he used to- sometimes does, sometimes doesn't • Child with ABI 'spark' not affected • Keeping photo of pre injury child on phone with white hair-		seemed important to her, such as his hair colour and his voice. Despite these changes and the impact on Andy, she maintained that he was still her brother and contradicted herself stating that he was not different. This might reflect a need to reassure herself that he remains her brother. The core part of her brother, his 'spark', was not altered, but that he was just hidden beneath the changes. She described a role of advocating this to her brother when he felt different.	horrible and like and he, he just really frightened me like it" "But it didn't affect his spark, it just affected his… paralysed done one side, his right side, he used to be right-handed but now he's left-handed, better than his right …And he only smiles with one side of his mouth *((pause))* and it's weird" "No, he's exactly the same, some things are just different about him, like he can't swallow, he's got a tube in his stomach, he's got a hole in his

memories of before. • In recognising similarities between other children in hospital and her brother- same boy just underneath all this thing • Her brother feels different to his friends now but sib arguing that he's not • Sib enjoying times he acts like he used to but just a bit differently • Sib reassured brother still there when he starts laughing with friends and joking but recognises still different		Andy recognised that she would rather have her old brother back but that having him in any way was better than not at all. Andy reflected that these experiences of her brother changing had impacting on her perspective of difference in general. This has made her more tolerant and understanding of difference in others.	throat, he's got scars everywhere and he doesn't talk the same but that doesn't really bother me just because I've got him back and he's mine and I'm not gonna let him go" "you've got to bring him out of his shell a bit to get him to be like the same boy he used to being and he used to be dead, like, boist.., he used to be like, what's the word, I don't know, he didn't used to be shy at all with anyone, now he's like dead shy with the kids"

• The differences are there but it doesn't matter to sibling as more important she has her brother back • Rather have her old brother back with annoyances than him not be there at all • Changed perspective of sib. re difference of others as sib feels a lot nicer/accepting of other who are different from her			

Section 3: Critical Appraisal

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This section of the thesis aims to give some context to the two papers and reflections on the process. I will first give an overview of the findings of the literature review and the research paper and explore how they might interact. I will then consider my personal reasons for embarking on this research, the strengths and weakness of the thesis and challenges involved before considering the need for future research. I hope that this paper will inform further research with children of this age group and specifically siblings and families of children with acquired brain injury (ABI).

Research Findings

This research found four interrelated themes that captured siblings' experience of having a brother or sister with ABI. These themes were (1) "A nightmare that you live"; (2) Disconnection from family relationships; (3) "Still the same underneath all this thing"; and (4) Changing togetherness. These findings are interesting to compare to the metasynthesis themes of parents' experiences: (1) Disconnection: Cut off from internal emotions and isolated from society; (2) Seeking understanding and support to manage in an insecure world; and (3) New parent to a different child.

Reflections from parents and siblings indicate that ABI is a traumatic and intense emotional experience from initial onset until long after. Both parents and siblings talked about the need to share their emotional burden with others. Siblings and parents experienced fear at the unpredictable nature of the situation but differed in their level of involvement with the ABI. Siblings were often separated from the injured child for many weeks with restricted information, so increasing fear for some but protecting the youngest siblings from the gravity of their sibling's condition until seeing them. The parents, however, were present, and aware of their child's condition but still felt a lack of knowledge about the ABI.

These findings suggest that disconnection of some sort was common to parents and siblings. For the parents, this was experienced in removal from their own emotional response as well as their relationships with others. This included a disconnection from the wider society that was not experienced by siblings, for whom disconnection was more focused on immediate family relationships, i.e. with their injured sibling, parents and the family unit as a whole. The only sibling who made comparisons with others families was the oldest, at 12 years. It is important to note that some parents and all the siblings experienced distance in their parent-child relationship. For parents this reflected feeling overwhelmed and lacking in resources to maintain the level of care, whereas siblings felt excluded from the initial experiences of ABI and physically separated from their parents.

Both the parents in the metasynthesis and the five siblings interviewed appeared to have difficulty grappling with the changes to the injured child and the meaning that this had for their relationships and roles. For parents, this meant additional roles and adjusting their interactions and behaviour management strategies. This is mirrored by siblings taking on additional caring and rehabilitation support roles, as well as adapting to changed play etc. Parent's seemed to have much more of a focus on how these changes might influence the future than siblings, who were more focused on the present. Again, the one sibling who did express concerns for the future was the oldest.

It may also be interesting to consider both siblings and parents experience from an attachment perspective. For example, how does an ABI affect attachments with the family, and equally how do prior experiences of attachment influence coping and experience of an ABI. This appears to be an under researched area in paediatric ABI. Attachment theory (developed by Bowlby, 1969) is generally considered in relation to primary caregivers, however there has been research and discussion about its application to siblings (Bank & Kahn, 1997). Given that half of siblings were found to adopt caring roles when needed in

typical sibling relationships (Stewart, 1983), it is not surprising that siblings in this research took on caring and rehabilitation responsibilities. Bank and Khan (1997) suggests that sibling relationships vary in their level of closeness and attachments. This suggests that the impact of ABI might be specific to each sibling dyad. Indeed, there seemed to be some variation in the emotional impact of the sibling separation in this research. For siblings where attachment plays an important role, a reduction in physical proximity could have significant consequences in their attuned reciprocal responses.

In this research, the combination of parents' and siblings' experience indicates a need for family interventions after paediatric ABI. Available interventions might include family therapy which may allow their shared experience to be voiced. However, this thesis raises an important question: how do services help to support siblings without increasing the burden on parents: by asking them to bring them to sessions or by highlighting the need for emotional support to siblings when they are already overwhelmed. Interventions, such as family therapy involves significant emotional investment for parents. Therefore, we may need to think more systemically about support for siblings, for example working through schools.

Why This Research?

There are a number of clinical experiences that led me to this research. I was initially interested in this area due to previous clinical experience running a group intervention for siblings of children with a diagnosis of autism. I continued this interest by completing a literature review of siblings' experience of children with developmental disorders. This review found that this experience is often extremely challenging but that there were also positive aspects for many siblings. These siblings had only known their brother or sister with a developmental disorder from birth. I wondered then whether they are likely to have related to their brother and sister in a similar way all their life. However, I started to wonder what

this would be like for siblings when there is a sudden and unexpected change in their brother and sister and whether this influences the sibling relationship. In addition, I was involved in analysing a research project of adult siblings' experiences after ABI and it occurred to me that younger siblings' experiences might be quite different due both to their dependence of parents and also still living with their brother or sister.

I chose to look at the experiences of children whose siblings had any type of ABI, as I was interested in exploring the shared experience of this group. However, recognising the need to capture any differences, I recorded the type of ABI so I could consider this during analysis. This is important as I acknowledge that different ABIs may influence sibling experience, for example a brother or sister having a road traffic accident as opposed to a brain tumour. However, the well siblings' experience of the cognitive, physical and behavioural changes may be similar. Indeed the types of ABI varied in this research, yet they shared similar experience. The Royal College of Physicians and British Society of Rehabilitation Medicine (2003) commented that that ABI services in the UK were organised around patients' needs, not underlying pathology. This has also been my observations while working in paediatric services. Therefore, both the literature review and research paper included all types of ABI to understand shared experience.

Strengths And Limitations

The strengths of this research were often accompanied by challenges. For example, this research seeks to understand the perspectives of a group which is difficult to access. This resulted in recruitment difficulties but also makes the findings really important to allow their voice to be heard. I will discuss some of the challenges including conducting research with children and practical issues with interviews.

Recruitment

There were significant challenges with recruitment throughout this study. Recruitment took place over a period a period of eight months over three different pathways. Navigating the NHS ethics approval process alongside three different pathways (a Research and Development NHS Trust department and two charities) was a challenge in co-ordination and timing (See appendix 3-A for a recruitment timeline).

In order to facilitate recruitment, I kept regular contact with the link workers in all services. Despite this comprehensive approach, including two major brain injury charities, all of the final participants approached me through the NHS pathway. This may reflect more developed relationships between the recruiting clinicians and potential families. In addition, the service was invested in the project as I was on placement there which meant staff were mindful of recruitment.

In addition to planned recruitment pathways, I also explored alternatives, such as brain injury case management companies. However, all of the companies that I contacted were either not interested or did not have current families meeting the criteria. Additionally this would have needed careful considerations in relation to the ethical practice of recruiting through companies who seek legal compensation for families after an injury.

On reflection, it may have been helpful to recruit through multiple NHS services from the beginning. In discussion with the clinicians in the services, it did not appear that this was necessary when planning the research, but my experience has been that siblings are particularly difficult to recruit. I considered recruiting with another similar NHS service, however the set up and resources meant that recruitment in this service would have taken too long. Additionally the area was already covered by workers from the first charity. Given the pragmatic restrictions of the clinical psychology doctorate, it was decided that this additional recruitment pathway was not viable. Initially recruitment was focused in the North West,

then broadened to include anywhere in the UK. At this point, it was too late to approach other NHS services. However, for any further research with this group, I would recommend using a wide range of NHS services as well as relevant charities.

Additionally to distribution difficulties, there may have been reasons why parents did not respond. The literature review provides insight into the experiences of parents of a child with ABI and offers possible hypotheses underlying recruitment difficulties. A clear finding was that parents are required to take on many roles that carry significant practical and emotional burdens. It may be that many parents felt too overwhelmed to engage. Parents in some of the studies also talked about a need to focus on the child with an ABI, which was also reflected in siblings' comments in the empirical research. As this research involved siblings, I wonder if parents did not have capacity to focus on the sibling at this time. Additionally, engaging in this research might prompt parents to engage with any concerns of the impact on siblings, as raised in the metasynthesis. This may have been difficult for parents to contemplate when struggling to support the siblings. Certainly, the parents of one young person I interviewed expressed a high level of concern about the sibling after the interview due to guilt at their own actions, what she had witnessed and their own capacity to be available to her.

Despite difficulties I was able to recruit five participants. Smith, Flowers, & Larkin, (2009) emphasise the importance of retaining the detailed ideographic understanding of the individual, and therefore small samples sizes are essential to retain the concentrated focus. Therefore, Smith and colleagues (2009) recommend between four and ten participants for clinical doctorates with IPA. Additionally, Hefferon & Gil-Rodriguez, (2011) highlight that "more [participants] is not always more" (p756). Unsure of the likely depth of reflections given the age of participants, I originally planned for between six and twelve participants. In

the event, larger numbers were not required due to the rich conversations that developed during the interviews.

Research with children

Historically there has been a tendency to explore children's experiences through parents' perspectives (Irwin & Johnson, 2005). This has proved helpful in some domains for example, emotional wellbeing and behaviour. However, there is rightly an increasing trend to consult children directly about their own lives (Morrow & Richards, 1996; Shaw, Brady & Davey, 2011). The right for children to express their own views freely about matters affecting them is specified in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC). I believe that children and young people are able to provide insights into their own experience and therefore a strength of this research was giving these children an opportunity to share their own experiences. Children as young as 4 have been shown to be able to provide insights into their experiences (for example, Alex & Ritchie, 1992). As a result, I chose a qualitative research methodology.

Shaw and colleagues (2011) highlight particular challenges to conducting research with children, such as gaining access to participants through gatekeepers (i.e. often parents). There are also adult-child power discrepancies to consider when interviewing children. Although it is argued that this cannot be eliminated completely, Shaw and colleagues suggest strategies for avoiding this. I tried to create a relaxed atmosphere using my clinical skills in child engagement and having informal conversation and pre-interview activities, dressing informally and avoiding formal room settings.

Building rapport with children is really important in qualitative research but takes time (Irwin & Johnson, 2005). I felt that my experience building working relationships with similar aged children in clinical training and prior working experiences helped me in

developing each interview. Part of this was developing appropriate communication. I tried to ascertain some understanding of the young person's level of ability before I attended the interview, and assessed and monitored this throughout, adapting my language to match. An interview guide was developed but the specific ages and abilities of the participants were not known in advance of recruitment. Clearly, questions needed to be tailored to the needs of individual participants but I always tried to keep questions short and used simple language. IPA uses open-ended questions to structure interviews, allowing the participant freedom to explore their experience. However due to the age range, I felt it is important to adapt the phrasing of questions and the balance of open and closed questions for each child. More closed questions were generally used at the beginning before becoming more open-ended, as this has been helpful in building a child's engagement and provided a scaffold for further questions (Irwin & Johnson, 2005). Shaw and colleagues (2011) also point out the need to recognise that children have shorter attention spans and therefore may not be able to focus for long periods. Therefore, I was prepared to follow children off topic for short periods to facilitate comfort as well as limit fatigue (Irwin & Johnson, 2005).

"Research with children demands flexibility and creativity on the part of both the researchers and their 'data collection' approaches" (Darbyshire, Macdougall, & Schiller, 2005, p.428). I involved drawing in my interviews as it is appreciated by children (Elden, 2013) and offers many benefits such as "engaging and empowering the child, facilitating interaction, allowing the child to respond in their own time (Duncan, 2013, p. 303) and enhancing their level of comfort (Irwin & Johnson, 2005). Drawing provides an opportunity to understand the perspective of children who do not have the verbal language skills to communicate complex information (Duncan, 2013). Drawings are therefore often analysed as part of the results. In this research, as the siblings were able to communicate their thoughts verbally, drawing and writing were just used as a facilitative tool.

Drawing may not always be welcomed by all participants and therefore was optional but I felt that these young people responded well to the use of drawing. Even Chris, who chose mostly to write rather than draw, seemed to benefit from this distraction from any pressure of talking. I used a general activity to start where both myself and the young person wrote or drew ourselves, for example things we liked doing, eating, and important people in our lives. I think it was helpful that I also completed my own page as I felt this put young people at ease. I also instigated a timeline of children's life events to help facilitate discussion and give a visual and concrete way to structure later conversation i.e. being able to point at the time before and after injury. All but one of the children chose to put their brother or sister's injury on their timeline. The other child did not want to because she was too distressed by the memory.

The ethical considerations when interviewing children needed careful thought. I was very aware that, as researchers, we have a responsibility to ensure that we do no harm to those we involve in research (Noret, 2012), and children may be more vulnerable in managing distressing interview content. Who to ask consent from was an interesting issue as "many researchers, [including myself], recognise the need to view [children] as autonomous individuals capable of making their own decision" (Noret, 2012, p1). In the UK, there is no stipulated age when children under the age of 16 can give consent in health and social care issues (Department of health, 2001). However most studies involving children under 16, requires the consent of parents but the child's agreement should always be sought (Shaw, Brady & Davey, 2011). I took advice from my local NHS ethics committee and NHS Research and Development department and they felt it was appropriate to gain parental consent but child assent, as suggested by Noret (2012).

To assist the young people in making as informed a decision as possible, I provided age-specific information sheets (see section 4; ethics Appendix 4-B, p90-100), as

recommended by Noret (2012). I also discussed the information, asked them to summarise it back to me and tried to make explanations as concrete as possible. For example, I trial recorded our voices prior to starting and played it back so they understood it was recorded. I felt this helped to ease any anxiety about this and facilitate trust and engagement. Additionally I was continuously monitoring consent throughout the interviews (Shaw, Brady & Davey, 2011).

Parents' involvement

I offered children the opportunity for their parents to remain in the room for the interview, which can sometimes be necessary when researching with children (Irwin & Johnson, 2005). Smith and Osborn (2008) advise that the interview for IPA be conducted just with the participant in the room, however they recognise that interviewing children may be an exception to this. I recognised that parents being present may influence a child's answers and make them less comfortable talking about difficult issues, particularly if related directly to their parents. However, the prospect of being interviewed by a stranger may have provoked anxiety and ethically it seemed appropriate to offer this choice. All but one child (the youngest) chose to be interviewed alone. I explained to the parent the need to remain neutral so as not to influence the child's responses, as recommended by Shaw and colleagues (2011). Once initial activities were finished with this child and rapport established , I checked whether she might feel comfortable with her parent/caregiver leaving the interview for a period. However, she expressed a wish for them to remain. On reflection, this did influence the interview as there were a number of times when she started to talk about something and then looked at her parents and stopped. For example, she told me that she felt left out at times, made eye-contact with her mother and seemed anxious and shy. She then got up, sat on her mother's lap and embraced her. I noted the presence of the parent on this occasion in the analysis. However, she was still able to give helpful insights.

Location of interview

I gave families flexibility of where the interviews took place in order to reduce burden on the participant and family. However, I also recognised that the location might influence the child's level of anxiety and therefore their engagement. I interviewed one child in the hospital while all the others took place at their home. The location was noted for analysis purposes to see whether this had any impact on the data, however this did not seem to be the case. There were challenges of interviewing children in their own home, as some required tolerating background noise and distractions, including the sibling with an ABI playing. One child was very specific in ensuring that their injured sibling would not be able to hear what they were saying.

Research methodology

Interpretative phenomenological analysis (IPA) was chosen because of its focus on exploring a significant life event and on trying to understand a person's perspective of their own experience (Smith, Flowers & Larkin, 2009) and is particularly useful within health research (Smith, 1996). A growing body of IPA research has enabled the voices of under researched groups to be heard including children (for example, Back, Gustafsson, Larsson & Bertero; Bolas, Wersch & Flynn, 2007; Doutre, Gree & Knight-Elliott, 2013). Research with children requires adaptation of IPA guidelines (Smith, 2008). For example, how to develop and conduct a semi-structured interview (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008) would need adapting for children to include being more interventionist (Smith, 2008). This means that I had to include more direct questions, and guide participants more than in an adult interview. Smith (2008) recommends that "practitioners conducting research with these groups can draw on their own professional experience with clients to help them modify existing protocols when collecting data" (p. 49). I drew on my prior experience when working with children of this age group in school settings, holiday camp settings and within

clinical psychology to modify procedures appropriately under the guidance of an IPA consultant who has been involved in children's IPA research previously (Dixon, Murray & Daiches, 2013). Duncan and Smith (2003) offered helpful suggestions for interviewing children for IPA such as playing games with them beforehand to build reciprocity. As a result, alongside other recommendations, I included the initial activities (the timeline and the 'all about me').

Despite my efforts to meet the potential challenges of conducting IPA with children, I built in a contingency of changing the method of analysis to thematic analysis if the data was not rich enough in its detail and reflections. I assessed the quality of the interview data with the IPA consultant and concluded that the data was sufficiently rich for IPA.

Future research

This thesis has clearly found that children can offer helpful and detailed insights into how they experience the world. It therefore endorses research exploring children's own perceptions, particularly using qualitative methodology and IPA.

The metasynthesis has highlighted the need for further research including the perspectives of more fathers. There is also need for a metasynthesis of parent's experiences of young adult children. Given how informative the sibling research focusing specifically on the sibling-sibling relationship has been, it might be helpful to have that same focus when exploring parent-child relationships, as this has not yet been fully explored.

The research paper recognises the need for further research exploring the trajectory of the sibling relationship, preferably longitudinal. Given the small and homogenous sample, it is also important that there is further research exploring diverse groups, such as different socio-cultural backgrounds, sibling gender dyads and sibling order.

Both the papers also highlight the need for more research into interventions to support families of paediatric ABI. The thesis has looked at siblings' and parents' experience but clearly a key member of the family system is missing, the child with the ABI. This is particularly important when focusing on relationships because a sibling or parent is only one half of a relationship dyad.

Conclusion

This thesis has explored parent and siblings' perspectives on paediatric ABI and demonstrates the powerful changes that occur in these families and how each member attempts to make sense of these. The significance of seeking children's own views is evident in the rich and thoughtful findings and the importance of being flexible and creative in eliciting these. The power of the sibling relationship and the important part they play in each other lives was striking in this research. When combining these findings with parents' perspectives, it offers an insight into the world of these families which was not fully understood.

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Appendix 1. Timeline of recruitment process

Ethical approval process		Recruitment pathway	
July ‘14	Application to university sponsor approval		
Sept ‘14 Sept ‘14 Sept ‘14	Application to NHS ethics Application to R&D ethics Application to charity 1		
Nov ‘14	Received approval for NHS and R&D		
		Start NHS recruitment- weekly contact with key recruiters	Dec ‘14
Nov ‘14	Make changes for charity 1 requirement and request ethics amendment		
Dec ‘14	Receive amendment approval		
		Start charity 1 recruitment- weekly contact with key recruiters	Dec ‘14
March ‘14	Request amendment to alter age range		
March ‘14	Receive amendment		
		Widen recruitment from north west to national	March ‘15
		Considered alternative options for recruitment • Explored additional NHS services • Rang six case management companies • Discussed recruitment with charity 2	March/April ‘15
April ‘15	Request amendment to recruit with charity 2		
		Start recruitment with charity 2	July ‘15
		Close recruitment	July ‘15

Section Four: Ethics Section

Ethics Application for the Research Paper

Emma Tyerman

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Covering note: This section includes the ethics proposal that was submitted to the NHS trust. Three amendments were made to this proposal which are also included as well as the approval letters.

NHS REC ethics application

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Siblings' experiences of childhood acquired brain injury

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (●) No

b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (●) No

c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (●) No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

England
Scotland
Wales
Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] National Information Governance Board for Health and Social Care (NIGB)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

(●) Yes ( ) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
Undertaken as part of a Doctorate in Clinical Psychology. The student will be named the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS
Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Siblings' experiences of childhood acquired brain injury

Please complete these details after you have booked the REC application for review.

REC Name:
North West-Lancaster

REC Reference Number:
14/NW/1418

Submission date:
28/10/2014

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Exploring siblings' relationships with their brother or sister with an acquired brain injury

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Miss	Emma	Tyerman

Address: Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness College, Lancaster University
Post Code: LA1 4YG
E-mail: tyerman@exchange.lancs.ac.uk
Telephone: 07894983038
Fax:

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	[redacted]	[redacted]	[redacted]

Address	Doctorate in Clinical Psychology
	Facaulty of Health and Medicine, Furness College,
	Lancaster University, Lancaster
Post Code	LA1 4YG
E-mail	f.eccles@lancaster.ac.uk
Telephone	01524 592807
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Miss Emma Tyerman	☑ [redacted]

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (●) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

Title	Forename/Initials	Surname
Miss	Emma	Tyerman

Post
Trainee Clinical Psychologist Qualifications BSc
Degree in Psychology in Education Employer
Lancshire Care NHS Foundation Trust Work Address
Doctorate in Clinical Psychology

	Faculty of Health and Medicine
	Furness College, Lancaster University
Post Code	LA1 4YG
Work E-mail	tyerman@exchange.lancs.ac.uk
* Personal E-mail	tyerman@exchange.lancs.ac.uk

Work Telephone	07894983038
* Personal Telephone/Mobile	07894983038
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
		Debbie	Knight
Address	Research Ethics Officer, Research Support Officer		
	University House, Lancaster University		
	Bailrigg, Lancaster		
Post Code	LA1 4YW		
E-mail	ethics@lancaster.ac.uk		
Telephone	01524592605		
Fax	015244843087		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	
Protocol Version:	2
Protocol Date:	23/09/2014
Funder's reference number:	
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language*

easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

The research aims to increase understanding of siblings' experiences of their relationships with their brother and sister who has had an acquired brain injury (ABI).

In particular the research seeks to understand children's perspectives on any change in their relationship that may have occurred since their sibling's injury and how this affects them.

An ABI was defined by the UK Acquired Brain Injury Forum as 'A non-degenerative injury to the brain occurring since birth. It can be caused by an external physical force or by metabolic derangement' (UK Acquired Brain Injury Forum, 2014). The effects of an acquired brain injury are varied and are experienced differently by individuals but can include physical and/or cognitive impairments, and emotional and behavioural changes. This can have a significant impact on the family such as parental stress, depression and family functioning.

The evidence suggests that siblings of children with an ABI can experience difficulties such as emotional and behavioural problems, obsessive compulsive thinking and a lower self esteem. Part of these difficulties may be due to the change in the sibling relationship and therefore it is important to explore this further.

There has been a limited amount of research asking children about their own experiences and younger children particularly have been neglected. Therefore, this study aims to ask children about their perspectives on their relationship with their sibling through approximately 30-45 minute interviews with 6-12 siblings aged 5-11 years.

The children will be recruited through [redacted] and [redacted]

The researcher will then collate all the experiences of these siblings and analyse them using Interpretative Phenomenological Analysis (IPA) because this method focuses on lived experiences of important life events. Themes will be developed from the data and a summary will be sent to families if requested.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Purpose of research
It is important to further knowledge in this area to identify need in this population. Research has so far shown that siblings of children with an acquired brain injury can suffer some adverse affects but there has been a limited focus on their own perspectives on this, particularly younger children. It is important that children are given the opportunity to voice their experiences. A qualitative interview research design seemed the most appropriate choice to access this. Interpretative phenomenological analysis was chosen for analysis because of its emphasise on individual lived experience, which is appropriate for this group due to our aim of developing individual understanding of experience.

MAIN ISSUES

Confidentiality
Every effort will be kept to keep interviews confidential and in a private space. The young person will have the opportunity to choose if they want a parent/caregiver to accompany them in the interview and this will also be discussed with the parent/caregiver.

The researcher will ensure that participants understand the limits of confidentiality and when they would have to pass information on to relevant services. If this happens, the researcher will inform both the child and parent that they plan to share information unless this will significantly increase the risk to the child or the researcher themselves at that time. The researcher can contact her field supervisor [redacted] for support with clinical and safeguarding issues is necessary. If there is an immediate concern, the researcher will contact the local Children's Service.

The researcher will make every effort to keep data collected safe and secure.All transcripts will be anonymised as far as possible and information such as participant names and place names will be removed. The paper form data will be kept in a locked box in the home of the principal investigator during the project. Electronic data will be kept on the password protected file space on the university server or encrypted on electronic devices. Any personal information

(except consent forms) will be deleted as soon as they are no longer needed.

Consent
All parents will be asked to give consent for their child to participate. The siblings will be asked for assent after considering the age appropriate child information sheets. If the sibling does not assent or withdraws at any time, the interview will not continue.

Lone working
The [redacted] lone worker policy will be adhered to.
The location will be provided in a password protected word document that will be emailed to a fellow healthcare professional just prior to the interview. The password will be sent in a separate email. When the principal investigator has finished the interview they will contact the colleague. If the colleague does not hear from the researcher they will try to make contact. If this is unsuccessful, then the colleague will use the password to access the information about the interview and will call the appropriate authorities. The colleague and the investigator will then delete the emails containing the attachment after the interview has taken place.

Support available
It is recognised that there is the potential that participants might feel distressed by the content of any interview. The researcher will be sensitive to this, as well as offering breaks, should the need arise and giving options to stop completely, miss questions or reschedule to their convenience. The researcher will remind participants of sources of support that might be helpful at the end of the interview, as in the information sheet.

Power in research with children
The researcher has tried to reduce the power imbalance when working with children by providing accessible information sheets. They have been sent to a number of primary school teachers and clinicians that work therapeutically with the age group for feedback. They have also been offered to children and parents at [redacted] for their feedback, however we did not receive any comments.

The researcher will make it clear to children that they do not have to participate and their engagement will be monitored throughout. The researcher has included a number of introductory activities to support the child to feel comfortable and reduce the power imbalance.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study

☑ Qualitative research

☑ Questionnaire, interview or observation study

☐ Randomised controlled trial

☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

-What is the impact of childhood brain injury on sibling relationships?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

-What are the needs of these siblings?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Research has shown that a childhood brain injury can have a significant impact on the family but in particular, siblings of children and adolescents who have had a brain injury can experience difficulties such as emotional and behavioural problems impacting on school as well as home life (Fay & Barker-Collo, 2003). Increased experiences of obsessive compulsive thinking have also been found (Orsillo, McCaffrey & Fisher, 1993), as well as lowered self esteem (McMahon et al. 2001). However, there is inconsistent evidence as other research found no difference to controls in sibling behaviour (McMahon et al. 2001 and Swift et al. 2003).

Qualitative studies have extended these findings. Gill and Well (2000) interviewed eight siblings (aged between 14 and 30) and found that siblings' lives were now very different because of a change in their brother or sister with a brain injury. For example, they described differences in their emotional reactions and change in their daily life. In addition to their own reactions, siblings are acutely aware of parental distress, and may support parents or take on more responsibility generally (O'Hara et al. 1991; Willer et al. 1990).

Part of the distress for siblings following brain injury may be due to changes in the sibling relationship. In the quantitative literature a more negative sibling relationship in families of children with a traumatic brain injury was found in mixed gender dyads (Swift et al. 2003) when compared with families where a child had had an orthopaedic injury. However, this study did not address the siblings' perspectives of these changes. No known qualitative study has focused specifically on the sibling relationship after a traumatic brain injury. Using qualitative methodology to explore this might indicate other contributory factors to the negative changes in a sibling's relationship.

In summary, quantitative research has highlighted that siblings can experience a range of difficulties after their brother or sister's acquired brain injury. The limited qualitative research available examined siblings' experiences in more depth and support the quantitative findings, but have also found positive effects of the experience. However, the impact on the sibling relationship has not been specifically explored. In a recent review of the literature of siblings experiences in general, Sambuco, Brookes and Lau (2008) raise the need for further research specifically looking at the younger siblings' experience (primary school age). No studies have been found, since this review, which focus on this.

Consequently, this study will aim to investigate and understand the experience of a child being in a relationship with a sibling who has had an acquired brain injury. interpretative phenomenological analysis (IPA) will be used to analyse results because it focuses on lived experience and important life events.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This is a qualitative study using semi structured interviews of children with a sibling with an acquired brain injury.

Potential participants will be accessed through [redacted] t and [redacted]. The two services will access their databases and send out letters to parents of the young person with an acquired brain injury that have been seen by the service and meet the inclusion/exclusion criteria. The researcher will not have access to this information. The letter will include information about the project (both for parents and the child) and the opportunity to contact the researcher if they are interested in participating (i.e. contact details of the research and an expression of interest form). The researcher will then contact the parents and answer any questions before arranging

an interview if they still wish to take part.

After consent is obtained from parents and assent from children themselves, the data collection will consist of approximately 30 minutes to an hour face to face semi-structured interviews. These will take place at a location convenient to the family, for example their home or the local children's centre.

Interpretative phenomenological analysis (IPA) is planned to be used to analyse the data because this research is exploring a significant life event and the aim is for the researcher to try and access the young person's understanding of their experience.

If the family wish to receive a summary of the research, they will receive this after completion of the project.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [x] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
Children and parents of young people attending psychological services at ******** hospital were offered the opportunity to comment on the design of the study and the information sheets. These were approached by *****to inquire whether they were interested in giving their thoughts on the design, however we received no comments.

The plan if possible is for the research findings to be presented at an organised siblings support event and to get feedback from siblings about the themes and get their ideas about how that can translate into how services can meet any identified needs.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

-Siblings of children with any form of sudden onset acquired brain injury.
-Age range of participant is primary school age 5-11.
-Age range of child with an acquired brain injury is school age at time of injury 5-11.
-Time period after sibling injury between 6 months and 3 years post injury.
-The young person with a brain injury must live with the sibling or have lived with the sibling prior to having a brain injury.
-The sibling must be able to communicate in English and tolerate a half hour to 3/4 hour interview.
-The young person with a brain injury will have spent more than two weeks in hospital to capture the more moderate/severe brain injuries

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

-Bereavement of another family member in the same incident as sibling's injury
-Siblings whose brother or sister has a life limiting condition

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the

research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Participants given information about the project in written format.	1		5 minutes	Clinical staff in the services will send out the information to families via letter or in regular clinical contact.
After participants have given consent to be contacted, they will be approached to discuss involvement in the research	1	0	Approx. 10 mins	The principal researcher will contact participants by telephone or a preferred method of the participant (e.g email) and offer further information if wanted. If consent is given, an interview time will be arranged.
Interviews	1	0	Approx. 30-60 mins	The principlal researcher will interview participants in a location convenient to them (their home/ hospital/children's centre)
Summary report sent to participants	1	0	N/A	A summary report of the finding will be sent to participants after completion of the research if they wish to receive this.

A21. How long do you expect each participant to be in the study in total?

From the point of giving consent/assent, individuals will be involved in the interview for approximately 45 minutes. If individuals want to receive a summary of the finished research project this may be a delay of approximately five months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

It is recognised that there is potential for participants to feel upset about the experiences they may have found difficult. The young person's welfare is a key priority and the researcher will ensure that they always discuss options for support, for example, their parents, their GP and the support offered from [redacted]

If at any point in the interview, the young person appears uncomfortable or in distress, the researcher will offer breaks, to skip questions and remind them that they can withdraw at any time.

The interviews will take place at a convenient location to minimise the burden of attending the interviews. Expenses of up to £20 will be offered for participants who need to travel for the interviews if they need to travel outside their home.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

It is recognised that there is a potential that some children may find the topic of their relationship with their sibling and experiences at the time of the acquired brain injury distressing. As a Trainee Clinical Psychologist, the researcher is continuing to have training and experience supporting people in distress. The research will always approach the issues in a sensitive and non judgemental way. If this occurs the researcher will offer breaks, skip questions and remind them that they can withdraw.

At the beginning of the interview and on the participant information sheet, participants will be informed of limitations of confidentiality and when this has to be broken (e.g. if there is a concern that they are at risk). If a disclosure occurs

at the time, the researcher will remind the young person that they have a duty to pass this information on to make sure that risks are managed. The parents will also be informed of this and the appropriate services would be informed. The researcher will ensure they have the contact details of the local social services for support if needed. The researcher can also contact her supervisors for advice in managing any concerns after the interview.

A24. What is the potential for benefit to research participants?

Although there are no direct benefits of participating in this research for participants some individuals may experience a positive response to the opportunity to share their experiences and contribute to knowledge and understanding. The research has the potential to benefit future siblings of young people with an acquired brain injury in identifying need so that this group can be better supported.

A26. What are the potential risks for the researchers themselves? *(if any)*

There is a potential risk for the researcher if they conduct a home visit for interviews. This is important to offer as their may be a high level of strain on families with a young person with an acquired brain injury. The family will be given the opportunity to choose where they would like the interview to take place (e.g. their home/ the hospital or a local Sure Start Centre). The lone working polici[redacted] will be followed to ensure that if there is risk to
the researcher there is support available. This includes sharing the address and time of the interview with an allocated colleague who will follow a clearly defined procedure if they do not hear from the researcher by a certain time to ensure the safety of the researcher. The personal information will only be accessed by the colleague if they do not hear from the researcher and will be deleted as soon as reasonably possible after the interview.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Potential participants will be accessed from the records of both [redacted] and the [redacted] by members of these organisations. The service will allocate someone to do this from within the clinical staff team. The researcher will not see any of these names or details prior to them giving consent by showing interest in the project and contacting the researcher directly.

The researcher will provide the services with an information pack which includes:
-Letter from the service
-Information sheet for parents
-Information sheet for the child
-Consent to be contacted form
-Stamped address envelope

The services will send out these packs or give them directly to service users in any regular clinical contact. The potential participants will then contact the researcher if they are interested.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

◉ Yes ○ No

Please give details below:
Identification of potential participants will be completed by a member of the clinical team from their records of current and previous service users.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information

of any potential participants?

○ Yes ◉ No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

The potential participants will first be approached by a member of their care team. From [redacted] A Clinical Psychologist).

From the [redacted], this would be [redacted] Regional Child and Family Support Co-ordinator, North West).

The services would either send this out via the post or give out in person at a clinical meeting.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

As I am interviewing children under the age of 16, I will be obtaining parental consent from parents before the interview. I will go through the information sheet and the consent form to check they understand and to see if they have any questions.

I will also be asking the young person themselves for assent. Once the parent has consented, I will then run through the child information sheet and make sure the child understands as much as posssible and obtain the child's agreement to complete the interview before proceeding. If the child does not want to take part, the interview will not go ahead.

The researcher will record consent for parents and the young person. If the child chooses for their parent to stay for the interview, the parent will also be asked whether they consent for any data they choose to share to be used in the analysis.

If you are not obtaining consent, please explain why not.

N/A

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants have from when they receive the information (planned for September/October) until recruitment will close (planned for December). After initial contact has been made and the family have had the opportunity to ask any questions, they will have the opportunity to consider it further before booking an interview if they wish. No pressure will be put on participants to be involved in the research.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

The methodology of Interpretative Phenomenological Analysis explores peoples' interpretation of their own life experience. Using interpreters would be an issue with this methodology as there is a risk that the data collected would be influenced by the translator's interpretation of the participant's experience. This means that the participant needs to be able to speak English and therefore no translation service will be available.

Some children in the research may have very limited reading ability and so pictures have been included on the information sheet. The sheets will always be read through by the researcher to ensure the child has heard all of the information.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ◉ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If the participant loses the capacity to give consent before or after data collection then they will no longer be included in the research to protect these individuals. Due to the difficulty of extracting data from qualitative analysis, if the data has already been collected with their consent when they were able to give it, and the analysis process has begun, it may not be possible to withdraw the data. The same principles of ensuring anonymity would apply.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☑ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☑ Publication of data that might allow identification of individuals
- ☐ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:

- ☐ NHS computers
- ☐ Home or other personal computers
- ☑ University computers
- ☐ Private company computers
- ☐ Laptop computers

Further details:
The Principal Researcher is responsible for storing all the data while the project is being completed. Data will be stored in the university secure network (Z) drive which is password protected and encrypted. This will be accessed from a home laptop and university computers however, it will not be saved on these devices if possible. If required to be saved on these devices, it will be encrypted. Any paper form information will will be kept securely locked at the researchers home. After contact with participants has ended any personal information will be destroyed appropriately (except consent forms).

After completion of the project, a member of the Lancaster Univesity Clinical Psychology course team will store the data. Most data will be put in electronic form. Any non electronic data will be stored locked in a secure location. The data will be kept for a period of ten years, at which point it will be destroyed.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

The contact details of participants will be collected from participants and retained only for the purpose of contacting them and attending interviews at home addresses. Once the research has been completed, these will be disposed of securely.

The audio recordings from the interviews will be copied to the Lancaster University secure Z drive as soon as possible which is password protected and encrypted. This file will then be deleted from the audio device. Once the research process has been completed the audio files will be deleted.

Any information that is in the data will be made anonymous, for example, names (people and places). The original data will be replaced with an alternative for the purpose of analysis and the write up of the research. Every effort will be made to make sure service users are not identifiable, however the researcher recognises that the details of people's experiences may place them at risk of being identified by others that know the participants really well. The participants are being recruited from a large pool and from different services so this reduced the risk that professionals could recognise a partipant. They will not be aware of who has shown interested or participated unless the participant chooses to tell the service themselves.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Participants personal information will only be accesssed by the direct care team. The only information that the research will see is the information that the participants and family choose to share with the team.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ○ 6 – 12 months
- ○ 12 months – 3 years
- ◉ Over 3 years

If longer than 12 months, please justify:
The consent forms of participants will be kept for 10 years alongside the data. This is the Lancaster Unversity policy.

summary, their details will be kept until after this is sent out.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will recieve expenses for travel to the interview if required up to a value of £20. This is specified in the information sheet. Lancaster University Doctorate in Clinical Psychology fund this.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
No appropriate database has been identified.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☐ Conference presentation
☐

☐ Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will have the option to receive a summary of the results if they wish to.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi−centre research group

☑ Review within the Chief Investigator's institution or host organisation

☐ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A research proposal was submitted to Lancaster University which was reviewed by other Trainee Clinical Psychologists and tutors at the university.

The research is continually monitored by a research supervisor (from Lancaster University) and a field supervisor (working in the field). An additionally consultant may support the analysis process [redacted] Deputy research director and senior lecturer at Lancaster University) with specialist knowledge of Interpretative Phenomenological

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	10
Total international sample size (including UK):	10
Total in European Economic Area:	10

Further details:
The sample size will be 6- 12 siblings of young people who have had an acquired brain injury. Offers for participants will generally be accepted on a first come first serve basis as the researcher receives interest. However, if a lot of participants come forward at a similar time, priority will be given to those who are most homogenous with the group already recruited. If the limit has been filled when a participant shows interest, they will be thanked for their interest and the researcher will explain that again the constraints of the project does not allow for more participants to be involved. However, they can still request a copy of the results should they wish.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The researcher will aim to interview between 6 and 12 participants because interpretative phenomenological analysis (chosen methodology) requires a balance between capturing the quality of individual narratives and finding common experience.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The interviews will be transcribed verbatim and interpretative phenomenological analysis (IPA) will be used to analyse the data. The data will be analysed according to the recommendations by Smith, Flowers & Larkin (2009).

The researcher will analyse the data systematically and keeping accurate records of developing themes. Evidence for the themes will be presented through direct quotes from participants in the write up of the research.

Supervisors will provide support throughout the analysis process, and ensure the quality of the analysis.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

Title Forename/Initials Surname

[redacted]

Post	Clincal Psychologist
Qualifications	Doctorate in Clinical Psychology
Employer	[redacted]
Work Address	[redacted]
Post Code	[redacted]
Telephone	[redacted]
Work Email	[redacted]

Title Forename/Initials Surname

[redacted]

Post	Deputy Research Director and senior lecturer
Qualifications	
Employer	Lancaster University
Work Address	Clinical Psychology, Furness College Lancaster University
Post Code	LA1 4YT
Telephone	[redacted]
Fax	
Mobile	
Work Email	[redacted]

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation	Lancaster University
Given name	Debbie
Family name	Knight
Address	Research Ethics Officer, Research Support Officer
Town/city	University House, Lancaster University
Post code	LA1 4YW
Country	
Telephone	01524592605
Fax	015244843087
E-mail	ethics@lancaster.ac.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

- ○ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ◉ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

[redacted]

Organisation [redacted]
Address [redacted]
Post Code [redacted]
Work Email [redacted]
Telephone [redacted]
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2014
Planned end date: 31/05/2015
Total duration:
Years: 0 Months: 8 Days: 31

A71-2. Where will the research take place? *(Tick as appropriate)*

☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

○ ◉

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☑ NHS organisations in England 1
☐ NHS organisations in Wales

☐ NHS organisations in Scotland
☐ HSC organisations in Northern Ireland
☐ GP practices in England
☐ GP practices in Wales
☐ GP practices in Scotland
☐ GP practices in Northern Ireland
☐ Social care organisations
☐ Phase 1 trial units
☐ Prison establishments
☐ Probation areas
☑ Independent hospitals 1
☐ Educational establishments
☐ Independent research units
☐ Other (give details)

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the <u>management</u> of the research? *Please tick box(es) as applicable.*

<u>Note</u>: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University Liability cover will apply.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the <u>design</u> of the research? *Please tick box(es) as applicable.*

<u>Note</u>: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the <u>conduct</u> of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☑ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

Age range 5-11 years

It is important to access the views of young children to understand their needs. There has been no known research that has focused on the experience of this age group specifically on exploring their relationship with their brother or sister with an acquired brain injury.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

No children will be recruited as controls. All recruited participants will be interviewed.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

Parents will be asked to give informed consent for their child to participate in all instances because the children are under 16. Children will be provided with age approriate information sheets and the researcher will go through these with the children to ensure that they understand. Children will then give assent which will be recorded on the assent form. On arrival the researcher will check that the participant (both parent/caregiver and child) understands the information in the relevant participant information sheets before being asked to carefully consider the consent (or assent) forms.

The child's engagement will be monitored throughout the interview and if the child appears to be reluctant to continue, the interviewer will raise this and make sure that they understand that they do not have to continue.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

A separate information sheet has been developed for children age 5, age 6-10 and age 11. This has been given to primary school teachers, clinicians working therapeutically with children in this age group and offered to children and parents at ******** for feedback. The information sheets include pictures to make them more accessible. The information sheet will always be read through by the researcher to manage differences in reading ability and to ensure that they have had all the information.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	[redacted]	[redacted]	[redacted]
Department name	[redacted]	[redacted]	[redacted]
Street address	[redacted]	[redacted]	
[redacted]	[redacted]	[redacted]	[redacted]
[redacted]	[redacted]		
Institution name	[redacted]	Title	
Department name		First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
[redacted]	[redacted]		
[redacted]	[redacted]		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

(●) Chief Investigator

( ) Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Emma Tyerman on 22/10/2014 12:22.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancashire Care/Lancaster University
Email:	tyerman@exchange.lancs.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 27/10/2014 17:13.

Job Title/Post:	Research Support Officer
Organisation:	Lancaster University
Email:	s.c.taylor@lancaster.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by [redacted] on 22/10/2014 12:32.

Job Title/Post:	Lecturer
Organisation:	Lancaster University
Email:	[redacted]

NHS ethics approval

04 December 2014

Miss Emma Tyerman
Doctorate in Clinical Psychology
Faculty of Health and Medicine Furness College,
Lancaster University LA1 4YG

Health Research Authority
National Research Ethics Service

Dear Miss Tyerman

Telephone: 0161 625 7109
Fax:0161 625 7919

NRES Committee North West - Lancaster
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Study title: **Exploring siblings' relationships with their brother or sister with an acquired brain injury**
REC reference: **14/NW/1418**
IRAS project ID: **161002**

Thank you for your submission of 04 December 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 November 2014

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant consent form [Parent Consent Form]	3	19 November 2014
Participant consent form [Parent consent form for parent data]	3	19 November 2014
Participant consent form [Child Assent Form]	3	19 November 2014
Participant information sheet (PIS) [Parent/Care Giver]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 5 years]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 6-10 years]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 11 years]	3	19 November 2014
Research protocol or project proposal	3	19 November 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers liability insurance]	1	01 August 2014
Interview schedules or topic guides for participants [Interview Guide]	2	23 September 2014
Letter from sponsor [Letter from sponsor]	1	23 October 2014

Letters of invitation to participant [Letter of invitation/expression of interest NHS site]	2	23 September 2014
Letters of invitation to participant [Letter of invitation/expression of interest NHS site]	2	23 September 2014
Other [Public Indemnity Insurance]	1	04 August 2014
Other [Public Liability Insurance]	1	04 August 2014
Participant consent form [Parent Consent Form]	3	19 November 2014
Participant consent form [Parent consent form for parent data]	3	19 November 2014
Participant consent form [Child Assent Form]	3	19 November 2014
Participant information sheet (PIS) [Parent/Care Giver]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 5 years]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 6-10 years]	3	19 November 2014
Participant information sheet (PIS) [Participant Information Sheet 11 years]	3	19 November 2014
REC Application Form [REC_Form_28102014]		28 October 2014
Research protocol or project proposal	3	19 November 2014
Summary CV for Chief Investigator (CI)	2	23 September 2014
Summary CV for student	2	23 September 2014
Summary CV for supervisor (student research) [Fiona Eccles CV Supervisor]	2	23 September 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/NW/1418 **Please quote this number on all correspondence**

Yours sincerely

Margaret O'Connor
REC Assistant

E-mail: nrescommittee.northwest-lancaster@nhs.net

Copy to: *Ms Debbie Knight*

NHS Trust [redacted]

Amendment request 1

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Siblings' experiences of childhood acquired brain injury

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes
(●) No b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes
(●) No c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

England
Scotland
Wales
Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

NHS/HSC Research and Development offices
Social Care Research Ethics Committee
Research Ethics Committee
National Information Governance Board for Health and Social Care (NIGB)
National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

(●) Yes ( ) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- [x]
- [ ]
- [x]
- [ ]
- [ ]

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
Undertaken as part of a Doctorate in Clinical Psychology. The student will be named the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Emma	Tyerman
Work Address	Doctorate in Clinical Psychology		
	Faculty of Health and Medicine		
	Furness College, Lancaster University		
PostCode	LA1 4YG		
Email	tyerman@exchange.lancs.ac.uk		
Telephone	07894983038		
Fax			

Full title of study:	Exploring siblings' relationships with their brother or sister with an acquired brain injury
Lead sponsor:	Lancaster University
Name of REC:	North West-Lancaster
REC reference number:	14/NW/1418
Name of lead R&D office:	[redacted]
Date study commenced:	15.12.14
Protocol reference (if applicable), current version and date:	Research protocol version 5 26.02.15
Amendment number and date:	Amendment 1 26.02.15

Type of amendment

(a) Amendment to information previously given in IRAS

◉ Yes ○ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

Please see summary of changes

(b) Amendment to the protocol

◉ Yes ○ No

If yes, please submit <u>either</u> the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

Revised protocol submitted (version 5 26.02.15)

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

○ Yes ◉ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

○ Yes ◉ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific c[redacted]ed.

After review from the [redacted] ving amendments are requested. The first six points add additional information which the [redacted] t asked to be made explicit, although they do not alter the procedure as previously giv[redacted] 7-8) change the recruitment process for both the NHS [redacted] ent through the [redacted] The final point refers only to recruitment through th

All additions in the research protocol have been highlighted in yellow.

1. Additional explanations about the interview guide (page 10 and 11 in protocol- see below)

Page 10: The interviews will broadly follow the interview guide (Appendix J), in relation to the topics that will be introduced. However, the direct questions asked will be dependent on the young person's age and ability. This will be informally assessed by the researcher in initial conversations with parents and the young person themselves. The questions will also be adapted to the participants communication skills in the interview.

Page 11: After the initial interview and at subsequent supervision sessions, the researcher, along with the supervisors, will review the interview and transcript and revise the interview guide and topic areas if required.

2. Additional explanation for choice of methodology (see page 11/12 in protocol) and review of type of qualitative analysis in light of collected data(see page 6).

3. Additional explanation for how I will ensure informed assent (see page 9 in protocol)

4. Added further reflections in the protocol about the impact of time after injury and siblings recalling their relationship prior to the injury (please see page 6 of the protocol).

5. Additional refections added to the protocol regarding the impact of the environment of possible presence of parents (please see page 9 and 14 of protocol).

6. Removal of the [redacted] from the documents at their request.

The following changes impact on the recruitment process for both the NHS recruitment at [redacted] and non-NHS recruitment through [redacted]

7. Change in inclusion criteria: Time after injury for brother/sister with an acquired brain injury changing from six months to three months to expand recruitment opportunities. Advice from supervisor [redacted] (Consultant Clinical Neuropsychologist) is that this stills allows sufficient time after injury for siblings to notice a difference in relationship.

8. Change in inclusion criteria: The young person with a brain injury will have spent one or more weeks in hospital to [redacted] derate brain injuries. This has changed from two or more weeks as recommended by the

[redacted]

The following change refers only to the [redacted] Recruitment.

9. Rather tha[redacted]Regional Child and Family Support Co-ordinator to pass out packs when she sees families, the [redacted] have agreed to send out a summary of the research including the researcher's contact details (see Appendix B in the research protocol) via email to families in the north west. If there are difficulties with recruitment, this will be expanded to other areas. Additionally the project will be displayed/made available on their Facebook page and Twitter account and during other contact with familes (e.g. events such as conferences). The summary will also be passed out via the Regional Child and Family Support Co-ordinator when she sees clients in the North West as originally planned. The original letter from ********** trust (Appendix B in original protocol) will therefore not be needed any more and has been replaced by the summary (see Appendix B in the version 5 research protocol).

Parents/caregivers whose child is interested in the research will then contact the researcher through email or phone at which time the researcher will send out the packs to the address supplied or via email depending on the preferences of the family.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Research Protocol	5	26/02/2015

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Miss Emma Tyerman on 26/02/2015 10:26.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancashire Care NHS Trust
Email:	e.tyerman@lancaster.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 06/03/2015 14:08.

Job Title/Post:	Research Support Officer
Organisation:	Lancaster University
Email:	s.c.taylor@lancaster.ac.uk

NHS approval of amendment 1

Health Research Authority
National Research Ethics Service

NRES Committee North West - Lancaster

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7819

13 March 2015

Miss Emma Tyerman
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness
College
Lancaster
University LA1
4YG

Dear Miss Tyerman

Study title:	**Exploring siblings' relationships with their brother or sister with an acquired brain injury**
REC reference:	**14/NW/1418**
Amendment number:	**1**
Amendment date:	**09 March 2015**
IRAS project ID:	**161002**

- The amendment seeks approval for additional information to be made explicit and changes to the recruitment process.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

There were no ethical issues raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	1	09 March 2015

Research protocol or project proposal	5	26 February 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

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

14/NW/1418:	**Please quote this number on all correspondence**

Yours sincerely

Signed on behalf of:
Dr Lisa Booth
Chair

E-mail: nrescommittee.northwest-lancaster@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [redacted]

[redacted]

NRES Committee North West - Lancaster

Attendance at Sub-Committee of the REC meeting on 12 March 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Lisa Booth	Senior Lecturer / Chair	Yes	In the Chair
Professor Jois Stansfield	Professor of Speech Pathology	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Regina Caden	REC Assistant
Mrs Carol Ebenezer	REC Manager

Amendment request 2

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Siblings' experiences of childhood acquired brain injury

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (●) No

b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (●) No

c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (●) No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

England
Scotland
Wales
Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

NHS/HSC Research and Development offices
Social Care Research Ethics Committee
Research Ethics Committee
Confidentiality Advisory Group (CAG)
National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

(●) Yes ( ) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

- [x]
- [ ]
- [x]
- [ ]
- [ ]

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
Undertaken as part of a Doctorate in Clinical Psychology. The student will be named the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Emma	Tyerman
Work Address	Doctorate in Clinical Psychology		
	Faculty of Health and Medicine		
	Furness College, Lancaster University		
PostCode	LA1 4YG		
Email	tyerman@exchange.lancs.ac.uk		
Telephone	07894983038		
Fax			

Full title of study:	Exploring siblings' relationships with their brother or sister with an acquired brain injury
Lead sponsor:	Lancaster University
Name of REC:	North West-Lancaster
REC reference number:	14/NW/1418
Name of lead R&D office:	[redacted]
Date study commenced:	15.12.14
Protocol reference (if applicable), current version and date:	Research protocol version 6 20.04.15
Amendment number and date:	Amendment 23: 20.04.15

Type of amendment

(a) Amendment to information previously given in IRAS

◉ Yes ○ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

Changes to ages of children in inclusion criteria.

(b) Amendment to the protocol

◉ Yes ○ No

If yes, please submit <u>either</u> the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

Amendment to inclusion criteria

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

○ Yes ◉ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

○ Yes ◉ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

The inclusion criteria requires the child with an acquired brain injury and the sibling to be 'school aged' which we originally defined as 5-11. However, it has since been recognised that some children start school at aged 4, and therefore we request to change the age range to start at 4 instead of 5.

The project has also had difficulty recruiting and we therefore plan to relax the age criteria to also include 12 year olds. This cut off was chosen due to cognitive development theories (e.g. Piaget) which often states about 12 years as the end of the concrete operations stage. Saari's (1999) theory of emotional competence also marks the ages of 10-12
as pre-adolescence and different from age 13+. It is recognised that there is a lot of difference between individual childrens development at any one age but this will be taken into account when interviewing and analysing the data.

It should also recognised that two of the current participants are 10/11 years old and therefore we do not anticipate that a 12 year old's experience will vary greatly from the group.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Research protocol	Version 6	20/04/2015

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Miss Emma Tyerman on 23/04/2015 16:16.

Job Title/Post: Trainee Clinical Psychologist

Organisation: Lancashire Care/Lancaster University

Email:	tyerman@exchange.lancs.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 01/05/2015 16:10.

Job Title/Post:	Research Support Officer
Organisation:	Lancaster University
Email:	s.c.taylor@lancaster.ac.uk

NHS approval of amendment 2

Health Research Authority

National Research Ethics Service

NRES Committee North West – Lancaster
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7819

06 May 2015

Miss Emma Tyerman
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness College
Lancaster University
LA1 4YG

Dear Miss Tyerman

Study title:	**Exploring siblings' relationships with their brother or sister with an acquired brain injury**
REC reference:	**14/NW/1418**
Amendment number:	**2**
Amendment date:	**01 May 2015**
IRAS project ID:	**161002**

- Changes to inclusion criteria.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

There were no ethical issues raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	2	01 May 2015
Research protocol or project proposal	6	20 April 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

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

14/NW/1418: Please quote this number on all correspondence

Yours sincerely

Regina Caden.

Signed on behalf of: Dr Lisa Booth
Chair

E-mail: nrescommittee.northwest-lancaster@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [redacted]

Ms Debbie Knight, Lancaster University

*Fiona Eccles, Lancaster University***NRES Committee North West – Lancaster**

Attendance at Sub-Committee of the REC meeting on 06 May 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Lisa Booth	Senior Lecturer / Chair	Yes	In the Chair
Professor Jois Stansfield	Professor of Speech Pathology	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Regina Caden	REC Assistant

Amendment 3 request

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Siblings' experiences of childhood acquired brain injury

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (●) No

b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (●) No

c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (●) No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

England
Scotland
Wales
Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- (●) England
- ( ) Scotland
- ( ) Wales
- ( ) Northern Ireland
- ( ) This study does not involve the NHS

4. Which review bodies are you applying to?

NHS/HSC Research and Development offices
Social Care Research Ethics Committee
Research Ethics Committee
Confidentiality Advisory Group (CAG)
National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

(●) Yes ( ) No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

( ) Yes (●) No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

(●) Yes ( ) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (●) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
Undertaken as part of a Doctorate in Clinical Psychology. The student will be named the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Emma	Tyerman
Work Address	Doctorate in Clinical Psychology		
	Faculty of Health and Medicine		
	Furness College, Lancaster University		
PostCode	LA1 4YG		
Email	tyerman@exchange.lancs.ac.uk		
Telephone	07894983038		
Fax			

Full title of study:	Exploring siblings' relationships with their brother or sister with an acquired brain injury
Lead sponsor:	Lancaster University
Name of REC:	North West-Lancaster
REC reference number:	14/NW/1418
Name of lead R&D office:	[redacted]
Date study commenced:	15.12.14
Protocol reference (if applicable), current version and date:	Research protocol version 7:12.06.15
Amendment number and date:	Amendment 3: 12.06.15

Type of amendment

(a) Amendment to information previously given in IRAS

◉ Yes ○ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

Addition of another recruitment pathway with a charity: **********

(b) Amendment to the protocol

◉ Yes ○ No

If yes, please submit <u>either</u> the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

Addition of another recruitment pathway with a charity: The **********

The main change is on page 8/9 with some additional minor changes:
-Addition of ********** as a recruitment pathway p.7
-To the time schedule on p17

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

◉ Yes ○ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

-Amendment to the parent participant information sheet to include:
-The ********** contact details
-Explaining recruitment will stop when sufficient participants have been recruited.
-Adding new box at the end with my contact details
-Amendment to the expression of interest form to request that participants contact me within a week of receiving the packs.

Is this a modified version of an amendment previously notified and not approved?

○ Yes ◉ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Due to recruitments difficulties, an additional recruitment pathway has been planned. Currently 5 participants have taken part in the study but we hope to recruit at least one more to meet our initial planned number of 6-12. No more than 6 will be recruited from the charity due to time restrictions.

[redacted] s a leading charity in the UK for children with a brain injury. They work with children and young people from across t e UK within their specialist centre and in communities around the country. They provide rehabilitation services, expert nursing and medical care, special education, information, research and policy development.

[redacted] have agreed to access their databases of families to find appropriate possible participants who meet the inclusion criteria. They will then pass on the information pack about the project to parents/caregivers when they see the families (or alternatively via post or email if needed).

The pack will include:
- parent/caregiver information sheet
- child information sheets
- a freepost addressed envelope to return the expression of interest form.

Parents/caregivers whose child is interested in the research will then contact the researcher through email, phone (supplied by the university) or an expression of interest form with a freepost address envelope [redacted] will not be informed of who has chosen to participate.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Research protocol	version 7	12/06/2015
Parent participant information sheet	version 7	12/06/2015
Expression of Interest form	version 7	12/06/2015

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Miss Emma Tyerman on 12/06/2015 13:26.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancashire Care/Lancaster University
Email:	tyerman@exchange.lancs.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 22/06/2015 17:28.

Job Title/Post:	Research Support Officer
Organisation:	Lancaster University
Email:	s.c.taylor@lancaster.ac.uk

NHS approval amendment 3

Health Research Authority

National Research Ethics Service

NRES Committee North West - Lancaster

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7818
Fax: 0161 625 7299

25 June 2015

Miss Emma Tyerman
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness College, Lancaster
University LA1 4YG

Dear Miss Tyerman

Study title:	**Exploring siblings' relationships with their brother or sister with an acquired brain injury**
REC reference:	**14/NW/1418**
Amendment number:	**3**
Amendment date:	**22 June 2015**
IRAS project ID:	**161002**

Additional recruitment pathway.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The members had no ethical issues with this amendment.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP)	3	22 June 2015
Other [expression of interest]	7	12 June 2015
Participant information sheet (PIS) [parent]	7	12 June 2015

Research protocol or project proposal	7	12 June 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

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

14/NW/1418: Please quote this number on all correspondence

Yours sincerely

pp.

Dr Lisa Booth
Chair

E-mail: nrescommittee.northwest-lancaster@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [redacted] *NHS Trust*
Ms Debbie Knight

NRES Committee North West - Lancaster

Attendance at Sub-Committee of the REC meeting on 25 June 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Lisa Booth	Senior Lecturer / Chair	Yes	
Dr Brenda Leese	Lay Member	Yes	
Professor Jois Stansfield	Professor of Speech Pathology	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Carol Ebenezer	REC Manager

Appendix 4-A. R & D approval

[redacted]

Emma Tyerman
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
c12 Furness College
Lancaster University
Lancaster
LA1 4YG

10/12/2014

RE: Exploring siblings' relationships with their brother or sister with an acquired brain injury
REC Ref: 14/NW/1418
R&D Ref: Dear [redacted]

Emma,

Thank you for submitting the above application to the Research & Development Office. It has now been reviewed against the requirements of the Research Governance Framework for Health and Social Care and relevant legislation. I am pleased to confirm that following completion of these checks approval is now granted for the study to commence within the [redacted]

All NHS Trusts are performance managed by the National Institute for Health Research (NIHR) by benchmarks which measure the time taken to recruit the first patient into a research study and the local site's recruitment to time and target. All investigators within the Trust are supported by Data Managers within the Clinical Research Business Unit who can interpret these benchmarks for you and advise you on the timing and format in which data should be submitted to the CRBU. R&D approval is conditional upon these data being submitted In a timely fashion each month.

It will be the responsibility of the local Principal Investigator to comply with the responsibilities laid down, in the Research Governance Framework for Health and Social Care, by the Department of Health. Please see the enclosed leaflet for further information.

A full copy of the Research Governance Framework for Health and Social Care can also be obtained from the Department of Health website at www.doh.gov.uk or the R&D Office.

Yours sincerely

☑
☐
☐
☐

C ———— [signature]

RESEARCH GOVERNANCE FRAMEWORK FOR HEALTH AND SOCIAL CARE

RESPONSIBILITIES OF THE PRINCIPAL INVESTIGATOR

It is the principal investigator's responsibility to ensure that:

- The dignity, rights, safety and well being of participants are given priority at all times by the research team.
- The research is carried out in accordance with the research governance framework.
- When a study involves participants under the care of a doctor, nurse or social worker for the condition to which the study relates, those care professionals are informed that their patients or users are being invited to participate and agree to retain overall responsibility for their care.
- When the research involves user or carer or a child, looked after or receiving services under the auspices of the local authority, that the agency director or her deputy agrees to the person (and/or their carer) being invited to participate and is fully aware of the arrangements for dealing with any disclosure or other relevant Information.
- Unless participants or the relevant research ethics committee request otherwise participants' care professionals are given Information specifically relevant to their care which arises in the research.
- The study complies with all legal and ethical requirements.
- A Material Transfer Agreement is in place with the receiving organisation for any samples sent outside of the Trust.
- Each member of the research team Is qualified by education, training and experience to discharge his/her role in the study.
- Students and new researchers have adequate supervision, support and training.
- The research follows the protocol approved by the research committee.
- Any proposed changes or amendments to or deviations from the protocol are submitted for approval to the ethics committee, the research sponsor and any other appropriate body.
- Procedures are in place to ensure collection of high quality, accurate data and the integrity and confidentiality of data during processing and storage.
- Arrangements are made for the appropriate archiving of data when the research has finished.
- The findings from the work are opened to critical review through the accepted scientific and professional channels.
- Once established, findings from the work are disseminated promptly and fed back as appropriate to participants.
- All data and documentation associated with the study are avallable for audit at the request of an auditing authority.

Appendix 4-B. Research Protocol

Research Protocol

Title: Exploring siblings' relationships with their brother or sister with an acquired brain injury

Emma Tyerman, Trainee Clinical Psychologist, Clinical Psychology Doctorate, Furness College, Lancaster University, Lancashire, LA1 4YG (e-mail: e.tyerman@lancaster.ac.uk).

Research supervisor: Dr Fiona Eccles Clinical Psychology Doctorate, Furness College, Lancaster University, Lancashire, LA1 4YG

Field Supervisor: Dr Victoria Gray, Clinical Psychologist, Psychological Services, Alder Hey Hospital, Liverpool, L12 2AP

Introduction

An acquired brain injury (ABI) includes injury caused by external insult to the brain (such as a car accident, otherwise known as traumatic brain injury) and injuries cause by internal damage (such as a stroke, infection or lack of oxygen to the brain) (Bodack, 2010). In the UK, approximately 40000 children have a brain injury each year (NHS, 2013).The effects of an acquired brain injury very hugely from child to child due to the differences in type and severity of injury as well as the age of the child, their pre-morbid functioning and social and family circumstances (Middleton, 2005). Physical impairments are common such as gross motor impairments, epilepsy, tremors, and sensory loss such as visual and hearing difficulties. Cognitive impairments are also experienced (e.g. speed of information processing, attention and concentration, language and communication, visuo-spatial skills, memory and learning and executive skills). Children can also experience emotional and behavioural difficulties including disinhibition, impulsiveness, increased anger, fatigue, anxiety and depression, fear and post-traumatic stress disorder.

Given the wide ranging nature of these difficulties, it is unsurprising that childhood brain injury can have a significant impact on the family for example, on parental stress (Wade, Taylor, Drotar, Stancin, & Yeates, 1996) depression (Stancin, Wade, Walz, Teated & Taylor, 2008), and wider family functioning (Gan, Campell, Gemeinhardt & McFadden, 2006). Research has also begun to investigate the impact on siblings of children with brain injury suggesting they can also experience difficulties such as emotional and behavioural problems which impact on school as well as home life (Fay & Barker-Collo, 2003). Increased incidence of obsessive compulsive thinking has also been found in siblings (Orsillo, McCaffrey &

Fisher, 1993), as well as lowered self-esteem (McMahon, Noll, Michaud & Johnson, 2001). However, evidence suggests that these difficulties are not universal, as other research found no difference to controls in sibling behaviour (McMahon et al. 2001 and Swift et al. 2003).

Qualitative studies have extended these findings. Gill and Well (2000) interviewed eight siblings (aged between 14 and 30) and found that siblings' lives were now very different because of a change in their brother or sister with a brain injury. For example, they described differences in their emotional reactions and change in their daily life. In addition to their own reactions, siblings are acutely aware of parental distress, and may support parents or take on more responsibility generally (O'Hara et al. 1991; Willer et al. 1990).

Part of the distress for siblings following brain injury may be due to changes in the sibling relationship. In the quantitative literature, a more negative sibling relationship in families of children with a traumatic brain injury was found in mixed gender dyads (Swift et al. 2003) when compared with families where a child had had an orthopaedic injury. The behaviour of the young person with a brain injury appeared to predict the sibling relationships when using a self-report sibling relationship questionnaire by both the injured and non-injured sibling. However, this study did not address in depth the siblings' perspectives of these changes. No known qualitative study has focused specifically on the sibling relationship after a traumatic brain injury. Using qualitative methodology to explore this might indicate other contributory factors to the negative changes in a sibling's relationship and allows for the exploration of any positive changes.

In summary, quantitative research has highlighted that siblings can experience a range of difficulties after their brother or sister's acquired brain

injury, although this may not be universal. The limited qualitative research available examining siblings' experiences in more depth supports the quantitative findings, but has also found positive effects of the experience. However, the impact on the sibling relationship from a sibling's perspective has not been specifically explored. In a recent review of the literature of siblings experiences in general, Sambuco, Brookes and Lau (2008) raised the need for further research specifically looking at the younger siblings' experience (primary school age). No studies have been found, since this review, which focus on this. Consequently, this study will aim to investigate and understand the experience of primary aged children of being in a relationship with a sibling who has had an acquired brain injury. Interpretative Phenomenological Analysis (IPA) will be used to analyse results because it focuses on lived experience in relation to important life events (Smith, Flowers & Larkin, 2009).

For clarity, throughout this protocol, the child with an acquired brain injury will be referred to as the 'child with an ABI' and non-injured brother or sister will be referred to as 'the sibling'.

Method

Design

This will be a qualitative study, with data collected using semi-structured interviews of up to 12 siblings of children with an ABI. Analysis will be conducted using IPA. This method had a focus on understanding 'how people make sense of their major life experiences' (Smith, Flowers & Larkin, 2009, p. 1). The research will ensure validity and reliability in line with Yardley's (2000) four principles for assessing the quality of qualitative research (sensitivity to context, commitment and rigour, transparency and coherence and impact and importance).

Participants

The participants will be up to 12 siblings of young people who have had an acquired brain injury. The researcher will aim to interview between 6 and 12 participants as IPA requires a balance between capturing the nuances of individual narratives and finding common experience (Smith, Flowers & Larkin, 2009). IPA specifically aims to 'say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims' (Smith & Osborn, 2008, p.55).

Inclusion criteria

-Siblings of children with any form of sudden onset acquired brain injury.

-Siblings will be between 4 and 12 years old both at the time of their brother or sister's injury and the time of participating in the research.

- The child with an ABI must have been school age (primary or secondary) at the time of injury (4-18).

-Time period since the child with an ABI's injury must be between 3 months and 3 years. This was chosen to allow siblings time to have a sense of their relationship with their brother or sister now, but also not too long to have difficulty accessing memories of their relationship prior to the injury. If there are problems with recruitment after approximately two months, the time period after injury will be extended. This will increase by one year in a staged process up to 5 years post injury. It is recognised that this has implications for siblings being able to remember their brother or sister with an ABI prior to injury, which could make it difficult to access their reflections about change. This would need to be carefully considered during the interview as well as in analysis. This may also have implications for the

homogeneity of the sample which is very important in IPA analysis. This would be considered on an individual basis and if the sample as a whole was not homogenous enough, an alternative method of analysis would be considered (e.g. thematic analysis).

-The young person with a brain injury will have spent one or more weeks in hospital to capture the more moderate/severe brain injuries.

-The young person with a brain injury must live with the sibling or have lived with the sibling prior to having a brain injury to ensure they have a consistent relationship with their brother or sister.

-The sibling must be able to communicate in English and tolerate a half hour to ¾ hour interview.

Exclusion criteria

-Bereavement of another family member in the same accident as the sibling's brother or sister due to the impact this might have on family outcome.

-Siblings whose brother or sister has a life-limiting health condition to maintain a homogenous sample. The experiences of this group may have additional concerns given the limited nature of the sibling relationship.

Materials

The materials needed for recruitment are the staff information sheets and participant information pack, which include the letter/summary from the service (Appendix : A NHS trust and B: Charity 1), the expression of interest form (Appendix C and D), parent/caregiver participant information (Appendix E), the child information sheets (Appendix F, G and H), and a freepost addressed envelope. The data collection process requires the consent to participate sheet

(Appendix I, J and K) and the interview guide (Appendix L). Due to practical, time and funding constraints, as well as the requirements of the analysis, information within the participant information and consent sheets will be provided only in English.

Procedure

Recruitment

There will be three recruitment pathways:

- Staff at NHS trust (Clinical Psychologist, Consultant Paediatric Neurologist and Trauma co-coordinator)
- Charity 1 (Head Office and Fiona Nelson, Regional Child and Family Support Co-ordinator)
- Charity 2 (Link worker Lorna Wales, Research Associate)

****** recruitment

***** have agreed to access their databases of patients to find appropriate possible participants who meet the criteria. The staff will be briefed on the inclusion and exclusion criteria prior to recruitment. They will then pass on the information pack about the project to parent/caregivers via post and when they see them at clinical appointments. This pack includes the parent/caregiver information sheet, child information sheets and a freepost addressed envelope to return the expression of interest form. Parents/caregivers whose child is interested in the research will then contact the researcher through email, phone (supplied by the university) or an expression of interest form with a freepost address envelope.

Charity 1 Recruitment

Charity 1 have agreed to send out a summary of the research including the researcher's contact details (see Appendix B). This will be sent via the Head Office to all families that have generally agreed to be approached about research opportunities. This will be sent out via email from the Head Office as well as displaying the research project on their Facebook pages and Twitter. The summary will also be passed out via …… Regional Child and Family Support Co-ordinator when she sees clients in the North West. …….. will be briefed on the inclusion and exclusion criteria prior to recruitment. If there are difficulties with recruitment, this will be expanded to other areas of the country.

Parents/caregivers whose child is interested in the research will then contact the researcher through email or phone (supplied by the university). After the family has contacted the researcher, they will send out the packs to the address supplied/ or via email depending on the preferences of the family.

Charity 2 recruitment

Charity 2 have agreed to access their databases of families to find appropriate possible participants who meet the criteria. The staff will be briefed on the inclusion and exclusion criteria prior to recruitment. They will then pass on the information pack about the project to parent/caregivers when they see the families (or alternatively via post or email if needed). This pack includes the parent/caregiver information sheet, child information sheets and a freepost addressed envelope to return the expression of interest form. Parents/caregivers whose child is interested in the research will then contact the researcher through email, phone (supplied by the university) or an expression of interest form with a freepost address envelope.

In all three recruitment pathways, the researcher will not have access to names or other clinical information prior to the family expressing interest to the researcher. The staff team in any of the recruiting services will not be informed of which participants have shown interest to ensure they remain anonymous.

Offers for participants will generally be accepted on a first come first served basis. However, if a lot of participants come forward at a similar time, priority will be given to those who are most homogenous with the group already recruited. It will be stated in the participation sheet that a limited number of children will be able to participate in this project. If this has been filled when a participant shows interest, they will be thanked for their interest and it will be explained again the constraints of the project does not allow for more participants to be involved. However, they can still request a copy of the results should they wish.

The data collection will consist of approximately 30-45 minutes face to face semi-structured interviews. Prior to the interview, the researcher will discuss with the parents/caregivers whether it is appropriate to discuss the project with the young person with an acquired brain injury and how they would like this to happen.

Interviews will take place at a location convenient to the participant, which may be their home, a local children's centre, another community venue or the hospital. This flexibility was chosen to reduce burden on the participant. However, it is recognised this may influence the child's level of anxiety and therefore their ability to engage in the interview. The location of the interview will therefore be noted for analysis.

Interview

Parents will be asked to give consent for their child to participate as the children are under the age of 16 (as recommended by the British Psychological Society, 2010). However, it is important that children have as much information as possible and are involved in the decision of whether or not to participate in the study (National Research Ethics Service, 2011). Therefore age appropriate information sheets have been developed. As recommended (National Research Ethics Service, 2011) a separate information sheet has been developed for children aged 5, aged 6-10 and aged 11. To ensure the child has understood the information, the researcher will ask them to explain the research to them, ensuring they understand what it would involve for them, how long it might take, what the advantages and disadvantages might be, and their right to withdraw etc. If the researcher is convinced that the child understand these issues, the child will then be asked if they assent to take part in the study. On arrival the researcher will check that the both the parent/caregiver and child understands the information in the relevant participant information sheets, before being asked to carefully consider the consent and assent forms. The child's engagement will be monitored throughout the interview and if the child appears to be reluctant to continue, the interviewer will raise this and make sure that they understand that they do not have to continue.

Consent will be sought from the parent/caregiver to use any data they provide, for example, if the child wishes for the parent/caregiver to be present for the interview (see Appendix K). However, it will be emphasized that it is the child's views that are being sought primarily and the adult is there to support this process.

The limits to confidentiality will be explained before the start of the interview, and repeated as required. It is estimated that the interviews will last approximately 30-45 minutes, and breaks will be offered if required. The interviews will broadly follow the interview guide (Appendix J) in relation to the topics that will be introduced. However, the direct questions asked will be dependent on the young person's age and ability. This will be informally assessed by the researcher in initial conversations with parents and the young person themselves. The questions will also be adapted in response to the participant's communication skills in the interview.

Interviewing children requires more flexibility and creativity to allow them to feel comfortable and participate fully (Hill, Laybourne & Borland, 1996). Two introductory icebreaker activities will be used if needed to introduce the researcher, support the child to feel comfortable and engaged and to create prompts and visual reminders for later in the interview (e.g. a timeline; Shaw, Brady & Davey, 2011). The researcher in these interviews will use drawings and toys (if appropriate) to facilitate discussion, however, any drawing will not be analysed themselves. For example, if when asked what their brother or sister was like before the brain injury, the child might choose to answer verbally, or they will be given the opportunity to draw what their sibling was like. The researcher can then ask questions around the drawing to facilitate verbal responses which can then be analysed. If the child would rather use toy props, the researcher might ask a child to choose a toy (e.g. puppet) to pretend to be their brother or sister and use the toy to facilitate a discussion around what they like doing etc.

The interviews will be audio recorded on an audio recording device loaned from Lancaster University. After the interview the researcher will thank the

participant for being involved and ask if they have any further questions about what happens next. The research will ask the participant and the parent/caregiver if they want to receive a summary of the research when the project has been completed.

After the initial interview and at subsequent supervision sessions, the researcher and supervisors will review the interview and transcript and revise the interview guide and topic areas as necessary.

Proposed analysis

The interviews will be transcribed verbatim and interpretative phenomenological analysis (IPA) will be used to analyse the data. This method of analysis was chosen because of its focus on exploring a significant life event and its focus on trying to understand a person's understanding of their experience (Smith, Flowers & Larkin, 2009). A growing body of IPA research has enabled the voices of generally under researched groups to be heard including children (for example, Petalas et al. 2009; Majors, 2005; Sugden, 2013). However IPA requires a level of depth from interviews and, given that this project is interviewing children, it is recognised that this might be a potential problem. Therefore, the interviews will be considered with the research supervisor and an IPA consultant as to whether they are appropriate for IPA analysis. If it is considered that they are not, then the alternative analysis of thematic analysis will be used. If the planned analysis, IPA is used, the data will be analysed according to the recommendations by Smith, Flowers & Larkin (2009).

The researcher will be supervised by an IPA consultant (Craig Murray) who is extensively published in IPA (e.g Eccles, Murray & Simpson, 2011; Donnellan,

Murray & Holland, 2014) and has been involved in children's IPA research previously (Dixon, Murray & Daiches, 2013).

These stages are:

Stage 1: Reading through the transcripts a number of times to become immersed and actively involved with the data

Step 2: Initial noting on the transcripts to highlight semantic content and language, descriptive comments, linguistic, and conceptual comments. Conceptual comments are more interpretative and questioning with a focus on participants overarching understanding of matters.

Step 3: Developing emerging themes. This step reduces the volume of detail but maintains the complexity and includes finding interrelationships, connections and patterns.

Step 4: Searching for connections across emerging themes and seeing how they fit together. This can involve 'abstraction' (clustering themes to form subordinate themes); 'subsumption', (identifying themes which are subordinate); 'polarising' (focusing on differences); 'contextualisation', (identifying contextual and narrative elements); 'function' (looking at the function of themes); and numeration (focusing on the frequency of evidence that support themes).

Step 5: Repeating the steps for each individual case.

Step 6: Examining all the patterns over all the participants' experiences.

The researcher will analyse the data systematically and will keep accurate records of the developing themes so that there is a clear audit trail. Evidence for the themes will be presented through direct quotes from participants in the write up of the research. Consultation will be sought from supervisors to support the analysis process, and improve the reliability of analysis.

Ethical issues

As the principal investigator is employed by Lancashire Care NHS Foundation Trust, their lone worker policy will be adhered to. A colleague (fellow trainee clinical psychologist) will be aware of the time of start and expected finish and the location of the interview. The location will be provided in a password protected word document that will be emailed to the colleague just prior to the interview. The password will be sent in a separate email. When the principal investigator has finished the interview they will contact the colleague. If the colleague does not hear from the researcher they will try to make contact. If this is unsuccessful, then the colleague will use the password to access the information about the interview and will call the appropriate authorities. The colleague and the investigator will then delete the emails containing the attachment after the interview has taken place.

It is recognised that, if interviews take place in the home, other family members in the house may overhear them. Every effort will be kept to keep interviews confidential and in a private space. The young person will have the opportunity to choose if they want a parent/caregiver to accompany them in the interview and this will also be discussed with the parent/caregiver. It is recognised that parents being present for the interview may influence a child's answers to questions and may mean they are less comfortable talking about difficult issues, particularly if they relate directly to their parents. However, particularly for the younger children, the prospect of being interviewed by a stranger may provoke anxiety and ethically it seems appropriate to offer this choice. Once the initial activities are underway and a rapport has been developed the researcher will judge the child's level of anxiety and check whether they feel

comfortable with their parent/caregiver leaving the interview for a period. The presence of the parent will be noted for analysis.

It is recognised that there is the potential that participants might feel distressed by the content of the interview. Previous research has shown that acquired brain injury can have a negative impact on the siblings and parents. It is important that the researcher is sensitive to this during the interviews, as well as offering breaks, should the need arise, if the young person looks to be in distress and giving options to stop completely, miss questions or reschedule for their convenience. The researcher will remind participants of sources of support that might be helpful at the end of the interview, as in the information sheet.

At the start of the interview, the researcher will inform participants that if the interview raises any concerns about anyone's safety then the researcher is required to pass this information on to relevant services. In this event, the researcher will inform both the young person and the parent that they plan to share information with other agencies unless this will significantly increase the risk to the child or the researcher themselves at that time. The researcher can contact my field supervisor for support with clinical and safeguarding issues is necessary. If there is an immediate concern, the researcher will contact the local Children's Service which is available 24 hours a day. The researcher will take these contact details with her on all interview visits.

Practical issues

The costs of the research including photocopying and freepost addressed envelopes will be met by Lancaster University Doctorate in Clinical Psychology. Participants will be offered up to £20 for travel expenses. Participants will be

asked to provide receipts for their travel expenses if using public transport. If using cars, participants can be reimbursed for their total mileage at 45p/mile.

While the study is taking place the principal researcher is responsible for the storage of the research data. This includes the audio interview recordings, any sheets worked on in the interview (e.g. drawings), transcripts of the interview, coded/analysed data and any personal information collected (i.e. consent forms, expression of interest forms and any further personal data). These data may be a mixture of electronic and paper form.

The researcher will transfer the audio file of the interview onto a computer which will be saved onto the university secure network which is password protected and encrypted. The audio file will then be deleted from the audio device. The interview will be transcribed and the audio files saved until the research has been examined and will then be deleted. All transcripts will be anonymised as far as possible and information such as participant names and place names will be removed. The raw data will only be shared with the research supervisor, (Fiona Eccles, Lecturer in the Doctorate of Clinical Psychology), but amalgamated data and anonymised quotes will be shared with both supervisors

The paper form data will be kept in a locked box in the home of the principal investigator during the project. Electronic data will be kept on the password protected file space on the university server or encrypted on electronic devices. Any personal information (except consent forms) will be deleted as soon as they are no longer needed.

After completion of the study, the data will then be stored securely on the Lancaster University network or in a secure location. The data will be kept for a period of 10 years by Lancaster University. At this point, this information will be

deleted. Any paper form data (e.g. coded transcripts) will be kept locked securely by the Clinical Psychology admin team and will again be destroyed in 10 years.

Estimated Timescale

Submit to NHS ethics and R&D:	Beginning of August 2014
Start recruitment:	December 2014
Interviewing and transcribing:	January to July 2015
Analysis:	February to July 2015
Writing up research paper:	January to August 2015

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Appendix A. Letter NHS Trust

Dear parent or guardian

I am writing to you as we are undertaking research into knowledge of siblings' experiences after childhood acquired brain injury. I am writing to you as your child was treated by staff at …… hospital. We are inviting all families where there is a sibling aged between 4 and 12 years old to take part in the research.

I have attached an information sheet that explains exactly what would be involved if you and your child participated in the research.

The researcher is called Emma Tyerman, a Trainee Clinical Psychologist at Lancaster University and she is supervised by Dr Victoria Gray, (Consultant Clinical Psychologist at …….. Hospital) and Dr Fiona Eccles (Lecturer at Lancaster University). Emma's contact details are on the information sheet. Please contact her should you have any questions.
Your decision about whether or not to participate will not affect your child's medical care and the staff at …… will not know whether you choose to participate in the research. The researcher will not have any information about you unless you choose to contact them.
If you are interested and would like the researcher to contact you regarding the study to discuss it further, we would be grateful if you could either:

- Complete and return the attached form in the freepost envelope
- Ring or email the researcher (Emma Tyerman) directly (details on the information sheet).

Please accept our apologies if you have already received this information. As we are recruiting through [……] hospital and [charity 1] you may receive this information through both organisations.

We look forward to hearing from you.
Yours sincerely,

[……]
Paediatric Clinical Neuropsychologist
[……]
Research Team:
Emma Tyerman (Trainee Clinical Psychologist at Lancaster University), Dr Victoria Gray (Clinical Neuropsychologist), Dr Fiona Eccles (Lecturer at Lancaster University)

Appendix B. Initial contact from the [charity 1]

Research Project:

Exploring siblings' relationships with their brother/sister with an acquired brain injury

Would your child be interested in sharing what it's like to be a sibling of a child with a sudden onset acquired brain injury?

Emma Tyerman (Trainee Clinical Psychologist at Lancaster University) is looking to talk to siblings aged between 4 and 12 years old about what this is like for them. It is important to understand the perspectives of all family members so services can develop more of an understanding and provide the most helpful information and support.

To be included in the study the brother or sister with a brain injury must have been of school age themselves at the time of injury and have been injured between 3 months and 3 years ago.

If you are interested in finding out more and to discuss possible participation, please contact Emma via email: e.tyerman@lancaster.ac.uk or phone: 07852 518 411.

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Appendix C: Expression on Interest Form [NHS trust]

Expression of interest form
Exploring siblings' relationships with their brother/sister with an acquired brain injury

If you are interested in contributing to the research please fill in the form below and return it in the freepost addressed envelope provided. Alternatively, you can contact me directly on e.tyerman@lancaster.ac.uk or [insert allocated university mobile number].

My child may be interested in participating in this research and we would like to be contacted to discuss this further:

Our contact details are:

Name of young person: .....
Name of parent or caregiver:.....
Email: .....
Postal address:
.....
.....
.....
Telephone: ..... Signature:
.....
Thank you for your interest, I will contact you shortly.
Emma Tyerman, Trainee Clinical Psychologist

Appendix D. Expression of Interest Form ([charity 1] and [charity 2])

Appendix B

Expression of interest form
Exploring siblings' relationships with their brother/sister with an acquired brain injury

If you are interested in contributing to the research **please contact me within a week of receiving this pack**. You can contact me on e.tyerman@lancaster.ac.uk or 01737 365 000. Alternatively, you can fill in the form below and return it in the freepost addressed envelope however it might take me longer to get back to you.

My child may be interested in participating in this research and we would like to be contacted to discuss this further:

Our contact details are:

Name of young person: .....
Name of parent or caregiver:.....
Email: .....
Postal address:
.....
.....
.....
Telephone: ..... Signature:
.....
Thank you for your interest, I will contact you shortly.
Emma Tyerman, Trainee Clinical Psychologist

Appendix E. Parent/caregiver information sheet

Parent/caregiver Participant Information Sheet
Study title: Exploring siblings' relationships with their brother/sister with an acquired brain injury

My name is Emma Tyerman and I am conducting this research project as a trainee clinical psychologist at Lancaster University as part of my clinical doctorate.

What is the study about?

To understand the experiences of young people who have a sibling with an acquired brain injury to identify any area of need. It focuses on their experiences of relationships with their brother or sister and how this might have changed since their sibling's brain injury.

Why have I been approached?

Your family has been approached because you have a child with an acquired brain injury with a sibling who meets the inclusion criteria of the study. We want to speak to children aged 4-12 about their experiences.

Does my child have to take part?

No. It's completely up to you and your child to decide whether or not your child takes part. It will not affect the care of you and your family in any way and the service who sent you this letter will not know whether you take part or not.

However there is a limit to how many children can take part so if this has been filled, your child will not be able to participate. You can receive a summary of the findings if you wish.
Your child can withdraw at any time before and during the interview taking place. If they withdraw after the interview, every effort will be made to withdraw their contribution up until the point of submitting the project to Lancaster University, however, this may not be possible if the data has been analysed.

What will we be asked to do if we take part?

If your child decides they would like to take part, they would have an interview with me at a location convenient to you. This could be your home, a local children's centre or other community venue or at the hospital. You can also be present at the interview if your child would like this. It is anticipated that the interview will take approximately 45 minutes.
Before the interview I will also ask some background questions from you, such as the type of acquired brain injury that the brother or sister has and when this

happened. I will stop recruitment when I have sufficient participants so it may be possible if you contact me that your child will be unable to participate. However, I can still send you a copy of the results when the research is completed if you are interested.
I will check that both you and your child who is participating understand and have the opportunity to ask any questions. I will then invite you both to sign a consent form before starting the interview. If your child is very young, only you will sign the consent form. During the interview, I will ask your child about their life with their sibling before the brain injury, and how things might have changed.

Will the information we share be confidential?

The information you provide will usually be kept confidential.
To maintain the researcher's safety, if the interview is held at your home, the address will be shared in a password protected file that will only be accessed by a colleague if they are unable to contact the researcher by an agreed time. This is to abide by lone working procedures. This will be destroyed following the interview.

The interviews will be audio recorded and stored and securely on the Lancaster University computer network. Only my university supervisor and I will have access to the interview material.

- Audio recordings will be transcribed and the audio file will be deleted after the analysis process has been completed.
- The typed version of your child's interview will be made anonymous by removing any identifying information including any names. Anonymised direct quotations from the interview may be used in the reports or publications from the study and they should not be able to be identified by any other party.
- Hard copies of interviews will be used temporarily and will be kept securely.
- Access to the files on the computer will be encrypted (that is no-one other than the researcher and the supervisors will be able to access them).
- At the end of the study, the anonymous transcribed interviews, scanned consent forms and data analysis information will be kept electronically for 10 years by Lancaster University on the secure system. At the end of this period, they will be destroyed.
-

There are some limits to confidentiality. If what is said in the interview raises concerns that your child, or someone else, is at significant risk of harm, I would have to bring this to the attention of an appropriate professional. If possible, I would tell you if I have to do this.

What will happen to the results?

The results will be summarised in a research report for Lancaster University. As far as possible, any personally identifiable information will be removed.
The findings may be shared with the local brain injury services to improve practice. They may also be submitted for publication in an academic or professional journal. If you would like a summary of the findings, I can send it to you.

Are there any risks?

There is a risk that your child may feel upset when recalling any difficult experiences that they choose to raise. If there is anything they would prefer not to discuss, please let the researcher know. However, if your child still experiences any distress following participation you are encouraged to inform the researcher and you may find it helpful to contact ********** or your local GP.

**********Trust: Telephone: **********
Website: **********

Are there any benefits to taking part?

Although your child may find participating interesting, there are no direct benefits for him or her taking part in the research. However, it is hoped that the research will provide valuable feedback to services for young people with a brain injury. Reasonable travel expenses will be paid up to a maximum of £20. If you use public transport you should keep your receipts.

Who has reviewed the project?

This study has been reviewed by a local NHS ethics committee, the ****** Research and Development Service as well ********.

Where can we obtain further information about the study if we need it?

If you have any questions about the study, please contact the main researcher:
Emma Tyerman: e.tyerman@lancaster.ac.uk Telephone: 07852 518 411
If they are unable to help, you can alternatively contact:

Field Supervisor: Dr Victoria Gray, Clinical Psychologist, ********.

Complaints
In the event that you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Jane Simpson
Title: Research Director
Email: j.simpson2@.lancaster.ac.uk
Tel: (0)1524 592858
Doctorate in Clinical Psychology, Faculty of Health and Medicine, Furness College
Lancaster University, Lancaster, LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:
Professor Roger Pickup Tel: (01524) 593718
Associate Dean for Research
Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine, (Division of Biomedical and Life Sciences),
Lancaster University, Lancaster, LA1 4YD
Thank you for taking the time to read this information sheet.

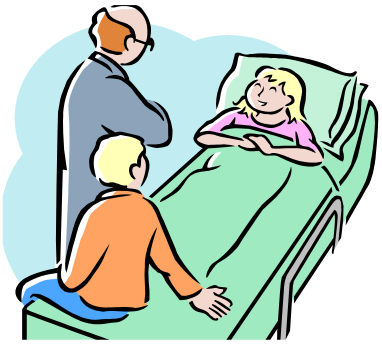
If you are interested in contributing to the research **please contact me within a week of receiving this pack**. You can contact me on e.tyerman@lancaster.ac.uk or 01737 365 000. Alternatively, you can fill in the form below and return it in the freepost addressed envelope however it might take me longer to get back to you.

Appendix F. Child Information sheet (4/5 years)

LANCASTER UNIVERSITY

Research Information sheet

Hello, my name is Emma.



I am asking children what it's like to have a brother or sister who has had an injury to their head or brain.

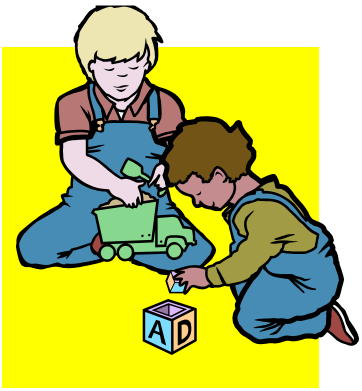
Would you like to tell me what it is like for you?
It's ok to say no.

If you say yes…

- You can still stop and say no at any time if you want to.
- We can meet together at your home or at the hospital.

- Mum, Dad or another adult can come too.

I will ask you about your life with your brother or sister.



I will ask you about change since they hurt their head or got ill.

I will record what we talk about.

What you tell me will be kept private and safe.

But I will tell another adult if I'm worried about you or someone else.

If you get upset when we talk tell me and we can stop.

We can tell Mum or Dad, or another adult in your family.

I will take what you say and put it together with what other children say.

I will then write about this to tell people what it's like to have a brother or sister who has hurt their head.

Do you have any questions?

If so you can ask Mum or Dad or another adult in your family to speak to me.

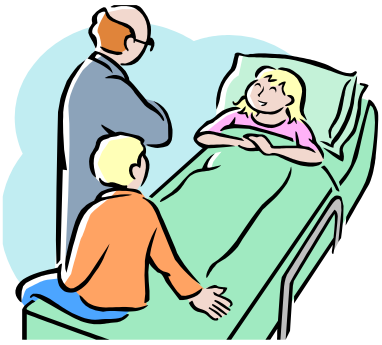
Thank you for reading this

Appendix G. Child Information sheet (6-10)

LANCASTER UNIVERSITY

Research Information sheet

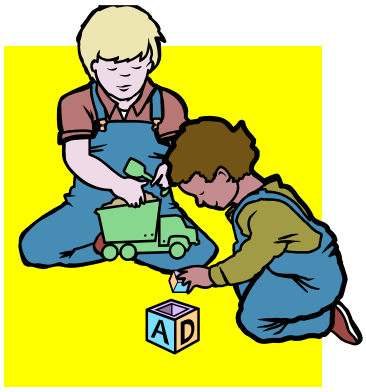
Hello, my name is Emma.



I am asking children what it's like to have a brother or sister who has had an injury to their head or brain.

Would you like to tell me what it is like for you?
You don't have to talk to me. It's ok to say no.

If you say yes, we will meet together at your home, somewhere near you or at the hospital. Mum, Dad or another adult can come too.
Even if you say yes now, you can change your mind later.



If we meet, I will ask you about your life with your brother or sister.
I will ask you if anything has changed since they hurt their head or got ill.

I will record what we talk about. I will keep this so I can listen to it again later.

What you tell me will be kept private.
But if I'm worried that you or someone else might get hurt, I will tell someone else to make sure you are safe.

If you get upset about anything that we talk about, you can tell me, Mum or Dad, or another adult in your family.

I will take what you say and put it together with what other young people say.
I will then write about this so more people know what it's like to have a brother or sister with a brain injury.

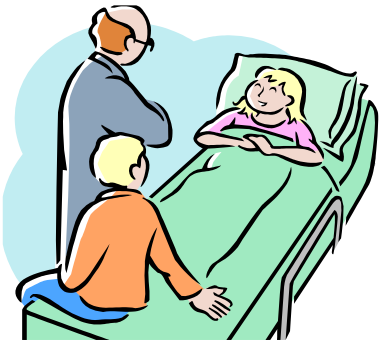
Do you have any questions?
If so you can ask Mum or Dad or another adult in your family to speak to me.

Thank you for reading this

Appendix H. Child Information sheet (age 11)

Research Information sheet

Hello, my name is Emma.



I am trying to find out what it's like to have a brother or sister who has had a brain injury.

Would you like to tell me what it is like for you?

You don't have to talk to me.

Even if you say yes now, you can change your mind later and say no.

If you want to do this, we will meet together at your home, somewhere near you or at the hospital. Mum, Dad or another adult can come too if you wish.

If we meet, I will ask you about your life with your brother or sister.

I will ask you if anything has changed since they had their brain injury.

I will record what we talk about. I will keep this so I can listen to it again later.

What you tell me will be kept private. However, if I am worried that you or someone else might get hurt, I will tell someone else to make sure we can keep you safe.

If you get upset about anything that we talk about, you can tell me, Mum or Dad, or another adult in your family.

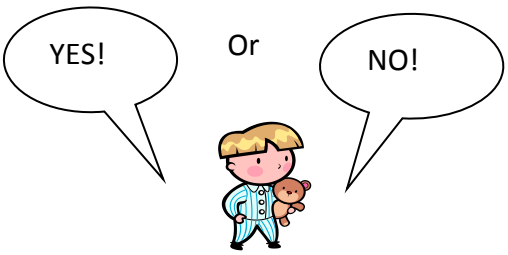
I will take what you say and put it together with what other young people say. I will then write about this so more people know what it's like to have a brother or sister with a brain injury.

Do you have any questions? If so you can ask Mum or Dad or another adult in your family to speak to me.

Thank you for reading this

Appendix I. Child assent form

Child assent form



Has somebody explained this project to you?	**Yes /No**
Do you understand what this project is about?	**Yes /No**
Have you asked all the questions you want?	**Yes /No**
Have you had your questions answered in a way you understand?	**Yes /No**
Do you understand that it OK to stop taking part at any time?	**Yes /No**
Are you happy to take part?	**Yes /No**

If you do want to take part, you can write your name below

Name:
Sign:
Date:

The researcher who explained this project to you needs to sign too:
Name of Researcher:
Signature:
Date:

Thank you for your help.

Appendix J

Parent/caregiver Consent Form

Study Title: Exploring sibling's relationship with their brother or sister with an acquired brain injury.

We are asking if you would like your child to take part in a research project to improve the understanding of the experiences of siblings of children/young people who have had an acquired brain injury.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Emma Tyerman.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me and my child within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that the interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be deleted after the analysis has been completed. ☐
5. I understand that my child's participation is voluntary and that we are free to withdraw at any time without giving any reason, without their medical care or legal rights being affected. ☐
6. I understand that once the data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract the data, up to the point of submission. ☐
7. I understand that the information from the interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to anonymous information and quotations from the interview being used in reports, conferences and training events. ☐
9. I understand that data collected from the study may be looked at by regulatory authorities and by persons from the Trust where it is relevant to me or my child taking ☐

part in this study. I give permission for these individuals to access this data.

10. I understand that any information my child or I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm, in which case the principal investigator will need to share this information with the appropriate person. ☐

11. I consent to Lancaster University keeping anonymous written transcriptions of the interview and consent forms for 10 years after the study has finished. ☐

12. I consent for my child to take part in the above study ☐

Name of Participant _____**Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix K

Parent/caregiver Consent Form for their data

Study Title: Exploring sibling's relationship with their brother or sister with an acquired brain injury.

We are asking if you would like your child to take part in a research project to improve the understanding of the experiences of siblings of children/young people who have had an acquired brain injury.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Emma Tyerman.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that any contribution in the interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be deleted after the analysis has been completed. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without their medical care or legal rights being affected. ☐
6. I understand that once the data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract the data, up to the point of submission. ☐
7. I understand that the information from the interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to anonymous information and quotations from the interview being used in reports, conferences and training events. ☐
9. I understand that data collected from the study may be looked at by regulatory authorities and by persons from the Trust where it is relevant to me or my child taking ☐

part in this study. I give permission for these individuals to access this data.

10. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm, in which case the principal investigator will need to share this information with the appropriate person. ☐

11. I consent to Lancaster University keeping anonymous written transcriptions of the interview and consent forms for 10 years after the study has finished. ☐

12. I consent to take part in the above study ☐

Name of Participant _____**Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix K. Interview Guide

Interview Guide

This is a guide for the interview. It will be used flexibly depending on the child's responses. Prompts such as drawing and toys may be used to facilitate a child's participation.

1. INFORMATION SHEETS AND CONSENT FORMS

2. INTRODUCTION

   This study is about you and your brother/ sister.....(name).

   We're going to do some activities and I will ask some questions but if you don't want to answer something that's fine, we can leave it out.

   Do you have any questions?

3. INTRODUCTORY ACTIVITIES : (to increase engagement and relaxed atmosphere and to obtain some demographic information)

   Get to know: Both researcher and the child draw a picture of themselves and draw and/or write things they enjoy doing on the paper.

   Timeline: The researcher and/or the child draws a timeline indicating how old they are now and when their brother/sister's brain injury happened. This will be used to support children to separate time before, just after and now.

4. INTERVIEW

   Relationships before ABI

   Do you remember your brother or sister before they had the accident/got ill/etc?

   Prompts
   -What was brother/sister like
   -Shared activity (play, school etc.)

   Relationships immediately after
   Do you remember your brother/sister just after accident/when in hospital/when they got ill etc?

   Prompts
   -What was your brother/sister like
   -Shared activity (play, school etc.)

Relationships now

Prompts

-What is brother/sister like now.
-Shared activity (play, school etc.)
-What is good about relationship.
- Is this different to other brothers/sisters? Different to peers?
-Anything that is challenging/difficult about relationship/shared activity.
-Anyone/ anything that helps with these things
-Any advice to other siblings who have a brain injury

5. OBTAIN ANY FURTHER DEMOGRAPHIC INFORMATION (if not done so already with parent/caregiver, some will be collected naturally during the interview)

Age of participant (sibling)	
Age of young person with ABI	
Gender of participant (sibling)	
Gender of young person with ABI	
Type of acquired brain injury	
Time since injury	
Others in household	

6. Thank child for participating and ask if they would like to receive information on the results.