

DOCTORATE IN CLINICAL PSYCHOLOGY

Parental Adjustment in Paediatric Acquired Brain Injury

Part 1: Systematic Literature Review

Parental Adjustment in Paediatric Acquired Brain Injury: A Review of the Literature

Part 2: Empirical Paper

“We knew our lives were changed forever from that point”.
Parental Adjustment and the Role of Social Support in Paediatric Acquired
Brain Injury: An Interpretative Phenomenological Analysis

Submitted by Sian Hocking, to the University of Exeter
as a thesis for the degree of Doctor of Clinical Psychology, May 2015

Supervised by Dr. Phil Yates & Dr Anna Adlam

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature:

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Sian Hocking, 2015

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Abbreviations

ABI: Acquired Brain Injury

CASP: Critical Appraisal Skills Programme

CCNR: Centre for Clinical Neuropsychology Research

DOH: Department of Health

EPHPP: Effective Public Health Practice Project

IPA: Interpretative Phenomenological Analysis

pABI: Paediatric Acquired Brain Injury

PRIMSA: Preferred reporting items for Systematic Reviews and Meta Analyses

pTBI: Paediatric Traumatic Brain Injury

TBI: Traumatic Brain Injury

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Part 1: Systematic Literature Review

Parental Adjustment in Paediatric Acquired Brain Injury:
A Review of the Literature

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Abstract

Paediatric acquired brain injury can lead to an array of long term physical, cognitive, emotional, and behavioural difficulties for the brain-injured child. Due to the long-term sequelae of more severe ABI, it presents a significant challenge to the child's family. This review offers a critical synthesis of the existing research evidence with the objective of understanding the adjustment experiences of parents who have a child with pABI. MEDLINE, PsycINFO, Embase and Web of Science databases were searched and the identified literature was checked in addition to backward and forward citations from the selected papers to ensure all relevant papers were attained. In total 28 articles were reviewed and the quality of each was appraised. The review highlighted the dynamic experience of adjustment for parents, with themes such as stress, loss, grief, coping, resources, relationships, parenting, and interactions with services arising from the literature. Future research may benefit from increased recruitment and retention rates in prospective cohort studies, particularly of male participants. Good quality, reflexive and transparent qualitative research that seeks to understand the different experiential journeys of parents would make a valuable contribution to the evidence base.

Key words: *children, brain injury, parenting, adjustment, stress*

Introduction

Theory and Research

The term acquired brain injury (ABI) is used to describe damage that occurs in the brain after birth; it includes both traumatic brain injury (TBI), resulting from external force, and non-traumatic brain injury. Paediatric acquired brain injury (pABI) can lead to an array of long term physical, cognitive, emotional and behavioural difficulties for the brain-injured child. (Chapman, 1997; Joseph & Wroblewski, 1995; Bruce, Selznick-Gurdin, & Savage, 1994). Children and adolescents are considered a significant risk group for head injury (Yates, Williams, Harris, Round, & Jenkins, 2006). Estimates for the number of children in the UK annually experiencing head injury is approximately 40,000, of which 35,000 are traumatic in nature (Department for Health, 2013). Childhood brain injury has thus been regarded as a “silent epidemic” (Snow & Hooper, 1994).

Due to the long term sequelae of more severe ABI, it presents a significant challenge to the brain injured child’s family (Rivara, Fay, Jaffe, Polissar, Shurtleff, & Martin, 1992; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Drawing on systemic theory, Maitz (1991) postulated that ABI not only impacts on individual family members but also alters the way in which the family system operates.

Some empirical research has supported a systemic theoretical perspective, with findings demonstrating changes to family structure, cohesion and adaptability following brain injury (Laroi, 2000; Curtiss, Klemz, & Vanderploeg, 2000). Evidence demonstrates the pervasive impact of paediatric ABI (pABI) on the family including: relationship difficulties, caregiver burden, impaired coping resources and overall deterioration in global family functioning (Rivara, Fay, Jaffe, Polissar, Shurtleff, & Martin, 1992; Perrott, Taylor, & Montes, 1991; Wade et al., 1998). Additionally, a

review of family outcomes by Perlesz and colleagues (Perlesz, Kinsella, & Crowe, 1999) discussed the high incidence of psychological difficulties experienced by family members following pABI.

In the absence of adjustment models detailing the specific experience of families of children with ABI; models intended to expound the linear experience of families of children with learning disability have been utilised to understand the phenomena further. A model of familial transition in brain injury proposed by Douglas (1990) described a series of discrete stages including: shock; expectancy; reality; mourning; and finally adjustment, where expectations, relationships and roles are re-defined, and the family environment restructured.

Findings of empirical research studies have however demonstrated that family members' level of distress does not diminish over time as these models of adjustment might indicate, with stress levels even increasing at certain time points (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986). This research lends more support to a non-linear model such as that of Wilker and colleagues (Wilker, Wasow, & Hartfield, 1981) that correlates family adjustment with life cycle changes. This model describes the rise and fall of an adjustment status over time, and specifies that it is neither time-bound nor predictable (Power & Dell Orto, 1981).

Rationale

It is clear that the well-being of the wider family is essential for the brain injured child's neuro-rehabilitative process. Parental wellbeing is of particular concern to clinicians working with the child with brain injury given the essential role parents can play in rehabilitation (Strike & Steptoe, 2004; Toker, Shirom, Shapira, Berliner, & Melamed, 2005; Limond, Adlam, & Cormack, 2014), the requirement for parents to be

able to cope with the demands placed on them given their child's increased need (Hawley et al., 2003), and the importance of creating an optimum environment for the child's rehabilitation to take place within (Sokol et al., 1996).

Objectives

This review offers a critical synthesis of the existing research evidence with the objective of understanding the adjustment experiences of parents who have a child with pABI. The aim of the review will therefore seek to answer the following question: what are the adjustment experiences of parents who have a child with pABI?

The review will endeavour to evaluate all literature pertaining to the adjustment experiences of parents. As such empirical evidence which focusses on coping, adaptation, stress, self-esteem, distress, anxiety, depression or experiences of parenting, which are indicators of adjustment, will be included within the review. This review identifies areas for further research, with the aim of informing the development of interventions for this population.

Methodology

Information Sources and Search Strategy

In January 2015, MEDLINE (1946 to November 2014), PsycINFO (1806 to December 2014), Embase (1974 to January 2015) and Web of Science (version 5.16.1) databases were systematically searched for relevant studies and reviews using the following string of search terms: [(Parent or Famil* or Mother or Father) and (Adjust* or Adapt* or Cop* or Psych? Adjust*) and (Traumatic brain injur* or Acquired brain injur* or Head injur* or Brain cancer or Brain infect* or Neurological) and (P?ediatric or Child)]. The surrounding literature was checked in addition to backward

and forward citations from the selected papers to ensure all relevant papers were attained.¹

Data Collection Process

Data was extracted from the databases and imported into EndNote X6 software, following which duplicate articles were removed. Titles were initially searched, followed by abstracts and then the full text article. At each stage papers were rejected if they did not meet the eligibility criteria.²

Eligibility Criteria

This systematic review was conducted using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)³ reporting protocol (Moher, Liberati, Tetzlaff, & Altman, 2009) as this allows for a standardised un-biased approach to the review. Population inclusion criteria included all studies of parents of children who were less than 18 years of age at data collection and had an acquired brain injury. Outcome inclusion criteria were (i) qualitative, mixed methods, or quantitative studies reported in peer reviewed journals; (ii) studies describing the adjustment processes of parents, including the investigation of coping, adaptation, stress, self-esteem, distress, anxiety, depression or experiences of parenting a child with ABI; and (iii) all searchable dates. Exclusion criteria were (i) review articles,

¹ See Appendix A: Full Electronic Search Strategy for Database

² See Figure 1 for exact numerical output

discussion papers, dissertations, posters, books and media material; (ii) any studies not published in English; (iii) any studies where the primary diagnosis of the child was not ABI; or (iv) studies focussing on the wider family adjustment processes not just that of parents.

Quality Appraisal

Quantitative and mixed design studies were appraised using the Effective Public Health Practice Project's (EPHPP) Quality Assessment Tool for Quantitative Studies (2006)⁴. The qualitative studies were appraised using the Critical Appraisal Skills Program (CASP, 2006) Quality Appraisal Tool⁵. Ten articles were rated by a second researcher, in addition to the author, using the relevant quality assessment tool. This was done to audit the accuracy of the researcher's ratings, and thus reduce bias.

Results

Study Selection

A detailed account of the study selection process is presented in Figure 1. Research articles were identified using the database searches after duplicates had been removed. Articles were subsequently removed after titles and abstracts had been reviewed. Full text journal articles were acquired for the remaining articles, and the inclusion and exclusion criteria were applied. After reviewing the references for each paper for forward and backwards citations, an additional article was found to meet the

⁴ See Appendix B: The EPHPP (2006) Appraisal Tool

⁵ See Appendix C: CASP (2006) Appraisal Tool

inclusion and exclusion criteria. In total 28 articles were reviewed and the quality of each was appraised.

Synthesis of Results

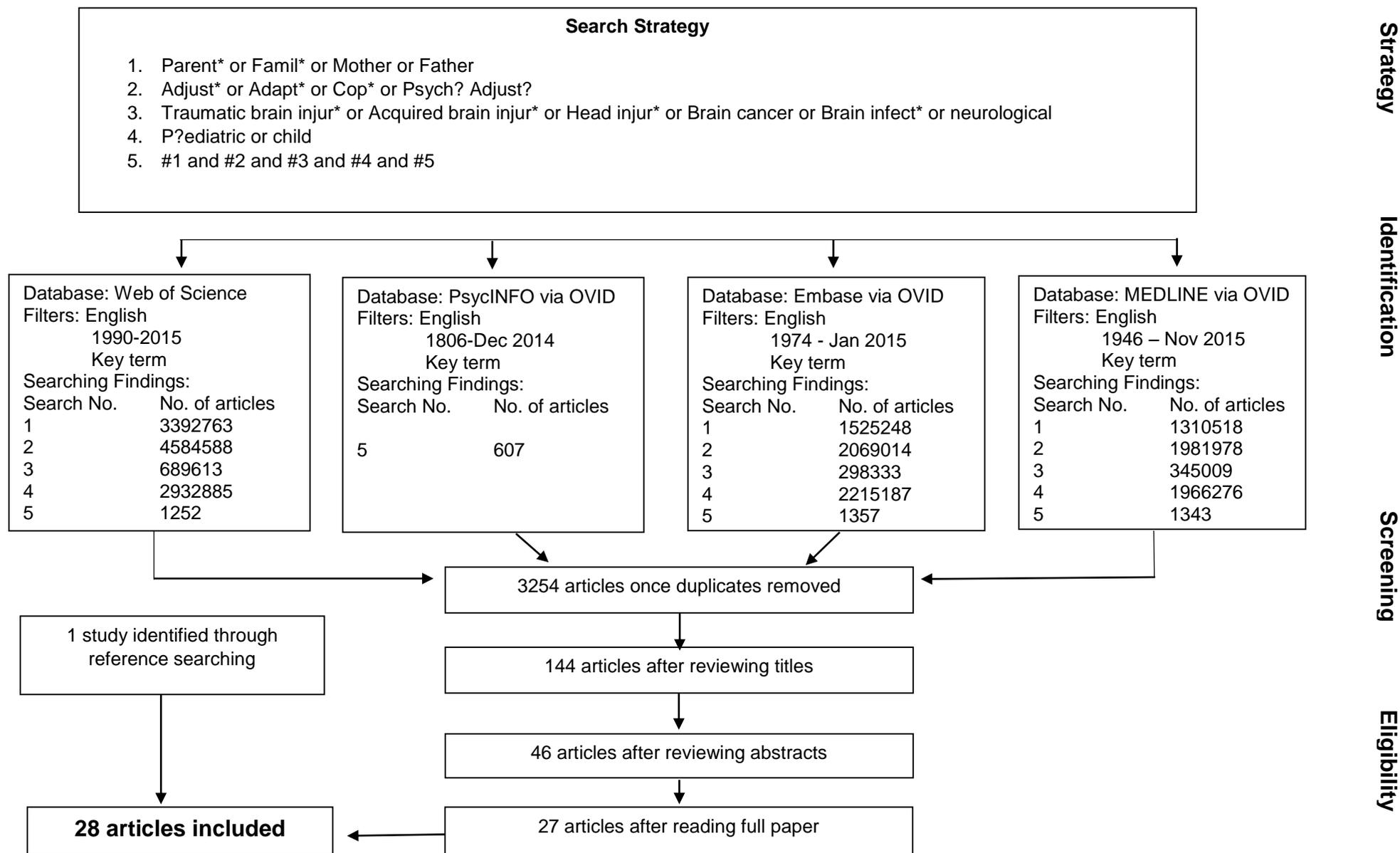
Summary details for the studies included in this review are provided in Table 1. A data extraction form was completed for each of the articles. Of the journal articles identified, twenty had quantitative methodologies, of which ten were cross-sectional and ten cohort research designs. The EPHPP quality appraisal criteria (1998) rated two articles as strong, sixteen as moderate and two as weak⁶. One research study used a mixed methods approach and was rated as moderate by the EPHPP checklist (1998). The remaining seven journal articles were qualitative studies, using research designs that included thematic analysis, phenomenology and symbolic interactionism. The CASP quality appraisal criteria (2006) rated the qualitative articles, rating one article as excellent, two as good and four as borderline.⁷

The review will synthesise the findings of the existing literature according to research design and methodology, before drawing the findings together within the discussion.

⁶ See Appendix D : A summary of the quality appraisal of twenty quantitative studies and one mixed methods design study included in the review, using the EPHPP tool (2006)

⁷ See Appendix E: A summary of the quality appraisal of the seven qualitative studies included in the review, using the CASP (2006) TOOL

Fig 1. Flow of Information through the Different Phases of the Review



Cross-sectional research studies. Of the quantitative research papers, ten had a cross-sectional research design. Several of the cross-sectional design studies reported on the quality of life (Chien, Lo, Chen, Chiang, & Chao, 2003) and high levels of stress experienced by parents (Bennett, English, Rennoldson, & Starza-Smith, 2013; Fuemmeler, Mullins, & Marx, 2001; Sokol et al., 1996), particularly during the active treatment phase (Hutchinson, Willard, Hardy, & Bonner, 2009). Parents most commonly reported experiencing fears about relapse and late effects of treatment (Anclair, Hovén, Lannering, & Boman, 2009).

Parental coping styles were reported in three of the research studies (Bennett et al., 2013; Benn & McColl, 2004; Fuemmeler et al., 2001). Overall findings suggested a relationship between perception focussed strategies and coping (Benn & McColl, 2004), whereas coping by acceptance, emotion focussed coping and an external locus of control were associated with increased levels of distress (Bennett et al., 2013; Fuemmeler et al., 2001). Parental distress was also found to be correlated with increased endorsement of authoritarian parenting practices (Micklewright, King, O'Toole, Henrich, & Floyd, 2012), and increased dysexecutive symptoms in the child (Hooper, Williams, Wall, & Chua, 2007). Sokol and colleagues (1996) found that parents were more likely to perceive their child as behaviourally impaired compared to normative samples.

Cross-sectional research designs can be a pragmatic way to seek to answer a research question because they require few resources and no follow-up is necessary. However, the study design limits an understanding of cause and effect and with information only gathered after the brain injury, and at one time point only, one cannot make assumptions about the cause of distress reported.

Table 1

Summary of the Twenty One Quantitative and Mixed Methods Research Articles Included in the Review

Study Type	First author and year	Country	Brain Injury type	Focus	Quantitative Measures	Sample	Summary	Quality Rating
Cross-sectional	Anclair , 2009	Sweden	Parents of children with diagnosis of CNS tumour	Illness related threats	Questionnaire based on categorisation made by Dongen-Melman et al (95a), list of parents fears transcribed into Swedish	82 parents of children with CNS tumour diagnosis, 208 parents of children with acute lymphoblastic leukemia	Most common illness-related threats experienced fairly or extremely by 40-90% of parents of children with CNS tumour was fear of relapse. Parents with children with CNS fears exceeded parents of children with ALL. Strength of fears in mothers and fathers approximately the same	2
Cross-sectional	Micklewright, 2012	U.S.A.	Parents of children with TBI	Parental distress, parenting practices	Hollingshead Four Factor Index of Social Status (Bornstein et al, 2003; Hollingshead, 1975) Brief Symptom Index(Derogatis, 1993) Parenting Practice Questionnaire (Robinson et al, 1995) Vineland Adaptive Behavior Scales- II (Sparrow t al, 2005) Weschler Abbreviated Scale of Intelligence	21 Parents of children with TBI, 23 Parents of children with orthopaedic injury	Results supported moderation and showed higher parental psychological distress was associated with lower child adaptive functioning in TBI group only. Higher levels of parenting distress was associated with authoritarian parenting practices and lower adaptive functioning in OI and TBI group.	1
Cross-sectional	Benn, 2004	Canada	Parents of children with ABI	Coping strategies, impact of social support, family environment	Telephone interview using the Ways of Coping Scale (WOCS) adapted from Ways of Coping Questionnaire	30 parents, 15 married couples	Perception focussed coping strategies used most often by parents of children with ABI, mothers had a more extensive repertoire of coping than fathers and relationships between maternal and paternal coping were complimentary. Study found a relationship between emotion focussed coping and instrumental support and perception focussed coping and family cohesion.	2
Cross-sectional	Bennett, 2013	U.K.	Parents of children with brain tumour	Stress levels, coping styles, parenting	Parenting Stress Index-Short Form (Abadin, 1995) Ways of Coping Questionnaire, Parental Locus of Control Scale	37 parents	51% of parents experiencing clinically significant levels of stress. External locus of control and coping by accepting responsibility accounted for 67% of variance in parenting stress.	2

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			locus of control,						
Cross-sectional	Chien, 2003	Taiwan	Parents of children with brain tumour	Quality of life	World Health Organization Questionnaire on Quality of Life: BREF-Taiwan Version	26 mothers, 3 fathers and 1 grandmother		Quality of life- The scores in the physical health and psychological domains for caregivers were lower than the norms for healthy adults.	3
Cross-sectional	Fuemmeler, 2001	U.S.A.	Parents of children with brain tumour	Post traumatic stress, general distress	Posttraumatic Stress Diagnostic Scale (Foa, 1996) Brief Symptom Inventory (Derogatis, 1993) Ways of Coping Questionnaire (Folkman & Lazarus, 1988) Parents Perception Uncertainty in Illness Scale (Mishel, 1997)	28 Parents		Participants reported high levels of post-traumatic stress and general distress. Greater levels of emotion focussed coping and perceived uncertainty were associated with higher frequency of post-traumatic stress and general distress. Perceived uncertainty was strongest predictor of distress, emotion focussed coping predicted general distress but not post-traumatic stress.	2
Cross-sectional	Hutchinson, 2009	U.S.A.	Parents of children with brain tumour	Distress	Brief Symptom Inventory (Derogatis et al, 1982) Impact of Event Scale (Horowitz et al, 1979) Parent Experience of Child Illness (Bonner et al, 2006) Impact on Family Scale (Stein & Reissman, 1980; Stein & Jessop, 2003) Caregiver Strain Questionnaire (Brammam & Heflinger, 997)	47 Parents of children in active treatment, 43 parents of children off treatment		Examined the psychological adjustment of caregivers of children with brain children on and off treatment. Groups different significantly in their reported symptoms of general psychological distress, with off treatment caregivers reporting significantly lower levels of general distress.	2
Cross-sectional	Sokol, 1995	U.S.A.	Parents of children with closed head injury	Behavioural adjustment, parental stress	Parent Report of Brain Injury Effects (Sokol, 1995) Child Behavior Checklist (Achenbach & Edelbrock, 1983) Parenting Stress Index (Abidin, 1990)	25 Parents		Examined parental stress and perceptions of children's behaviour problems. Parents in the study were more distressed than normative samples and rated their children's behaviour as more impaired regardless of severity.	2
Cross-sectional	Vilela, 2008	Canada	Parents of children with ABI	Challenges faced	Child Behaviour Checklist (Achenbach, 1992) Services and Support Questionnaire (Woodford, 1998) Interpersonal Support Evaluation List (McCull & Skinner, 1995)	27 Parents		Caregivers with 3 rd party funding reported a similar level of stress, however differences in what families perceived as stressful.	2

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				Family Environment Scale (Perry et al, 2004) AIMS Interview-Child version (Solish et al, 2003) Family Stress and Coping Interview (Nachsen et al, 2003)				
Cross-sectional	Hooper, 2007	U.K.	Parents of children with encephalitis	Parental mood, coping, disciplinary strategies	Demographic Questionnaire Dysexecutive Questionnaire for Children which is part of the Behavioural Assessment of the Dysexecutive Syndrome in Children (Emslie et al, 2003) Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) Brief Coping Orientation for Problem Experience (Carver, 1997) Disciplinary Strategy Questionnaire (Jelalian et al, 1997)	35 mothers and 1 grandmother	Higher levels of behavioural symptoms consistent with dysexecutive disorder were associated with greater parental distress. Parents remain distressed despite reporting proactive profiles of coping. Severity of dysexecutive disorders were associated with less use of proactive parental management strategies.	2
Retrospective Cohort	Freeman, 2004	U.S.A.	Parents of children with brain tumour	Stress and resources at differing phases of health care continuum	Survey, designed by themes from a qualitative study (Freeman et al, 2000, 2001) Subjective level of stress (0-10, 10=extremely stressed) reported for each phase.	130 parents representing 84 families – all participants brain tumour	At several phases (diagnosis, hospitalisation and discharge) important problems and helpful topics were reported. Mothers experience greater stress than fathers during treatment (p=0.009). Married respondents at risk of stress, stressors for all changed over phase of illness.	3
Prospective Cohort	Bendikas, 2011	U.S.A.	Parents of children with TBI	Marital relationship and family functioning	Family Assessment Device (Miller et al, 1985) Partnership Questionnaire (Braiker & Kelley, 1979) Child Rearing Disagreements Questionnaire (Jouriles et al, 1991)	53 parent TBI dyads, 94 parent orthopaedic injury dyads	Three time points 6, 12 and 18 months. Results showed differences in parental perceptions of marital relationship, and parenting amplified by TBI. Fathers of children with severe TBI endorsed significantly higher levels of love than mothers, and mothers of children with moderate and severe TBI reported increased child rearing disagreements that fathers.	2
Prospective Cohort	Hawley, 2003	U.K.	Parents of children with TBI	Parental stress and health	Structured Questionnaire – child's difficulties and problems Parenting Stress Index Short Form (Abidin, 95) General Health Questionnaire (Goldberg & Williams, 91) Problem Resolution Scale (Stilwell et al, 1999)	97 Parents and 31 parents with non-injured children as controls	2 time points: recruitment and 12 months later. 42.2% of parents showed clinically significant levels of stress. Regardless of injury severity, parents of injured children suffered greater stress than control parents as measured by the PSI (P=0.001). Highly significant relationship between the number of problems reported and level of parental stress (p=0.001). Financial burden was related to severity of TBI. At follow-up 1/3 of parents of children with severe TBI scored poor for their psychological health.	1

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Prospective Cohort	Palmer, 2011	U.S.A., Australia, Canada	Parents of children with embryonal tumour	Coping Styles	Coping Response Inventory- Adult Form (Moos, 1993)	219 Parents	Parents completed the measure at the time of diagnosis and yearly after. At the time of diagnosis, the highest observed coping method was seeking guidance. Over time, younger parents were found to seek guidance at a significantly higher rate than older parents ($p=0.16$) and the use of acceptance resignation ($p=0.011$) and seeking alternative results by all parents significantly increased ($p<0.0001$). The use of emotional discharge used more by fathers at diagnosis with younger fathers more likely to exhibit emotional discharge than older fathers ($p=0.002$).	2
Propective Cohort	Stancin, 2008	U.S.A.	Parents of young children with TBI	Parental burden and distress	General Functioning Scale of the Family Assessment Device (Byles et al, 1988; Miller et al, 1985) Life Stressors and Social Resources Inventory- Adult Version (Moos et al, 1984) Family Burden of Injury Interview (Burgess et al, 1999)	89 parents of children with TBI, 119 parents of children with orthopaedic injury	Chronic life stresses and interpersonal resources accounted for significant variance in measures of acute injury-related burden and parental distress in parents of younger children, although differences were small. TBI severity may not be sufficient to identify families at risk of burden.	2
Prospective Cohort	Wade, 2002	U.S.A.	Parents of children with TBI	Adaption, stress and burden	Socioeconomic Composite Index (Stevens & Featherman, 1981) Life Stressors and Social Resources Inventory- Adult Form (Moos et al, 1994) Family Burden of Injury Interview (Burgess et al, 1999) Impact on Family Scale- Version G (Stein & Jessop, 1985) Brief Symptom Inventory (Derogatis & Melisaratos, 1983) McMaster Family Assessment Device (Miller et al, 1985)	53 parents of children with severe TBI, 56 parents of children with moderate TBI and 80 parents of children with orthopaedic injury	Patterns of adaptation over time varied across groups but indicated long standing injury-related stress and burden in severe TBI group. Severe TBI results in persistent caregiver stress for a substantial proportion of families. Decline in psychological distress from baseline to 6 months ($p<0.0001$), and a significant increase in distress between 12 months and extended follow-ups ($p<0.05$).	2
Prospective Cohort	Wade, 2004	U.S.A.	Parents of children with TBI	Interpersonal stressors and resources	Socioeconomic Composite Index (Stevens & Featherman, 1981) Life Stressors and Social Resources Inventory- Adult Form (Moos et al, 1994) Family Burden of Injury Interview (Burgess et al, 1999) Impact on Family Scale- Version G (Stein & Jessop, 1985) Brief Symptom Inventory (Derogatis & Melisaratos, 1983)	53 parents of children with severe TBI, 56 parents of children with moderate TBI, 81 parents of children with orthopaedic injury	Assessed soon after TBI, then 6 months and 12 months, and an extended follow up. Support from spouse and friends was associated with less psychological distress, whereas family and spouse stressors were associated with more distress. Marked decline in injury related stress over time for parents of children with severe TBI who had reported high stressors and high resources. Interpersonal resources attenuated long term family burden because of severe TBI.	2

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Prospective Cohort	Wade, 2006	U.S.A.	Parents of children with TBI	Parental adaption-burden, distress and family dysfunction	Socioeconomic Composite Index (Stevens & Featherman, 1981) The Family Burden of Injury Interview (Burgess et al, 1999) Brief Symptom Inventory (Derogatis & Melisaratos, 1983) Family Assessment Device (Miller et al, 1985)	52 parents of children with severe TBI, 56 parents of children with moderate TBI, 80 parents of children with orthopaedic injury	Examined whether parents of children with TBI report increased injury related burden, distress and family function. Six time points from baseline to 6 years after injury. Attrition was higher among families in the severe TBI group with lower burden. Family functioning was moderated by social resources. Families of children with severe TBI and low resources reported deterioration functioning over the follow-up interval	2
Prospective Cohort	Wade, 2010	U.S.A.	Parents of children with TBI	Caregiver responses and gender differences	Family Burden of Injury Interview (Burgess et al, 1999) Brief Symptom Inventory (Derogatis et al, 1982) COPE (Carver et al , 1989)	64 TBI parent dyads Controls: 101 parent dyads of children with orthopaedic Injury	4 time points- after injury, 6 months, 12 months and 18 months parents of children with TBI and OI. Fathers were more likely than mothers to use denial to cope following moderate and severe TBI, but not OI. Mothers more likely to prefer acceptance and emotion-focussed strategies regardless of injury type. The use of active coping strategies varied as a function of injury type, parent sex and time since injury. Fathers reported greater injury related stress than mothers over time, with pronounced differences with severe TBI and OI groups.	2
Prospective Cohort	Yeates, 2002	U.S.A.	Parents of children with TBI	Race as a moderator of	Brief Symptom Inventory (Derogatis & Spencer, 1982) Family Burden of Injury Interview (Burgess et al, 1999) Impact on Family Scale (Stein & Jessop, 1985) Self-report version on the Family Assessment Device (Byles et al, 1988; Miller et al. 1985)	145 parents; TBI parents: 72 white, 18 black Controls- Orthopaedic injury parents: 32 white, 23 black	Race was a significant moderator of group differences in parental psychological distress and perceived family burden, mostly independent of socio-economic status. The negative consequences of TBI were less pronounced for parents of black children than for parents of white children at baseline, but became more pronounced at the two follow-ups.	2
Mixed Methods	Priaganto, 2007		Parents of children with TBI	Parental Concerns and distress	Child Behavioural Checklist (Achenbach, 2001) Care of Children with Traumatic Brain Injury in Maricopa Questionnaire for Parents (Priaganto, 2004)	81 parents of children with TBI, 19 parents of children with orthopaedic injury	Parents who report high levels of distress in the care of their children were specifically concerned about child's school performance, lack of friends, inability to control angry feelings and apathy. Fear for the future consequences of TBI.	2

The majority of the studies involved small sample sizes, limiting the generalisability of the findings. Several of the studies were at risk of selection bias as they either reported low response rates (Bennett et al., 2013; Hooper et al., 2007), or they did not report a response rate at all (Fuemmeler et al., 2001; Benn & McColl, 2004; Vilela, Phillips, & Minnes, 2008; Chien et al., 2003); this may indicate that families who were more likely to be affected by the brain injury chose to participate. Fathers were under-represented in the research studies, this has a significantly limiting effect on the generalisability of the findings.

Confounding bias was reduced in the Micklewright and colleagues (2012) study by matching the control group with parents of children with orthopaedic injury. Statistical analysis measuring differences between the two groups in Anclair and colleagues study (2009) revealed differences in treatment situation (on or off treatment), time elapsed since diagnosis to assessment, and age of child at diagnosis, though were similar regarding other background variables (i.e. porportion of male and female parent participants).

Cohort studies. Ten of the quantitative papers had a cohort research design, nine of which were prospective and one retrospective. Many of the studies reported on the high levels of parental stress and burden experienced by parents. Studies observed that parents of children with severe TBI were more likely to have poor psychological health (Hawley et al., 2003) including increased levels of depression, stress and burden (Stancin, Wade, Walz, Yeates, & Taylor, 2008; Wade et al., 2002). Race was also found to be a significant moderator of group difference in parental psychological distress and perceived family burden (Yeates et al., 2002). Studies observed that stressors varied throughout the phase of illness (Freeman, O'Dell, & Meola, 2004), though generally there is a decline in parents' injury related burden over

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time, except for parents of children with severe TBI (Wade et al, 2002; Wade et al., 2004; Wade et al., 2006).

Differences between mothers and fathers in their response to pABI were observed. Overall findings suggested differences in parents' perception of their relationship and child rearing (Bendikas, Wade, Cassedy, Taylor, & Yeates, 2011), in the coping strategies employed (Wade et al., 2010) and in the use of problem solving (Palmer et al., 2011).

Studies that investigated parental resources in their experiences of stress demonstrated the value of social relationships in psychological adjustment, indicating social support as a moderating function in adjustment. Parents of children who had a severe TBI, also had a decline in their experience of injury related stress if they had high social resources (Wade et al, 2004). Freeman and colleagues (2004) reported social support from friends and family as items rated as important by their participants during each phase of illness.

Implicit in the cohort design is the collection of data at several time points. This approach has enabled an understanding of how parental adjustment develops over time following pABI. The studies demonstrated good sample sizes, however some of the studies stratified the parents into groups depending on the severity of the child's pABI, leading some groups to become too small to establish statistical significance and generalise findings (Bendikas et al., 2011; Hawley et al., 2003).

All of the studies involved parents opting in, and some studies reported low response rates in addition (Wade et al., 2004; Wade et al., 2010). It is possible that the resulting sample bias may further impede the generalisability of the findings. As the cohort research design involved data collection at several time points, some of the

studies reported attrition bias (Yeates et al., 2002; Wade et al., 2002; Wade et al., 2004; Wade et al., 2006) and others did not report withdrawal and drop out data, indicating a risk for attrition bias also (Wade et al., 2010; Palmer et al., 2011).

As with the correlational design studies, some of the cohort design studies did not include an equal representation of fathers and mothers (Stancin et al., 2008; Yeates et al., 2002). Seven studies used parents of children with orthopaedic injuries as a control comparison, and one study used parents of non-injured children. Confounding variables were assessed during the quality appraisal and several of the studies showed excellent control in the comparison groups used, with strong ratings for this element (Hawley et al., 2003; Wade et al., 2002; Wade et al., 2004; Wade et al., 2006; Wade et al., 2010).

In all of the cross-sectional and cohort designed studies included in the review, the use of self-report data was relied on to collect data. Whilst subjective experiences are important, particular response styles may be more likely to be demonstrated and may lead to bias.

Mixed methods study. Priaganto and Gray (2007) used a mixed methods approach to investigate parental distress following TBI. The quality of this study was rated as moderate, as although there was a good sample size, the researchers' stratification of the sample into five groups limited the statistical power available to demonstrate effect sizes. In addition, a self-designed questionnaire that was used was neither a valid or reliable tool and the analysis of qualitative response was not outlined.

Qualitative studies. A variety of methods were used to collect and analyse data within the qualitative research papers: thematic analysis, interpretative phenomenological analysis, symbolic interactionism and a longitudinal

phenomenological approach. Table 2 summarises the content of each qualitative research study included in this review.

All of the studies included within the review adequately reported the aim and purpose of the research. Four of the studies partially met the criteria for an appropriate research design, in all cases this was due to the justification for the method chosen being omitted from discussion (Brown, Whittingham, Sofronoff, & Boyd, 2013; Forinder & Lindahl Norberg, 2010; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2014; Guerriere & McKeever, 1997). Two of the studies met the criteria for sampling (Brown et al., 2013; Roscigno & Swanson, 2011). All of the studies met the criteria for data collection. Only two of the studies demonstrated reflexivity in the planning, data collection and analysing of the data (Roscigno & Swanson, 2011; Clark, Stedmon, & Margison, 2008).

Four of the studies partially met the criteria for data analysis (Brown et al., 2013; Clark et al., 2008; Forinder & Lindahl Norberg, 2010; Kirk et al., 2014); several of these studies failed to give an illustration of the analysis procedure from the original text to theme generation (Forinder & Lindahl Norberg, 2010; Clark et al., 2008; Kirk et al., 2014). The majority of the research studies demonstrated the value of the research findings by reporting them in relation to theory and clinical practice.

Table 2

Summary of the Seven Qualitative Studies included in this Review

First Author, Date, Country	Brain Injury Type	Focus	Research Design	Sample	Findings	Comments	CASP Quality Rating
Brown, 2013 Australia	Parents of children with TBI	Experience , challenges and needs	Thematic analysis	10 parents, 5 health care professionals	Parents experience significant emotional distress, relationship discord, burden of care, further adding to the challenges of the parenting role. A sense of isolation, importance of empowerment, support and information pronounced. Coping styles of disengagement and avoidance often reported.	Limitations: -Sample not homogenous- professionals and parents -No discussion of reflexivity -Fathers not well represented by the sample (1 father, 1 step-father, 1 male professional) Strengths: -excellent analysis, good use of direct quotations	3
Clark, 2008 U.K.	Mothers of children with TBI	Emotional experience , qualities of change	Interpretative phenomenological analysis	10 mothers	Themes of change to and loss of past child, effects on mother's health, mother's processes of coping and support, changed roles, effects on the whole family and contact with services	Limitations: -Study recruitment through charity- sample bias? Strengths: -Good homogeneity, type of injury, all female -Transparency of reporting	2
*Forinder, 2010 Sweden	Parents of children with brain tumour	Existential issues	Inductive Thematic method	11 parents	Perceived threat, uncertainty and loss described as grief and sadness, loneliness, changes in the conditions for parenting, changed views of identity and meaning. Existential crisis – restoring assumptive world- “now we have to cope with the rest of our lives”	Limitations: -No justification of the research design -No descriptive details of the parent participants Strengths: -Second researcher conducted interviews -Appropriate research method design	3
*Guerriere, 1997 Canada	Mothers of children with ABI	Relationship with brain-injured child	Symbolic Interactionism	7 mothers	Mothers' lives abruptly changed, mothers now see themselves and their child as different people. Reconstructions after continuous self-reflection and interactions with others. Life gone from predictable and controllable to a life dominated by fate. Lack of choice.	Limitations: -Limited information about the recruitment strategy -Not clear who carried out the interviews - Strengths: -Homogenous group- just mothers	3
Kirk, 2014 U.K.	Parents of children	Information and emotional	Thematic analysis	29 parents or	Parents had unmet informational or support needs across the care trajectory and at transitional points.	Limitations: -No justification of approach -Response bias	3

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	with TBI	support needs	(Framework approach)	grandparents	Parents felt they needed emotional support. Lack of community support and understanding. Parents felt unsupported in coping with child's behaviour and psychological difficulties.	-No justification of methods chosen -No discussion of reflexivity -Experience of grandparents potentially not the same as parents. Poor homogeneity Strengths: -Good sample size	
Lindahl Norberg, 2009 Sweden	Parents of children with brain tumour	Parent's experience	Thematic Analysis	11 parents	Themes: survivor needs related to training and everyday life activities, where parents invested a large amount of time and commitment, the everyday family life was restricted: family life in focus, parenting role and routines had become more demanding, daily routine and view of life changed, parental concerns and worries regarding the survivor's current and future well-being were amplified. Parents struggle with the consequences of tangible strain, as well as existential challenges.	Limitations: -No discussion of reflexivity Strengths: -Clear why used methodology -Clear analysis	2
Roscigno, 2011 U.S.A.	Parents of children following TBI	Parental experience and cultural factors	Longitudinal phenomenological approach	42 parents	Two interview points (12-15 months apart). Parent themes were: grateful to still have my child, grieving for the child I knew, running on nerves, grappling to get what my child and family need. Parents report cultural barriers because of other's misunderstandings.	Limitations: Strengths: -Multisite recruitment- increased representativeness of sample -Discussions around recruitment and drop-out -Clear detailed analysis -Reflexivity of researcher reported -Longitudinal- changes over time	1

*articles rated for quality by a second independent rater

The emergent themes identified by the research studies rated as 'good' or 'excellent' by the CASP quality analysis tool (Clark et al., 2008, Roscigno & Swanson, 2011; Lindahl Norberg & Steneby, 2009) are synthesised below.

The experience of loss. Parents described the changes in their child following the ABI, expounding on their sense of loss and sadness for the child they had known before (Clark et al., 2008). Parents of children with moderate TBI described a faster move through their grief experience, with the assimilation between the pre-injury and post-injury child occurring sooner (Roscigno & Swanson, 2011).

The emotional experience. Parents described moving from the acute phase of relief at their child's survival and running on nerves (Roscigno & Swanson, 2011) to being psychologically exhausted (Lindahl Norberg & Steneby, 2009). An emotional conflict was presented between feeling gratitude for the child's life, whilst also experiencing feelings of sadness for lost abilities and the future; experiencing joy and sorrow (Lindahl Norberg & Steneby, 2009).

Changing roles. Parents described changes to their parenting as a consequence of the pABI. They expressed difficulties in establishing boundaries with their child, and an awareness of their over-protective approach (Lindahl Norberg & Steneby, 2009). Parents elaborated on the new roles they had acquired (Clark et al, 2008; Lindahl Norberg & Steneby, 2009).

The family system. Parents described the impact of the brain injury on the family system. Parents talked about a closer and more protective family life (Clark et al, 2008), and a stronger connection with the brain injured child (Lindahl Norberg & Steneby, 2009). Although the family was perceived as closer and more dependent on

one another, there was a sense of isolation from others, and having to re-negotiate greater independence between family members again.

The service system. Parents recounted their experiences with health, social and educational services. They appreciated those who were empathic, caring and compassionate towards them, though not all professionals interacted with them in this way (Roscigno & Swanson, 2011). Parents had a sense of feeling abandoned following discharge, receiving limited information about how to support their child, and not being able to process information in the midst of crises (Clark et al., 2008).

Discussion

Summary of Evidence

The studies outlined within this review have explored the adjustment experiences of parents of children with pABI. The quantitative studies that were reviewed reported parental stress as being within the clinically significant range (Bennett et al., 2013; Fuemmeler et al., 2001; Sokol et al., 1996; Hawley et al., 2002) particularly during the acute treatment phase (Hutchinson et al., 2009). Cohort studies were able to investigate the moderators of parental stress. They found that race (Yeates et al., 2002), gender (Freeman et al., 2004), marriage (Freeman et al., 2004), severity of the brain injury (Wade et al., 2002; Priaganto et al., 2007), increased executive dysfunction (Hooper et al., 2007) and coping strategies (Bennett et al., 2013; Benn & McColl, 2004) were significant moderators.

The qualitative studies reviewed elucidated the emotional process experienced by parents: relief and stress initially, and prolonged sadness and grief with the passage of time. They described the complexity of the feelings they experienced: joy at their child being alive and yet the sorrow for the changes their child experienced following

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injury (Lindahl Norberg & Steneby, 2009). Research indicated that parents of children with moderate TBI moved more quickly through their grief experience, with the assimilation of the pre-injury and post-injury child occurring, whereas the parents of children with severe TBI still experienced a chasm between the child they knew and the post-injury child (Rosignano & Swanson, 2011). These findings support a non-linear process model of psychological adjustment for parents, such as that offered by Williams & Kay (1991) who described the experience of “episodic loss reaction” of grief and sorrow by families experiencing brain injury.

Several of the studies explored the coping strategies employed by parents to manage internal and external stressors. External locus of control in parents, coping by acceptance and emotion focussed coping accounted for significant levels of variance in stress (Bennett et al., 2013; Benn & McColl, 2004; Fuemmeler et al, 2001), whilst perception focussed coping strategies were found to have a positive association with coping and family cohesion (Benn & McColl, 2004). The studies highlighted the resources parents had identified, such as social relationships, as paramount in alleviating their distress, whilst other resources varied in their importance at different phases of illness (Freeman et al., 2004; Wade et al., 2004). These findings support the model of caregiver process offered by Pearlin and colleagues (Pearlin, Mullan, Semple, & Skaff, 1990) which identified internal coping resources and social support to be mediators of stress levels in caregivers.

Despite the clinical and theoretical relevance of the study findings, it is important to apply caution to the implications of this review given the low quality of some of the studies included. The low sample sizes, low response rates, and high attrition rates, limit the findings’ generalisability. In addition, the stratification of the samples in some of the cohort studies according to the severity of the brain injury

limited the statistical power and effect sizes of the research. An issue throughout the studies was the lack of representation from fathers in the samples; further research is needed to investigate their adjustment experiences.

Strengths and Limitations of the Review

This review used several key terms to search for relevant literature to answer the research question, and as such a vast number of research studies were identified by the databases used. A robust strategy was employed to eliminate studies that did not meet the inclusion criteria, however, as a result, it may be that research articles that would be appropriate were not included. In an attempt to be as thorough as possible and to ensure that all relevant papers were identified, the reference list for each article was searched.

The analysis tool used to assess the quality of the quantitative papers may not have been the most appropriate tool to use given the observational nature of the research studies likely to answer a question regarding parental experiences of adjustment. The criteria within the tool gave greater weight to randomised clinical trials, with substantial control group comparisons, with confounding variables controlled for and researchers blind to the condition of each group. Some of these criteria were, therefore, not applicable for observational studies.

This review has incorporated both quantitative and qualitative research methodologies, stemming from different theoretical perspectives and methodological traditions. Whilst the quantitative studies have contributed a sense of the experiences that might be generalised to parents of children with pABI more broadly, the qualitative

studies have elucidated the complexities in the processes and experiences of being a parent to a child with pABI.

Conclusions

The systematic review has expounded on the multi-faceted experiences of parental adjustment within paediatric brain injury. The review highlighted the dynamic experience of adjustment for parents, with themes such as stress, loss, grief, coping, resources, relationships, parenting, and interactions with services arising from the literature. Future research may benefit from increased recruitment and retention rates in prospective cohort studies, particularly of fathers. Good quality, reflexive and transparent qualitative research that seek to understand the different experiential journeys of parents, including fathers, would make a valuable contribution to the evidence base.

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Appendices

Appendix A: Full Electronic Search Strategy for EMBASE, January 2015

1/6/2015
Ovid: Search Form

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<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Actions
<input type="checkbox"/>	1	parent*.mp.	408316	Advanced	Display More >>
<input type="checkbox"/>	2	famil*.mp.	1051648	Advanced	Display More >>
<input type="checkbox"/>	3	mother*.mp.	210697	Advanced	Display More >>
<input type="checkbox"/>	4	father*.mp.	41573	Advanced	Display More >>
<input type="checkbox"/>	5	1 or 2 or 3 or 4	1525248	Advanced	Display More >>
<input type="checkbox"/>	6	adjust*.mp.	475896	Advanced	Display More >>
<input type="checkbox"/>	7	adapt*.mp.	498527	Advanced	Display More >>
<input type="checkbox"/>	8	cop*.mp.	1202073	Advanced	Display More >>
<input type="checkbox"/>	9	psych? adjust*.mp.	2	Advanced	Display More >>
<input type="checkbox"/>	10	6 or 7 or 8 or 9	2069014	Advanced	Display More >>
<input type="checkbox"/>	11	traumatic brain injur*.mp.	35114	Advanced	Display More >>
<input type="checkbox"/>	12	acquired brain injur*.mp.	2104	Advanced	Display More >>
<input type="checkbox"/>	13	head injur*.mp.	48610	Advanced	Display More >>
<input type="checkbox"/>	14	brain cancer.mp. or brain cancer/	7578	Advanced	Display More >>
<input type="checkbox"/>	15	brain infect*.mp.	4983	Advanced	Display More >>
<input type="checkbox"/>	16	neurological.mp.	214416	Advanced	Display More >>
<input type="checkbox"/>	17	11 or 12 or 13 or 14 or 15 or 16	298333	Advanced	Display More >>
<input type="checkbox"/>	18	p?ediatric.mp. or pediatrics/	352293	Advanced	Display More >>
<input type="checkbox"/>	19	child*.mp.	2123868	Advanced	Display More >>
<input type="checkbox"/>	20	18 or 19	2215187	Advanced	Display More >>
<input type="checkbox"/>	21	5 and 10 and 17 and 20	1357	Advanced	Display More >>

Combine selections with:
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1 Resource selected | [Hide](#) | [Change](#)
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http://0-ovidsp.tx.ovid.com.lib.exeter.ac.uk/sp-3.13.1a/ovidweb.cgi
1/21

Appendix B: The EPHPP (2006) Appraisal Tool



EFFECTIVE PUBLIC HEALTH PRACTICE PROJECT (EPHPP)

Ref ID: _____
Author: _____
Year: _____
Reviewer: _____

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--	--------------------	----------------------	------------------

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

- No
- Yes

If Yes, was the method of randomization described? (See dictionary)

- No
- Yes

If Yes, was the method appropriate? (See dictionary)

- No
- Yes

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--	--------------------	----------------------	------------------

Parental Adjustment in Paediatric Acquired Brain Injury

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

- 1 Yes
- 2 No
- 3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

- 1 80 – 100%
- 2 60 – 79%
- 3 Less than 60%
- 4 Can't Tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--	--------------------	----------------------	------------------

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were the study participants aware of the research question?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--	--------------------	----------------------	------------------

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were data collection tools shown to be reliable?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--	--------------------	----------------------	------------------

Parental Adjustment in Paediatric Acquired Brain Injury

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

Parental Adjustment in Paediatric Acquired Brain Injury

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page.

A	SELECTION BIAS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
B	STUDY DESIGN	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
C	CONFOUNDERS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
D	BLINDING	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
E	DATA COLLECTION METHODS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
F	WITHDRAWALS AND DROPOUTS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3

GLOBAL RATING FOR THIS PAPER (circle one):

- | | | |
|---|----------|---|
| 1 | STRONG | (four STRONG ratings with no WEAK ratings) |
| 2 | MODERATE | (less than four STRONG ratings and one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- | | |
|---|---|
| 1 | Oversight |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study |

Final decision of both reviewers (circle one):

- | | |
|---|----------|
| 1 | STRONG |
| 2 | MODERATE |
| 3 | WEAK |

Parental Adjustment in Paediatric Acquired Brain Injury

<p><i>indication of how interviews were conducted, did they used a topic guide?)</i></p> <ul style="list-style-type: none"> <i>– if methods were modified during the study. If so, has the researcher explained how and why?</i> <i>– if the form of data is clear (e.g. tape recordings, video material, notes etc.)</i> <i>– if the researcher has discussed saturation of data</i> 	
<p>Reflexivity</p> <p><i>Consider whether it is clear:</i></p> <ul style="list-style-type: none"> <i>– if the researcher critically examined their own role, potential bias and influence during:</i> <i>– formulation of research questions</i> <i>– data collection, including sample recruitment and choice of location</i> <i>– how the researcher responded to events during the study and whether they considered the implications of any changes in the research design</i> 	
<p>Ethical Issues</p> <p>Have ethical issues been taken into consideration?</p> <ul style="list-style-type: none"> <i>- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</i> <i>– if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</i> <i>– if approval has been sought from the ethics committee</i> 	
<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p><i>Consider:</i></p> <ul style="list-style-type: none"> <i>– if there is an in-depth description of the analysis process</i> <i>– if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?</i> <i>– whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</i> <i>– if sufficient data are presented to support the findings</i> <i>– to what extent contradictory data are taken into account</i> 	

Parental Adjustment in Paediatric Acquired Brain Injury

<p>– <i>whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</i></p>	
<p>Findings</p> <p>Is there a clear statement of findings?</p> <p><i>Consider:</i></p> <ul style="list-style-type: none"> – <i>if the findings are explicit</i> – <i>if there is adequate discussion of the evidence both for and against the researcher's arguments</i> – <i>if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)</i> – <i>if the findings are discussed in relation to the original research questions</i> 	
<p>Value of the research</p> <p>How valuable is the research?</p> <p><i>Consider:</i></p> <ul style="list-style-type: none"> – <i>if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)</i> – <i>if they identify new areas where research is necessary</i> – <i>if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</i> 	
<p>Overall assessment of the study</p> <p>1= excellent, 2= good, 3= borderline, 4 = poor.</p>	
<p>Comments</p>	

Appendix D: A Summary of the Quality Appraisal of the Quantitative and Mixed Design Studies Included in the Review, Using the EPHPP Tool (2006)

First author and year	Brain Injury type	Focus	Study design	Quantitative Measures	Sample	Country	Selection bias	Study Design	Confounders	Blinding	Data Collection	Withdrawals and Dropouts	Intervention Integrity	Analyses	Global rating
Anclair , 2009*	Parents of children who had a diagnosis of Central Nervous System Tumour	Illness related threats	Cross-sectional	Questionnaire based on categorisation made by Dongen-Melman et al (95a), list of parents fears transcribed into Swedish	82 parents of children with CNS tumour diagnosis, 208 parents of children with acute lymphoblastic leukemia	Sweden	Researcher's ratings							Descriptives, Analysis of variance	2
							2	2	2	N/A	3	N/A	N/A		
							Second rater's ratings								
							2	2	2	N/A	3	N/A	N/A		
Bendikas, 2011*	Parents of children with TBI	Marital relationship and family functioning	Cohort	Family Assessment Device (Miller et al, 1985) Partnership Questionnaire (Braiker & Kelley, 1979) Child Rearing Disagreements Questionnaire (Jouriles et al, 1991)	53 parent TBI dyads, 94 parent orthopaedic injury dyads	USA	Researcher's ratings							Descriptives, Mixed Model Analysis	2
							2	3	3	N/A	2	N/A	N/A		
							2	3	3	N/A	3	N/A	N/A		

Parental Adjustment in Paediatric Acquired Brain Injury

Benn, 2004*	Parents of children with ABI	Coping strategies, relationships between coping strategies of parents, the impact of social support and family environment on coping strategies	Cross-sectional	Telephone interview using the Ways of Coping Scale (WOCS) adapted from Ways of Coping Questionnaire	30 parents, 15 married couples	Canada	Researcher's rater						Descriptives, Analysis of variance, chi-squared analysis, Mann whitney U test	2	
							2	3	N/A	N/A	1	N/A			N/A
							Second rater's ratings								
							2	3	N/A	N/A	1	N/A			N/A
Bennett, 2013	Parents of children who were diagnosed with brain tumour	Stress levels, and relationship between stress levels and coping styles, parenting locus of control, child disability and time since diagnosis	Cross-sectional	Parenting Stress Index-Short Form (Abadin, 1995) Ways of Coping Questionnaire, Parental Locus of Control Scale	37 parents	U.K.	2	3	N/A	N/A	1	N/A	N/A	Descriptives, correlational analysis, Mann Whitney U test	2
Chien, 2003	Parents of children who were diagnosed with brain tumour	Quality of life	Cross-sectional	World Health Organization Questionnaire on Quality of Life: BREF Taiwan Version (The WHOQOL Taiwan Group, 2001)	26 mothers, 3 fathers and 1 grandmother	Taiwan	2	3	N/A	N/A	3	N/A	N/A	Descriptives, Mann Whitney U Test, Kruskal-Wallis test	3
	Parents of	Sress, problems	Cohort		130 parents representing	USA	Researcher Rating						Descriptives. Bivariate	3	

Parental Adjustment in Paediatric Acquired Brain Injury

Freeman, 2004*	children who were diagnosed with a brain tumour or spinal chord tumour	and resources at differing phases of health care continuum		Survey, designed by themes from a qualitative study (Freeman et al, 2000, 2001) Subjective level of stress (0-10, 10= extremely stressed) reported for each phase.	84 families – all participants brain tumour		2	3	N/A	N/A	3	1	N/A	analysis, analysis of regression	
							Second Rating								
							2	2	N/A	N/A	3	1	N/A		
Hawley, 2003	Parents of children and adolescents with TBI	Parental stress and health	Cohort	Structured Questionnaire – child’s difficulties and problems Parenting Stress Index Short Form (Abidin, 95) General Health Questionnaire (Goldberg & Williams, 91) Problem Resolution Scale (Stilwell et al, 1999)	97 Parents and 31 parents with non-injured children as controls	U.K.	1	2	1	N/A	1	1	N/A	Descriptives, analysis of variance, Cross tabulations	1
Hooper, 2007	Parents of children who were diagnosed with encephalitis	Parental mood, coping and disciplinary strategies	Cross-sectional	Demographic Questionnaire Dysexecutive Questionnaire for Children which is part of the Behavioural Assessment of the Dysexecutive Syndrome in Children (Emslie et al, 2003) Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) Brief Coping Orientation for Problem Experience (Carver, 1997) Disciplinary Strategy Questionnaire (Jelalian et al, 1997)	35 mothers and one grandmother	U.K.	2	3	2	N/A	2	N/A	N/A	Descriptives, Correlational Analysis	2

Parental Adjustment in Paediatric Acquired Brain Injury

Fuemmeler, 2001*	Parents of children with brain tumour	Post traumataic stress and general distress	Cross- sectional	Posttraumatic Stress Diagnostic Scale (Foa, 1996) Brief Symptom Inventory (Derogatis, 1993) Ways of Coping Questionnaire (Folkman & Lazarus, 1988) Parents Perception Uncertainty in Illness Scale (Mishel, 1997)	28 parents	U.S.A.	Researcher Rating						Descriptives, multivariate analysis of regression, heirarchy of regression	2	
							2	3	N/A	N/A	2	N/A			N/A
							Second Rating								
							2	3	N/A	N/A	1	N/A			N/A
Hutchinson, 2009	Parents of children with brain tumour	Adjustment	Cross- sectional	Brief Symptom Inventory (Derogatis et al, 1982) Impact of Event Scale (Horowitz et al, 1979) Parent Experience of Child Illness (Bonner et al, 2006) Impact on Family Scale (Stein & Reissman, 1980; Stein & Jessop, 2003) Caregiver Strain Questionnaire (Brammam & Heflinger, 997)	47 parents of children in active treatment, 43 parents of children off treatment	U.S.A.	2	3	2	N/A	2	N/A	N/A	Descriptives, Multivariate analysis of variance	2

Parental Adjustment in Paediatric Acquired Brain Injury

Micklewright, 2012	Parents of children with TBI	Parental distress and parenting practices	Cross-sectional	Hollingshead Four Factor Index of Social Status (Bornstein et al, 2003; Hollingshead, 1975) Brief Symptom Index(Derogatis, 1993) Parenting Practice Questionnaire (Robinson et al, 1995) Vineland Adaptive Behavior Scales- II (Sparrow t al, 2005) Weschler Abbreviated Scale of Intelligence	21 Parents of children with TBI, 23 Parents of children with orthopaedic injury	U.S.A.	2	2	1	N/A	1	N/A	N/A	Descriptives, heirarchical multiple regression, bootstrapped estimates	1
Palmer, 2011	Parents of children with embryonal tumour	Coping styles	Prospective cohort	Coping Response Inventory-Adult Form (Moos,1993)	219 Parents	U.S.A. , Australia and Canada	1	2	N/A	N/A	2	3	N/A	Descriptives, Random coefficient models, regression models for repeated measures, multivariate models, linear analysis	2
Sokol, 1995	Parents of children with closed head injury	Behavioural adjustment an parental stress	Cross-sectional	Parent Report of Brain Injury Effects (Sokol, 1995) Child Behavior Checklist (Achenback & Edelbrock, 1983) Parenting Stress Index (Abidin,1990)	25 parents	U.S.A.	2	3	N/A	N/A	2	2	N/A	Descriptives, paired t-test, anova	2

Parental Adjustment in Paediatric Acquired Brain Injury

Stancin, 2008	Parents of young children with TBI	Parental burden and distress	Concurrent cohort	<p>General Functioning Scale of the Family Assessment Device (Byles et al, 1988; Miller et al, 1985)</p> <p>Life Stressors and Social Resources Inventory- Adult Version (Moos et al, 1984)</p> <p>Family Burden of Injury Interview (Burgess et al, 1999)</p>	89 parents of children with TBI, 119 parents of children with orthopaedic injury	U.S.A.	2	2	2	N/A	1	3	N/A	Descriptives, Hierarchical regression analysis	2
Vilela, 2008*	Parents of children with ABI	Challenges faced	Cross-sectional	<p>Child Behaviour Checklist (Achenbach, 1992)</p> <p>Services and Support Questionnaire (Woodford, 1998)</p> <p>Interpersonal Support Evaluation List (McColl & Skinner, 1995)</p> <p>Family Environment Scale (Perry et al, 2004)</p> <p>AIMS Interview-Child version (Solish et al, 2003)</p> <p>Family Stress and Coping Interview (Nachsen et al, 2003)</p>	27 Parents	Canada	Researcher's ratings							Descriptives, T-tests	2
							2	3	N/A	N/A	2	N/A	N/A		
							Second rater's ratings								
							2	3	N/A	N/A	3	N/A	N/A	Descriptives, T-tests	

Parental Adjustment in Paediatric Acquired Brain Injury

Wade, 2002	Parents of children with TBI	Adaptation, stress and burden	Prospective concurrent cohort	<p>Socioeconomic Composite Index (Stevens & Featherman, 1981)</p> <p>Life Stressors and Social Resources Inventory- Adult Form (Moos et al, 1994)</p> <p>Family Burden of Injury Interview (Burgess et al, 1999)</p> <p>Impact on Family Scale-Version G (Stein & Jessop, 1985)</p> <p>Brief Symptom Inventory (Derogatis & Melisaratos, 1983)</p> <p>McMaster Family Assessment Device (Miller et al, 1985)</p>	53 parents of children with severe TBI, 56 parents of children with moderate TBI and 80 parents of children with orthopaedic injury	U.S.A.	2	2	1	N/A	1	3	N/A	Descriptives, General linear mixed model analysis	2
Wade, 2004	Parents of children with TBI	Interpersonal stressors and resources	Cohort analytic	<p>Socioeconomic Composite Index (Stevens & Featherman, 1981)</p> <p>Life Stressors and Social Resources Inventory- Adult Form (Moos et al, 1994)</p> <p>Family Burden of Injury Interview (Burgess et al, 1999)</p> <p>Impact on Family Scale-Version G (Stein & Jessop, 1985)</p> <p>Brief Symptom Inventory (Derogatis & Melisaratos, 1983)</p>	53 parents of children with severe TBI, 56 parents of children with moderate TBI, 81 parents of children with orthopaedic injury	U.S.A.	2	2	1	N/A	1	3	N/A	Descriptives, Mixed linear model analysis	2

Parental Adjustment in Paediatric Acquired Brain Injury

Wade, 2006	Parents of children with TBI	Parental adaption – burden, distress and family dysfunction	Prospective concurrent cohort	<p>Socioeconomic Composite Index (Stevens & Featherman, 1981)</p> <p>The Family Burden of Injury Interview (Burgess et al, 1999)</p> <p>Brief Symptom Inventory (Derogatis & Melisaratos, 1983)</p> <p>Family Assessment Device (Miller et al, 1985)</p>	52 parents of children with severe TBI, 56 parents of children with moderate TBI, 80 parents of children with orthopaedic injury	U.S.A.	2	2	1	N/A	1	3	N/A	Descriptives, General linear mixed model analysis	2
Wade, 2010*	Parents of children with TBI	Caregiver responses and gender differences	Prospective concurrent cohort	<p>Family Burden of Injury Interview (Burgess et al, 1999)</p> <p>Brief Symptom Inventory (Derogatis et al, 1982)</p> <p>COPE (Carver et al, 1989)</p>	<p>64 TBI parent dyads</p> <p>Controls: 101 parent dyads of children with orthopaedic injury</p>	U.S.A.	<p style="text-align: center;">Researcher's ratings</p> <p style="text-align: center;">2 2 1 N/A 1 3 N/A</p> <p style="text-align: center;">Second rater's ratings</p> <p style="text-align: center;">2 2 1 N/A 1 2 N/A</p>						Descriptives, General linear mixed model analyses, logistic regression analysis	2	
Yeates, 2002	Parents of children with TBI	Race as a moderator of outcome	Retrospective Cohort Analytic	<p>Brief Symptom Inventory (Derogatis & Spencer, 1982)</p> <p>Family Burden of Injury Interview (Burgess et al, 1999)</p> <p>Impact on Family Scale (Stein & Jessop, 1985)</p> <p>Self-report version on the Family Assessment Device (Byles et al, 1988; Miller et al. 1985)</p>	<p>145 parents;</p> <p>TBI parents: 72 white, 18 black</p> <p>Controls-Orthopaedic injury parents: 32 white, 23 black</p>	U.S.A.	2	2	2	N/A	1	N/A	N/A	Descriptives, repeated measures multivariate analysis of covariance	2

Parental Adjustment in Paediatric Acquired Brain Injury

Priaganto, 2007	Parents of children with TBI	Parental Concerns and distress	Mixed model design	Child Behavioural Checklist (Achenbach, 2001) Care of Children with Traumatic Brain Injury in Maricopa Questionnaire for Parents (Priaganto, 2004)	81 parents of children with TBI, 19 parents of children with orthopaedic injury as controls	U.S.A.	2	2	2	N/A	3	N/A	N/A	Rank order correlation coefficient, frequency distribution	2
--------------------	---------------------------------------	--------------------------------------	-----------------------	---	--	--------	---	---	---	-----	---	-----	-----	--	---

1= strong, 2= moderate, 3= weak *Articles rated by a second and independent rater

Parental Adjustment in Paediatric Acquired Brain Injury

Appendix E: A Summary of Quality Appraisal of the Seven Qualitative Studies Included in the Review, Using the CASP (2006)

First author and year	Brain Injury Type	Parental Adjustment focus	Analysis Method	Sample	Country	Aim	Qualitative method appropriate	Appropriate research design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of the research	Overall assessment (1=excellent, 2=good,
Brown, 2013	Parents of children with TBI	Experiences, challenges and needs	Thematic analysis	10 parents, 5 health care professionals	Australia	✓	✓	P	✓	P	×	P	P	P	✓	3
Clark, 2008*	Parents of children with TBI	Emotional experience, qualities of change	Interpretative Phenomenological Analysis	10 mothers	U.K.	✓	✓	✓	P	P	✓	✓	✓	✓	✓	2
						✓	✓	✓	P	P	✓	✓	P	P	✓	
Forinder, 2010*	Parents of children with brain tumour	Existential issues	Thematic analysis	11 parents	Sweden	✓	✓	P	P	P	×	P	P	✓	P	3
						✓	✓	P	P	P	×	P	P	✓	P	
Guerriere, 1997*	Parents of children with ABI	Relationship with brain-injured child	Symbolic Interactionism	7 mothers	Canada	✓	✓	✓	×	P	P	✓	✓	✓	P	3
						✓	✓	P	P	P	P	×	✓	P	P	
Kirk, 2014	Parents of children with TBI	Information and emotional support needs	Thematic analysis (framework approach)	29 parents or grandparents	U.K.	✓	✓	P	P	P	×	✓	P	P	✓	3
Lindahl Norberg, 2009	Parents of children with brain tumour	Parental experiences	Thematic analysis	11 parents	Sweden	✓	✓	✓	P	P	×	✓	✓	✓	✓	2
Roscigno, 2011	Parents of children with TBI	Parental experiences and cultural factors	Longitudinal phenomenological approach	42 parents	U.S.A.	✓	✓	✓	✓	P	✓	✓	✓	✓	✓	1

*articles rated by a second and independent rate

DOCTORATE IN CLINICAL PSYCHOLOGY

Major Research Project

“We knew our lives were changed forever from that point.” Parental Adjustment and the Role of Social Support in Paediatric Acquired Brain Injury: An Interpretative Phenomenological Analysis

Sian Elin Hocking

Word count: 7,997
(Exc. Abstract, Appendices and References)

Main Supervisor: Dr Phil Yates, Centre for Clinical Neuropsychology Research, University of Exeter

Secondary Supervisor: Dr Anna Adlam, Centre for Clinical Neuropsychology Research, University of Exeter

Nominated Journal: Neuropsychological Rehabilitation

The author certifies that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Abstract

Paediatric acquired brain injury (pABI) can lead to an array of long term physical, cognitive, emotional, and behavioural difficulties. Due to the long-term sequelae of more severe pABI, it presents a significant challenge to the child's family. Studies have suggested that social support can positively impact psychological adjustment following a stressful life event, and can aid personal resilience. There remains limited qualitative investigation of subjective family and parental adjustment experiences following pABI. Researchers have argued for future research that include the experiences of parents who have children younger than 16 years old, and are able to shed light on the individual experiential journey of parents. The current study used interpretative phenomenological analysis (IPA) to explore to the experiences of adjustment and social support of parents of children with pABI. Purposive sampling was used to recruit 10 participants who were individually interviewed. Five superordinate themes emerging from the data were identified: 1) Lives changed forever, 2) Sense of self, 3) Interaction with services, 4) The psychological experience, 5) Coping and adjustment. Relevant literature and implications for future research and clinical practice are discussed.

Keywords: Paediatric, acquired brain injury, parents, adjustment, social support

Introduction

The term paediatric acquired brain injury (pABI) is used to describe damage that occurs in the brain after birth. It is most commonly caused by traumatic brain injury (TBI), resulting from external force, but also includes non-traumatic brain injury such as stroke, brain tumour and brain infection. Children and adolescents are considered to be a significant risk group for pABI (Yates, Williams, Harris, Round, & Jenkins, 2006). Hospital admission rates have been used to calculate the incidence of traumatic brain injury in children, and it is estimated that each year approximately 280 out of every 100,000 children in the United Kingdom (UK) will experience a TBI (Hawley, Ward, Long, Owen, & Magnay, 2003). It is also a leading cause of mortality and morbidity in children (Brazil, 1992), and a leading cause of disability in those who survive (Fleminger & Ponsford, 2005). pABI has thus been regarded as a “silent epidemic” (Snow & Hooper, 1994).

pABI can vary in severity, and can impact on the physical, cognitive, social, emotional and behavioural abilities of the child (Chapman, 1997; Joseph & Wroblewski, 1995; Bruce, Selznick-Gurdin, & Savage, 1994). The impact of the pABI may be observed in the immediate term, or may unfold over time as cognitive, emotional, social, and communication skills fail to develop or mature at the same rate as age-matched peers, termed ‘neurocognitive stalling’ (Chapman, 2007).

The Impact on the Family

An increased emphasis of the impact of pABI on the family has been observed within the neuropsychological rehabilitation literature (Clark, Stedmon, & Margison, 2008). pABI can present a significant challenge to the brain injured

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child's family who likely assume the responsibility for care, identifying as both caregiver and parent, sibling or other family member (Rivara et al., 1992; Wade, Taylor, Drotar, Stancin & Yeates, 1998).

Drawing on systemic theory, Maitz (1991) postulated that ABI not only impacts individual family members, but also alters the way in which the family system operates as a whole. This is referred to as the principle of wholeness, where "every part of the system is so related to its fellow parts that a change in one part will cause a change in all of them and in the total system" (Watzlawick, Beavin, & Jackson, 1997, p. 123). Families may experience feelings of loss for the child they knew before the brain injury, and loss for the adult they thought their child would become, whilst also learning to become equipped to care for the child who plays a new role in the family.

Some empirical research has supported a systemic theoretical perspective, with findings demonstrating changes to family structure, cohesion and adaptability following both adult and pABI (Laroi, 2000; Curtiss, Klemz, & Vanderploeg, 2000). Evidence has demonstrated the pervasive impact of pABI on the family, including relationship difficulties, caregiver burden, impaired coping resources and overall deterioration in global family functioning (Rivara et al., 1992; Perrott, Taylor, & Montes, 1991; Wade et al., 1998). The lack of available social and practical support, necessary changes in roles and responsibilities within the family, increased financial issues, and marital conflict all contribute to the level of stress experienced (Ponsford, Sloan, & Snow, 2013).

Parental Adjustment

Parental wellbeing is of understandable concern to clinicians working with the child with brain injury given the essential role parents can play in rehabilitation

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(Strike & Steptoe, 2004; Toker, Shirom, Shapira, Berliner, & Melamed, 2005; Limond, Adlam, & Cormack, 2014), the requirement for parents to be able to cope with the demands placed on them given their child's increased need (Hawley et al., 2003), and the importance of creating an optimum environment for the child's rehabilitation to take place within (Sokol et al., 1996).

Several research studies have described the high levels of distress experienced by parents (Bennett, English, Rennoldson, & Starza-Smith, 2013; Fuemmeler, Mullins, & Marx, 2001; Sokol et al., 1996; Hawley et al., 2003) particularly during the acute phase of treatment (Hutchinson, Willard, Hardy, & Bonner, 2009). Research has described the emotional processes experienced by parents, from the initial short-term feelings of relief and stress, to prolonged sadness and grief with the passage of time (Lindahl Norberg & Steneby, 2009). These findings support Williams & Kay's (1991) dynamic framework for understanding the adjustment experience of families, termed 'episodic loss reaction', which amalgamates the experience of loss of the child known to the family and the daily burden of caring for the child with a brain injury. Developmental and neurodevelopment events that occur throughout the family life cycle lead to episodes of loss reaction in the family, and feelings of grief and distress follow.

The paediatric neuropsychological literature has become increasingly concerned with factors that mediate parental experiences of distress, and factors that facilitate coping and adjustment. Empirical research has indicated that the stress levels experienced by parents are impacted on by race (Yeates et al., 2002), gender (Freeman, O'Dell, & Meola, 2004), marital status (Freeman et al., 2004), severity of brain injury (Wade et al., 2002; Priaganto & Gray, 2007), levels of executive dysfunction in the child (Hooper, Williams, Wall, & Chua, 2007), and

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the coping strategies used by the parent (Bennett et al., 2013; Benn & McColl, 2004). The existing literature, however, is limited; many of the findings are drawn from small sample sizes that are not necessarily representative of the group, and high attrition rates further limit the generalisability of the findings.

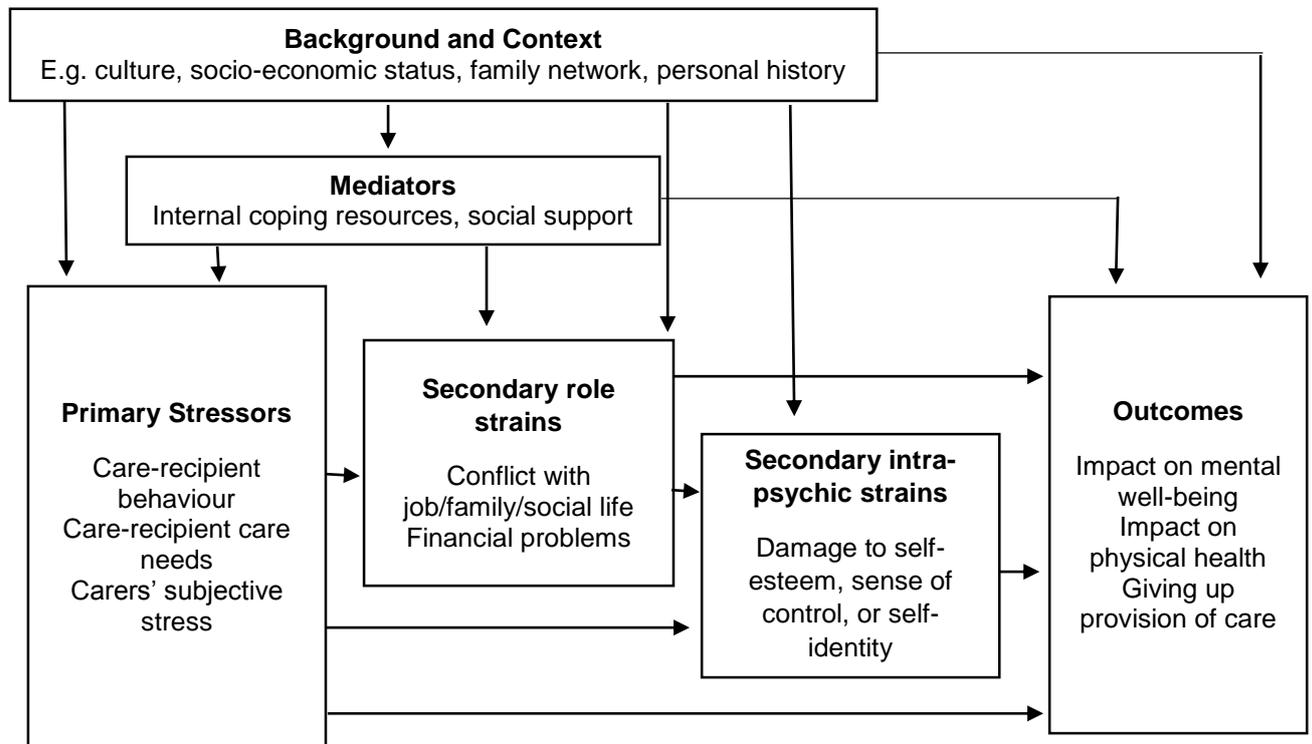
Social Support and Adjustment

Social support has been found to positively impact upon psychological adjustment following a stressful life event (Wade & Kendler, 2000), and can aid personal resilience (Stewart & Sun, 2004). The model of caregiver distress (Pearlin, Mullan, Semple, & Skaff, 1990) expounds the mediating effect of social support on stress in terms of buffering the effects of primary stressors, and inhibiting the development of secondary stressors.

The interaction between social support and levels of distress levels in parents of children with a diagnosis of brain tumour was observed by Freeman and colleagues (2004). Findings suggested that parents placed value on social support at each stage of their child's treatment. Wade and colleagues (Wade et al., 2004) also observed the positive effect that social resources had on the adjustment levels of parents of children with TBI.

Figure 2.

The Pearlin Model (Pearlin et al., 1990)



The Current Study

There remains limited qualitative investigation of subjective family and parental adjustment experiences following pABI (Brown, Whittingham, Sofronoff, & Boyd, 2013). The current study will use a qualitative methodology to explore the experiences of parents of children with pABI. It aims to add to the evidence-base by exploring parental experiences and the role of social support in adjustment to pABI. More specifically, it will identify emergent themes in the data using interpretive phenomenological analysis (IPA). The study aims to answer the following research questions:

- (i) How do participants make sense of their experiences as parents of a child with pABI?

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- (ii) What are the experiences of psychological adjustment for parents of children with pABI?
- (iii) How do parents of children with pABI make sense of the role of social support in their experience of adjustment?

The findings of the present study are intended to inform theory, guide larger scale research in the future, and to inform clinicians about parents experiences of adjustment and social support, which may be used to guide clinical practice.

Methodology

Participants

Recruitment. Purposive sampling was used to recruit 11 participants.

Recruitment was conducted via the following pathways:

1. Local clinical services. This included the paediatric neurology department in Bristol Children's Hospital (University Hospital Bristol NHS Foundation Trust) and through the Mardon Neuro-rehabilitation Centre (Royal Devon & Exeter NHS Foundation Trust). Recruitment sites were sent information sheets¹⁰ and senior clinicians (Consultant Paediatric Neurologist and Specialist Occupational Therapist) were asked to approach eligible participants to inform them of the study. Those who expressed an interest in the study were asked to complete a 'consent to share contact details form'¹¹ which was subsequently sent to the researcher.
2. Voluntary sector organisations and child brain injury charities. An advertisement for the study was placed on the websites and social media

¹⁰ See Appendix F: Participant Information Sheet

¹¹ See Appendix G: Consent to Share Contact Details Form

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forums of charities including Cerebra, The Brain Tumour Charity and Brain Tumour Support. Posters¹² were displayed in three Brainwave centres in the U.K., The Children's Trust, and Dame Hannah Rogers Trust. Parents were given the opportunity to contact the charity or the researcher for an information sheet.

3. University of Exeter, Clinical Centre for Neuropsychology Research (CCNR) website that included a page on the project: <http://psychology.exeter.ac.uk/research/centres/ccnr/familymembersexperience>.¹³

Sample. Inclusion and exclusion criteria were applied to ensure a homogenous sample. Participants were included in the study if they were fluent English speakers, had a child who was less than 18 years old with pABI, who had experienced normal pre-natal and peri-natal development. Participants were excluded from the study if they themselves were directly injured in the event causing the pABI, if there were any deaths in the event causing the pABI, or if the children with pABI had a life-limiting condition.¹⁴

Eleven participants were recruited to take part. An interview conducted with a parent of a child with neurofibromatosis was subsequently excluded from the results, as it was considered that its inclusion would reduce the homogeneity of the sample. This was due to the increased risk of the child developing subsequent tumours, and the unknown premorbid effects of the condition.

The inclusion of 10 participants' interviews enabled a detailed understanding of each participant's experience while also providing sufficient opportunity to observe similarities and differences between cases. Demographic

¹² See Appendix H: Study Poster

¹³ See Appendix I : Study Information on CCNR website

¹⁴ See Appendix J : Discussion regarding Recruitment Issues

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data and information pertaining to their child's pABI was collected prior to the interview (Table 4). The participants consisted of eight mothers and two fathers. All participants described themselves as white British, except for one participant who described themselves as white/black Caribbean. The mean age of the parents was 43 years. The mean age of the child at brain injury was 8 years and 2 months, and the mean time since injury was 4 years and 4 months. The cause of each child's pABI is displayed in Table 4.

Service User Involvement

The University of Exeter volunteer research panel, which included parents of children with pABI, was consulted regarding the study aims and methodology.

Ethics

University ethical approval¹⁵ was granted from the University of Exeter¹⁶, and NHS ethical approval was given by the Exeter National Research Ethics Service (NRES) committee¹⁷. The study received approval from the Royal Devon and Exeter NHS Foundation Trust Research and Development department¹⁸ and from University Hospital Bristol NHS Foundation Trust Research and Innovation department.¹⁹

¹⁵ See Appendix K: Discussion of the main ethical issues in current study

¹⁶ See Appendix L: University of Exeter Ethical Approval

¹⁷ See Appendix M : REC NHS Ethical Approval

¹⁸ See Appendix N : Royal Devon and Exeter NHS Foundation Trust Research and Development Approval

¹⁹ See Appendix O: University Hospital Bristol NHS Foundation Trust Research and Innovation Department Approval

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Table 4.

Participant Demographic and Child Data

P.I.	Mother or Father (M/F)	Age	Ethnicity	Occupation	Nature of Child's Brain Injury	No. of additional siblings at home	Gender of Brain Injured Child (F/M)	Age (of child) at Brain Injury (Years)	Current age of child (Years)	Time since brain injury (Years)
P1	M	33	White, British	Unemployed	Medulloblastoma, posterior fossa syndrome	3	F	6	7	1
P2	M	50	White, British	Research support officer	Medulloblastoma	0	M	13	16	3
P3	F	53	White, British	Retired policeman	Medulloblastoma	0	M	13	16	3
P4	M	41	White, British	Unemployed	Medulloblastoma	2	M	6	9	3
P5	M	48	White, British	Project officer, Council	Optic chiasm ganglioglioma	1	M	8	15	7
P6	F	48	White, British	Unemployed	Road Traffic Accident, TBI	2	M	6	11	5
P7	M	49	White, British	Unemployed	Road Traffic Accident, TBI	2	M	6	11	5
P8	M	33	White/ Black Caribbean	Head of business development, Finance	Subarachnoid haemorrhage	0	M	12	17	5
P9	M	43	White, British	Social worker	Acute disseminated encephalomyelitis	0	M	3	13	10
P10	M	32	White, British	Service department for fire department	Motor cross accident, TBI	0	M	9	10	1
		Mean age= 43 years						Mean= 8.2 = 8 years, 2 months	Mean= 12.5 = 12 years, 6 months	Mean= 4.3= 4 years 4 months

Procedure and Ethical Considerations

Participants were given an information sheet and asked either to return the 'consent to share contact details' form to the researcher, or to contact the researcher directly. An interview date was subsequently arranged. Participants were sent a consent form²⁵ to sign and return prior to the interview, as some of the interviews were conducted over the telephone. With participants' consent, their general practitioners (GP) details were collected, enabling the researcher to inform the GP of their participation²⁶. Participants were also informed that if the researcher had any concerns regarding the participant's emotional and/or psychological wellbeing following the interview, that they would request the participant's consent to contact their GP.

All participant data was anonymised. Participants were informed that the findings of the research would be disseminated to participants, the participating NHS services, charities, and to the wider organisations and clinicians interested in neuro-rehabilitation²⁷.

Interview

A one-to-one interview was conducted between the participant and the researcher. A semi-structured interview schedule²⁸ was used to set an agenda for the interviews, anticipate sensitive questions, and frame questions in a suitable manner. Questions were open, expansive, and allowed the participants to talk at length about their experiences. The researcher used these questions flexibly, and used prompts to gain clarification and to elicit additional information. Participants were able to choose whether they wanted to meet face-to-face or to

²⁵ See Appendix P: Consent Form

²⁶ See Appendix Q: Letter to GP regarding their Patient's Participation

²⁷ See Appendix R :Dissemination statement

²⁸ See Appendix S : Semi- structured Interview Schedule

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talk over the telephone. Three of the interviews were conducted face to face, and seven were conducted over the telephone. The interviews ranged in length between 29 and 62 minutes, and were audio recorded before being transcribed verbatim.

Qualitative Methodology

One of the aims of qualitative research is to understand how people make sense of the world and the life events that they encounter, and is, therefore, concerned with the richness of experience rather than making inferences about cause and effect (Willig, 2001). Qualitative researchers acknowledge that the researcher plays a part in the construction of meaning throughout the research process and aim to exercise reflexivity about their own values and existing theory to address this (Willig, 2001; Elliot, Fischer, & Rennie, 1999). A qualitative methodology was deemed most appropriate for the current study as it would allow parents to reflect on their experiences.

Interpretative Phenomenological Analysis

IPA is a qualitative approach used to explore how people make sense of their life experiences (Smith, Flowers, & Larkin, 2009). IPA is conducted in a manner that allows experience to be expressed in participant's own terms, rather than according to predefined categories (Smith et al., 2009). IPA has its theoretical roots within phenomenology: the study of experience, humanity, values, and context (Smith et al., 2009). IPA is interpretative because it is shaped by the participant as well as the values and beliefs of the researcher; the researcher uses these values and beliefs to make sense of the experience of participants (Smith, 1996; Smith, 2003). IPA is an idiographic approach, it is

interested in seeing people within their contexts, and explores specific cases rather than generalising findings to a population. It is concerned with understanding detail and depth of experience in particular contexts for particular people (Smith et al., 2009).

Rationale for using IPA. Alternative qualitative methods were considered prior to selecting IPA. Thematic analysis (Braun & Clark, 2006) could have resulted in several themes that may have elucidated the adjustment experience of parents. Narrative analysis could have provided an opportunity for parents' stories of their adjustment to emerge (Crossley, 2000). Grounded theory (Glaser & Strauss, 1967) could have been used to ascertain the factors that influence parental adjustment. Whilst these methods may have been appropriate, IPA was selected given its focus on how specific cases make sense of their lived experience. IPA would enable a better understanding of how parents of children with pABI make sense of their experiences of adjustment following the brain injury. IPA would also allow flexibility for parents to describe the process of adjustment over time rather than at specific time points.

Analysis Process

Smith and colleagues' (2009) guidelines for conducting IPA were followed²⁹. The researcher exercised reflexivity throughout the research process, being mindful of personal beliefs, values and preconceptions. The researcher utilised a reflective diary³⁰ throughout data collection and analyses to acknowledge the researcher's subjective position. The cases were analysed by the researcher. Two clinical psychologists familiar in using IPA also analysed a

²⁹ See Appendix T: IPA Procedure (Smith et al., 2009)

³⁰ See Appendix U: Excerpts from Reflective Diary

transcript to ensure methodological rigour and enable discussions regarding emergent themes³¹.

Results

The results are the researcher's interpretation of the sense that participants made of their experiences of adjustment following their child's pABI. Idiographic excerpts from the interviews will be used to capture the themes. Five superordinate themes, influenced by the research aims of the study, were used to organise the experiences of parents of children with pABI; themes within each of the superordinate themes were identified. The number of participants who experienced each theme is presented in Table 5.³²

Table 5

Table of Key Themes

Superordinate themes	Emerging themes	No. of Parents
1.Lives changed forever	Old life versus new life	6
	A changed child	6
	A changed future	7
	The impact on the family system	5
2.Sense of self	Parent identity	8
	Changing stance in relation to achieving personal values	5
3.Interaction with services	Listening and empathic communication	6
	Information for schools	5
4.Psychological experiences	The immediate aftermath	9
	Psychological experiences over time	9
5.Coping and adjustment	Finding belonging, empathy and understanding through others	7
	Defence mechanisms	5
	Personal characteristics and resilience	5
	A changed perspective	7

³¹ See Appendix V: Example of Transcript Coding

³² See Appendix W: Analysis of Emergent Themes according to Two Groups: parents of children with gradual onset pABI and parents of children with acute onset pABI

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One of the aims of the research was to explore the role of social support in parent's adjustment processes; whilst parents reflected on the importance of finding belonging, empathy, and understanding, the importance of social support did not feature largely in the parents' responses. As such it has not been included as a superordinate theme.

1. Lives Changed Forever

1.1 Old life versus new life. Participants discussed pABI as representing a significant change in their lives. They spoke of the normality that encapsulated their lives before pABI, considering themselves to be normal families with a sense of routine and knowing what to expect from their daily lives. Participants often reminisced about their old lives in a somewhat idealised manner, identifying their home-life, work-life and social-life as fulfilling and seemingly care-free. Participants recognised a distinct and permanent change in their lives, a change that represented pain and loss. The stage at which parents realised and accepted the permanence of the changes to their lives varied across participants.

“So naively you think that everything will go and be back to normal. And nobody really tells you that there's a very high chance it won't be, almost a certainty it won't be and so you carry on the journey. In the end you start thinking that things won't ever be the same again, but nobody ever tells you that at the start”

P.3. Male, 53, 3 years since ABI

1.2 A changed child. Many of the participants reflected on their experiences of their changed child, in terms of their cognitive, motor, social and emotional abilities; though for some participants the changes were more apparent than for others. Some of the parents had been able to assimilate the child before and after the ABI in terms of their personality, attributes and interests. For the majority, however, the ABI led to significant changes; one participant described how they struggled to recognise their own child:

“You can’t even put it into words...³³ within a month he’s just a completely different lad – hair changed colour, everything, overnight. You, sort of, look at him, and it didn’t even compute to who was there...you are sitting looking at a lad and you are thinking, is it (child’s name)? Is that (child’s name)?”

P. 6-7. Male, 48, 5 years since ABI

Some of the parents talked about the emotional and social difficulties experienced by their child, and a sense of disparity between them and their peers. Many of the participants described their experiences of loss throughout the journey of their child’s brain injury; for the child that they knew, for their child’s potential, and for their child’s missed experiences. Participants reflected on the sense of “blossoming” potential and anticipation that they held for their child’s future prior to the brain injury.

“I remember absolutely so clearly...I thought, “My young man is just blossoming into a really, lovely young man”. And I could see, the absolute exuberance of being a teenager on his face and I was excited for him...I felt it with him”

P. 4. Female, 50, 3 years since ABI

1.3 A changed future. Participants discussed their child’s dependence on them as something that would not change with time, altering the future they had imagined for themselves and their child.

“But, you know, he’s 18 now. Not that I’m saying he would have moved out at 18 anyway, because he probably wouldn’t, but children leave home eventually. He’s not going anywhere”

P. 9. Female, 33, 5 years since ABI

³³ Omissions in the transcript as denoted as “...”

1.4 The impact on the family system. Many of the parents discussed the ways in which the ABI had impacted both on individual family members but also on the way in which the family system operated, as systemic theorists might expect with any significant change in the family. During the initial phase following the pABI, many of the parents stayed with the child in hospital, sometimes this was for a significant period of time. One of the participants described the challenges of taking on his wife's role whilst she spent a year in hospital with their son:

“The hardest thing was taking on (wife's name) role. Because I'd always been Dad, I'd never been Dad and Mum. And that was the difficult bit that I found so hard. I'm far from the strongest person, I'm like, what you call, emotionally weak [laughter] and I don't hold out that well. I'm half empty and (wife's name) is half full. And it works well together, but it doesn't work well on its own.”

P. 4, Male, 48, 5 years since ABI

Those with additional children in their family described the challenges of making time for siblings whilst trying to meet the increased needs of their brain injured child. Parents recognised how unfair it was that they were not as available for the siblings, and discussed the attempts that they made to reconcile this and limit the impact of the pABI on them.

“It does seem to be (child's name) is on the pedestal and everything goes around (child's name). To a certain extent, it does go like that; you just try not to advertise the fact and just deal with it as best you can.”

P. 5, Male, 48, 5 years since ABI

Some of the parents were mindful that as a consequence of the neurological changes in the brain injured child, siblings often had to deal with difficult behaviours. Parents perceived the siblings as becoming more responsible, and neglecting their own needs. Some of the participants reflected on the changes

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that occurred within the relationship between parents, as parents employed different coping strategies to manage their distress that, in some cases, did not complement one another. Despite these challenges, however, some participants reflected on how they pulled together as a family and perceived their family as stronger as a consequence.

2. Sense of Self

2.1 Parent identity. Many of the participants discussed the challenges that the pABI raised for their sense of self, particularly their parental identity. Participants talked about their experiences of intuition and holding alternative views to medical staff on their child's prognosis and the best course of action. Parents described that doing the best for their child was not merely a job like it is for health professionals, but an intrinsic part of who they are. Many experienced their identity as a parent of the child as being neglected by services. Parents experienced challenges to their identity, such as no longer being the sole decision maker for their child, but now being part of a group of people who have responsibility in making decisions for their child.

“I'm used to it now, absolutely used to it now, there were 12-13 people in the room yesterday all talking about your child, your child's future... (Son's name) isn't just mine anymore, he's quite a few people's property at the moment, there's a lot of few stakeholders in this.”

P. 11, Female, 50, 3 years since ABI

2.2 Changing stance in relation to achieving personal values. For some of the parents, the pABI had a substantial impact on their capacity to engage in anything outside of meeting the needs of their child. Parents took lengthy periods of time off work, amended their working hours, or gave up their jobs in order to do this. One of the participants described how they had planned to “*explore new avenues in work*” which was no longer feasible, and another left

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a university course prior to completion. During the initial phase following the pABI, parents described not questioning the need to prioritise their child's health, even though this was at the expense of pursuing other things that were important to them. However, their stance in relation to achieving other goals and values changed with time. One parent described the emotional process of this realisation in terms of their career potential.

“I did feel loss. So, my overriding feelings with regards to (child's name), apart from the despair and plight of this diagnosis was the lost potential for (child's name) for me was devastating. But I went through that for my own potential as well.”

P. 6. Female, 50, 3 years since ABI

3. Interaction with Services

3.1 Listening and empathic communication. Participants expressed the importance of being listened to and empathised with, particularly by professionals. Whilst some of the participants described positive experiences of being involved in discussions, and having empathy shown to them, many encountered experiences where they had not felt heard. Participants recalled interactions with health care professionals as too clinical, insensitive, and, on occasion, even harsh. This was particularly scarring for some of the parents who described holding onto every word of the health care team.

3.2 Information for schools. Some parents described positive relationships with schools; they valued clear communication, were appreciative of specialist equipment and resources provided to meet their child's needs, and the supportive visits from staff whilst in hospital. However, many parents described a more difficult relationship with school that added to their burden. Parents described how the lack of education about pABI in schools increased the possibility of their child's behavioural and cognitive presentation being wrongly

attributed. Parents discussed the importance of schools receiving specialist information regarding pABI; one parent described how she developed a fact sheet to assist schools with this, and another described the benefits of a neuropsychological report in aiding their understanding.

4. The Psychological Experience

4.1 The immediate aftermath. The participants described their psychological experiences during the early stages following the pABI. Parents described their experiences of shock and the inability to comprehend what was happening to their child who appeared incredibly vulnerable. The early days were devastating for the parents, who in many of the cases were faced with the possibility that their child may not survive.

“It was just the lack of the... It was the fear of the unknown, I suppose. It was like you want all the information and they couldn’t give us any. So it was devastating, to be quite honest. And then obviously you think is she going to die, what’s going to happen, is it cancer, that sort of thing. It was a shock and devastating.”

P. 3. Female, 32, 1 year since ABI

Parents described how little they understood about what was happening to their child, and told of their experiences of trying to make sense of the all-encompassing horror that was before them. Some described physical manifestations of their internal conflict such as falling to the floor and as though they were unable to breathe. Some parents described how traumatic it had been to witness the event leading to their child’s pABI, or the scenes immediately following it, and described experiencing visual flashbacks as a consequence.

4.2. Psychological experiences over time. As time passed, parents described a process of realisation of what had happened to their child. Some of the parents described how they had grappled with the question of why it had

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happened, harbouring feelings of anger and a sense of injustice. Many of the parents described their experiences of anxiety, panic and post-traumatic stress symptomatology. Participants identified anxiety for their child's future, particularly for those children who were more dependent on their parents. For parents of children with a brain tumour, the experience of threat deriving from the possible return or growth of the tumour still loomed over them. Several parents described feelings of loss, heartbreak and "brokenness". Coupled with their experiences of depression, participants described a sense of loneliness and isolation.

"(Child's name) can't do contact sport and they are doing rugby. And I was sitting up in the yard and all I could hear is kids running in with their rugby boots on, and I just sat on the bench and I cried because I knew (child's name) was in the class... my heart breaks for him knowing that he can't do these things."

P. 6-7, Female, 41, 3 years since ABI

5. Coping and Adjustment

5.1 Finding belonging, empathy and understanding. The majority of the participants talked about their experiences of finding a sense of belonging as a result of their interactions with people who understood and were able to empathise with what they were going through. For some of the participants this was with family, though for others it was connecting with families who had gone through or were going through similar experiences.

"It was good being part of a big family in the place we were staying...And, and everyone was in it together and that was good"

P. 3. Male, 53, 3 years since ABI

Whilst some participants described the benefits of being able to meet with other families during the treatment and rehabilitative process, or through connections made using online social forums, one parent described how there

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was still huge variation in the experiences of each child, which distinguished their experience from other families.

“Everybody’s child is different, no story is the same.”

P. 10, Female, 50, 3 years since ABI

There were mixed feelings about the value of online support groups; some found that it was a useful space to be honest and open with those who understood, while others found them to be quite depressing particularly as time moved on and their needs changed. Whilst some of the participants described supportive friendships, in the large part participants described relationships with those in existing social groups as becoming increasingly distant, either due to practical constraints associated with the pABI or because of fears about over-burdening friends.

5.2 Psychological defence mechanisms. Many of the participants described blocking out their feelings and putting up a “barrier” to be able to remove themselves from their emotional experiences to function in their role. Some parents described how they tried to suppress thoughts about their old life, and yet it was sometimes impossible not to. Many of the parents who described coping using these defence mechanisms also acknowledged the possible lack of utility in these strategies.

“And maybe I’ve just put it behind another door and it’s locked away and hopefully it won’t open again. And that’s how I deal with things. Whether it’s right or not, I don’t know.”

P. 8, Male, 48, 5 years since ABI

5.3 Personal characteristics and resilience. Some of the parents considered the role of their own personal characteristics and sense of resilience

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and were able to elaborate on how this assisted their ability to cope. Participants discussed their sense of their own character as being positive, strong willed, resilient, stubborn and forthright. Some of the parents described cognitive strengths such as their ability to rationalise, be logical or to problem solve. Two of the participants discussed how their occupational training as a social worker and policeman had given them the experience of dealing with very difficult situations that had aided their adjustment.

5.4 A changed perspective. Some of the participants reflected on the way that they had been able make sense of their experiences in giving them a changed perspective for the future. Parents discussed how their experiences had enabled them to re-evaluate their priorities, made them a “better person” and helped them to embrace uncertainty.

“So ironic as it might sound, I think in some ways it’s made me a better person because it’s made me step back and see... you know, it doesn’t matter if I’m not highflying in my job because... I mean, I was looking for promotion, I was looking for... I don’t do those types of things no more because they are not important”

P. 10. Female, 48, 7 years since ABI

Parent’s experiences often led to feel a greater bond with their family, and had enabled them to witness the strength of character and resilience of their child. For some parents, they felt as though they had been given a second chance, and they embraced a renewed sense of how precious life was. Many of the parents valued the opportunity to share their experiences to support other families, increase the public’s awareness of pABI, and contribute to research.

Discussion

The discussion will comment on the emergent themes identified using IPA, considering the relevance of the existing theoretical and research base relating to participants' accounts of their experiences.

The Psychological Experience

Participants described their shock and devastation during the initial crisis phase. Their early experiences were full of uncertainty, often with little knowledge of what the diagnosis entailed, what the impact of the brain injury would be and whether their child would survive. The impact of shock on parents' ability to comprehend information following diagnosis has been observed in the literature (Shiminski-Maher, 1994). Several studies have reported on the clinically significant levels of distress in parents of children with pABI (Bennett et al., 2013; Hawley et al., Fuemmeler et al, 2001; Sokol et al., 1996), particularly during the acute treatment phase (Hutchinson et al., 2009; Freeman et al., 2004). As parents gained clarity over their situation, some parents shared their feelings of anger and a sense of injustice at the diagnosis, reactions reported as common in the immediate aftermath of TBI (DePompei, Zarski, & Hall, 1988).

Many participants reported experiences of anxiety, the source of which evolved over time. Exclusive to the parents of children with brain tumour diagnoses was the ongoing anxiety that many of the participants experienced regarding the threat of the tumour returning, similarly, a common source of threat experienced by parents in the study by Anclair and colleagues (Anclair, Hovén, Lannering, & Boman, 2009). Some parents described the experience of traumatic visual memories that were associated with witnessing the traumatic event, and

the shocking scenes in the hospital that followed, as in Lindahl Norberg & Steneby's study (2009).

Grief and Loss

Parents described great disparity between the expectations held for their child's future, and their present reality. Parents referred to the potential encapsulated within their child before the brain injury, and their realisation of this loss. In considering the future, they indicated that their child would no longer be leaving the family home and seeking independence as they may have previously hoped for, and as might be expected with the family life cycle model offered by Carter and McGoldrick (1988). The model describes distinct stages through which families progress, including the launching and moving on of children. When expected transitions do not occur or appear compromised then the model purports that a loss and grief reaction may follow.

Parents not only described their feelings of loss in connection to the changed child and of the imagined future, but also for the loss of their "old life" and their own potential. Lezak (1986) presented a bereavement model to conceptualise the experiences of adjustment, grief and loss that follow pABI, where families experience a process of adaptation to their loss. Rape and colleagues (Rape, Bush, & Slavin, 1992) proposed the experience of 'mourning' by families to be a commonly reported stage in their critique of family adjustment models. Whilst participants in the present study described their emotional responses to their experiences, the process by which parents moved through these emotional experiences was neither predictable nor linear, a finding noted by Power & Dell Orto (1981). The findings support a more dynamic model such as Williams & Kay's (1991) 'episodic loss reaction' framework for understanding

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the adjustment experience of families, which considers the interaction between the experiences of loss, daily stressors experienced and the need for families to keep functioning.

Systemic Change

Participants recognised how the pABI had impacted upon various family members and on the family system as a whole, an experience noted by Minuchin and colleagues (Minuchin et al., 1975). In accordance with the previous research, some of the participants now perceived their families as stronger (Clark et al., 2008). Participants, however, also discussed the strain placed on the family from absent members during the crisis phase, and the impact of the ABI on their ability to meet the needs of siblings, an experience well-documented in previous research (Lindahl Norberg & Steneby, 2009; Sambucco, Brookes, & Lah, 2008; Brown et al., 2013; Gill & Wells, 2000; Rivara et al., 1992). Participants also discussed tension in the relationships between parents as a consequence of differing coping strategies, a finding similarly reported by Brown and colleagues (2013).

Identity and Sense of Self

Participants described being consumed by their parenting role in the initial aftermath of the pABI. Their other identities, such as their working identity, or interests outside of the family ceased as their focus became their unwell child. John Rolland, explained this pattern in families of children with chronic illness who can “exert a centripetal pull on a family system” (Rolland, 1987. P. 10), refocusing a family inwardly, leading to interests outside of the family being given up.

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The pABI had challenged the parent's sense of who they were. Features of their parental identity, such as being the decision-maker for their child, were challenged by healthcare professionals who alongside the parents sought to influence decisions according to their knowledge and expertise. Parents differentiated themselves from professionals whose involvement with their child was not built on the foundations of knowing the child before the brain injury.

Coping and Adjustment

Participants described various ways in which they were able to cope with their distressing experiences. Parents described the use of psychological defence mechanisms such as blocking out feelings, which enabled them to sustain their role as parent. A psychodynamic approach has been used to understand the experiences of denial in parents of children with pABI (Romano, 1972; Perlesz, Kinsella, & Crowe, 1999). The theory suggests that defence mechanisms enable the opportunity to filter levels of distress at a tolerable pace, allowing parents to continue to function and meet the demands of their daily lives, thus serving a beneficial function.

Participants described the support received from those who were able to empathise with their experiences. They found a particular sense of belonging with understanding friends and parents who had been through, or were going through, a similar experience. Many of the participants, however, described difficulties in maintaining social relationships with those in existing social groups, for practical and psychological reasons. Consequently, social support was not a consistent facilitator of coping amongst the participants in this study. This is an interesting finding given the benefits of social support that have been presented within the

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pABI and wider coping literature (Wade et al., 2004; Freeman et al., 2004; Schwarzer & Leppin, 1991).

The results of the study, therefore, do not confirm the model of caregiver distress proffered by Pearlin and colleagues (Pearlin et al., 1990) in terms of the mediating effect of social support on stress. Research has suggested that social isolation and withdrawal from social contact is a common experience for the relatives of those with TBI (Tyerman, 2010; Kozloff, 1987). It may be that experiences of isolation from support networks account for social support not being utilised consistently by the participants, rather than social support as being ineffectual in their coping and adjustment processes.

Coping models, particularly Lazarus and Folkman's stress and coping model (1984) emphasise the role of the individual in managing stressful situations. Two distinct forms of coping are distinguished: problem-focussed and emotion-focussed coping. Parents described drawing on their personal characteristics, resiliencies and strengths to aid their coping using both problem-focussed and emotion-focussed coping. Some of the parents reflected on differences in the coping strategies employed by themselves and their partners.

Parents were able to reflect on the ways in which the experience had assisted them to re-evaluate their priorities, notice strengths and gain a sense of closeness with their family, which allowed them to embrace a renewed sense of how precious life is. Many of the parents valued sharing their experiences, supporting other families, increasing the public's awareness of pABI, and contributing to research. Studies investigating positive experiences following brain injury, such as post traumatic growth have emerged more recently (McGrath & Linley, 2006).

Strengths and Limitations of the Current Study

Methodology and design. IPA was chosen to explore the aims of this study as it enabled the emergence of themes that may not have been considered in the existing literature base. It also allowed the researcher to maintain proximity to the experiences of participants and to construct themes based on the idiographic content of participants. The inclusion of participant quotes demonstrates transparency (Meyrick, 2006; Yardley, 2000) and enables the reader to generate new interpretations based on their sense of the data (Elliot, Fischer, & Rennie, 1999). The study design was presented clearly, however the variance in how the data were collected may be considered as a flaw in the study design. There may have been several differences in participant's openness in reflecting on their experiences depending on whether the interview was conducted face-to-face or over the telephone. Additionally, the researcher may have missed non-verbal communication relevant for the interpretation of the data during telephone interviews, which may have been present face-to-face.

Recruitment. Participants were selected purposively, across a variety of settings. Three of the participants were recruited through a charity website commonly used by family members of people with pABI to access emotional support. The sample may, therefore, contain bias as these families may have been more likely to be experiencing difficulties or more likely to be in receipt of social support. Ten participants were included in the study, which is a sufficient number to enable an in-depth exploration of this area whilst maintaining a manageable data set (Smith et al., 1999). Of the ten participants, only two were males. Additionally, the length of time since diagnosis ranged significantly between participants, as did the nature of onset in terms of acute onset (i.e. road

traffic accident) and gradual onset (i.e. medulloblastoma), and the severity of the child's pABI. This may have impacted on the homogeneity of the sample.

Results and analysis. IPA relies on participants' ability to reflect on their own lives (Willig, 2008), which for some participants was difficult. Thematic analysis may therefore have been a more suitable qualitative methodology given this limitation as there is less reliance on participants' ability to reflect in this way. Additionally, IPA relies on the researcher's competence at making sense of the participants' accounts of their experience. Given the novice status of the researcher, thematic analysis may have been a more appropriate methodology to pursue given the accessibility of the approach, and its inherent ability to report similarities and differences and unanticipated insights from the data.

Rigour and commitment. A position of reflexivity was undertaken during the research process (Willig, 2008) assisting the researcher's reflection on personal beliefs, values and preconceptions. The analysis process involved two clinical psychologists with experience of using IPA, which supplemented the analysis of the researcher, ensuring methodological rigour. The researcher used their clinical skills to facilitate engagement and openness with participants, in person and over the telephone. Triangulation of the data occurred with the researcher offering a summary of the study findings to the participants, and inviting feedback. This helped to ensure the validity of the data.

Clinical Implications

The study findings support previous research that describe the significant psychological and emotional impact that pABI has on parents. This adds more support to the need for psychological assessment, formulation, and intervention to be available to parents during the initial aftermath of the pABI, and following

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discharge from hospital, to enable them to manage difficult emotional and psychological experiences. Given the impact of pABI on the wider family, there is a need for psychological interventions available for use with the whole family. Parents in the study discussed the role of personal resilience and problem solving as facilitating their coping; it may therefore be important to integrate these cognitive elements into a comprehensive intervention for parents and their families.

Parents discussed the sense of belonging and support gained from meeting with parents who were going through similar experiences. The study has indicated that the provision of support groups, and the facilitation of informal events, where parents can meet with those who are in a similar stage following the pABI, may aid parent's adjustment and coping.

The study detailed the lack of public knowledge and awareness of pABI. The development of information sheets that detail common symptoms, and corresponding management strategies, following pABI, would be useful for parents to disseminate, particularly to schools.

A novel finding in the study is the experience of post-traumatic growth that participants reflected on; this is particularly interesting and could be used by clinicians to consider applying positive psychology models, such as the organismic valuing theory of growth following adversity (OVP) model presented by Joseph and Linley (2005), to their work with parents. This may also be an interesting area to explore in future research.

Conclusion

The current study investigated parental experiences of adjustment and social support following pABI. Parents described the varying ways in which they

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had been able to adjust to the psychological challenges presented to them by the pABI. The findings suggested that psychological defence mechanisms, personal resilience and characteristics, cognitive strategies, and support from others all played a role in facilitating the adjustment of parents. However, social support was not a consistent facilitator of coping amongst the participants in this study. This remains an interesting finding given the benefits of social support that have been presented within the pABI and wider coping literature. The study reported on parents' experiences of post-traumatic growth, which is a further interesting and novel findings.

Future investigations should explore the experiences of fathers and siblings given their poor representation currently within the pABI literature. Additional studies are also needed to explore the positive experiences of parents following pABI, particularly given the bias in the literature towards reporting negative emotions associated with caregiving (Tyerman, 2010).

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Appendices

Appendix F: Participant Information Sheet

PARENT/GUARDIAN INFORMATION SHEET

The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support.

Researcher: Sian Hocking

My name is Sian Hocking and I'm completing a PhD in Clinical Psychology. As part of my PhD I'm conducting a piece of research exploring the adjustment of siblings and parents of children with an acquired brain injury (ABI). ABI is a term used to describe damage that occurs in the brain after birth; it includes both traumatic brain injury, resulting from external force, and non-traumatic brain injury such as stroke, brain tumour, meningitis and so on. The research study will be focussing on the sibling's and parent's experience of adjusting to the changes that follow the brain injury. The researcher is not being paid to conduct this study.

I would like to invite your child to take part in this study as your child has a sibling with an acquired brain injury and is between 13 and 17 years of age. I would also like you to consider whether you would like to take part in an interview. In total, we are looking for 12-15 participants for this study.

If you and your child choose to take part in the study, you will be asked to meet with me for 45-90 minutes, and answer some questions about their experiences of adjustment and social support following the brain injury.

Using this information, we hope to learn more about what helps family members to adjust to their child or sibling having an acquired brain injury, and to discover more about the role of social support in this adjustment.

Does my child/ Do I have to take part in this study?

It is both you and your child's choice whether they would like to be part of this study. If it would be useful, elements of this information sheet can be explained more fully. If your child would like to take part I will ask you to sign a consent form to show that you have agreed for your child to take part. I will also ask for your child to complete an assent form, indicating that they have agreed to take part in the study. Likewise, if you would like to participate, I will ask you to complete a consent form indicating this. You and your child are free to withdraw from the study at any time up until September 2015, when it is anticipated that the study will be submitted for publication. A reason does not have to be given for wanting to withdraw from the study.

What will happen if my child takes part / I take part in this study?

If you and your child wish to take part in the study, then we will ask you to complete a consent for agreeing to their/ your participation in the research, and for your child to complete an assent form, agreeing that they would like to take part. I will then meet with you/your child for 45-90 minutes to carry out an interview, where questions about your/their experiences of adjusting to your child's/ your child's sibling's brain injury will be asked. The interview will also ask questions about the role of social relationships in this adjustment. The

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interview will be conducted in a setting which is convenient and comfortable for you or your child, but ensures safety, confidentiality and is free from interruptions; this may be in your own home or in a room in a local charity or hospital setting. Any travel or parking costs will be reimbursed by the researcher. The interview will be audio recorded so I can transcribe participant's responses after.

What are the advantages and disadvantages of taking part in the study?

The major advantage is that you and your child will help us to better understand the experience of being a family member of a child with an acquired brain injury. We hope this will lead to professionals knowing more about how they can support family members in the rehabilitative process. Taking part in this study will take approximately 45-90 minutes which could be considered a disadvantage.

Are there any risks in taking part in the study?

Given the nature of the study some of the topics that may be discussed during the interview, it may prove to be emotionally distressing for you and your child. The interview will be carried out in a sensitive and supportive way, and I will gain support from my supervisors to manage this carefully. I will be contacting your and your child's GP prior to participation in the study to inform them of your/ their involvement in case there is a need to provide additional support after the interview.

Will I find out what happens after my child has taken/ I have taken part?

At the end of this research we will produce a report and a leaflet summarising the results. You will be sent a copy of the leaflet so that you know the outcome of the research; more detailed information will be available on request. This information will also be provided in a way that is accessible for your child.

The results will be submitted to journals and presented at conferences and meetings. Your name and your child's name will not be included on any research outputs, and all data will be presented anonymously.

Will the information be kept confidential?

We will follow ethical and legal practice and all information about you and your child will be handled in confidence. The only time we may break confidentiality would be if we were concerned about your child's or someone else's safety. In this event, where possible, we would inform you and your child first.

Who has reviewed the study?

To protect your interests, before any research starts it needs to be checked that it is fair. This study has been reviewed by the Local NHS ethics committee.

What to do if you would like my son or daughter to take part?

Enclosed is a consent form to share contact details for you to complete if you would like to take part in the study. You need to fill in the form, initial all the boxes, sign and send it back to us using the Freepost envelope provided or give it to the clinician who alerted you about our study. We will then telephone you to arrange

Parental Adjustment in Paediatric Acquired Brain Injury

the first meeting. We can only contact you if you return the consent to share your contact details form to us.

What if I have concerns or want to complain about the way I or my child has been treated?

If you or your child have any concerns or wish to complain about the way that you or your child has been treated while participating in this study, you can do so by contacting Dr Phil Yates or Dr Anna Adlam who are supervising this project.

Dr Phil Yates

Tel: 01392 724635

E-mail: P.J.Yates@exeter.ac.uk

Dr Anna Adlam

Tel: 01392 722209

Email: A.R.Adlam@exeter.ac.uk

Please feel free to ask me if there is anything that is not clear or if you would like more information about participating in this study.

Tel: 07894519490

E-mail: seh219@exeter.ac.uk

Thank you for your time

Appendix G: Consent to Share Contact Details Form

PARENT/GUARDIAN CONSENT TO SHARE CONTACT DETAILS

The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support.

Researcher: Sian Hocking

**Please initial
boxes**

1. I have received information about the above study.
2. I agree to be contacted by the research team about the above study.
3. I understand that my contact details will be kept confidential and will not be shared outside of the research team.
4. I understand that I am under no obligation to take part in this study.

Please include your contact details below and return in the SAE provided.

Address:

Contact Tel:

E-mail:

Name of Parent/Guardian:

Date:

Signature:

Appendix H: Study Poster

VOLUNTEERS NEEDED

The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support (Researcher: Sian Hocking)

What is the study about?

When a child has an acquired brain injury, it can have a significant impact on their family, practically and emotionally. This research aims to investigate the experiences of siblings and parents of children with an acquired brain injury. The research will explore the adjustment of family members, and whether social support has been able to facilitate adjustment to the many changes brain injury within the family brings.

What will the study involve?

The study involves taking part in an interview, which should last between 1 and 1.5 hours, where several questions about the sibling or parent's adjustment, social groups and life post- brain injury will be asked. The interview will be facilitated by Sian Hocking, a Trainee Clinical Psychologist from the University of Exeter and will be supervised by Dr Phil Yates (Consultant Clinical Psychologist) and Dr Anna Adlam (Senior Lecturer and Clinical Psychologist).

Who can take part?

To take part in this study you must be a parent of a child with acquired brain injury or a sibling of a child with an acquired brain injury and be between 13 and 17 years of age. We are hoping to recruit participants who live in the South West of England or Wales.

How do I find out more?

If you are interested in taking part in the study you can discuss it with **Sian Hocking**, contact seh219@exeter.ac.uk or **07894519490**.

Centre for Clinical Neuropsychology Research

Get involved in the family members experiences of paediatric acquired brain injury study

This research will be talking to family members of children with an acquired brain injury about their experiences of adjustment and social support following the brain injury. The research will be carried out by Sian Hocking who is completing a Doctorate in Clinical Psychology with the University of Exeter. Sian will be supervised by Dr Phil Yates and Dr Anna Adlam.

Parents of children with an acquired brain injury

If you, or your child who is the sibling of your brain injured child, are interested in participating in the research study, then please tick the statement which applies to you and complete the relevant sections below. If you and your child wish to participate in this study then please complete both sections 1 and 2 below.

Siblings of children with acquired brain injury, aged 13-15 years

If you are a sibling of a child with an acquired brain injury, and you are between 13 and 15 years old then you may be eligible to take part in this study. If you are interested in taking part, and your parent or guardian have agreed for you to take part, then please ask them to tick the relevant statement and enter their contact details in the appropriate section below.

Siblings of children with acquired brain injury, aged 16-17 years

If you are a sibling of a child with an acquired brain injury, and you are between 16 and 17 years old then you may be eligible to take part in this study. If you are interested in taking part, then please tick the relevant statement and enter your contact details in the appropriate section below.

What happens with my contact details?

Completing the relevant section/s will enable your contact detail to be shared with Sian directly. No information about you or your child will be shared with third parties. You will receive a response from Sian once your contact details have been received. You will only be contacted about Sian's study, which has the appropriate ethical approval. Thank you for your interest in this study.

More information about the study can be found below:

- [Summary Poster \(.pdf\)](#)
- [Parents Information Sheet \(.pdf\)](#)
- [Siblings Information Sheet \(age 13-15 years\) \(.pdf\)](#)
- [Siblings Information Sheet \(age 16-17 years\) \(.pdf\)](#)

Appendix J: Discussion regarding Recruitment Issues

Recruitment was one of the major challenges to the feasibility of this research project. The study initially aimed to explore the experiences of adjustment and social support of siblings of children with pABI, as research has suggested that both families and clinical services can neglect the experience of siblings (Perlesz, Kinsella & Crowe, 1999). However, the researcher was aware of the potential difficulties in recruiting siblings directly, given the likelihood of siblings only gaining awareness of the study through parents. In addition, the researcher was aware of the need for further research into the parental experience of adjustment and social support following pABI. The study was therefore designed to include both the experiences of siblings and parents of children with pABI. Whilst the researcher planned an extensive recruitment strategy involving recruitment from two NHS services, several brain injury charities, and via the University of Exeter CCNR website, unfortunately only one sibling was recruited. The researcher discussed this issue with the research supervisors after several months of active recruitment, and it was felt that in order to maintain the homogeneity of the sample, that the sibling data would be excluded from the current research analysis.

Appendix K: Table Summarising Main Ethical Issues

Ethical Issue	Management Strategy
Consent	All parents were given information sheets detailing the purpose of the research and the nature and duration of the procedure. An age appropriate information sheet was prepared for siblings aged 16-18, and for siblings less than 16 years old. Information was presented to the participants in an appropriate manner that facilitated comprehension and retention of information, to support them to give consent. Participants were given at least 24 hours to consider the study before being contacted by the researcher to discuss the research and to answer any questions. Informed and voluntary written consent was obtained from all parent participants. The study also planned to attain written consent from parents of children younger than 16 years who wished to take part in the study. For children younger than 16 years old, the study planned to obtain written assent. Sibling participants who were aged 16 and over were given their own written consent to take part, although parents were given information sheets for their reference.
Right to withdraw	It was made clear to participants on the information sheet that they were able to withdraw from the study at any time without giving reason. The study intended to let child participants under the age of 16 years be aware of their right to withdraw from the study even if their parents had consented for their participation in the study, though no siblings below 16 years of age were recruited. Participants were made aware that their right to withdraw from the study would not prejudice any further treatment that they might receive.
Risk of distress	The interviews were conducted with minimal risk of distress to the participants. Some of the questions elicited responses regarding psychological distress such as anxiety, depression and burden. All of the participants were asked for their consent to contact their GP prior to their involvement in the research to inform them of their participation. No personal information was shared with their GP. If the researcher had become concerned about the level of distress or risk to the participant or anyone else during the interview, the researcher planned to inform the participant that the researcher would need to discuss the issue with the research supervisors. A detailed risk assessment would have then been conducted with the participant (or parent, where participant is the sibling). If appropriate, the researcher planned to advise the participant to contact their GP or a health professional already involved in their care. If significant and urgent risk issues were identified then the researcher planned to inform the necessary agencies as appropriate.
Lone working	As the research involved interviewing participants in their own homes, the researcher followed the university and local NHS trust lone working policy. The researcher informed a trainee clinical psychologist of the location and time of the appointments, and made arrangements to report back on safe return.

Confidentiality Participants were assigned an identification code and this was stored separately from personal identifiable data. Publication of direct quotations from respondents were anonymised and are used to evidence outcomes of the analysis.

Data was coded and stored anonymously in accordance with the Data Protection Act (1998). Participant contact details were stored separately in a locked filing cabinet. Audio recordings of each interview were stored on a password protected computer, and any transfer of this information occurred using an encrypted memory stick. Data will be stored for a minimum of 5 years and a maximum of 10 years following the study ending.

Appendix L: University of Exeter Ethical Approval

4/30/2015

Your application for ethical approval (2014/626) has been a... - Hocking, Sian

Your application for ethical approval (2014/626) has been accepted

apache@exeter.ac.uk on behalf of Ethics Approval System

D.M.Salway@exeter.ac.uk

Tue 8/12/2014 12:45 PM

Research Project

To: Hocking, Sian <seh219@exeter.ac.uk>;

Ethical Approval system

Your application (2014/626) entitled The psychological adjustment of family members of children with ABI has been accepted

Please visit <http://www.exeter.ac.uk/staff/ethicalapproval/>

Please click on the link above and select the relevant application from the list.

<https://outlook.office365.com/owa/projection.aspx>

Appendix M: NHS REC letter of ethical approval



NRES Committee South West - Exeter

Whitefriars
Level 3
Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1332
Fax: 0117 342 0445

01 August 2014

Mrs Sian Elin Hocking
42 Waterloo Road
Pen-y-lan
Cardiff
CF23 9BG

Dear Mrs Hocking

Study title: The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support

REC reference: 14/SW/1004

Protocol number: 1

IRAS project ID: 149803

Thank you for your letter of 30 July 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you

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wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Kirsten Peck, .

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below. The Chair has asked that you proof read your changes as a few 'typo's' have crept in.

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

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

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

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

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

Registration of Clinical Trials

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

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

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

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

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

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Research Poster]	1	01 April 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public Liability Form]	1	01 May 2014
IRAS Checklist XML [Checklist_28052014]		28 May 2014
IRAS Checklist XML [Checklist_30072014]		30 July 2014
Letter from sponsor [Sponsor Letter]	1	01 May 2014
Other [Information sheet for parents/parent participants]	1	01 April 2014
Other [GP Letter]	1	29 July 2014
Other [consent to contact participants aged 16 years]	1	01 April 2014
Other [Information sheet for participants aged 13-15 years]	1	01 April 2014
Other [Parent Information Sheet]	2	29 July 2014
Other [Consent to contact parents form]	1	01 April 2014
Other [Letter to REC Committee following provisional opinion]	1	29 July 2014
Other [Short assent form]	1	01 April 2014
Other [Participant info sheet 13-15]	2	29 July 2014
Other [Letter confirming evidence of insurance and professional indemnity]	1	01 May 2014
Other [Thesis proposal pass mark]	1	29 July 2014
Participant consent form [Participant consent form]	2	29 July 2014
Participant information sheet (PIS) [Participant Info Sheet 16-17]	2	29 July 2014
REC Application Form [REC_Form_28052014]		28 May 2014
Research protocol or project proposal [Research Protocol]	1	01 May 2014
Response to Request for Further Information		30 July 2014
Summary CV for Chief Investigator (CI) [Research Supervisor's CV]	1	01 April 2014

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Summary CV for student [Sian Hocking CV]	1	01 April 2014
Summary CV for supervisor (student research) [Phil Yates CV]	1	01 April 2014

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

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

14/SW/1004	Please quote this number on all correspondence
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With the Committee’s best wishes for the success of this project.

Yours sincerely

Kirsten Beck

Parental Adjustment in Paediatric Acquired Brain Injury

p.p. Dr Chris Vallance

Acting Chair

Email: nrescommittee.southwest-exeter@nhs.net

Enclosures: "After ethical review – guidance for
researchers" [\[SL-AR2\]](#)

Copy to: G M Seymour, University of Exeter
Ms Lynda Garcia, Royal Devon & Exeter NHS Foundation
Trust

Royal Devon and Exeter 

NHS Foundation Trust

Mrs Sian Elin Hocking
42 Waterloo Road
Pen-y-lan
Cardiff
CF23 9BG

Royal Devon and Exeter
Hospital (Wonford)
Barrack Road
Exeter
EX2 5DW

13 August 2014

Tel: 01392 411611
**RESEARCH AND DEVELOPMENT
DIRECTORATE**
Direct Dial: 01392 406933
Direct Fax: 01392 403012
Email: rde-tr.Research@nhs.net
Ref: CB/R&D/CG

Dear Sian

Study Title: The psychological adjustment of siblings and parents with acquired brain injury and the role of perceived social support

R&D No: 1505090

MREC Ref: 14/SW/1004

I have reviewed the Trust R&D file for the above named study, which has received approval from the appropriate regulatory bodies, and I am happy to give approval on behalf of the Royal Devon & Exeter NHS Foundation Trust (RD&E).

The documents approved for use in this study are those approved by ethics, these are detailed on a separate sheet.

As named Investigator for this research that is being undertaken at the RD&E, it is your responsibility to manage and conduct this study in accordance with;

- The requirements of the **Research Governance Framework for Health and Social Care (2005)** and **Medicines for Human Use (Clinical Trials) Regulations 2004** (if applicable).
- **ICH-GCP** (Good Clinical Practice) – It is mandatory for those staff who will be consenting participants into this study to have undertaken GCP and to ensure it is updated every 2 years.
- The **Human Tissue Act 2004** and the **EU Tissue and Cells Directive (2006)** for research involving human tissue.
- The **Data Protection Act 1998** which details the eight principles of 'good information handling'.
- **R&D Standard Operating Procedures (SOPs)** and **Trust policies** which are available on the Trust intranet site

As Lead Investigator for this research, you are required to ensure study specific duties are appropriately delegated and clearly documented on the study Delegation Log. This guarantees clarity of roles and must be signed and dated by each individual on the study and yourself as Lead Investigator.

Safety Reporting

Guidance on the classification of Adverse Events/Reactions (AEs/ARs) / Serious Adverse Events/Reactions (SAEs/SARs) and Suspected Unexpected Serious Adverse Reactions (SUSARs) and the requirements for reporting to the sponsor can be found in the study protocol. For RD&E sponsored studies this is also detailed in the sponsorship letter. All safety events that involve RD&E patients, that require reporting to the Sponsor, must also be reported by fax to the R&D Office within

Parental Adjustment in Paediatric Acquired Brain Injury

24 hours of becoming aware of the event, using the appropriate Trust R&D fax template which can be found on the Adverse Event Reporting pages of the R&D intranet site (<http://ian.exe.nhs.uk/welcome/directorates/research-and-development/rd-administration/adverse-event-reporting/>).

Progress Reporting

You are required to submit regular recruitment updates to the R&D Office, as well as annual progress reports to Ethics, MHRA (where applicable) and R&D. Please note that new government and Trust targets require you to have recruited your **first patient within 30 days of the date of Trust Approval** and to have recruited your target number of participants within the time frame stipulated on your SSI form (Time to Target).

Monitoring and Audit

Your study may be monitored by the Sponsor and selected for audit by the R&D Office (where RD&E is not the Sponsor) and Regulatory Authorities at any time. The team involved in conducting this research must ensure full co-operation with any requests from any of these bodies. Action may be taken to suspend research if it is found to not be conducted in accordance with the protocol and all applicable regulations.

Archiving

Upon completion of this Research an **End of Study Report** must be submitted to the Regulatory Authorities (this will be done by the CI) and a copy submitted to the R&D Office. All studies must be archived appropriately and in accordance with the applicable Law. Where RD&E is the Sponsor or where the Sponsor has delegated archiving to the Investigator team, it is your responsibility to contact the R&D Office to discuss appropriate archiving arrangements.

Any publications arising from the Research conducted at this site must be sent to the R&D Office as part of the on-going Research Governance Process.

You should be aware that the Trust accepts no responsibility for the provision of any study drug outside of Clinical Trials and specifically would not fund the continuing prescription of any therapy once the trial has concluded unless there is a written agreement.

Trust Approval is for the duration of the study, as specified in your SSI form. If you have received an Honorary Contract or Letter of Access in order to conduct the above research at this Trust, it is important that you check the termination date on these documents and if applicable contact the R&D Office to extend the document end date.

We wish you every success with your study.

Yours sincerely



Martin Cooper
Medical Director

CC: Dr Phil Yates – philyates@nhs.net

Enc: Approved Documents

Appendix O: University Hospital Bristol NHS Foundation Trust Research and Innovation Department Approval

Research and Innovation
University Hospitals Bristol NHS Foundation Trust
Education & Research Centre Level 3
Upper Maudlin Street
Bristol BS2 8AE
Tel: 0117 342 0233 Fax: 0117 342 0239

email: research@uhbristol.nhs.uk

website:
<http://www.uhbristol.nhs.uk/researchinnovation>

18/12/2014

Dear Dr Andrew Mallick

RE: The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support (R&I number: CH/2014/4631)

NHS permission has been given for the identification of participants for the above study at University Hospitals Bristol NHS Foundation Trust.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, Good Clinical Practice, and NHS Trust policies and procedures available at

http://www.uhbristol.nhs.uk/media/2097744/research_policy_final_v0_7_21_02_14.pdf

We wish you every success with this study.

Yours sincerely



Diana Benton
Head of Research and Innovation/Deputy Director of Research

**Copy to: Sian Hocking
Dr Phil Yates**

Appendix P: Participant Consent Form

CONSENT FORM

The psychological adjustment of siblings and parents of children with acquired brain injury and the role of perceived social support.

Researcher: Sian Hocking

Participant Identification Number:

Please initial **all** boxes before returning this form to the researcher in the envelope provided at you earliest convenience.

1. I confirm that I have read and understood the information sheet (version 1) which I received on _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my/my child's participation is voluntary and that I/ my child is free to withdraw at any time, up until the end of September 2015 when it is anticipated the study will be complete, without giving any reason.

3. I understand that the data I/my child provides during the study may be looked at by others involved in the research [from the Exeter University), I give permission for these individuals to review information collected about me/my child as part of this study.

4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

5. I understand that the research interview will be audio recorded on a digital recorder to enable transcription.

6. Yes, I agree to take part in the above study/ Yes, I agree for my child to take part in the above study.

Name of Participant:

Date:

Signature:

Complete if participant is under 16 years old (If applicable)

Parental Adjustment in Paediatric Acquired Brain Injury

Name of Parent/ Guardian:

Date:

Signature:

Appendix Q: Letter to GP regarding their patient's participation

GP
GP Practice
Address
Environmental Sciences

Washington Singer Laboratories
Psychology
College of Life and
University of Exeter
Exeter
EX4 4QG

DATE

Dear Dr _____,

Re. SURNAME participant, First name participant, Date of Birth participant, Address participant

I am writing to you to inform you that your patient, as detailed above, has agreed to take part in a research study which will be exploring the experiences of siblings and parents of children with acquired brain injury (ABI) with particular focus on their experiences of psychological adjustment following the brain injury. The research will involve your patient being interviewed for 60-90 minutes on their experiences as a sibling or parent of an individual with ABI. The study is being carried out as part of my doctorate of clinical psychology with the University of Exeter.

Whilst it is not anticipated that the research will cause high levels of distress for participants, it may be that thinking about, and talking about some of their experiences will raise difficult emotions for them. I will be supervised throughout the research project by Dr Anna Adlam and Dr Phil Yates who are both Clinical Psychologists to enable effective and sensitive management of this issue. However if I become aware of any risk issues whilst carrying out the research, I will, where appropriate with the patient and the patient's parent's/guardian's consent, contact you as the health care professional responsible for their health and wellbeing.

If you have any further questions or require clarification, then please do not hesitate to contact me at the address above or via my email address: seh219@exeter.ac.uk. I enclose a participant information sheet for your reference.

Yours Sincerely,

Sian Hocking
Trainee Clinical Psychologist

cc. Participant name, participant address
enc. Participant Information Sheet

Appendix R: Dissemination Statement

Prior to dissemination, all of the participants will be presented with the findings of the study to gain their feedback and to check the validity of the results and analysis. A summary report will then be issued to all participants, and participating NHS trusts and charities. A report will also be included on the University of Exeter CCNR website. The research will be presented at a research event at the University of Exeter for colleagues and other interested parties. It is planned that the study will be written-up for publication for the Neuropsychological Rehabilitation journal and opportunities to present the findings at relevant conferences and research events will be explored.

Appendix S: Semi-structured Interview Schedule

1. Can you tell me a little about you and your family?
2. Can you tell me about *your* life before the brain injury?
3. Can you tell me about *your family's* life before the brain injury?
4. Can you tell me about some of the changes in your life following the brain injury?
5. Can you tell me about some of the changes in your family' life following the brain injury?
6. Can you tell me in what ways you have adjusted to the changes?
7. Can you tell me if there are ways in which you do not feel as though you have adjusted to the changes?
8. Can you tell me about what has helped you to adjust to the changes?
9. Can you tell me about your experience of social support?
10. If you could give advice to professionals helping people who have had similar experiences to yourself, what would that be?

Appendix T: IPA Procedure (Smith et al., 2009)

IPA Procedure (Smith et al., 2009)

Stage number	Stage Title	Description
1	Reading and re-reading	Listening to audio and reading the transcript, author notes anything of interest of significance
2	Initial noting	Producing a detailed set of notes and comments on the data which are descriptive, linguistic and conceptual in nature
3	Developing emergent themes	Search for emergent themes and attempt to reduce the volume of detail yet keeping complexity of data
4	Searching for connections across themes	Drawing together themes and exploring how they relate to each other, including abstraction, subsumption and polarisation
5	Moving to the next case	Move to next transcript and repeat the process
6	Looking for patterns across cases	Measuring the recurrence across cases using a table of themes, re-label and re-configure themes.

Appendix U: Excerpts from Reflective Diary

March 2013

After meeting with my supervisor to discuss the opportunity of basing my research project on the experiences of siblings of children with ABI, I have gone away to see what the current literature says about their experiences and consider what a useful project might be. I've been able to read a chapter written by Audrey Daisley on neglected subsystems, of which siblings are described as one. It seems really interesting that the lack of sibling experiences represented in the literature might mirror the feelings of neglect that siblings may experience within the family and rehabilitative process. I feel really excited to engage with siblings, though as a parent myself, am nervous about how to engage parents in supporting this research given that the findings may be painful for them.

June 2013

I've contacted various charities who work with families of brain injured children who are willing to support the study by advertising it on their websites or in social media forums. Still wondering how I go about reaching siblings themselves who may not be using these services themselves.

November 2013

After the feasibility of my study was questioned during my research proposal mini-viva, I have decided to extend the study to explore both the experiences of parents and siblings. Whilst more is written about the experiences of parents, little is known about the trajectory of their experiences over time. I wonder whether engaging with parents will also increase the chances of being able to access siblings also.

July 2014

I attended the NHS REC ethics committee today. The general feedback was good, although certain questions made me think about issues I hadn't considered before: excluding participants where the child's diagnosis is life limiting. They also asked whether I would want to interview several members from one family, and what the issues around this might be. I found this such a helpful process.

Parental Adjustment in Paediatric Acquired Brain Injury

October 2014

Started recruiting and had a few parents email me following a post on a social media forum by a charity. Really excited to start the interviews, though nervous about what might arise. Still no sibling participants signed up.

October 2014

Thinking about my position in the research process. I'm a Welsh, white, middle-class, Christian, female and 29 years old. I live in Wales, and commute to work. I'm a wife, and a mother. I am also a daughter, and a sister. I have a close family, and several close friends. I see myself as sociable, easy to get on with and hard-working. I'm studying to be a clinical psychologist and see work as a strong part of my identity. I'm interested in social justice issues. I don't have many personal connections with pABI. One friend of the family had a brain tumour when he was young and had difficulties with his short term memory following. I've elected to have my final placement in pABI in Bristol Children's Hospital.

November 2014

A close friend has recently found out that her baby has a brain tumour, and has to go through various surgeries and cycles of chemotherapy. It feels so close to my research and I'm wondering how I might be able to be separate myself in my researcher and friend roles. Thinking about social support and how useful it may be. It's given me a renewed sense of how important it is to represent the experiences of parents accurately, and what the clinical implications of the research may be.

December 2014

I have carried out a few interviews and overwhelmed by the experiences some families have had to go through. Reflecting on being a parent myself, and the ages at which the children were diagnosed, imagining how I might feel. Parents seem so open to sharing their experiences. There's a sense in which they want to tell people about their experiences to change things for others. I'm questioning my interview style, trying to maintain ask questions in an open, non-leading way. It can be hard to be in the moment with someone, and listen to what they say, whilst also trying to monitor how questions are phrased. It seems quite hard over the telephone as there is an increased reliance on verbal communication to show you are hearing what someone is saying. I've now starting preparing parents that I may stay much quieter than I would if we were having a normal conversation just to prepare them and not to put them off.

January 2015

Parental Adjustment in Paediatric Acquired Brain Injury

Interviewed my first sibling participant; felt quite a difficult interview as they had witnessed the RTA and I was conscious that there may be many complex emotions following this. Some of my assumptions were challenged as this participant seemed to engage much more with the positive aspects of life following the brain injury rather than complaining at how things has changed their life.

March 2015

Feeling quite disappointed that I haven't been able to recruit more siblings. I'm wondering why that is. Are parents worried what the siblings might say? Do parents feel as though siblings have been through enough? Do families have any spare time to commit to research?

April 2015

I have been thinking quite a lot about the role I am playing as the researcher in trying to make sense of all of the parent's experiences. It's difficult to make sure that I am representing all of the participants as sometimes the shared by certain participants appear more poignant or were perhaps delivered using more emotion, as they are easier to remember than some of the others.

Appendix V: Example of Transcript Coding

step-Dad said to [redacted], "You alright, [redacted]? You've got a bit of a limp there". And I thought, you're right, I didn't really see it before and you kind of (pause), the doctor initially said, "have you found that you're being a bit clumsy recently" and we laughed and said he's a fifteen year old boy, of course he's clumsy! So that was another niggly little thing. We got on the train, um, and just before the tunnel, [redacted] phoned and said that they had found something on the scan, they need to see him, we're going to have to go back. So we had to, I can't remember, I cannot remember the next station but it was somewhere in France. We had to get off and get back onto another and that was going to bring us back home. We went to the local hospital, and [redacted], at least I had [redacted] with me and [redacted], but [redacted] had to drive down from the Lake District on his own and meet us at the hospital, and then it all got a bit nasty.

Symptoms noticed
Explains/ coping through 'most likely'
Holding onto incorrect assumptions

I: And what happened when it all got a bit nasty?

P: Unfortunately [redacted] had seen me, I don't know what it was, something in [redacted] voice, I got up from the chair and moved out into the passageway, um and [redacted] must have seen something, because he came straight out behind me, and when [redacted] said that they found something, I sort of, I didn't collapse but I sort of, touched the floor, and, and, [redacted] saw me, and to this day I regret that because I didn't want him to see me panic. You know, I think he saw me panic, and that's why he ultimately didn't panic because he was more worried about how we were. So obviously you're upset but you're trying not to be in front of your child. So we got the hospital, [redacted] met us there, and we got taken into the paediatric emergency bit, and basically a doctor told us that, um, there was a mass I think they said, a mass, on, sitting on his brainstem. Now, I kind of knew that wasn't good, but my partner definitely knew that wasn't good. So that was horrible because I could see his despair immediately. And [redacted] was, we all cuddled each other, and got into a big circle and had a cry, but [redacted] was really quite, um, um, oh you know, "oh ok, but it's going to be ok". He really hadn't, I don't know whether he hadn't connected to himself or what, I don't know. The first few, certainly the first few weeks, were really hard.

Panic
Protect child
Guilt
togetherness
physical expression of internal reaction

Priority is protection
Guilt, regret
Carrying memories of open, vulnerable expression of internal reaction
Protection
understanding through emotional communication

I: What was hard?

R: Because every time you look at your child you feel sorry for them. And that then makes you feel dreadful. Your child becomes the diagnosis. There's something a specific, something that needs to, something in your child that you absolutely love to bits and something in them that you absolutely hate. And, it's really, really hard. I because I found myself not actually knowing how to be around him because I didn't know how he wanted me to be around him.

sense of self diagnosis and child as 1
insecurity
attachment relationship

full of dread
child synonymous w/ diagnosis
Shift in parents child relationship
sadness
Losing child's sense of self
disconnect sense of self
internal conflict

I: Can you tell me a bit more about that?

R: All you want to do is to scoop them up and cuddle them and say everything's going to be okay. And you do that of course you do, but A. you don't know it's going to be okay so you feel a fraud and B. it's just as likely for him so say, "yeah I know Mum, I know Mum", you know sort of push you off a bit. I don't know whether, whether it was a kind of thing for him, he was dealing with his own thing, so hang on I don't need you to fix it. I don't know.

Protective mother instinct
Conflicting emotions

uncertainty in attachment

Maternal instinct
Protection, safe uncertain meeting child needs
Conflicting emotions

I: So what were some of the other changes in your life after you had got that diagnosis?

Appendix W: Analysis of Emergent Themes According to two Groups: Parents of children with Gradual Onset pABI and Parents of children with Acute Onset pABI.

Table of shared themes experienced by parents of children with gradual onset (GO) and acute onset (AO) pABI

Superordinate theme	Themes	No. of ss from GO group p	No. of ss from AO group p
1.Lives changed forever	Old life versus new life	3	3
	A changed child	2	4
	A changed future	4	3
	The impact on the family system	2	3
2.Sense of self	Parent identity	4	4
	Changing stance in relation to achieving personal values	3	2
3.Interaction with services	Listening and empathic communication	2	4
	Information for schools	3	2
4.Psychological experiences	The immediate aftermath	4	5
	Psychological experiences over time	5	4
5.Coping and adjustment	Defence mechanisms	3	2
	Personal characteristics and resilience	2	3
	Finding belonging, empathy and understanding through others	4	3
	A changed perspective	4	3

Table of key themes experienced by parents of children with gradual onset ABI

Superordinate theme	Themes	No. of participants
6. The attachment relationship	Attachment behaviours	3
	The drive to protect	5

Appendix X: Instructions for Authors

Neuropsychological Rehabilitation An International Journal

Instructions for authors

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