VOLUME I

RESEARCH COMPONENT

CHILDHOOD BRAIN INJURY:

THE FAMILY AND IMPACT ON

IDENTITY

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A thesis submitted to the

University of Birmingham

for the degree of Doctor

of Clinical Psychology

OVERVIEW

This thesis submitted for the degree of doctor of Clinical Psychology comprises of two volumes. Volume I is the research component of the thesis and consists of the literature review, empirical paper and public dissemination document. The literature review examined childhood brain injury and the family, including the impact the family (e.g. functioning) has on a child with a brain injury and vice versa. The empirical paper describes a research project examining how mothers conceptualise their child's identity following a brain injury.

Volume II is the clinical component of the thesis and consists of five clinical practice reports (CPR). The first CPR presents the case of a 13 year old girl with weight management difficulties formulated from a cognitive and systemic perspective. The second CPR describes a small-scale service-related research project, which examined the views of 12 to 18 year olds attending child and adolescent mental health services (CAMHS). The third CPR is a single case experimental design evaluating a mindfulness-based intervention with a sixty year old man with anxiety and panic attacks. The fourth CPR is a case study of a 33 year old male with risk and challenging behaviour in an inpatient setting. The final CPR is an abstract summarising a presentation of a neuropsychological case study.

ACKNOWLEDGMENTS

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VOLUME I

CHAPTER ONE

LITERATURE REVIEW

CHILDHOOD TRAUMATIC BRAIN INJURY AND THE FAMILY

Word count: 7171

ABSTRACT

This review focused on literature relating to the family and traumatic brain injury in childhood published between 1996 and 2013. AIM: The review sought to answer three questions: a) How does the family environment impact on recovery from childhood brain injury? b) How does childhood brain injury impact on the family? c) What moderates the relationship between childhood brain injury and the impact on the family? METHOD: Several databases were searched through Ovid using search terms relating to the area and 29 papers were identified. The papers were evaluated using a quality framework specifically designed for this review. RESULTS: A similar review was conducted by Wade et al. in 1995. Since this review there have been developments in terms of identifying factors that may lead to better child outcomes (e.g. parental style and parental worrying); detailing the potential impact of the brain injury on the family (e.g. financial and emotional impact); and identifying factors that may moderate the relationship between the family and childhood brain injury (e.g. time since injury and ethnicity). However the support for many of these areas comes from only one or two papers and the overall quality of the research was relatively poor, suggesting more research is needed. Several methodological limitations are highlighted including the use of self-report and retrospective measures, the lack of long term follow-up and the poor comparability of control groups. CONCLUSIONS: Although the literature suggests a range of associations between childhood brain injury and family functioning, it is difficult to draw any firm conclusions because the amount of research is limited and its quality is poor.

INTRODUCTION

A traumatic brain injury (TBI) is defined as a brain injury that occurs after birth resulting from an external force, for example a road traffic accident or fall (West, 2014). Exact incidence and prevalence figures for TBI amongst children in the UK are lacking, but it is estimated that approximately 150,000 children under fourteen attend hospital every year with a TBI (British Society of Rehabilitation Medicine, 1998). However it is suggested that these figures are likely to be an underestimate because of inaccurate recording (House of Commons Select Committee on Health, 2001). The most common causes of TBI in older children and adolescents are road traffic accidents, falls and non-accidental injuries. In younger children, being dropped is more common (Hawley, Ward, Long, Owen & Magnay, 2003) .

The impact that a brain injury can have on the child has been well documented, with long term consequences such as poorer school performance, employment difficulties, poor quality of life and increased risk of mental health difficulties (Anderson, Brown, Newitt & Hoile, 2009). It has been suggested that severity of injury is associated with impairment, with severe brain injury being associated with greater impairment and dysfunction (Anderson et al., 2001; Kinsella, Ong, Douglas, Prior & Sawyer, 1999). It is also suggested that children with inflicted injuries (brain damage due to violence by another person) have worse outcomes than children with non-inflicted injuries (Keenan, 2006).

As well as the impact on the child, research suggests that TBI impacts on the child's family, with families often experiencing a variety of emotional responses from guilt and anger to shock and denial (Wagner & Stenger, 2000). Verhaeghe, Defloor and Grypdonck (2005) reviewed literature on the psychological reactions to TBI. They summarised that the nature of

the injury, not the severity, predicts the level of stress. They suggested that the levels of stress experienced by family's warrants professional intervention and that better family coping influences better patient recovery.

Perlesz, Kinsella and Crowe (1999) also reviewed the literature in this area, with a focus on family psychosocial outcome after TBI. The studies reviewed suggested that TBI can have a negative impact on family members; however not all families are affected in this way.

These reviews mostly looked at studies where the impact of adult TBI was examined, for example, the impact on parents of adult children, spouses or children of a parent with a TBI. Although they did not specifically discuss the impact of childhood TBI some of the key themes highlighted may also apply to families where the child has had a brain injury.

Wade, Drotar, Taylor and Stancin (1995) reviewed the literature between 1975 and 1995 on the effects of paediatric TBI on the family. Their search terms related to family/parenting stress, family burden, family functioning, and parent or sibling psychological adjustment following TBI. In all they reviewed 29 papers. They summarised that severe TBI (STBI) can have an adverse impact on the functioning of the family and members of the family individually, although they used functioning in a general sense and did not elaborate on the areas affected. However, the research also suggested that many families do not experience deterioration in functioning, and in some cases the family is drawn closer together as a result of the crisis. They highlighted several factors that appear to increase families' risk of long term disruption such as poor pre-injury functioning and parental psychological disorder. Wade et al. (1995) highlighted several methodological limitations including a lack of measurement at different time points, lack of consideration of the multifaceted effect of TBI, the use of self-report measures without objective measures being used, not differentiating between generic family impact and changes that may be specific to

TBI, lack of assessment of pre-injury functioning, lack of long term follow- up and issues about the comparability of the control group. Given that this review was done over 15 years ago and there has been further research in this area conducted since then, it was felt that a review examining the more recent literature was needed.

AIM

The main aim of this review is to present and evaluate the recent research that has been conducted relating to childhood TBI and the family. The research is summarised into sections with subheadings identifying the key points. The first three sections address the main questions posed in this review:

1. How does the family environment impact on recovery from childhood brain injury?
2. How does childhood brain injury impact on the family?
3. What moderates the relationship between childhood brain injury and the impact on the family?

The review continues to summarise the needs of families with a child with a brain injury, methodological considerations, implications for clinical relevance and future research and finally limitations of the review.

SEARCH STRATEGY

Databases were searched through Ovid, including PsycINFO, MEDLINE and EMBASE for articles between 1996 and 2013. Reference lists of the identified papers were also checked for relevant papers.

Search terms were as follows (in both the title and abstracts):

1. Famil* OR Parent* OR Sibling* OR Sister* OR Brother* OR Mother* OR Father*

    AND

2. Brain injur*

    AND

3. Child* OR Paediatric OR Pediatric OR Adolescen*

Inclusion criteria

1. English articles

2. Journal articles

3. Papers published since 1996

4. The article addressed one of the three aims of the study, and provided quantitative data about the relationship between variables

5. Brain injury occurred in childhood i.e. between the ages of 0 and 16 years of age

6. Person with a brain injury was under the age of 16 years of age at the time of the study

Exclusion criteria

1. Papers relating to parental brain injury

2. Papers relating to medical intervention/treatment

3. Papers relating to intervention and assessment

4. Qualitative papers

5. Case studies and single-case studies

Rationale for exclusion criteria

Journal articles were included for this review and other formats were excluded. Papers that related to parental brain injury were excluded, as the focus of this review is child brain injury. Papers where the injury had occurred after the age of 16 years were also excluded. Given that a similar review was published in 1995 (Wade et al., 1995), only papers published after this time were included. Studies relating to medical procedures and treatment were excluded, unless the paper addressed one of the aims of the research. Those relating to psychological assessment and intervention were excluded as this was not the focus of this review. Finally qualitative papers were excluded as the majority of the research was quantitative, so it was decided that quantitative studies would be the focus of the review. The reference lists of retained papers were also hand searched for any additional references that met the inclusion criteria. The process of applying these inclusion and exclusion criteria is shown in Figure 1. The initial search yielded 588 papers, which was reduced to a final total of 29 papers for the review.

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                    │      Original search= 588           │
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                    │      Deduplicate = 281              │
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            ┌─────────────────────────────────────────────────┐
            │  Inclusion criteria 1: English articles = 280   │
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            │  Inclusion criteria 2: Journal articles =121    │
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            │  Inclusion criteria 3: Papers published since   │
            │  1996 = 100                                     │
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            ┌─────────────────────────────────────────────────┐
            │  Inclusion criteria 4: The article addressed    │
            │  one of the three aims of the study= 78         │
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            ┌─────────────────────────────────────────────────┐
            │  Inclusion criteria 5: Brain injury occurred    │
            │  in childhood e.g. between the ages of 0 and    │
            │  16 years of age =78                            │
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            │  Inclusion criteria 6: Person with a brain      │
            │  injury was under the age of 16 years of age    │
            │  at the time of the study=74                    │
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            │  Exclusion criteria 1: Papers relating to       │
            │  parental brain injury= 68                      │
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            │  Exclusion criteria 2: Papers relating to       │
            │  medical intervention/treatment = 60            │
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            │  Exclusion criteria 3: Papers relating to       │
            │  intervention and assessment=37                 │
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            │  Exclusion criteria 4: Qualitative papers = 27  │
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            │  Exclusion criteria 5: Case studies and         │
            │  single-case studies= 27                        │
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            │  Checked references for additional papers= 29   │
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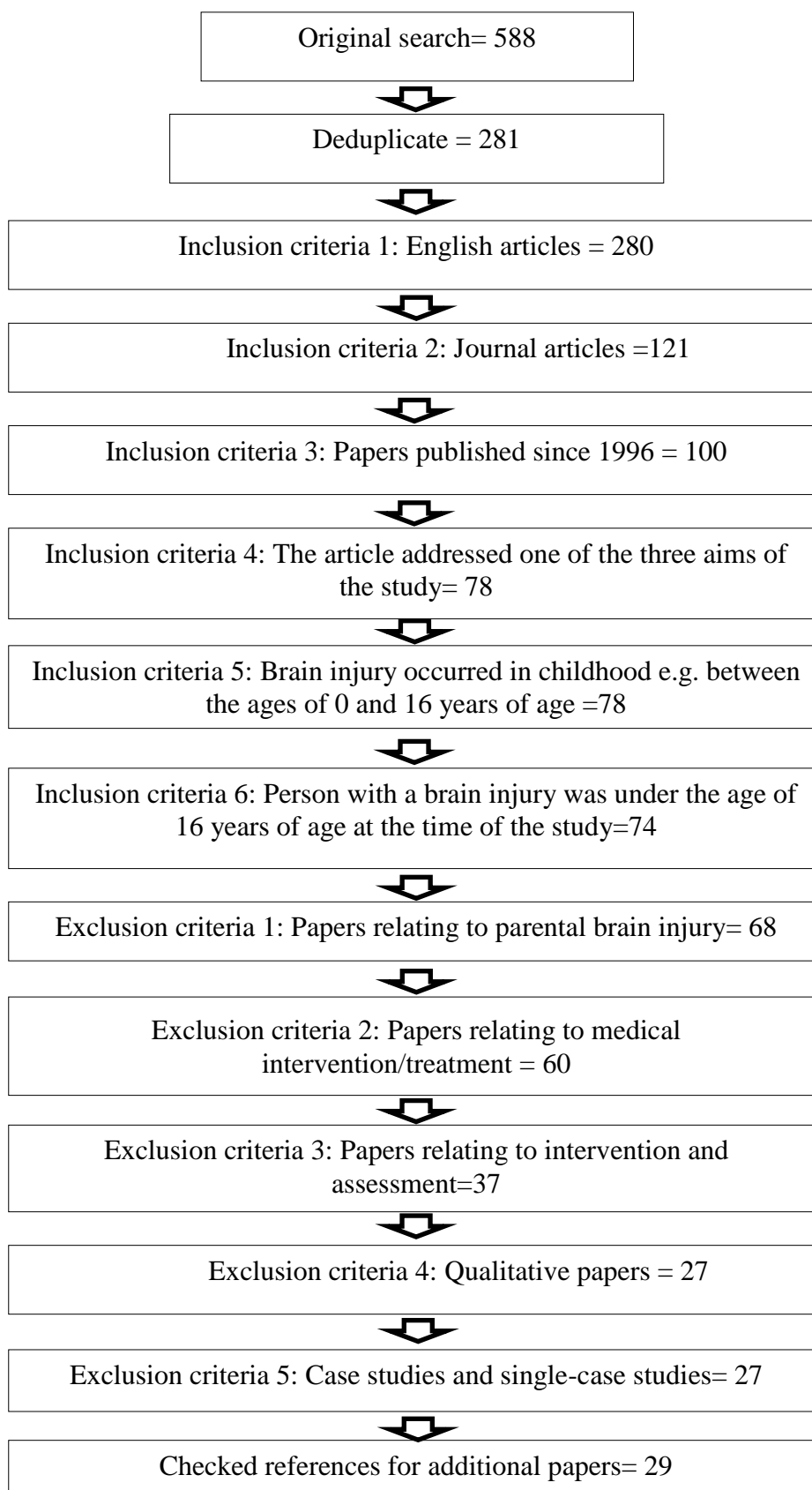
Figure 1: Process of applying inclusion and exclusion criteria

EVALUATION CRITERIA

The framework used to evaluate the quality of the papers was designed specifically for the current review and was compiled on the basis of a number of published quality frameworks (specifically, those described by Caldwell et al., 2005; CASP, 2011; Sale & Brazil, 2004; Salter, Hellings, Foley & Teasell, 2008). A framework was specifically designed for this review because many of the published frameworks, as well as including criteria relating to the validity of the conclusions drawn from the research (e.g. whether participant selection was random or not), also incorporate broader criteria that relate to the quality of the reporting of the research (e.g. whether or not it is reported that ethical approval had been given). For the purposes of this review, the focus was more on the validity of the conclusions drawn from the research and so criteria specifically related to this issue were used. The criteria and associated scoring are outlined in Table 1.

Table 1: Critical appraisal criteria

Criteria	*Points*
Potential recruitment bias:	
Random sample	2
Paper has checked whether sample is representative of population on key variables	1
Opportunity sample with no check on how representative it is, or check reveals potentially important differences between sample and population	0
Sample size:	
Power calculation reported and sample size meets requirements of calculation	2
Sample size 82 or larger for correlation studies or 64 or larger in each group for group comparison studies or 34 or larger in each group for matched group studies (Figures based on GPower programme = sample size required to detect medium effect size with alpha set at .05 and power at 0.80, two-tailed tests)	1
Sample size under 82 for correlation studies, under 64 or 34 for group studies (Figures based on GPower programme = sample size required to detect medium effect size with alpha set at .05 and power at 0.80, two-tailed tests)	0
Reliability and validity of measures used (including response biases):	
Measures used have good reliability and validity when used for children/families in brain injury in the way that they are used in the study	2

Measures have good reliability and validity when used with other populations, but not reported for children with brain injury or their families; or measures have good reliability and validity when used in child brain injury but there are potentially significant differences between the reliability/validity studies and the study in question	1
Measures have poor reliability and/or validity in some respect	0
Missing data:	
No missing data or statistical methods used to address missing data	2
No use of statistical methods to deal with missing data, but amount of data missing is small	1
No report on whether data are missing or not, or large amount of missing data and no attempt to deal with it statistically	0
Statistical analysis:	
Analysis is appropriate for hypotheses	2
Analysis is not appropriate	0
Design:	
Experimental methodology used	2
Longitudinal design is used in a way that tries to address the causal relationship between variables	1
Method is non-experimental and cross-sectional, or non-experimental and longitudinal but the longitudinal aspect does not shed any light on the causal relationship between variables	0
Confounding variables:	
Wide range of potentially confounding variables identified and addressed by methodological or statistical means	2
Limited range of potentially confounding variables identified and addressed by methodological or statistical means	1
Potentially confounding variables are not addressed by methodological or statistical means	0
Robustness of findings:	
Paper reports more than one result supporting the relationship between the relevant variables (or absence of relationship) (including follow-up results)	2
Paper reports only one result supporting the relationship	0

1. EVALUATION OF METHODOLOGY

The methodology of the reviewed papers was evaluated in two stages. First, each paper was scored against the quality framework described earlier to identify strengths and weaknesses within the papers. A total score was also used to give an idea of the strength of individual papers relative to the other papers. Second, more specific limitations in the methodology of the reviewed research were identified. These are described in more detail below.

Table 2 shows how each paper scored against the criteria. There was some variation in the quality of the individual papers with scores ranging from 7 to 11 out of a possible 16, with a mean score of 8.9. General areas of weakness were potential recruitment bias (with none of the studies using a random sample), missing data (missing data were not commented on or there was no use of statistical methods to deal with missing data), sample size (no use of power calculations), design (experimental methodology was not used in any of the studies) and reliability and validity of measures (the majority of the measures used in the papers were not specifically designed for use in the TBI population). Table 4 shows a summary of the final papers and table 3 clarifies abbreviations used in table 4.

Table 2: Individual papers scored against quality criteria

	Potential recruitment bias	Sample size	Reliability and validity of measures used	Missing data	Statistical analysis	Design	Confounding variables	Robustness of findings	Overall
Limond et al. (2009)	1	0	1	1	2	0	0	2	7
Osberg et al. (1997)	0	1	0	1	2	1	0	2	7
Zinner et al. (1997)	0	1	1	0	2	1	0	2	7
Kinsella et al. (1999)	0	0	1	0	2	1	1	2	7
Stancin et al. (2010)	0	1	1	0	2	0	1	2	7
Micklewright et al. (2012)	0	0	1	0	2	1	1	2	7
Josie et al. (2008)	0	1	1	0	2	1	1	2	8
Wade et al. (1998)	0	1	1	0	2	1	1	2	8
Schmidt et al. (2010)	0	1	1	0	2	1	1	2	8
Max et al. (1998)	0	0	1	1	2	1	1	2	8
Anderson et al. (2001)	0	1	1	0	2	1	1	2	8

Hawley et al. (2003)	0	1	1	0	2	1	2	2	9
Rivara et al. (1996)	0	1	1	0	2	1	2	2	9
Ganesalingam et al. (2007)	0	1	1	0	2	1	2	2	9
Wade et al. (2002)	0	1	1	0	2	1	2	2	9
Kurowski et al. (2011)	0	1	1	0	2	1	2	2	9
Hajek (2011)	1	1	1	0	2	0	2	2	9
Stancin et al. (2008)	0	1	1	0	2	1	2	2	9
Yeates et al. (2002)	0	1	1	1	2	1	1	2	9
Anderson (2005)	0	1	1	1	2	1	1	2	9
Ewin-Cobbs et al. (2013)	1	1	1	0	2	1	2	2	10
Taylor et al. (2001)	0	1	1	1	2	1	2	2	10
Wade et al. (2004)	0	1	1	1	2	1	2	2	10
Yeates et al. (2010)	1	1	1	0	2	1	2	2	10
Yeates et al. (1997)	0	1	1	1	2	1	2	2	10

Wade et al. (2001)	0	1	1	2	2	1	2	2	11
Wade et al. (2006)	0	1	1	2	2	1	2	2	11
Keenan (2006)	1	1	1	1	2	1	2	2	11
Aitken et al. (2009)	1	1	1	1	2	1	2	2	11

Table 3: List of abbreviations

ABAS= Adaptive Behavior Assessment System	LOC=Loss of Consciousness
BRIEF=Behaviour Rating Inventory of Executive Functioning	LOS=Length of Stay
BSI=Brief Symptom Inventory	ModTBI=Moderate Traumatic Brain Injury
CAFAS=Child and Adolescent Functional Assessment Scale	MTBI=Mild Traumatic Brain Injury
CBCL=Child Behaviour Checklist	OI=Orthopaedic Injury
CRI=Cumulative Risk Index	PCS=Post Concussive Symptoms
CVLT=Californian Verbal Learning Test	PCS-I=Post Concussive Symptom Interview
DAS= Dyadic Adjustment Scale	PedsQL=Pediatric Quality of Life Inventory
DIAB=Diabetes	PIC=Personality Inventory for Children
FAD= Family Assessment Device	PKBS=The Preschool and Kindergarten Behavior Scales
FBII= Family Burden of Injury Interview	POPC=Paediatric Overall Performance Category
FFS= Family Functioning Scale	PSI/SF=Parenting Stress Index/Short form
GCS=Glasgow Coma Scale	QOL=Quality of Life
GEI=Grief Experience Inventory	RBRI= Rowe Behavioural Rating Inventory for Children
GFR=General Functioning Rating Scale	SCI=Social Composite Index
GHQ-12=General Health Questionnaire	SES=Socioeconomic Status
GSI=Global Severity Index	STBI=Severe Traumatic Brain Injury
HBI=Health and Behaviour Inventory	VABS=Vineland Adaptive Behaviour Scale
HCSB= The Home and Community Social and Behavior Scales	VSTBI= Very Severe Traumatic Brain Injury
HOME= The Home Observation for Measures of the Environment	WASI=Wechsler Abbreviated Scale of Intelligence
ISEL=Interpersonal Support Evaluation List	WISC=Wechsler Intelligence Scale for children
ISS= Injury Severity Score	WOCS=Ways of Coping Scale
LIRES-A=Life Stressors & Social Resources Inventory-Adult form	WPPSI=The Wechsler Preschool and Primary Scale of Intelligence

Table 4: Summary of final papers

Authors	Sample	Groups	Measures a)Time points b)Outcome measures	Findings
Aitken et al. (2009)	330 (79% of those approached) families enrolled in the study. 312 follow-up at 3 months and 288 at 12 months	n/a	a) Baseline within 3 weeks of hospitalisation then 3 and 13 months after injury. b) *Pre-injury family functioning*: FAD *Caregiver distress and burden:* Emotional impact scale of the child health questionnaire including general worry or interference with family routine, impact on everyday activities and caregiver ability to work. *Child health related QOL*: Peds QL *Unmet needs*: Caregiver perceptions of whether health care needs were met or unmet and days missed from work were also measured.	Parental perception of unmet care needs was strongly related to family burden outcomes (general worry or interference with routine), child dysfunction (predicted by the PedsQL) predicted parental burden at 3 and 12 months. Psychosocial problems were associated with more pronounced and persistent parental worry and interference at a year. Relatively few families (15%) reported poor pre-injury family functioning.
Anderson (2005)	150 children (104 boys & 46 girls)	MTBI (n = 42), ModTBI (n = 70), STBI (n = 38).	a) Three time points: admission (pre-injury), 6 and 30 months. b) *Adaptive functioning*: VABS *Behavioural functioning*: RBRI *Parental style*: FFS *Burden:* FBII *Cognitive ability*: WPPSI & WISC	Families in the STBI reported higher levels of burden. Family function at 30 months predicted by child behaviour and adaptive function before injury. Family burden predicted by severity, physical impairment, age, pre-injury behaviour.
Anderson et al. (2001)	112 children (75 male, 37	MTBI (n = 31), modTBI (n = 52) STBI (n =	a)As soon as possible after admission and 6 months post injury. b) *Physical Function:* GCS	STBI associated with greater impairment. Pre-injury behavioural and family functioning was closely related to post-injury function. Family

				functioning remained unchanged post injury and level of burden was high predicted by severity, functional impairments and post-injury behavioural disturbance.
female)	29).	*Cognitive ability:* WPPSI or the WISC *Behavioural functioning:* behavioural functioning or RBRI, PIC *Adaptive functioning*: VABS *Family functioning:* Family functioning scale *Burden:* Family burden interview scale		
Ewing-Cobbs, Prasad, Mendez, Barnes, & Swank (2013)	185 children and families	Accidental TBI (n=61), inflicted TBI (n=64), typically developing children (n=60)	a)2 and 12 months after injury b) *Resources:* Family resource scale. *Development:* Bayle scales of infant development, *Adaptive functioning:* VABS, *Social functioning:* semi-structured sequence of social interactions between child and examiner.	Children with inflicted TBI who were less socially responsive and had lower levels of family resources had the least favourable outcomes.
Ganesalingam et al. (2007)	278 children	MTBI (n=71) with LOC, MTBI without LOC (n=110), OI (n= 97).	a) Shortly after injury and at 3 months post injury. b*) Pre-injury family functioning:* FAD, general functioning scale, *Burden:* FBII *Parental distress*: BSI, GSI. *PCS*: PCS-I, HBI.	MTBI with LOC was associated with greater family burden at 3 months than OI, independent of SES and premorbid family functioning. Higher PCS shortly after injury was related to higher ratings of family burden and distress at 3 months.
Hajek et al. (2010)	285 children	MTBI (n=186) OI (n=99).	a) 2 weeks, 1 month, 3 months and 12 months post-injury b) *PCS*: HBI and PCS-I parent and child versions.	Scores on HBI were somewhat higher in the OI group. Mean symptom ratings were higher for children compared with parents. Modest agreement when reporting PCS but children report higher mean levels of symptoms.
Hawley, Ward, Magnay, & Long (2003)	97 parents of children with TBI	STBI (n=29) ModTBI (n=19), MTBI (n=49),	a) At recruitment and 12 month later. b) Caregiver s*tress:* PSI/SF *General caregiver health*: GHQ-12	41.2% of parents exhibited clinically significant levels of stress. Parents of injured children suffered greater stress than controls. At follow-

	and 31 families in control group	controls (parents asked to select a similar family and child in terms of age, social background, same school class. (n=31)	*Problems*: Problem resolution scale.	up one third of parents with children with STBI had poor psychological health.
Josie et al. (2008)	108 children with STBI or ModTBI and their families		a) Immediately after injury, 6, 12 months and 4 years after injury. b)*SES:* SCI, life stressors and social resources inventory-adult, *Adaptive functioning*: VABS, *Emotional and behavioural:* CBCL, children's depression inventory. *Pre-injury family functioning:* FAD *Parental distress:* BSI *Burden*: FBII. *Injury related risk*: medical charts.	Risk variables were dichotomised into high and low risk and summed to create a CRI for each child. CRI predicted family burden at all assessments points. They found that the time point immediately after the injury best predicted future levels of family burden.
Keenan, (2006)	72 maternal caregivers	Inflicted injuries (n=41) Non-inflicted (n=31)	a)At least one year post-injury. b) *Functional morbidly and cognitive outcome*: Paediatric outcome performance category *Health status:* Stein-Jessup Functional status II R *General health, physical well-being, role functioning, psychological distress, and social functioning:* Global health index. *Family characteristics:* whether the child was in the home of origin, educational status, marital status of	Children with inflicted injuries had worse outcomes. Family characteristics at 1 year were not different when compared according to injury type.

			the maternal caregiver, number of children in the home and maternal caregiver employment. *Social capital:* maternal social support, neighbourhood support, church attendance and whether the maternal caregiver had a partner.	
Kinsella, Ong, Douglas, Prior & Sawyer (1999)	51 children	MTBI (n=29), ModTBI (n=10), STBI (n=12)	a) As soon as possible after admission. b) *Emotional and behavioural*: CBCL *General caregiver health:* GHQ-12 *Pre-injury family functioning:* FAD.	Presence of a partner and acute emotional reaction of the parent to injury were predictive of child behavioural outcome. Severe injury group were at highest risk for dysfunction.
Kurowski et al. (2011)	154 of 221 from the wider study completed follow-up.	ModTBI to STBI (n=68), OI (n=75)	a) At post-acute, 6, 12 and 18 months after injury. b) *Pre-injury family functioning:* FAD, *Parenting practices:* The parenting practices questionnaire *Executive function:* behaviour rating inventory of executive function (parent rated), the global executive composite. *Emotional and behavioural*: CBCL.	Lower family dysfunction was associated with better functioning. Attention deficits were associated with more permissive parenting.
Limond et al. (2009)	47 with ModTBI to STBI	MTBI (n=31) ModTBI (n=7), STBI (n=5).	a) One to five years post injury. b) *Child health related QOL:* PedsQL *Cognitive, emotional and behavioural functioning*: Strengths and difficulties questionnaire.	QOL was significantly lower in children with TBI than expected from normative population. Parents reported that more than 43% of children had cognitive, emotional and behavioural difficulties that impacted on their daily life.
Max et al. (1998)	50 parents	n/a	a) 3, 6, 12 and 24 months after TBI. b) *Pre-injury family functioning*: FAD.	Strongest influence on family functioning after childhood TBI were pre-injury family functioning, the development of a novel

			Psychiatric: schedule for affective disorders and schizophrenia for school age children. *SES*: four factor index of social status. *Life events*: family inventory of life events and changes *Neurological assessments*: GCS *Immediate post injury coping*: semi structured interview	psychiatric disorder in the child and pre-injury family life events or stressors
Micklewright, King, O'Toole, Henrich, & Floyd (2012)	44 families	TBI (n=21), OI (n=23)	a)12-36 months post injury. b)*SES:* Hollingshead four factor index of social status *Parental distress*: BSI *Parenting practices*: parenting practices questionnaire *Adaptive functioning:* VABS *Cognitive ability*: WASI.	Higher parental distress was associated with lower child adaptive functioning in the TBI group. Higher parental distress was associated with authoritarian parenting and lower adaptive functioning in both groups.
Osberg et al. (1997)	82 families	MTBI (44%) ModTBI (37%), STBI (17%)	a) 1 and 6 months post-acute hospital discharge b) *Finances*: 5 work and financial questions responded to using strongly disagree to strongly agree (1 to 4). *Severity*: ISS *SES*: Measure incorporates information on education, occupation, gender & marital status. *LOS*: Acute hospital LOS *Number of impairments at discharge:* including vision, hearing, feeding, dressing, eating, walking, bathing, cognition & behaviour.	Trouble maintaining work schedules and injury related financial problems were common. Families of children with severe injuries, with 4 to 9 impairments and children hospitalised for longer than 2 weeks and not discharged home were at highest risk.

			Discharge location: To home or rehabilitation facility.	
Rivara et al. (1996)	81 available for inclusion in the current study. Part of a larger study of 103 in original	n/a	a) Completed at 4 intervals: 3 weeks after injury, 3 months, 1 year and 3years b) *Emotional and behavioural:* CBCL *Family functioning*: 4 semi structured parent interviews, The family interview rating scale, FES, FAD, Family global assessment scale, family inventory of life events, NYU problem checklist *Mental health*: health insurance study wellbeing scale *SES*: Hollingshead four factor index of SES	Pre-injury functioning was the best predictor of 3 year outcomes. Fewer changes in family functioning were reported in the mild and moderate groups. Pre-injury variables explained between 29% and 69% of variation in 3 year outcomes.
Schmidt, Orsten, Hanten, Li, & Levin (2010)	142 children	TBI (n=75) and OI (n=67).	a) Three time points: baseline (within one month), 3 months and 1 year post injury. b)*Family environment*: LIRES-A *Emotional prosody*: Task where children were asked to identify the emotion from 4 semantically neutral sentences. *Face emotion recognition*: Children asked to sort photos of faces by emotion. *Reaction time*: Eriksen Flanker + No-go task	Financial resources and stress significantly related to emotional prosody performance in TBI group only, particularly for younger children (higher perceived resources better performance).
Stancin, Wade, Walz, Yeates &	208 children	STBI (n=21), ModTBI	a)As soon as possible after injury (no later than 3 months)	Parents of children with TBI reported greater burden, stress, parental depression and global

Taylor (2008)		(n=22),complicated MTBI (n=45), OI (n=199)	b)*Pre-injury family functioning*: FAD, *Family environment*: LIRES-A *Burden:* FBII *Parental distress:* GSI *Coping*: COPE	distress compared with parents of children with OI.
Stancin, Wade, Walz, Yeates, & Taylor (2010)	221 with TBI	TBI (n=102) and OI (n=119).	a) Shortly after injury, 6, 12, 18 months post injury. b) *Pre-injury family functioning*: FAD, *Family environment*: LIRES-A, *Burden*: FBII *Parental distress:* BSI *Behaviour*: adaptive behaviour assessment, *SES*: defined in terms of maternal education and median income	TBI was associated with higher injury related stress compared to OI, with stress diminishing over time in all groups. STBI was associated with greater psychological distress. Family functioning and social resources moderated the relationship of TBI severity and injury related burden and caregiver distress.
Taylor et al. (2001)	147 children and their parents	STBI (n=40), ModTBI (n=52), OI (n=55)	a) 6 and 12 month follow-ups post injury. b) *Emotional and behavioural:* CBCL *Parental distress*: BSI, GSI *Burden*: FBII.	Higher parent distress at 6 months predicted more child behavioural problems at 12 months and more behavioural problems at 6 months predicted poorer family outcomes at 12 months.
Wade et al. (1998)	189 children and parents	STBI (n=53), ModTBI (n=56), OI (n=80)	a) Baseline: as soon as possible, 6 and 12 months. b)*Burden*: FBII, impact on family scale *Pre-injury family functioning:* FAD *Family functioning*: DAS *Parental distress:* BSI *SES*: SCI	Caregivers in the STBI group were significantly more likely to exceed the clinical cut-off on the BSI and to report clinically significant levels of family dysfunction at follow-up.
Wade et al. (2001)	103 TBI and 71 OI	Not specified	a)Baseline and 6 and 12 months post injury	Acceptance was associated with lower burden and denial was associated with greater distress

			b) *SES*:SCI *Coping*: COPE.	in both groups. The use of humour was related to diminishing distress following TBI but unrelated to distress in OI. Active coping resulted in higher distress following TBI but not OI.
Wade et al. (2005)	188 children and parents	STBI (n=52), ModTBI (n=56), OI (n=80)	a) Baseline, 6 months and then 5 time points. b) *SES:* SCI *Family environment:* LIRES-A *Burden*: FBII *Parental distress:* BSI *Pre-injury family functioning:* FAD	Attrition was higher among families in the STBI group with lower burden. STBI group reported higher injury related burden over time after injury. Lower social resources were associated with greater likelihood of family dysfunction. Families of children with STBI and low resources reported a deterioration functioning.
Wade et al. (2004)	189 parents	STBI (n=53), 56 ModTBI (n=56), OI (n=80).	a)Baseline, 6, 12 and extended follow-up b) *SES*: SCI *Family environment*: LIRES-A, *Burden*: FBII *Parental distress*: BSI	Support from friends and spouse was associated with less psychological distress. Family and spouse stressors were associated with greater distress.
Wade et al. (2002)	189 families	STBI (n=53), ModTBI (n=56), OI (n=80).	a)Baseline, 6, 12 and extended follow-up b) *SES*: SCI *Family environment*: LIRES-A *Burden*: FBII, impact on family scale, *Parental distress*: BSI *Pre-injury family functioning*: FAD.	Patterns of adaptation over time varied across groups but indicated long-standing injury related stress and burden in the STBI group.
Yeates et al. (1997)	189 children	STBI (n=53), ModTBI (n=56), OI (n=80)	a) Baseline, 6 and 12 months post injury. b) *SES*: SCI *Pre-injury family functioning*: FAD *Family environment:* LIRES-A	Measures of pre-injury family environment predicted cognitive and behavioural functioning at 12 months.

Yeates et al. (2002)	109 children with TBI and 80 OI and their families	White (n=73), black (n=18) children with ModTBI to STBI and 32 white (n=32) & black (n=23) with OI	a) Baseline, 6 and 12 months. b) *Parental distress*: BSI, GSI *Burden*: FBII, impact on family scale *Pre-injury family functioning*: FAD, *Coping*: COPE.	Race was a significant moderator of group differences in parental psychological distress and perceived family burden. Black and white parents differed in preferred coping strategies.
Yeates, Taylor, Walz, Stancin, & Wade (2010)	206 children	STBI (n=23), MTBI-ModTBI (n=64), OI (n=119)	a) 6,12 and 18 months b) *Parenting style*: Parenting practices questionnaire *Home environment*: HOME *Pre-injury family functioning*: FAD, *Behavioural and emotional*: CBCL, *Adaptive functioning*: ABAS, PKBS, HCSB.	Groups differed in social competence, but family environment did not moderate difference. Behavioural adjustment became more pronounced across time at higher levels of authoritarian and permissive parenting in children with STBI.
Zinner, Ball, Stutts, & Philput (1997)	102 mothers of children and adolescents with TBI	91% natural mothers, 6% adoptive mothers, 3% stepmothers. MTBI (n=11), ModTBI (n=12), STBI (n=28), VSTBI (n=51)	a)3-36 months after injury b) *Grief*: GEI & GFR	More severe grief was reported by mothers who rated their children as having poor neurobehavioural functioning. Time since injury significantly influenced guilt, Mothers of low functioning children expressed anger, loss of control and increased sleep disturbance.

More specific methodological weaknesses identified in the research include issues relating to assessment measures, retrospectively measuring prospective functioning, drawing causal conclusions, control group and follow-up.

1.1 Assessment measures

One of the main issues with the measures used in this area is the reliance on parental self-report. Therefore, these measures are susceptible to bias, in terms of social desirability. Also when you correlate two self-report measures, the variable being measured by one of the measures might bias how they respond to the other measure, or a third variable might bias how they respond to both measures. So the correlation might be spurious because it reflects this bias, rather than any genuine correlation between the two constructs that the two measures purport to measure. For example, a parent who is depressed may give answers to a questionnaire about the child's functioning that paints a biased more negative picture of how the child is doing (compared to a parent who is not depressed). As a result the correlations between poor functioning and depression may be spurious ones, reflecting the fact that depressed parents are more likely to report poor functioning because they have more negative perceptions of the child's functioning, rather than the fact that poor functioning results in parental depression.

Another issue that has been highlighted by Hajek et al. (2010) is that correlations between child and parent measures are not always accurate. This may cast doubt on the validity of the measures, the child or parent rating might be inaccurate, or both might be inaccurate. To minimise these sources of inaccuracy, multimodal forms of assessment could be used, with the use of more objective measures for example observations, as recommended

by Wade et al. (1995).

Although a lot of the studies reviewed used measures that were designed for the TBI population, there were some studies that used measures that were not, for example the VABS, CBCL. One issue this poses is whether these measures are sensitive enough to issues that are most relevant to a TBI population.

1.2 Retrospectively measuring prospective family functioning

One of the main issues with studies examining pre-injury family functioning is the way this is measured. All of the studies reviewed attempted to measure pre-injury functioning after the child injury had occurred, usually at admission. Measuring functioning retrospectively has several limitations.

One of the main difficulties with measuring functioning in this way is that memory may be inaccurate, increasing measurement error and reducing the probability of obtaining significant findings. Also it may be that it is easier for the biases outlined in the previous section to operate when the person is being asked to recall something, than when they are being asked to report on what is currently the case. It may be psychologically easier for people to report in a biased way on a past situation that no one can readily verify, compared with a current situation that can more readily be verified.

As highlighted by Wade et al.'s. (1995) review, there is still a need for large scale longitudinal cohort studies where pre-injury factors can be measured before the injury has occurred rather than retrospectively. However this requires researchers and families to commit for a long period of time and is often subject to high dropout rates. Another

alternative would be to integrate school records into the pre-injury assessment, as often used in clinical practice (Wade et al., 1995).

1.3 Drawing causal conclusions

As has been outlined it appears that the relationship between the family and child brain injury is bi-directional. This makes it very difficult to make claims about the direction of the influence. For example, Souza et al. (2007) found an association between parental worries and child self-evaluation of their QOL. However it is not possible from this correlation to know whether the child evaluates their QOL more poorly because of the parent's worrying, or the parents worry more because their child's QOL is so poor.

Longitudinal studies may be a way of trying to address this issue. For example, Taylor et al. (2001) found that higher parental distress at 6 months predicted more child behavioural problems at 12 months. Although this is more convincing evidence of the causal relationship, it is not conclusive. It may be the case that both variables might be related to some other variable that explains this relationship, or the measures of child behaviour may be insensitive to more subtle changes that pre-date the more obvious behavioural problems and that make the parent distressed. Fundamentally, none of the studies carried out in this area are experimental, so inferences about causality cannot be conclusive.

1.4 Control group

Typically children who have sustained an OI and their families are used as controls for comparison with children with a brain injury. It is argued that the use of this group can control for the experience of being hospitalised for a severe injury and more rigorously assess

the effects of brain injury per se (Wade et al., 2006). However OI can also be seen as a traumatic event, with long-term consequences, with an impact on family factors that the studies are measuring. This focus on comparisons with the OI group may run the risk of overlooking the impact of the traumatic and long-term effects on the child and family functioning that both groups share. Therefore it may be important to compare family and child outcomes in brain injury with the general population as well as the OI population.

1.5 Follow-up

The majority of the studies included in this review used a baseline, 6 and 12 month follow-up period, with the longest follow-up being at 3 year post injury (Rivara et al., 1996). Again this was highlighted by Wade et al.'s. (1995) review as a weakness of the literature at the time of their review. This lack of long term follow-up makes it difficult to draw any conclusions about the impact of the family on the child with a brain injury or vice versa in the longer term. This long term follow-up is needed as the impact of the brain injury may become more or less pronounced as the child ages.

2. HOW DOES THE FAMILY ENVIRONMENT IMPACT ON RECOVERY FROM CHILDHOOD BRAIN INJURY?

Research suggests that the family environment can have an impact on the recovery and outcomes of children with TBI. Studies have focused on different areas of recovery including function, for example executive functioning, attention and psychosocial. In this section the impact of pre-injury and post-injury family factors on the outcome of the child with the brain injury will be discussed.

2.1 Pre-injury

Pre-injury family functioning has been found to impact on recovery, with some findings suggesting it may be the best predictor of outcome (Anderson et al., 2001; Anderson, 2005; Yeates et al., 1997; Max et al., 1998; Rivara et al., 1996). These studies will be discussed further in the section on the moderators of the relationship between childhood brain injury and the family. Rivara et al. (1996) conducted a prospective cohort study examining predictive factors for family outcome at 3 years post injury. They found that pre-injury variables explained between 29% and 69% of variation in 3 year outcomes in children with TBI, with pre-injury family functioning being the best predictor of 3 year outcomes when compared with other factors such as injury severity. At 3 years about one third to half of the parents in the moderate TBI or severe TBI group reported medium to high strain in 19 of the 34 problem areas examined, for example concentration, forgetfulness and temper outbursts.

Specific pre-injury family characteristics and their impact on child outcomes have also been explored in the literature. Rivara et al. (1996) assessed family and child functioning at four time points. The first time point was used to assess pre-injury functioning (administered at 3 weeks post-injury) and the other time points were utilised to assess post-injury functioning (3 months, 1 year and 3 years post injury). Self-report measures were

completed by the primary caregiver and variables derived from the pre-injury assessments were used as predictors and variables based on post-injury were used as outcomes. They found that low levels of control or rigidity and high levels of expressiveness were strongly correlated with positive outcomes (measured by the Child Behaviour Checklist) at 3 years in families of severely injured children.

Rivara et al.'s (1996) paper scored 9/16 on the quality criteria. They controlled for a wide range of confounding variables and used a 3 year follow-up, strengthening the robustness of their findings. However they used an opportunistic sample with no analysis to check the how representative this sample was. Missing data were also not commented on.

2.2 Post-injury

Following injury, family functioning has also been suggested to impact on functioning in children with brain injury. Research suggests that higher family functioning is associated with better child outcomes (Kurowski et al., 2011). Kurowski et al. (2011) examined this association in relation to executive functioning and attention in children with TBI compared to children with an OI. They found that lower family dysfunction was associated with better executive function and attention in children with both TBI and OI. In terms of emotional prosody (identifying emotion through tone of voice) worse performance has been found to be associated with higher family financial stress. However family functioning was not associated with performance on a face emotion recognition task (Schmidt et al., 2010). Kurowski et al. (2011) scored 9/16 on the quality criteria. Strengths included the researchers controlling for a wide range of confounding variables (including excluding participants where there was child abuse or other neurological disorders reported) and using three follow-up points (6, 12 and 18 months). Weaknesses included using an opportunistic sample and the majority of the measures used were not designed for use with the TBI population.

In terms of social competence, Yeates et al. (2010) found that the family environment did not moderate the difference between the TBI and OI groups. Yeates et al.'s (2010) paper scored 10/16 when scored against the quality criteria. Strengths included selecting an appropriate statistical analysis and again they used a follow-up period (18 months). Weaknesses included not commenting on missing data.

Studies that have focused on parents have examined both parenting styles and parent characteristics and the impact on the child with the brain injury. In terms of parenting styles, Kurowski et al. (2011) found that attentional deficits after STBI were associated with more permissive parenting compared to children with OI. Yeates et al. (2010) also found that the effects of childhood TBI (in terms of social competence, behavioural adjustment, adaptive functioning) were more pronounced in families who reported higher levels of authoritarian and permissive parenting.

Parental worry is another area that has been suggested to affect outcomes in children with a brain injury. Parental distress has also been suggested to influence child outcomes. Taylor et al. (2001) found that in relation to child behavioural outcomes, higher parental distress at 6 months predicted more child behavioural problems at 12 months. Taylor et al.'s (2001) paper scored 10/16 when measured against the quality criteria. They controlled for a wide range of confounding variables (including excluding children in the control group who had signs of concussion). Weaknesses included using an opportunistic sample and not carrying out a power analysis to check what sample size was required.

Summary

The literature examining the impact of family factors pre and post injury appears to suggest that family and parental factors both pre and post injury are related to child outcomes following a brain injury.

3. HOW DOES CHILDHOOD BRAIN INJURY IMPACT ON THE FAMILY?

Research suggests that when a child has a brain injury there can be a substantial impact on the family, with families reporting increased subjective burden, distress and stress (Stancin et al., 2010). In this section the impact will be discussed in relation to these areas separately and then summarised.

3.1 Burden

The family burden of childhood brain injury has been commented on by many researchers over the past 18 years that this literature review covers. Research suggests that families with a child with a STBI experience higher levels of burden compared with families with moderate or MTBI (Anderson, 2005; Rivara et al., 1996; Wade et al., 2005). For example, Ganesalingam et al. (2007) used measures of post concussive syndrome (PCS) following injury to examine the relationship between level of injury and family burden, as measured by the Family Burden of Injury Interview (FBII). The FBII is a structured interview in which parents are asked to assess injury related stress and responses are then averaged to provide an index of injury related burden (Burgess, Drotar, Taylor, Wade, Stancin, Yeates, 1999).They found that higher PCS shortly after injury was related to higher ratings of family burden and distress at 3 months. Mild TBI with loss of consciousness (LOC) was associated with greater family burden at 3 months compared with OI, independent of SES and premorbid family functioning (Ganesalingam et al., 2007). Ganesalingam et al.'s (2008) scored 9/16 when scored against the quality criteria. Again they used two time points to strengthen the robustness of their findings (as soon after injury as possible and 3 months). Weaknesses included using an opportunistic sample with no analysis to check the representativeness of their sample and no power calculation was carried out.

In terms of parents specifically, Aitken et al. (2009) found that parental burden was apparent at both 3 and 12 months post injury and was predicted by child dysfunction in physical, emotional, social and school domains (defined by the PedsQL). Aitken et al.'s (2009) paper scored 11/16 when scored against the quality criteria and was one of the highest scoring papers. Strengths included using two time points for measurement (3 & 12 months) and controlling for a wide range of confounding variables (including children being excluded where there was a history of child abuse or pre-existing medical condition). Weaknesses included failing to comment on missing data. Stancin et al. (2008) also found that parents of children with early childhood TBI reported significant levels of injury related burden compared to parents of children with an OI. Stancin et al.'s (2008) paper scored 9/16. They controlled for a wide range of confounding variables. However the majority of the measures they used were not designed for use with the TBI population and they did not comment on missing data.

In terms of financial burden, families with a child with a TBI appear to be at risk of financial problems (Hawley, Ward, Magnay, & Long, 2003; Osberg et al., 1997). Difficulties maintaining work schedules and financial problems were common with families of children with severe injuries, with children with 4 to 9 impairments, hospitalised for longer than 2 weeks and not discharged home at highest risk (Osberg et al., 1997). Osberg et al.'s (1997) paper was one of the lowest scoring papers, scoring 7/16 when scored against the quality criteria. Strengths included using two time points (1 and 6 months post injury). Weaknesses included confounding variables not being identified or controlled for and inclusion/exclusion criteria not being documented (and therefore the representativeness of the sample was unclear because the population was not clearly defined). A further weakness was the measurement of the dependant variable (finances) which was measured using a subjective measure (questions answered by parents on a Likert scale).

3.2 Stress

Stress has also been shown in families with a child with a brain injury, with stress being measured by the PSI/SF (Hawley, Ward, Magnay, et al., 2003; Stancin et al., 2008). The PSI/SF provides scores on total stress from three scales, parental distress, parent-child dysfunctional interaction and difficult child (Abdin, 1995). Hawley, Ward, Magnay, et al., (2003) found that parents of a child with a brain injury exhibited clinically significant levels of stress when compared to controls (parents of children with OI) (Hawley, Ward, Magnay, et al., 2003). Hawley et al.'s (2003) paper scored 9/16 when scored against the quality criteria. Strengths included controlling for a wide range of confounding variables, but they did not describe the inclusion/exclusion criteria or address missing data.

However, there is conflicting evidence regarding the length of time stress persists after injury. Stancin et al. (2004) found that levels of stress diminished over time. In contrast Wade et al.'s. (2004) findings indicated long-standing injury related stress in families with children with STBI. Wade et al.'s (2004) paper scored 10/16 when scored against the quality criteria. Again they controlled for a wide range of confounding variables and used multiple time points (6 and 12 months). Weaknesses included using an opportunistic sample with no analysis carried out to check how representative this sample was.

3.3 Psychological distress

In parents and families of children with a brain injury psychological distress has been examined. Compared to controls (children with OI) higher rates of parental depression have been found in parents of children with early childhood TBI (Stancin et al., 2008).

Focusing on caregivers, Wade et al. (1998) found that caregivers in the STBI group were more likely to exceed the clinical cut-off on the Brief Symptom Inventory (BSI) and report significant levels of family dysfunction compared to the OI group. The BSI is a brief

self-report psychological symptom scale (Derogatis & Melisaratos, 1983). Wade et al.'s (1998) paper scored 8/16 when scored against the quality criteria. Weaknesses included not reporting whether a power calculation was carried out and not commenting on missing data. More severe TBI was associated with greater psychological distress and poor psychological health (Hawley et al., 2003; Stancin et al., 2008; Stancin et al., 2010). In a more recent study, Micklewright et al. (2012) also found support for the association between distress and child functioning after TBI, with higher parental distress being associated with lower child adaptive functioning in the TBI group. They also found that higher parental distress was associated with authoritarian parenting and lower adaptive functioning in both TBI and OI groups. Micklewright et al.'s (2012) paper scored 7/16 and was one of the lowest scoring papers. Strengths included the paper presenting more than one result that supported the relationship between the relevant variables. Weaknesses included the sample size not meeting the minimum number to detect a medium effect size and not commenting on missing data.

Parents have reported a range of emotions associated with their child's brain injury including worry, with psychosocial problems leading to more pronounced and persistent parental worry at one year post injury (Aitken et al., 2009). Zinner et al. (1997) also found that parents reported grief, anger, loss of control and despair as a result of their child's TBI (Zinner et al., 1997). With more severe grief reported by mothers who rated their children as having poor neuro-behavioural functioning (Zinner et al., 1997). Zinner et al.'s (1997) paper scored 7/16 when scored against the quality criteria and was one of the lowest scoring papers. Although they used various time points, they did not address potential confounding variables or comment on missing data.

Zinner et al. (1997) sought to clarify the grief process for mothers who are adjusting to having a child with a TBI. There were 102 mothers of children aged between 15 and 24 at the time of their injury who took part. They found that time since injury significantly

influenced guilt and guilt was especially intense in the earliest months (3-9 months) and latest time periods (27-36 months). Mothers of low functioning children were more likely to express anger, loss of control and increased sleep disturbance. They also found that mothers of children who were older at the time of their injury reported more despair, anger, social isolation and physical complaints than mothers of younger children.

Summary

The research summarised in this section appears to support the negative impact that a brain injury can have on families, in terms of stress, burden and distress.

4. WHAT MODERATES THE RELATIONSHIP BETWEEN CHILDHOOD BRAIN INJURY AND THE FAMILY?

This section of the review will summarise research where moderators of the effects of a brain injury on the family have been examined. The moderators will be divided into injury related and demographic factors.

4.1 Injury related factors

4.1.1 Time since injury

Josie et al. (2008) studied 108 children with severe or moderate TBI and their families. They found that family burden increased over time in families with a child with a TBI. Findings suggested that the baseline measurement administered immediately after the injury was the best predictor of future levels of family burden (at 6 and 12 months), suggesting that the time immediately after the injury may be important in predicting future burden in families. Josie et al.'s (2008) paper scored 8/16. They used multiple time points, strengthening the robustness of their findings; however they did not report on missing data and the majority of the measures used were not designed for the TBI population.

4.1.2 Severity

It has been suggested that severity of injury is associated with impairment, with severe brain injury being associated with greater impairment and dysfunction (Anderson et al., 2001; Kinsella et al., 1999).

The research seems to suggest that the severity of the injury may be linked to levels of stress, distress and burden families and parents' experience, with those families where the child has a more severe injury being most at risk (Hawley, Ward, Magnay, et al., 2003; Stancin et al., 2010; Yeates et al., 1997). However, Verhaeghe, Defloor, & Grypdonck's

(2005) review suggested that the nature of the injury, not the severity, determines the level of stress.

4.1.3 Age at injury

The age of the child at the time of the injury also seems to impact on the levels of burden reported (Stancin et al., 2008). Stancin et al. (2008) found that parents of children aged between 5 and 6 years old at the time of injury reported higher levels of burden than parents of children aged between 3 and 4 years old.

4.2 Demographic factors

4.2.1 Race

Yeates et al. (2002) examined race and the impact this factor has on coping of families where their child has a brain injury. They found that there was a difference in terms of preferred coping strategies between black and white parents. They also found that the negative consequences of TBI were less pronounced for parents of black children than for parents of white children at baseline. However this difference became more pronounced at the two follow-ups. These findings suggest that race was a significant moderator of group differences in parental psychological distress and perceived family burden, independent of SES. Yeates et al.'s (2002) paper scored 9/16 when scored against the quality criteria. Weaknesses included using an opportunistic sample with no check on how representative the sample was. However this is the only study found in this review that examined race as a moderator, suggesting that more research is needed to examine this relationship further.

4.2.2 Resources and coping

Research suggests that the impact of a brain injury, including distress and burden, can be attenuated by family and social resources (Stancin et al., 2010; Wade et al., 2010; Wade et

al., 2001; Wade et al., 2004). Lower family resources were also associated with deteriorating family functioning over time (Wade et al., 2005).

In terms of child outcomes, Ewing-Cobbs et al. (2013) found that social interaction behaviours were influenced by family access to material and social support but not SES, with greater resources being associated with enhanced social communication. However, the level of resources did not affect the growth of social behaviours. Ewing-Cobbs et al.'s (2013) paper scored 10/16 when scored against the quality criteria. Strengths included controlling for a wide range of confounding variables. Weaknesses included not addressing missing data and the majority of the measures used were not designed for the TBI population.

Family financial resources and the association with performance have been explored by Schmidt et al. (2010). They looked specifically at emotional prosody performance. They found that higher perceived resources were associated with better performance, particularly for younger children. Schmidt et al.'s (2010) paper scored 10/16 when scored against the quality criteria. Strengths included controlling for a wide range of confounding variables. Weaknesses included not commenting on missing data and the majority of the measures used were not designed specifically for use with the TBI population.

Wade et al. (2001) examined the role of caregiver coping as a predictor of caregiver and family outcomes following TBI. They found that the use of humour was related to diminishing distress following TBI; active coping was associated with higher distress following TBI. They also found that acceptance was associated with lower burden and denial was associated with greater distress in both groups. Wade et al.'s (2001) paper scored 11/16 and was one of the highest scoring papers. Strengths included using statistical methods to address missing data and controlling for a wide range of confounding variables. Weaknesses

included using an opportunistic sample, with no check on the representativeness of this sample.

4.2.3 Support

The impact of support from friends and spouses has been examined. Wade et al. (2004) found that support from friends and a spouse was associated with less psychological distress. They also found that family and spouse stressors were associated with greater distress.

Kinsella et al. (1999) also supported the positive impact of a spouse. Parents were asked to complete a number of measures examining parental and family functioning including emotional status and psychological well-being (measured by the GHQ). At the 3 month follow-up child behavioural problems were more common in single parent families and in families where the parent was more emotionally distressed. However, this was not found at follow-up 2 years after injury. Kinsella et al.'s (1999) paper scored 7/16 and was one of the lowest scoring papers. They used multiple time points (3 months, 1 and 3 years) increasing the robustness of their findings. Weaknesses included the sample size not meeting the minimum size to detect a medium effect size and not commenting on missing data.

Summary

The literature in this section has supported the role of numerous factors that moderate the relationship between a brain injury and the family. Whilst there are a good number of papers supporting the role of resources and coping in moderating this relationship, there are less examining race, time since injury and support, so caution should is needed when drawing conclusions from these studies.

5. DISCUSSION

This review has summarised the literature relating to the family and childhood TBI. Wade et al.'s. (1995) review suggested that there was an association between STBI and difficulties in overall family functioning and functioning of individual family members. They highlighted poor pre-injury family functioning and a parental psychological disorder in the acute phase of the injury as being associated with an increased risk of long term disruption and dysfunction.

Since Wade et al.'s. (1995) review there have been some developments in terms of identifying pre-injury factors that may lead to better child outcomes, for example, better communication, expressiveness, problem solving, use of resources, role flexibility, greater activity orientation and less conflict, control and stress (Rivara et al., 1996).

The impact of post-injury family functioning and factors on child outcomes is also an area that has been developed since Wade's review. For example, the research has highlighted parenting style, parental distress and parental worry as factors that may impact on child outcome (Kurowski et al., 2011; Taylor et al., 2001; Yeates et al., 2010). Research also appears to support the negative impact that a brain injury can have on families, including increases in stress, burden and distress.

In terms of factors that may moderate the relationship between the family and childhood brain injury the literature reviewed since Wade et al.'s. (1995) review has attempted to consider these factors. With injury related factors such as time since injury, severity and age at injury and demographic factors such as race, resources, coping skills and support being suggested (Anderson et al., 2001; Ewing-Cobbs et al., 2013; Josie et al., 2008; Kinsella et al., 1999; Schmidt et al., 2010; Stancin et al., 2008; Stancin et al., 2010; Wade et al., 2001; Wade et al., 2004; Wade et al., 2010; Yeates et al., 2002). Despite these developments it is worth noting that support for some of these factors comes from only one study, suggesting more research is needed.

Although the findings suggest that a brain injury impacts on the family of a child with a TBI and family factors influence child outcomes, it is difficult to ascertain causality. Also it is worth noting the methodological issues and weaknesses in the research highlighted. Methodological issues such as the use of self-report measures with no objective measures used, retrospectively measuring prospective functioning, the lack of long term follow-up and the choice of control group. Weaknesses highlighted included studies not reporting on the standardisation of observers, not reporting power calculations, not stating the design used and not stating the confidence intervals. Given these issues it would be difficult to draw any firm conclusions from the research reviewed.

6. LIMITATIONS OF REVIEW

As this review concentrated on quantitative research there is a gap in terms of the findings of qualitative research and what this contributes to our understanding of this topic. Unpublished studies were also excluded, which again may have contributed to the review. After the original search 7 extra papers were uncovered through searching the reference lists of the identified papers, this suggests that the search terms were missing relevant papers.

7. FUTURE RESEARCH

Areas for future research include examining specific family functions (e.g. transactional patterns, family structure) and environmental factors (e.g. cohesion, conflict) that are associated with better recovery (Epstein, Bishop & Levin, 1978; Moos, 1990; Kurowski et al., 2011). As previously highlighted in Wade et al.'s (1995) review, there is still a need for longitudinal studies looking at the long-term consequences of brain injury and the need for follow-up in the post-acute period (Limond et al., 2009).

Future research could also look at using comparison groups other than just OI groups, such as the general population. Using a multi-modal approach to assessment (e.g. the inclusion of observational measures) may act as a way of addressing the problems with the reliance on self-report and retrospective recall.

8. CLINICAL RELEVANCE

The research reviewed has made recommendations for clinical practice at different levels including service, intervention and assessment. However, given the methodological issues these implications are only tentatively suggested.

From both clinical and public heath perspectives it is important that families at risk are identified (Max et al., 1998). Post-injury variables highlighted by the research such as family functioning, parental coping styles, parental distress and worry could be areas where assessment and intervention is targeted (Kurowski et al., 2011; Taylor et al., 2001; Yeates et al., 2010). As well as a consideration of some of the moderators of the relationship between the family and childhood brain injury such as social support, resources and coping skills (Anderson et al., 2001; Ewing-Cobbs et al., 2013; Josie et al., 2008; Kinsella et al., 1999; Schmidt et al., 2010; Stancin et al., 2008; Stancin et al., 2010; Wade et al., 2001; Wade et al., 2004; Wade et al., 2010; Yeates et al., 2002). Assessment should include consideration of environment, both child and parent reports and clinical measures of symptoms such as PCS and executive functioning, which have been suggested to be predictive of family outcome (Ganesalingam et al., 2007; Hajek et al., 2010; Yeates et al., 2010).

In terms of intervention, research suggests that proactive and preventative intervention can help families and minimise the problems that are associated with brain injury (Anderson, 2005; Josie et al., 2008; Max et al., 1998; Stancin et al., 2008). It is important that rehabilitation programmes devote resources not only to the child but to the family also, with those at high risk receiving early intervention (Josie et al., 1998; Kinsella et al., 1999; Yeates

et al., 2010). Simple interventions such as giving information, education and providing support may be beneficial (Hawley et al., 2002; Kurowski et al., 2011; Zinner et al., 1997). Recommendations include interventions being based on injury severity rather than type of injury, adaptation of interventions for this unique group and interventions supporting both family members and the family environment (Armstrong & Kerns, 2002; Kennan et al., 2006; Yeates et al., 2010). Interventions should facilitate adaptation and acceptance after brain injury (Wade et al., 1998; Wade et al., 2001; Wade et al., 2004). Developing coping and communication skills within the family has also been suggested as a beneficial area for intervention (Rivara et al., 1996; Wade et al., 2001).

Findings suggest that better provision and availability of services is needed for families of children with a brain injury, with reports suggesting that current provision is inadequate (Limond et al., 2009; Zinner et al., 1997). Research has explored the needs of families of children with a brain injury. It is suggested that families where the child has a TBI have more unmet needs (Armstrong & Kerns, 2002; Aitken et al., 2009). Armstrong & Kerns (2002) compared three groups, OI, DIAB and TBI. The TBI group reported more unmet needs, including the need for medical/health information, professional support, community support, networks and involvement in their child care. However this is the only study to examine the family's needs following TBI, suggesting more research is needed in this area to improve our understanding.

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VOLUME I

CHAPTER TWO

EMPRICAL PAPER

MOTHERS' PERCEPTIONS OF THE

IDENTITY OF CHILDREN WITH

ACQUIRED BRAIN INJURY

Word count: 6110

ABSTRACT

INTRODUCTION: Acquired brain injury (ABI) can have a life changing impact on both the individual themselves and their families. Research with adults has examined changes in identity following a brain injury; however there is lack of research examining identity in children following a brain injury. The aim of this study was to explore mothers' perceptions of their children's identity following a brain injury using interpretative phenomenological analysis (IPA). METHOD: Five mothers were interviewed between 1 and 8 years after their child's injury and children were aged between 4 and 15 years at the time of injury. RESULTS: The analysis generated two main themes and one non-dominant theme. Loss was something that was highlighted by all of the mothers, including loss of abilities and participation, loss of friendships and relationships, loss of a future, loss of pre-injury child: different child and loss of place and status in society (including not fitting in, negative labels from others and the contribution of the 'hidden injury'). Alongside the theme of 'loss' was the non-dominant theme of 'positives' (e.g. achievements, continued friendships), which seemed to enhance the feelings of 'loss'. The final theme related to the 'construction of a new identity' which describes the ways the mothers constructed the child's new identity after the injury, including comparisons with pre-injury child, comparisons with other children and the child's own responses. Participants in this study had reconstructed the identity of their child following the brain injury, and this reconstruction was a rather negative one in which the child was defined in terms of loss, deficit and difference. These themes are discussed in relation to the literature relating to conceptualisation of a different child, grieving and re-bonding with a new child, changes to relationships and understanding of the injury. The relevance of the findings to clinical practice and recommendations are discussed and a critique of the study is provided.

INTRODUCTION

Research with adults who have experienced acquired brain injury (ABI) has explored identity change following the injury. ABI can affect personality, emotional response and abilities (social as well as cognitive and physical); these may in turn have an impact on the person's ability and willingness to participate in valued roles and activities in employment, family life and leisure. All these changes can challenge the person's sense of who they are and also other people's perception of their identity (Persinger, 1993; Muenchberger, Kendall & Neal, 2008; Ylvisaker & Feeney, 2000).

These changes in perceived identity can have negative consequences. Negative views of the self can be associated with shame, worthlessness, depression, social withdrawal and lack of achievement (Morton & Wehman, 1995; Parker, 1996; Simpson, Mohr & Redman, 2000). Negative perceptions of others can also have unhelpful consequences. They may lead to stigmatization and lack of access to important social activities and roles within society (Cloute, Mitchell & Yates, 2008). Social feedback and perceptions of others are also key to how we perceive our own identity: a negative construction of our identity by others can have a negative impact on our construction of our own identity (Gelech & Desjardin, 2011). In particular the perceptions of those who are particularly important to us, for example our parents, friends and family, are crucial (Bowen et al., 2009; Cloute et al., 2008). For example, someone who is avoided by other people in social situations may incorporate this into their sense of who they are, e.g. as being someone who is unpopular and disliked.

Given the potential significance of these consequences of identity change, it is important to understand how ABI affects how people perceive themselves and how others see them. Helping them to feel more positive about themselves and facilitating a more positive perception of them by others may have significant benefits (Cloute et al., 2008).

The majority of research examining the impact of ABI on identity has been with

adult populations. However there is less research concerning this issue in children. There is some research on the perceptions of parents in general, but this has not focused specifically on their perceptions of their child's identity.

For younger children, the parents are particularly important figures in their life, and so they may be particularly important influences on the child's self-perception after ABI (Roscigno & Swanson, 2011). Therefore it is important to understand how parental perceptions of the child may be affected by the ABI. Some themes have emerged from qualitative research with parents which suggest that parental perceptions of the child's identity can be significantly challenged by ABI: experiencing grief for the child they have lost (which implies a new identity for the child post-injury); the need to rebuild their relationship with the child (which similarly implies change in the child's identity); and protecting the child from stigma and devaluation by others (which suggests changes in how others perceive the child's identity) (Clark, Stedmon, & Margison, 2008; Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2005). However, these themes have emerged as part of an exploration of the wider experience of being the parent of a child with an ABI, and there appears to have been no studies that have addressed the issue of identity directly.

As a result of this gap, this research focused on a qualitative investigation of mothers' perceptions of their child's identity pre- and post-injury. The aim of this study was to explore how mothers perceive the identity of their child following ABI; and to explore whether there is a change in their perceptions.

METHOD

Design

Interpretative phenomenological analysis (IPA) was chosen to gain a rich understanding of how mothers' perceive their child's identity following a brain injury. It was anticipated that there would be differences in how mothers reacted to their child experiencing ABI and therefore a method was needed that allowed a detailed exploration of each individual case, with less emphasis on commonalities across individuals and no emphasis on theory. IPA aims to enable the experience to be expressed in its own terms, rather than according to predefined category system (Smith et al., 2013). This approach is unique as it uses a combination of psychological, interpretative and ideographic components. IPA involves a two-way process; the participant attempting to make sense of their world and the researcher attempting to make sense of the participants' attempts to make sense of their world (Smith, 2008). This approach also acknowledges that this process is done through the researcher's own interpretative lens (Willig, 2003).

IPA holds the assumption that the researcher can gain access to sTable and enduring cognitions and beliefs, through analysing what participants say (Smith, 2008). This is important in the current study as at times the mothers were asked to think about their child retrospectively.

Alternatives such as thematic analysis could have been used; however this type of analysis has limited interpretative power and can provide a more descriptive account if not used with an existing theoretical framework (Braun & Clarke, 2006). Qualitative approaches with a more theoretical focus, such as grounded theory, were less appropriate because of the larger samples required by this approach, and because this area of research is in its earlier stages and the more exploratory focus of IPA seemed preferable.

Participants

The current study sought a purposive sample, in line with IPA methodology (Smith et al., 2008). Five participants were recruited through the Child Brain Injury Trust (CBIT) (a UK charity supporting children with a brain injury and their families). Participants were mothers of children who had experienced an ABI.

Potential participants were identified and contacted by a member from the CBIT team and sent an invitation-to-participate letter. Names of mothers who expressed an interest in participation were then given to the researcher, who contacted them and gave an information sheet which outlined the research in more detail. They were then given the opportunity to ask any questions about the study and given 24 hours to consider the research. After this time they were contacted and interviews were arranged with those who agreed to participate. All interviews were conducted in the homes of the participants and at a convenient time for them.

Children who had an acquired brain injury were included. It was decided that only children with suddenly-acquired non-degenerative conditions, such as traumatic brain injury, would be included. Children with degenerative conditions were not included as it was felt that these types of conditions could be associated with a different range of parental reactions.

Children were required to be at least one year post-injury; this was used as it was felt that more substantial changes in perceptions of identity might not occur during the earlier stages after the ABI. Also the early stages of acquired brain injury often involve rapid recovery, which may make it more difficult for mothers to form a settled perception of their child's identity. Mothers were English speaking, as funding was not available for interpreters. Children were required to be at least 4 years old at the time of the injury. This meant that they had started education; this was important as an interest in the research is the way mothers perceive others' reactions to their child. At the time of interview children were under 18 years old, as this is a study relating to children.

Mothers who were known to be particularly distressed by the injury were excluded, due to the emotive nature of the interviews. Also mothers with severe mental health difficulties or learning difficulties were not included. This exclusion criterion was included as the interviews required the mother to have an ability to reflect meaningfully on their situation and these types of difficulties may affect this ability.

Table 1: Participant characteristics

Participant name[1]	Age of mother	Occupation of mother	Number of children	Child name[2]	Type of injury	Gender	Age at time of injury	Age at time of interview	Time since injury
Mary	42 years	Catering assistant	Three	Martin	TBI Bicycle accident	M	4 years 11 months	12 years and 7 months	7 years and 8 months
Elizabeth	47 years	Government worker	Two	Alan	TBI Bicycle accident	M	8 years and 5 months	16 years and 5 months	8 years
Laura	50 years	Administrator	Two	Emma	ABI Stroke	F	15 years and 6 months	17 years	1 year 6 months
Clare	48 years	Midwife before injury but gave up work to care for son	Three	Jack	ABI resulting from a heart condition	M	4 years	6 years and 11 months	3 years 11 months
Melissa	48 years	Care assistant before injury but gave up work to care for son	Three	Peter	ABI Encephalitis	M	11 years and 10 months	16 years	4 years and 2 months

[1] All names have been changed to maintain confidentiality
[2] All names have been changed to maintain confidentiality

Interviews

The interviews were semi-structured with four broad areas covered. These areas were derived from reading relevant literature, leaflets and through discussions between the researcher, research supervisor and clinical supervisor. During the interview the mothers were asked to think about their child, for example their strengths, likes, dislikes and personality; school, in terms of relationships with teachers and friends and their role as a pupil; family life, including their role within the family, relationships with siblings, father, grandparents; and finally they were asked to think about their child in a wider social context, for example the community view of the child and friendships outside of school. As well as covering these areas, mothers were asked to think about the child's identity from the perspective of others, for example fathers, teachers, friends, community. The interviews covered these areas in terms of how the child was pre-injury and how they are post-injury (see Appendix 2 for the interview schedule). Mothers were given the opportunity to bring photographs or show footage of their child pre- and post-injury if they felt this would add to their description. One of the mothers chose to show footage and photographs. The interviews lasted from between 35 minutes and 2 hours 50 minutes. The participants were given the option of having one or two interviews. Four of the five participants covered both pre- and post-injury in one interview.

Ethical considerations

The study was reviewed and granted approval by the University of Birmingham ethics committee, as the participants were not clients of a recruiting NHS service (see Appendix 3 for ethics approval letter). Approval was also granted from the CBIT research and development committee. Participants were not approached by the researcher until this

had been discussed and agreed with them by a member of the CBIT team. The researcher also followed the guidelines for confidentiality outlined in the Data Protection Act 1998.

PROCEDURE

Data collection

Informed consent was obtained from mothers who agreed to participate and they signed a consent form before starting the interviews (see Appendix 4 for consent form). Interviews were either conducted as two interviews or one longer interview that covered pre- and post-injury. Interviews were audio-taped with the permission of the mothers and then transcribed for analysis. Mothers were asked if they were happy for the entire interview to be transcribed or if there were parts they would like omitted, although all mothers agreed for the whole interview to be used.

During the interviews the researcher monitored any distress experienced by the participants. The researcher and interviewer was a Trainee Clinical Psychologist who is experienced in identifying and dealing with distress. If the interviewer felt that the mother was becoming distressed, the interview was paused or stopped and emotional support provided. Mothers were given the chance to reflect on the process of being interviewed and highlight any difficulties. The intention was that, with their consent, mothers who became distressed could be signposted to services and their local collaborator informed so that they could access support available within the service (although no one requested this). The CBIT helpline was also included on the information sheet. If there were any concerns about the mothers or child's well-being, it was intended that the services involved and the GP should be informed and this was communicated to mothers prior to participation in the information sheet (again this was not necessary in any of the five cases).

Analysis

IPA does not prescribe a specific technique or method of analysis (Smith et al., 2013). The main aim of the analysis is to move from the descriptive to the interpretative (Smith & Osborn, 2003).

In order to be immersed in the data the transcripts were read and re-read, with initial notes on anything of interest recorded (exploratory comments). During this stage the analyst maintained an open mind and developed a familiarity with the transcript and the ways the participant talked about, understood and thought about their child's identity (Smith et al., 2013). The transcripts were analysed individually, with exploratory comments made on the each transcript before moving on to the next one. The exploratory comments were then analysed to identify emerging themes and ordered chronologically. Following this, connections across emergent themes were identified.

Following this stage of analysis, patterns across cases were identified, asking questions such as how does a theme in one case help illuminate a different case, and which themes are the most potent (Smith et al., 2013). This stage resulted in two main themes and one non-dominant theme.

Establishing credibility

The researcher's interpretations of the transcripts and emerging themes were further developed in discussions with a research supervisor and clinical psychologist and modified in accordance with these discussions. These discussions took place in regular meetings scheduled throughout the analysis process.

The findings of the research were also presented at a paediatric psychology team meeting at Birmingham Children's Hospital and feedback was obtained. Feedback suggested that the findings mirrored the clinical experience of Clinical Psychologists

working in the area. The participants were also contacted once the preliminary themes had been identified and participants were able to provide comments on these themes (see Appendix 5 for participant feedback). Feedback was sent by four of the five participants, suggesting that the findings were an accurate representation of what the mothers had experienced and that it was normalising for the mothers to find out others had a similar experience. None of the mothers disputed the findings.

Throughout the analysis the researcher sought to maintain a reflexive stance, with an awareness of the influence of personal experiences and values on the interpretation of the data. The researcher kept a reflective log in order to reflect on the process of analysis and increase awareness of what the researcher brought to the analysis process. Given that the researcher had previous experiences of working with families of children with ABI, it was important to recognise the impact this may have had. One example from the log was the researcher being mindful of previous experience with individuals with a brain injury not fitting into services and the frustration associated with this experience. Reflecting on this, it was important to make sure that this aspect of the analysis reflected the concerns of the participants rather than the researcher's own concerns. Therefore particular care was taken to ensure that this aspect was thoroughly supported by excerpts from the interviews and that it was raised as an important issue by at least some of the participants.

As further steps to establishing credibility, verbatim quotes are used to highlight key ideas relating to each theme and illustrate similarities and differences between participants' experiences. An audit trail is also provided: Appendix 6 provides an example of how the themes were developed from the raw data and enables the reader to see the processes which have been used. Appendix 7 shows an example of coding on a section of transcript.

RESULTS

Two major themes were identified and are described in this section with interpretative comment. The non-dominant theme of 'Positives' will be discussed alongside the dominant theme of 'Loss'. These themes will be discussed in terms of the existing literature in the Discussion section.

The following themes emerged from the transcripts:

- Loss (dominant theme)

- Positives (non-dominant theme)

- Construction of new identity (dominant theme)

These main themes and the sub-themes are illustrated in Figure 1. This diagram is meant to aid the reader's understanding of the themes, and is not meant as a model or theory.
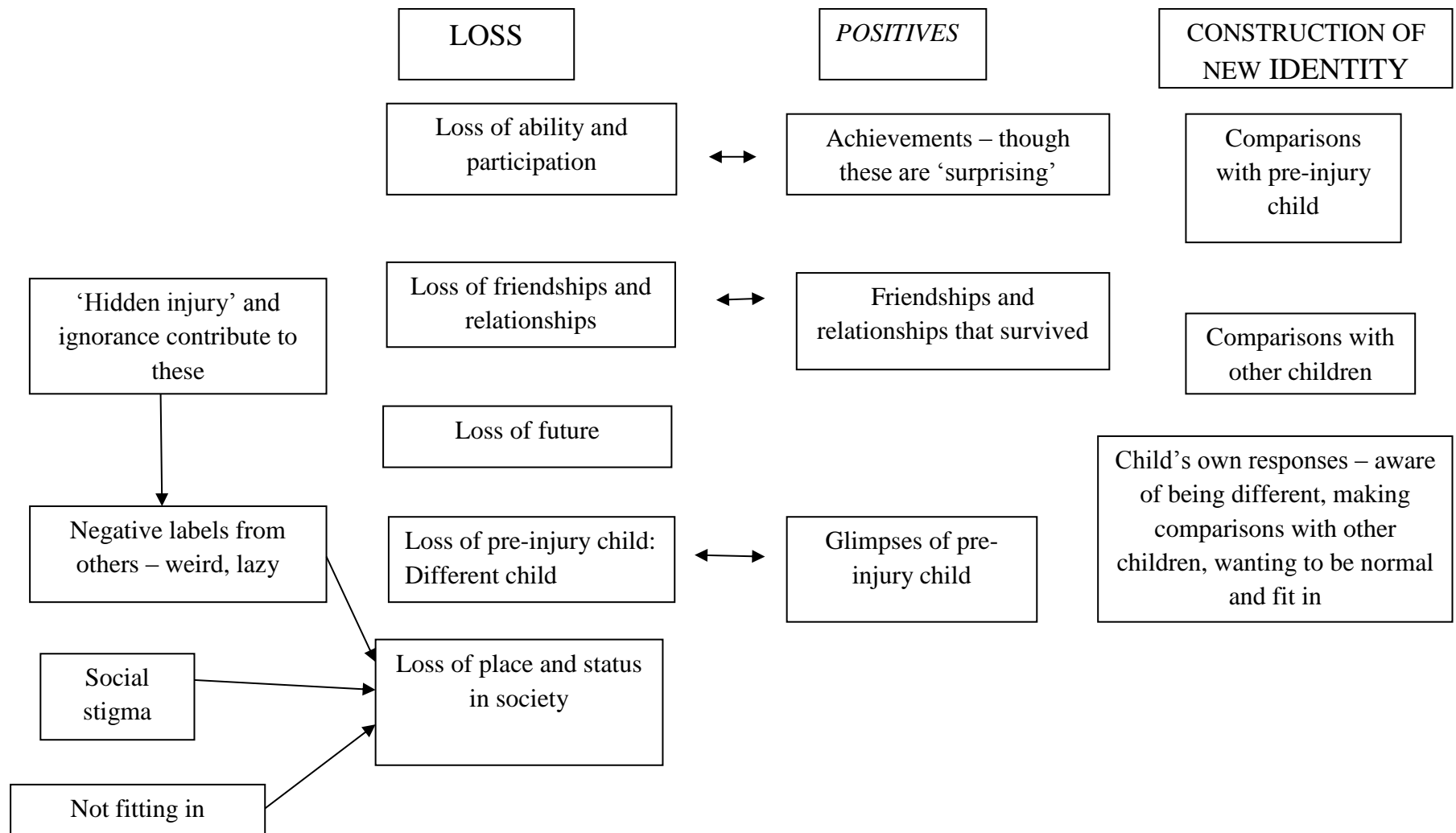
Figure 1: Development of themes

Loss

Loss was something that all of the mothers highlighted. The loss mothers discussed will be grouped into sub-themes including loss of abilities and participation, loss of friendships and relationships, loss of a future, loss of pre-injury child, different child ,and loss of place and status in society (including not fitting in, negative labels from others and the contribution of the 'hidden injury'). Alongside the theme of loss, the positives that were highlighted by mothers will be discussed, however in many cases these positives seemed to serve to enhance the feeling of loss.

Loss of abilities and participation

The impact the injury had on abilities and likes of the child was an area that the majority of the mothers commented on. They commented that as a result of the injury their children would avoid certain activities or the type of activities they participated in was different to before the injury.

'At the moment he just shies away from physical stuff um because he finds it difficult, so difficult' (Clare)

'"I'm (Alan) not doing anything" or "I'm (Alan) doing a jigsaw", you think that's a bit of a shame because he would be doing different, he wouldn't be doing that just' (Elizabeth)

They described the frustration that their child felt as a result of not being able to do the things they did before the injury.

'She has found it frustrating being poorly and tired because she can't do everything she wants to do' (Laura)

'He knew he was able to do things, so oh "I (Jack) used to be able to do it and now" and you can see the frustration in his eyes' (Clare)

Although there were abilities or hobbies that the child had lost, there were also some hobbies which were retained.

'Still loves his art, that's one thing he's kind of got in common before and after, still loves his art' (Melissa)

Positives: Achievements

Although mothers commented on loss of abilities, they also described their children surprising both themselves and others in terms of what they can do. However given that these achievements were viewed as a 'surprise', this may imply a general context of negative expectations and perceptions.

'All I would say to you is everything he does now is a surprise to us' (Elizabeth)

'Then she'll surprise herself, like with her exams' (Laura)

However there were times that the mothers highlighted things that the child was good at without expressing surprise at it. For one of the mothers in particular there was more a sense of pride in the achievement.

'He loves anything that's on the IPAD or the DS and games and he's very good at it, he's very quick thinking and this is stuff he can beat the pants off most people, my friend's son came round and he's fourteen and you know he was beating the pants off him on the Wii, so you know he knows what he excels at' (Clare)

Loss of friendships and relationships

A change in relationships with siblings, parents and peers was something described by the majority of mothers interviewed.

'I've noticed a marked difference…they don't play like this anymore, not just because she's (sister) older, they clash, she doesn't make allowances for his injury' (Clare)

Lost relationships as a result of the injury were also discussed, both with parents and with peers.

'He doesn't see his dad anymore so this is where it all went wrong, Sam was never accepting of the accident, the brain injury or anything could possibly be wrong with his son' *(Mary)*

'What he's lost is really huge because like he desperately, desperately wants friends' *(Elizabeth)*

Mothers also commented on re-establishing relationships, particularly the father-son relationship.

'Now it's a good relationship, it is a father and son relationship again which he's (Dad) worked really, really hard to re-establish' *(Elizabeth)*

Positives: Friendships and relationships that survived

Although some relationships were changed or lost, mothers also commented on the importance of relationships that remained constant. In particular this tended to be relationships with grandparents.

'He still has a very good relationship with my dad, um my dad, my mum' *(Mary)*

Although some of the children had lost friendships, others had retained friends that did not see them as any different to before the injury. Mothers felt that this was an important source of support for their child.

'She (Jack's best friend) sees Jack, she doesn't see the lack of ability and she makes him do stuff, which I love, I absolutely adore that she does that and she's the one true friend he will always have…doesn't see him as the kid that wobbles, she just sees him for who he is and it's wonderful' *(Clare)*

One of the mothers described her daughter retaining all of her friends following the injury. Laura's story was different to the other mothers as Emma retained all of her relationships following the injury.

'She's got a really close knit circle of friends that she's had the whole time…all her friends have come through it, and they're all still really good friends now' (Laura)

Loss of the future

All of the mothers discussed a change in expectations, with the majority of the mothers feeling that they do not have any particular expectations for their child; they feel the future is uncertain and they take things 'day by day'.

'You can't say that's going to happen, you can't say that he's going to be the same person when he's fourteen as he is now' (Clare)

'I don't know what the future holds' (Mary)

'You kind of take it day by day' (Melissa)

The majority of mothers described hoping that their children will be happy in the future.

'She's more open minded and to be quite honest I couldn't care less, I've got to that stage now where as long as she's doing something that makes her happy' (Laura)

'My bottom line is I just want to see him happy, I don't want to say I want him to do x, y and z because then again that's going to put pressure on him' (Elizabeth)

'I do hope that he'll get a job where he's happy' (Melissa)

Mothers also discussed the loss of future abilities such as being able to drive and living independently.

'There are going to be some things that these others, like when they drive he probably will never drive' (Elizabeth)

'There are still things Martin can't do or will never be able' (Mary)

'Will he always need someone around to help him, I think that could be the case, would he be able to live alone?' (Mary)

Loss of pre-injury child: Different child

All of the mothers interviewed commented on feeling like they had a different child after the injury. This appeared to happen at different stages for the mothers, ranging from as soon as the injury happened (Mary and Laura) to later in the recovery stage, as seen in Clare's quote.

'Instantly from when he woke up after the accident after the operation I knew I had a different child' (Mary)

'I said to him um I needed to get up the next day ready to take home a child that I didn't recognise… you know I had Emma for 15 years as this bright, bubbly, full of energy um child, who's to say what I could have taken, or who I was going to take home' (Laura)

'This is on the cardiac ward at Birmingham children's hospital (shows footage)…we didn't see a lot of the personality stuff because we were concentrating on him' (Clare)

Positives: Glimpses of the pre-injury child

Mothers described still seeing elements of the child they had before, but it seemed as though these occurrences could sometimes serve to enhance the sense of difference because they invited a contrast between then and now.

'Catch a glimpse of who he used to be… but uh he is totally different in a lot of ways, you know very, very different and I think that's probably going to be the hardest thing for me to cope with' (Clare)

They described a process of adjusting to a new child and grieving for the child they had before the injury. Mothers commented on getting to know and bonding with this 'new' child.

'You know it's like somebody dying isn't it…in some respects coz we've still got him, but you know have we still got him, you know it is that old scenario of changeling isn't it' (Clare)

'It's like re-bonding with a different child, it's like someone's taken them away and brought them back different' (Melissa)

Positives

Some mothers also commented on some positive changes that happened as a result of the injury, for example trying new things or becoming more empathetic or loving.

'He is very loving so maybe he might not have been that loving' (Mary)

'Whereas now we've got a completely different Peter, he'll want to try new things, he's in the sea cadets you know he loves it, you know he wants to join clubs' (Melissa)

Loss of place and status in society

Mothers commented on the social stigma of having a child with a brain injury, not 'fitting in' and negative perceptions of others.

Social stigma

Social stigma and how others perceived their child was something that the majority of mothers commented on, with mothers feeling that others would avoid them or that they would feel others were looking at them.

'Nobody would come near you; they would cross the street rather than look into my eyes, and look at me and say ah you poor thing' (Elisabeth)

However it was sometimes unclear whether other people were looking at them or whether the mother thought that they were looking at them.

'He cleared a whole physio department by pressing the fire alarm once, we actually cleared it and this bells going…you know there's all these people looking at you thinking oh god I don't believe this' (Elizabeth)

Not fitting in

Normality was another area that mothers mentioned, with mothers feeling that their children wanted to 'fit-in' and be 'normal'.

'He's just trying to be normal or what's normal, fit into society when really he's just trying to manage' (Elizabeth)

'What she's really struggles with is the fact that um she just thought she'd be poorly in hospital, get better and go back to normal; and I think that's the biggest thing for Emma to come to terms with is the fact that in that split second her life changed dramatically' (Laura)

'Fitting in' particularly at school was described as a difficulty by the majority of the mothers, with a lot of the children having to move schools after the injury. Mothers generally had a sense that their child did not fit in to the groups that are prescribed by society.

'So this is what I mean about square peg in round hole; he doesn't fit - he can't - into a non-disabled youth club and he can't fit into a disabled one' (Elizabeth)

One of the mothers highlighted that normality can often be a challenge.

'It's a shame because we wanted him to try and have that bit of normality and it was totally ruined (by others leaving him alone)' (Melissa)

Negative labels from others

Mothers also commented on others' perceptions of their child, including teachers, grandparents, siblings and peers. Most of these perceptions were negative with mothers using

terms such as 'lazy', 'naughty' and 'weird' to describe others' views. One mother also described others not understanding that this is part of his injury.

'He has been labelled as lazy and uncooperative and not wanting to work' (Mary)

'"He's a naughty child", if I hear my father-in-law say that one more time I'm going to get exceedingly annoyed with him, so he's not a naughty child, this is a head injury' (Elizabeth)

'I think they thought he was weird or something you know, I mean it's just kids but it was um, I think they found when he's a bit childish and acts like a child sometimes I think they find that, you know, they didn't understand that it was part of an injury or illness you know, they just thought he was a target you know' (Melissa)

Linked to this theme is what mothers described as a 'hidden injury' and ignorance, and how this may contribute to others' negative views of the child. Four of the five mothers interviewed commented on the brain injury being a 'hidden injury' that is not visible to others. They compared the injury to visible changes such as a broken leg.

'You wouldn't see that he's got a head injury' (Elizabeth)

'It really is the hidden injury, you know people can't see it, it's not like a broken leg' (Clare)

'I think that's another thing that she found frustrating when she did go back to school as she tried to, um the assumption was that she was back to normal' (Laura)

Linked to the injury being 'hidden' is the choice that the family has of whether to disclose the injury to others. Mothers commented on this being a difficult choice and the advantages and disadvantages of both disclosing and not disclosing.

'She found it really hard when she was in school because she said on the one hand she didn't want to keep talking about it, but on the other hand she felt that perhaps they didn't realise how much she was struggling' (Laura)

'The thing is it's the lesser of the two evils; the school and the sea cadets have said to me do you want us to make the children aware of his disabilities and illnesses, and it's the lesser of two evils, yes certain children will think ok now we understand how he is and there's the other half that will find him a target for bullying, so you don't know what to do, you can't do right for doing wrong, you know, what do you say yes or no?' (Melissa)

'When you look at a child that looks normal and acts normal up till an extent it's difficult to try and explain to people "no he has got these problems"' (Melissa)

One mother also commented on holding different views about disclosure to her husband.

'You either go two ways you either hide them away and think that's it or you say to hell with everybody this is Alan...and I said to my husband will you stop telling everyone, stop telling them he's got a brain injury'(Elizabeth)

Construction of new identity

This theme highlights processes involved in the mother's construction of her child's identity following the injury. This includes comparisons with pre-injury child, comparisons with other children and the child's own responses.

Comparison with pre-injury child

In talking about loss, mothers often used comparisons of their child before (pre-injury) to illustrate the difference.

'Looking at how he was, he is completely different, "who are you and what have you done with my son?" is something you want to say on a regular basis, you know because I know, I know that is your brain is what makes you, you isn't it?' (Clare)

'So before the accident I would say he was having quite a good social life, after the accident that stopped' (Mary)

'Another thing he lost was his sense of humour, couldn't get a joke, had a wonderful sense of humour before his accident' (Elizabeth)

'He'd never be able to do music now, before he could read the notes and understand, now he can't, and he wouldn't be able to do it' (Melissa)

Comparisons with other children

The majority of the mothers made comparisons both pre- and post- injury between their child and peers and siblings. These comparisons were in terms of progress at school, friendships, abilities, development and social activities, for example attending parties. Mothers compared their children positively to peers pre-injury, with mothers feeling that their child excelled in certain areas.

'He was up there with the best of them you know, he could write his name, he could recognise words, they were starting to read, yeah so he was no way behind or anything like that' (Mary)

'He was intelligent, he was in the top quota in his class' (Elizabeth)

Post-injury there appeared to be a shift in the type of children the mothers compared their children to, with the mothers comparing their children to children with disabilities.

'There are some up there that are non-verbal and they can't tell you whether they've had a good day or bad day or whatever you've just got to guess. He can actually tell you, which is lovely' (Elizabeth)

Post-injury in terms of social activities, mothers felt that siblings and peers were taking part in social activities that their child was not.

'He won't go to parties; he doesn't go to friends' houses if he is invited' (Mary)

'I see other children his own age now and they've just left school and they've all done proms' (Elizabeth)

One mother also compared her child to his friend, feeling her son was not as mature and his friend has to 'look after' him.

'You can see the difference between him and Martin even though they are the same age; Mathew is more mature but he looks after Martin' (Mary)

Mothers also commented on how painful making these comparisons could be. They described distancing themselves from others or avoiding situations that were reminders of what their child would have been like or could have achieved.

'I have a constant comparison because my friends' daughter, Dawn, is born on the same day as Jack…. she is everything he was, and it's probably good that she has moved to Germany' (Clare)

*'Every time I walked in there was a constant reminder because I would have said the old Jack would have actually p****d all over these children in metaphorically speaking, in as he would have been top of the class for everything, he would have been top of the class for achieving everything, yeah, so half of me it was a constant reminder going there' (Clare)*

'I suppose she's (Elizabeth's niece) doing things that I would have expected Alan to be doing at this stage….and I couldn't do it, I couldn't go to events that she was doing and seeing her because I kept thinking what's Alan got, all his friends disappeared'(Elizabeth)

Child's own responses

As well as mothers and other people noticing a difference, they described the child being aware of being different, making comparisons with other children, and wanting to be normal and fit in.

'He knows he's different and he sees himself as different' (Melissa)

The mothers also described the child themselves identifying with children with their own difficulties.

'I think he feels comforTable around that environment because I think he thinks other people have either got problems like him, or the people looking after them know that they've got a problem' (Melissa)

Mothers also described their child themselves making comparisons with their peers.

'He is genuinely p****** off and angry and sad at the fact that he can't do stuff...the things that he wants to do now I mean he realises now he's comparing himself to his peers' (Clare)

'He will go to school today and no doubt have anything from one to a hundred reminders that he can't do what the other kids can do' (Clare)

DISCUSSION

The aim of the current research was to explore mothers' perceptions of their child's identity after an ABI. The data suggest that the participants had redefined their child's identity, and that the child was perceived as a different person to the pre-injury child. Furthermore, this redefinition was primarily shaped by a sense of loss, deficit and difference – the child was essentially viewed in terms of the loss of their abilities, friendships, relationships, place and status within society; and perceived as a child who does not fit in, who is vulnerable to bullying and negative labelling, and who has a worrying and uncertain future instead of a hopeful and expectant one. Although there were sometimes positive perceptions of the child's identity (e.g. excelling at computer games, retaining hobbies), these were often expressed in the context of surprise or a list of more negative perceptions, and the surprise or contrast seemed only to highlight the loss that dominated the mother's reconstruction of the child's identity.

Some of the themes arising from this study resonate with themes from other qualitative studies of parents of children with ABI, and with other evidence in this field. This research will be discussed in the sections below.

Loss of friendships and relationships

Disruption to peer relationships has been suggested as a consequence of childhood brain injury, which is of particular concern to the children themselves (Bohnert, Parker, & Warschausky, 1997). Loss of peer relationships was commented on by mothers in the current study, with one mother feeling that her son 'craved' peer relationships. However mothers also described positive peer relationships and continuity of relationships that were important to the child. Continuity of peer relationships was also found by Bohnert et al. (1997), although they

found that girls were more likely to have continuity in friendships that predated the injury, as in this study. More research is needed examining the factors that help maintain relationships despite the child having an injury (Bohnert et al., 1997).

Change in relationships with siblings was also reported by the mothers in the current study. In comparison with children with orthopaedic injuries, more negative relationships between a child with a brain injury and their siblings after the injury have been found (Swift et al., 2003). It has been suggested that siblings of children with brain injuries are at greater risk of developing psychological difficulties, including low self-concept, distress and depression (Perlesz, Kinsella & Crowe, 1999; Swift et al., 2003; Verhaeghe, Defloor, & Grypdonck, 2005). However further research is needed into the impact of brain injury on siblings.

Mothers also commented on loss of and changes to the father-child relationship. In one case the child had lost his relationship with his father and the mother felt that this was due to the father not accepting that there was something 'wrong' with his son. Elizabeth also commented on the 'hard work' that it took to 're-establish' the father-son relationship after the injury. This relationship has not been explored in the literature to date and may be an important area where understanding is needed into why relationships breakdown.

Loss of future

As well as grief for the lost child, mothers also commented on the loss of the future for their child, describing feeling uncertain about the future. Mothers described the loss of future abilities such as being independent and able to drive. Uncertainty has been previously reported in the brain injury literature and it is suggested that this uncertainty is a source of ongoing stress for mothers (Kao & Stuifbergen, 2004). Kao and Stuifbergen (2004) examined

both the experience of the survivor of the brain injury and their mother using a phenomenological approach. They found that during the period of uncertainty mothers can sometimes struggle to balance protecting their child and allowing them to be independent (Kao & Stuifbergen, 2004). Similar to the current findings, loss of a 'normal' future and the loss of hopes and dreams associated with 'normal' development has been previously reported (Collings, 2008). It has been suggested that parents often 'suspend' their expectations of normal family development following a brain injury (DeMarle & Le Roux, 2001). This was seen in the current study with mothers describing taking things 'day by day'.

A brain injury can also mean that the expected stages of parenting are prolonged, such as caring for the child longer than normal and the prevention of some stages of adulthood, such as having the child establish a career, relationships and their own families, with old hopes and expectations being dismissed (Collings, 2008). Mothers in the current study also commented on this, questioning whether their child would be able to drive or living independently in the future.

Loss of pre-injury child – different child

All of the mothers felt that they had a 'different' child following the injury and used comparisons to the child they had before. This was also something reported by the mothers in Clark et al.'s. (2008) study, with a comparison drawn between 'former self' who mothers felt had been 'lost' and the child they had now. This loss has been described as representing a 'partial death' or 'partial living' for the mother, as described by one of the mothers in the present study (Zinner, Ball, Stutts & Philpott, 1997). The process of re-bonding highlighted in the current study was also reported by mothers in Clark et al.'s. (2008) study. The need to rebuild their relationship with their child, would imply that there has been a change in the child's identity (Clark et al., 2008; Wongvatunyu & Porter, 2005). Grief for the 'lost child'

would imply a new identity for the child post-injury (Kao & Stuifbergen, 2004). The stage at when the mother realised they had a 'different' child was different, with some of the mothers feeling that their child was different from the time of the injury and others noticing the change later on. This variability is consistent with suggestions in previous literature that there is no 'formula' for the parental grieving process (Bruce & Schultz, 2001). Collings (2007) explored parental grief in response to ABI through interviews with five parents of young people who sustained ABI in late adolescence or early adulthood. Collings (2007) suggests that current models of grief suggesting a linear, time-bound process of grieving do not seem to account for this type of loss. The continued presence of the child complicates any process of grieving. It is suggested that a model that acknowledges the fluid, dynamic and ongoing nature of this kind of grief is more applicable to ABI (Collings, 2007). However more research is needed to explore this way of conceptualising grief.

Loss of place and status in society

A sense of their child not fitting in and the social stigma associated with having a brain injury was highlighted in the current study. Experiencing a brain injury can lead to the young person feeling 'abnormal', in terms of not meeting societies, families and their own expectations of 'normality' (Kao & Stuifbergen, 2004). This 'abnormality' can make individuals with a brain injury susceptible to criticism from others, with negative responses sometimes leading to social withdrawal and the family becoming estranged from the community (Kao & Stuifbergen, 2004).

The majority of the mothers commented on the others' perceptions of their child, including teachers, grandparents, siblings and peers, with these often being negative perceptions. Negative perceptions can lead to stigmatisation, lack of access to important social activities and roles within society (Cloute, Mitchell & Yates, 2008). The way others

perceive us is also key to how we perceive our own identity, with a negative construction of our identity by others having a negative impact of our own construction (Gelech & Desjardin, 2011).

Linked to this theme is the dilemma parents faced about whether they disclosed their child's injury to others. Mothers highlighted the pros and cons of disclosure and feeling that a brain injury is a 'hidden' injury. 'Managing perceptions of others' is seen as crucial to identity formation and this seems to be what the mothers in the current study were describing (Cloute et al., 2008). One of the issues highlighted with disclosure is the child being singled out as different and the associated stigma (McClure, Buchanan, McDowall & Wade, 2008). Parents may also fear that their child may be ridiculed or bullied as a result as being seen as part of an 'out-group' (McClure et al., 2008). Again parents seeking to protect their child from stigma and devaluation by others would suggest changes in how others perceive their child's identity (Clark, Stedmon, & Margison, 2008).

LIMITATIONS OF THE STUDY

The findings presented in this study are those derived from five mothers' experience of parenting a child with a brain injury. The findings are not intended to be generalizable to the whole population, but the intention was to present the experience of five mothers that others may use to guide their own understanding of this area.

In line with Yardley's (2000) principles of assessing quality in qualitative research, the researcher has attempted to be transparent about the stages of the research process including the selection of participants, the interview process and what steps were used in the analysis stage. In order to enhance credibility the findings were developed in meetings with a research and clinical psychologist; the findings were fed back to a paediatric psychology team and feedback obtained; a summary was sent to the participants with feedback suggesting that the participants agreed with the findings; a reflective diary was kept throughout the process; verbatim quotes were used to illustrate themes and parts of the analysis are provided for the reader. However it is acknowledged that the results are the researcher's interpretation.

Unfortunately due to difficulties with recruitment, the study included children with both traumatic brain injuries and other forms of acquired brain injury (for example stroke, encephalitis). It is difficult to know whether some of the experiences described may have been specific to one or other form of injury and further research could seek to recruit mothers of children with only traumatic injuries. There was also variation in the severity of the injuries the children had experienced. Further research could just focus on mothers of children with severe injuries.

It is worth noting that the conclusions drawn about the child themselves and their perception of difference was derived from the mother's experience rather than the child's

themselves. Further research examining the child's perception of their own identity would be needed to explore this further.

RESEARCH AND CLINICAL IMPLICATIONS

The mothers in this study reconstructed their child's identity predominantly in terms of loss, deficit and difference. Their children were perceived as having lost abilities, friendships, relationships, place and status within society; and as children who do not fit in, who are vulnerable to bullying and negative labelling, and who have a worrying and uncertain future. One would expect that this might be a source of distress to the mothers, and a barrier to effectively coping with their child's ABI. More research needs to be done in terms of what impact these negative identifications have on the mother's emotional response to what has happened, and in terms of what impact they have on how they try to assimilate and cope with what has happened.

As noted in the introduction, the feedback and perceptions of others are key to how we perceive our own identity: a negative construction of our identity by others can have a negative impact on our construction of our own identity (Gelech & Desjardin, 2011). In particular the perceptions of those who are particularly important to us, for example our parents, friends and family, are crucial (Bowen et al., 2009; Cloute et al., 2008); and the parents' perceptions are critical to how the child constructs their own identity. More research is needed on this issue in the context of children with ABI. If the mother reconstructs their identity in some of the negative ways evident in this study, what impact does this have on how the child's own self-identity?

This issue about the negativity of the new identity also has clinical implications. Services should be more aware of how mothers might be struggling with the identity of the

child post-injury. Perhaps it would be beneficial for services to focus on helping mothers to reconstruct their child's identity in a more positive way. If there are issues of grieving to be dealt with, then it is important that traditional models of grief are not rigidly applied to this group. It appears that the grief process for parents of a child with a brain injury is different to what current models suggest (Collings, 2008). In this case more individualised conceptualisations of the grief process may be needed, with practitioners being sensitive to parents' needs and recognising that this process is not time limited and extended support may be needed.

Negative perceptions by the wider community also merit further research and clinical intervention. Such perceptions of others can be associated with stigmatisation and lack of access to social activities (Cloute et al., 2008). Again this was something that was described by the mothers in the current study in terms of their child missing out on social events such as going to parties. These negative views can be associated with shame, worthlessness and lack of achievement on the part of the person who is subject to this stigmatization (Morton & Wehman, 1995; Parker, 1996; Simpson, Mohr & Redman, 2000). This suggests the need for further research on the impact of the perceptions of the wider community on both the parents' perceptions of the child, and on the child's own identity. The impact of the perceptions of teachers on the child's identity would be an area of particular interest.

From the perspective of the mothers interviewed in this study, negative perceptions amongst the wider community were often the product of ignorance. For example, teachers often misattributed the child's lack of progress to 'laziness' etc. This indicates the need for better public awareness and education about ABI in childhood.

Research suggests that teachers are often not aware of the difficulties a child with a brain injury faces and this may mean that teachers misattribute a child's lack of progress in

class to some other cause (Linden & Hawley, 2013). Therefore it is crucial that teachers are made aware of how to screen for indications of brain injury and are given support, training and access to services and interventions to help with the child's education (Linden & Hawley 2013).

The present study highlighted the difficulties that children can face in maintaining and building new and positive relationships with peers (Bohnert et al., 1997). Therefore efforts to support children in building relationships with others should be made. For some children this may mean building relationships with others with their own difficulties, as this is the group that they feel more comforTable with. Facilitating positive views of others towards the child with the brain injury may also be of benefit (Cloute et al., 2008).

The impact of a childhood brain injury on the family has been well documented, however in the UK the care of the family is often over looked (Linden & Kristiansen, 2013). For siblings more focus on their relationship with the child with the brain injury may be needed, with an acknowledgment that they are at an increased risk of difficulties themselves (Perlesz, Kinsella & Crowe, 1999; Swift et al., 2003; Verhaeghe, Defloor, & Grypdonck, 2005). Interventions that are systemic may be the most appropriate for families where a child has had a brain injury, where the impact that the injury has had on all members of the family and the relationships can be acknowledged. Within the family, the impact of a childhood brain injury on fathers also seems to be an area that has been neglected. This would be an important consideration for practitioners in ensuring that they are not overlooked. However there are very few descriptions of the application of formal family therapy following a brain injury (Oddy & Herbert, 2003). Family support groups may also be another way that families can receive emotional support (Oddy & Herbert, 2003). There is a lack of evidence concerning the efficacy of family interventions following a family member experiencing a brain injury

(Oddy & Herbert, 2003). Therefore more research is needed in this area to provide support for appropriate family interventions.

CONCLUSIONS

This study has examined mothers' perceptions of their child's identity following a brain injury. Through this exploration, important elements of the mother's and child's experience were uncovered. All of the mothers commented on 'loss', including loss of abilities and participation, loss of friendships and relationships, loss of a future, loss of the pre-injury child, and loss of place and status in. The non-dominant theme of 'positives', including achievements being a surprise, friendships and relationships that survived and glimpses of the pre-injury child, seemed to enhance the feelings of 'loss'. The 'construction of new identity' by which the mothers developed the theme of loss, included comparisons with pre-injury child, comparisons with other children and the child's own responses. How the child, the parents and the wider community construct the child's identity after a brain injury may have important implications for how well the child and the family cope with ABI. Child identity after ABI is an issue that merits greater research and clinical attention than it has hitherto received.

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VOLUME I

CHAPTER THREE

PUBLIC DISSEMINATION

DOCUMENT

MOTHERS' PERCEPTIONS OF THE

IDENTITY OF CHILDREN WIH

ACQUIRED BRAIN INJURY

PUBLIC DISSEMINATION DOCUMENT

Research has examined identity following a brain injury in adults, however there is little research looking at this issue in children. For this reason the aim of this study was to explore mothers' perceptions of their children's identity following a brain injury.

Five mothers were recruited through the child brain injury trust (CBIT). Mothers were interviewed regarding their child before and after the injury. They were asked to think about their child, for example their strengths, likes, dislikes and personality; school in terms of relationships with teachers and friends and their role as a pupil; family life including their role within the family; relationships with siblings, father, grandparents; and finally they were asked to think about their child socially, for example community view of their child and friendships outside of school. All interviews were transcribed and analysed using interpretative phenomenological analysis (IPA), which is often used to offer insights into how a person makes sense of an experience, such as a major life event.

Three themes were identified from the analysis and will be discussed below.

Loss

All five of the mothers commented on losses. A loss of abilities after the injury was something the majority of mothers commented on, with their children often avoiding certain activities.

A loss of friendships and relationships was highlighted. They felt that their children struggled to make friendships after the injury and this was different to how things were before the injury. They also felt that relationships with siblings and fathers changed, with siblings and fathers struggling to come to terms with the injury.

The mothers expectations of their child's future had changed; the future seemed more uncertain and the mothers were unsure what their child could achieve or how their life might turn out. The mother's main concern was that their child would be happy in the future.

Loss of the child they had before and feeling like they had a different child was something that all of the mothers commented on. They felt that they sometimes saw glimpses of the child they had before and at times this could enhance the sense of difference between the child now and the child then. Some of the mothers felt that a process of re-bonding with this new child and grieving for the child they had before took place.

A loss of place and status in society was something that the majority of the mothers highlighted. They felt that there was a stigma associated with having a brain injury, with their children often finding it difficult to fit in and be 'normal'. They felt that other people often had negative views about their child and that due to the brain injury being 'hidden' there was a lack of understanding. Linked to the injury being 'hidden' was the dilemma they faced concerning whether to disclose the injury to others.

Positives

Most of the mothers felt that their child continued to surprise them in terms of what they had achieved since the injury, although this sometimes enhanced the feeling of loss.

Although most of the mothers described loss of relationships, there were also cases where relationships had survived the injury and they felt this was important source of support for their child.

Some of the mothers felt that the injury had, in some ways, resulted in a positive change for their child, for example being more sociable or loving than before the injury.

Another positive that was described was attempts by others to understand the injury, particularly teachers.

Construction of new identity

The mothers' awareness of loss and difference was associated with a number of processes, including comparing the child now with the child they had before, and comparing their child to peers. Some of the mothers felt that at times this comparison could be painful and they would try to avoid situations where they would make these comparisons.

The mothers felt that their children were sometimes aware that they were different and compared themselves with peers. Also the child wanting to fit in and be 'normal' was something the mothers highlighted.

Other people (such as teachers) did sometimes try to understand the injury, but the participants felt that more could be done to improve the understanding of brain injuries.

These themes are linked with previous research relating to identity and how identity is influenced by the views of others, grieving for a lost child and re-bonding with a new child, changes in relationships and others attempting to understand the injury.

Based on this research, I have made some recommendations. Based on the mothers experiences of the negative labels sometimes put on their children (e.g. being thought of as 'lazy' by teachers), I have suggested that services need to do more to educate others who come into contact with children with a brain injury about the impact of that injury. Also given that they highlighted the importance of friendships and how these can be a source of support, I recommended that children with a brain injury should be helped to build positive friendships. The mothers highlighted changes in relationships within the family (e.g. with siblings, grandparents, fathers) and these relationships, too, should provide a focus for intervention. More generally, mothers and families should be supported to manage the changes in the child's identity more effectively, for example by helping them to deal with the sense of loss.
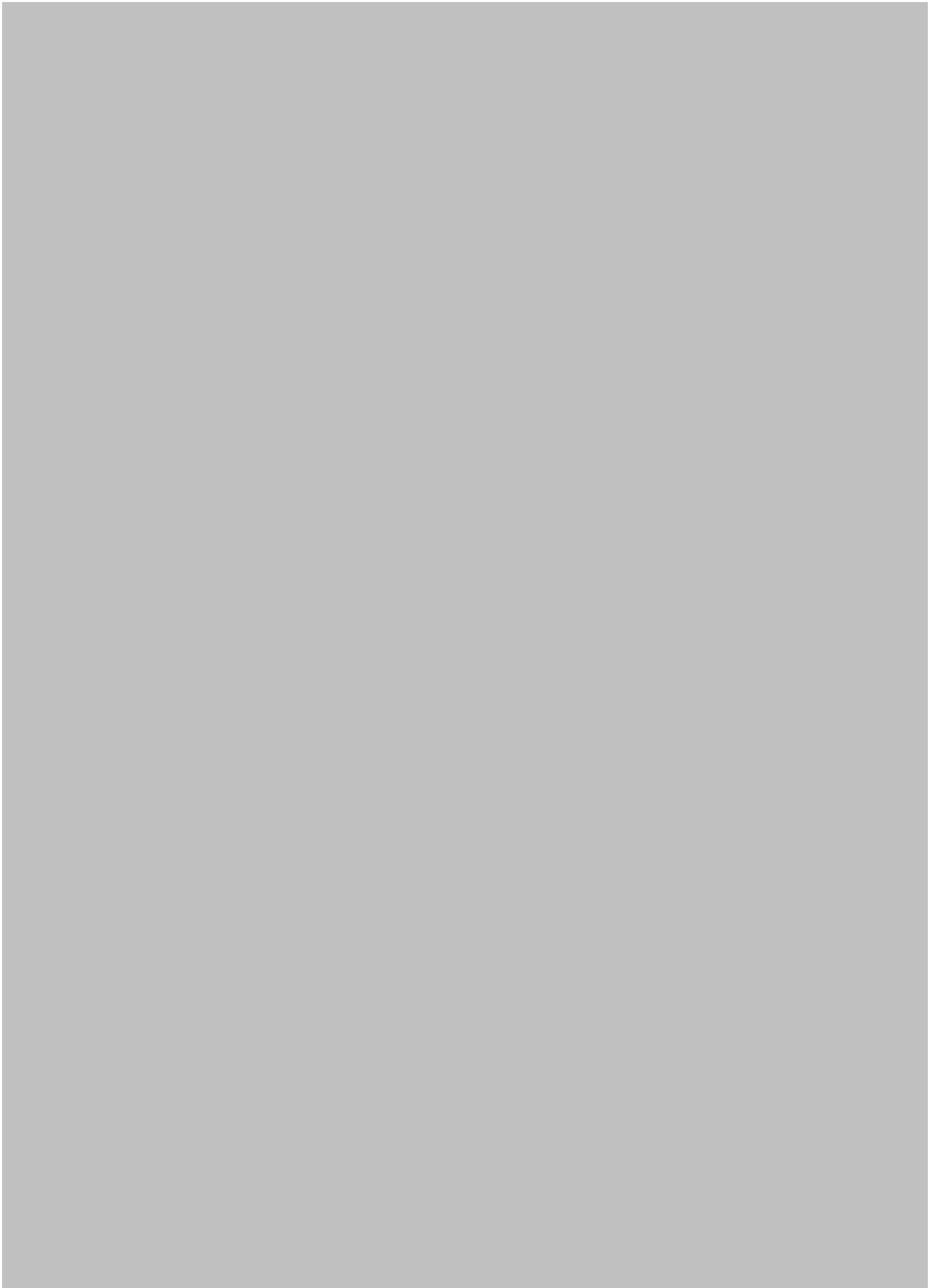
VOULME I

APPENDICIES
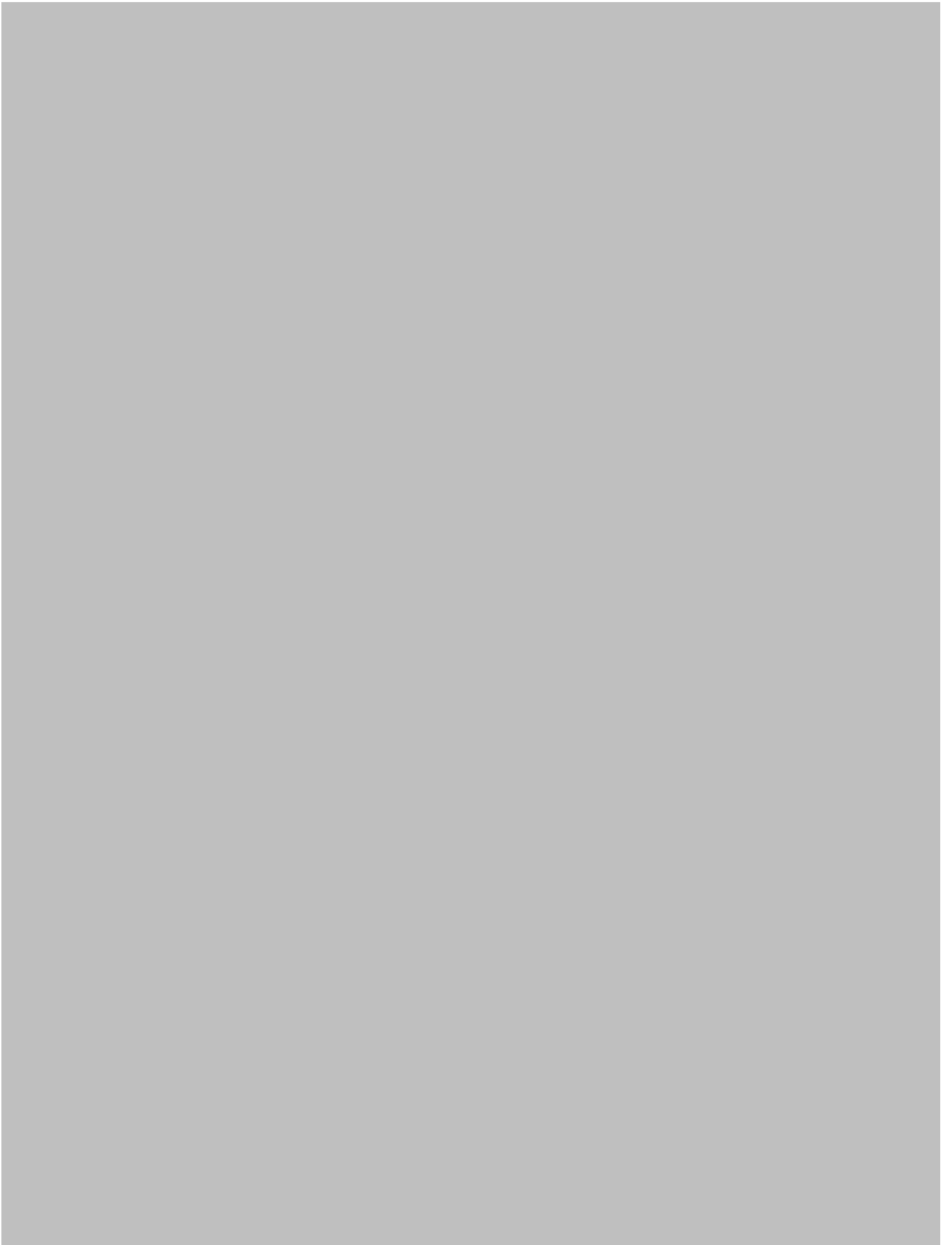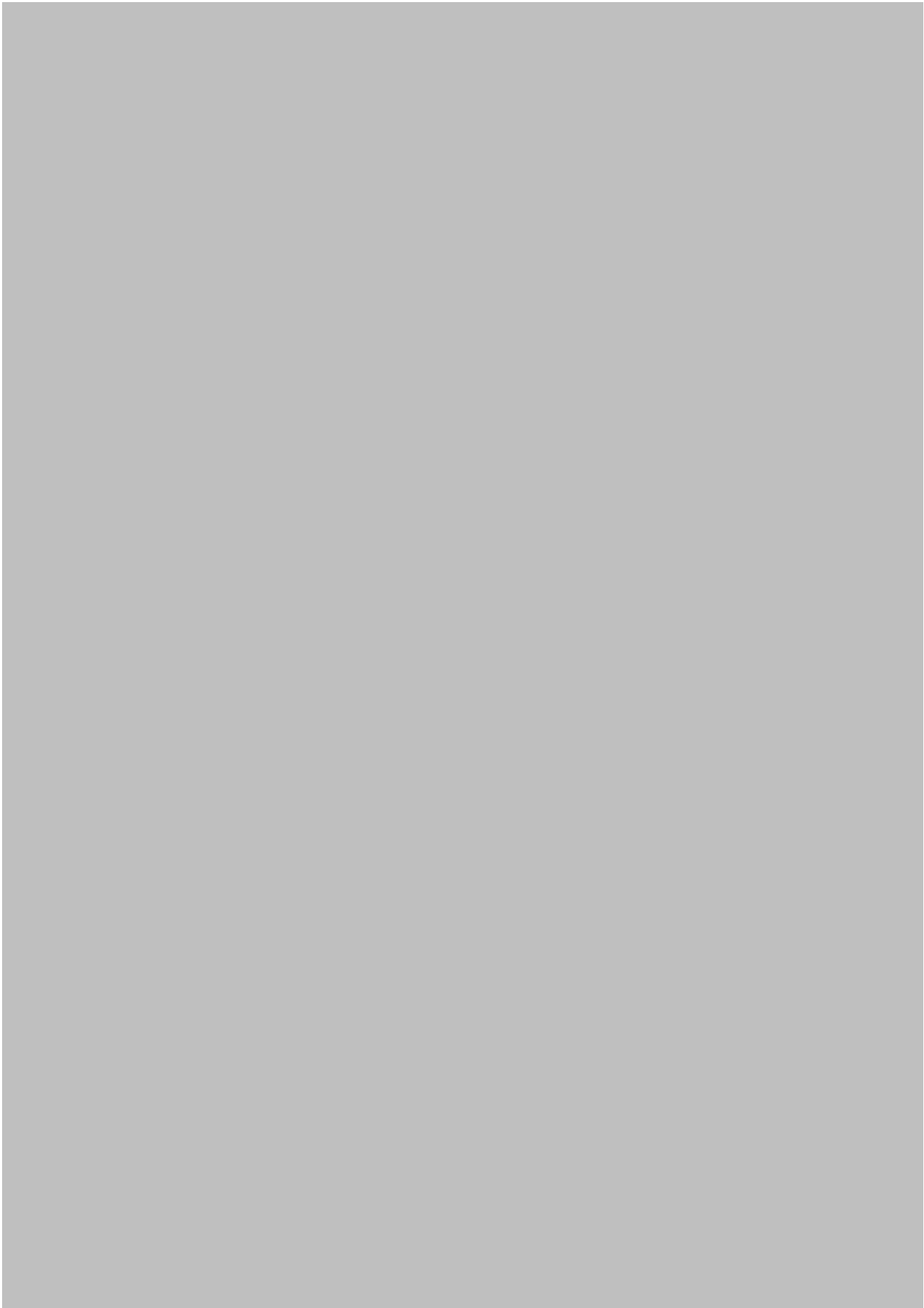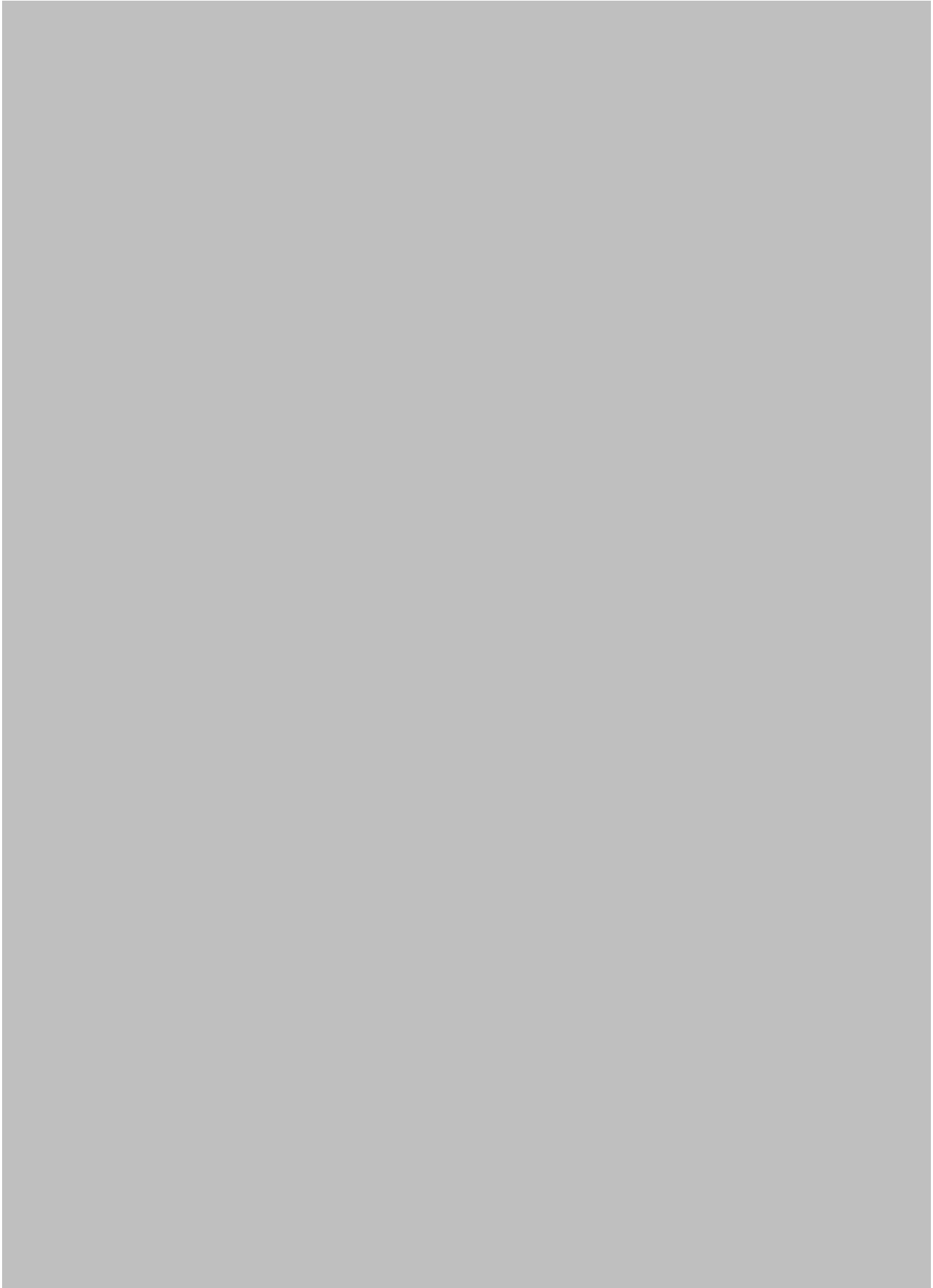
**Interview schedule (version 1, 29/09/12)**

Warm up questions:

How did the brain injury happen?

How long was he/she is hospital?

Set questions will not be used. Instead, the researcher will aim to cover certain topics within an otherwise unstructured conversation. Key topics will include:

- Description of the child as a person including
    - His/her personality (5 adjectives to describe him/her)
    - What are/were their strengths and weaknesses?
    - What are/were their likes and dislikes?
- School
    - Relationships with friends
    - What role does/did he/she have at school?
    - Who does/did he/she play with?
    - What are/were the teacher's perceptions?
- Family life
    - What role does/did he/she have in the family?
    - Relationships with other children in the family
    - Relationships with siblings
    - Relationships with parents/grandparents
    - Dad's perceptions of him/her
- Social
    - How he/she is perceived in the community (parents friends, other parents at school, strangers)?
    - Who does/did he/she play with outside of school?
    - What does/did he/she play outside of school?

Appendix 3: Ethical approval
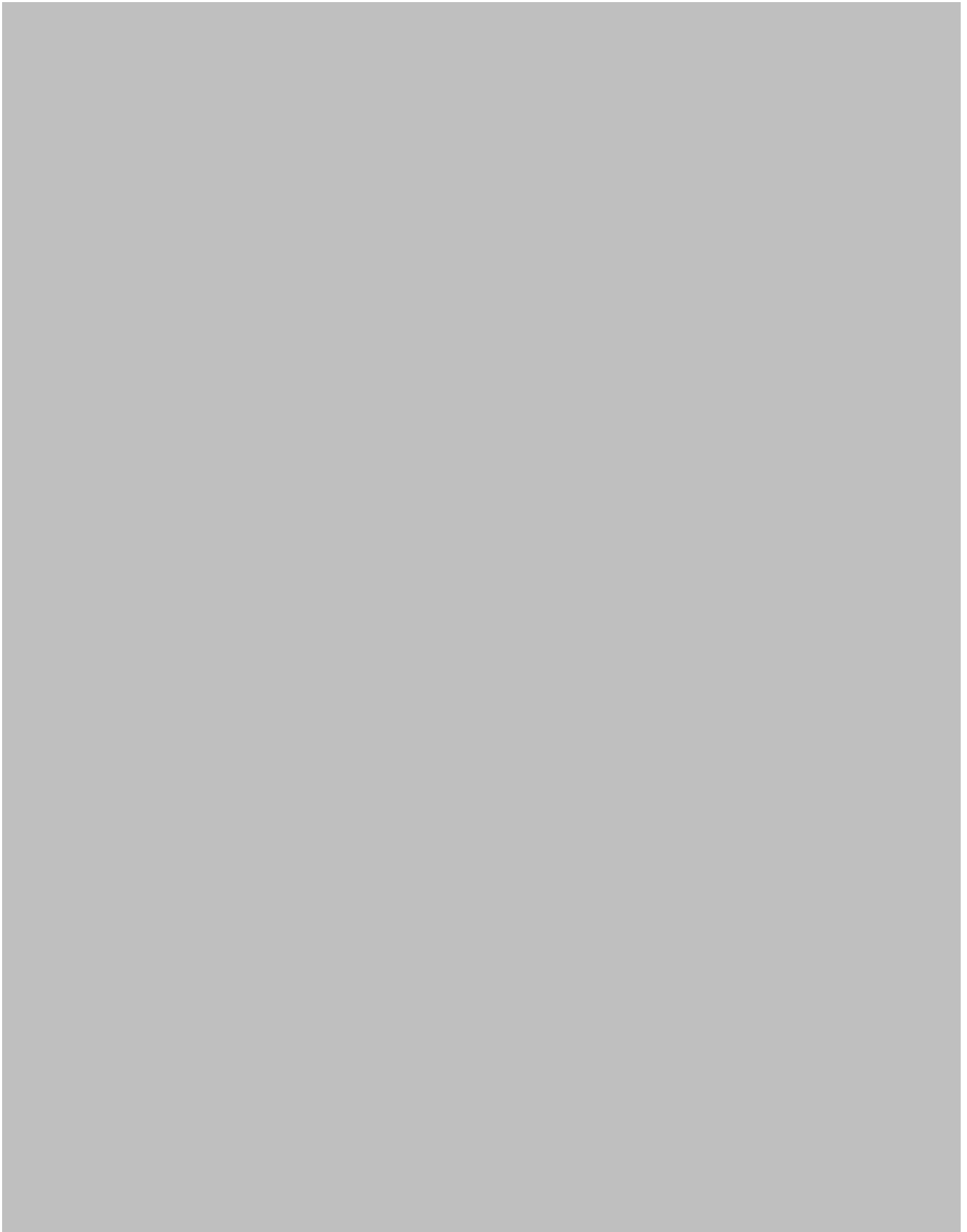
CONSENT FORM   *Version 1 (21/6/12)*

Study title: A qualitative study examining children's identity after brain injury: A mother's perspective.

Researcher: Selina Balloo

Participant Identification Number:...............

0. I confirm that I have understood information sheet 1 and 2 dated............ (Version ...) for the above study. I have been given the chance to consider the information, ask questions and have had these answered satisfactorily.

1. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.

2. I understand that the research interview will be audio-recorded

3. I understand that after the interview I will have two weeks to think about the study and process. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.

4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the NHS team responsible for me or my family member's care but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed.

5. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.

If you agree with what you have read and agree to take part in the study please sign below

....
Name of participant   Date   Signature

....
Name of researcher   Date   Signature

Appendix 5: Participant feedback

Dear participants,

Thank you again for taking part in my study examining 'mothers' perceptions of the identity of children with acquired brain injury'. I am very grateful for how honest you were about your experience and the time you gave to participate. The following information provides a summary of the research and findings. I would really appreciate your feedback on this summary. My contact details are at the end of the letter. Please do contact me with your feedback.

Five of you took part in this study. The following themes were identified from the analysis:

- Loss – of abilities, of relationships, and of a positive position in society; loss of the child you had before, and of expectations for the future
- Positives- achievements, relationships that survived the injury, positive changes and others trying to understand.
- Process- comparison to the child before the injury and peers and the child's own awareness of being different, trying to fit it and wanting to be normal.

Loss

All five of you commented on losses. A loss of abilities after the injury was something the majority of you commented on, with your children often avoiding certain activities.

A loss of friendships and relationships was highlighted. Some of you felt that your child struggled to make friendships after the injury and this was different to how things were before the injury.

Your expectations for your child's future had changed, the future seemed more uncertain and you were unsure what your child could achieve or how their life might turn out. Your main concern was that your child would be happy in the future.

Loss of the child you had before and feeling like you had a different child was something that you all commented on. You felt that you sometimes saw glimpses of the child you had before and at times this could enhance the sense of difference, with a comparison to the child you had before. Some of you felt that a process of re-bonding with this new child and grieving for the child you had before took place.

A loss of place and status in society was something that the majority of you highlighted. You felt that there was a stigma associated with having a brain injury, with your children often finding it difficult to fit in and be 'normal'. You felt that other people often had negative views about your child and that due to the brain injury being 'hidden' there was a lack of understanding. Linked to the injury being 'hidden' was the dilemma you faced concerning whether to disclose the injury to others.

Positives

Most of you felt that your child continued to surprise you in terms of what they had achieved since the injury, although this sometimes enhanced the feeling of loss.

Although most of you described loss of relationships, there were also cases where relationships had survived the injury and you felt this was important source of support for your child.

Some of you felt that the injury had resulted in a positive change for your child, for example being more sociable or loving than before the injury.

Another positive that was described was attempts by others to understand the injury, particularly teachers.

Process

  The process or ways you highlighted this difference was through a comparison with the child you had before, as well as comparing your child to peers. Some of you felt that at times this comparison could be painful and you would try to avoid situations where you would make these comparisons.

  You felt that your children were sometimes aware that they were different and compared themselves with peers. Also your child wanting to fit in and be 'normal' was something you highlighted.

  Other people tried to understand the injury, but you felt that more could be done to improve the understanding of brain injuries.

  These themes are linked with previous research relating to identity and how identity is influenced by the views of others, grieving for a lost child and re-bonding with a new child, changes in relationships and others attempting to understand the injury.

  Based on this research, I have made some recommendations. Based on your experiences of the negative labels sometimes put on your children (for example being thought of as 'lazy' by teachers), I have suggested that services need to do more to educate others who come into contact with children with a brain injury about the impact of that injury. Also given that you highlighted the importance of friendships and how these can be a source of support, I recommended that children with a brain injury should be helped to build positive friendships. You highlighted changes in relationships within the family (e.g. with siblings, grandparents, fathers) and therefore I felt that involving family in interventions was an important recommendation.

Kind regards,

Selina Balloo

Appendix 6: Development of themes

	Main themes	**Sub-themes**	**Key quotes**	**Participant**
Loss	Loss of abilities and participation	1. Avoidance of activities 2. Loss of future abilities 3. Frustration at not being able to do things 4. Some hobbies retained	*'At the moment he just shy's away from physical stuff…'* *'I'm not doing anything or I'm doing a jigsaw…'* *'There are going to be something's that…'* *'There are still things Martin…'* *'Will he always need someone around…'* *'She has found it frustrating being poorly…'* *'He knew he was able to do things….'* *'Still loves his art, that's one thing…'*	Clare Elizabeth Elizabeth Mary Mary Laura Clare Melissa
	Loss of friendships and relationships	1. Change in relationships 2. Lost relationships	*'I've noticed a marked difference…'* *'He doesn't see his dad anymore so…'* *'What he's lost is really huge…'*	Clare Mary Elizabeth
	Loss of future	1. Lack of expectations and uncertain future 2. Hopes for a happy future	*'You can't say that's going to happen…'* *'I don't know what…'* *'You kind of take day by day'* *'She's more open minded and to…'* *'My bottom line is I just want to see…'* *'I do hope that he'll get…'*	Clare Mary Melissa Laura Elizabeth Melissa
	Loss of pre-injury child: Different child	1. Stages of noticing change 2. Comparisons to the child before 3. Grieving for the lost child	*'Instantly from when he….'* *'I said to him um I needed to…'* *'We didn't see a lot of….'* *'Looking at how he was, he is completely different…'* *'You know it's like somebody dying isn't it…'*	Mary Laura Clare Clare Clare

		4. Re-bonding with a new child	*'It's like re-bonding with a different child…'*	Melissa
		5. Positive elements of change	*'He is very loving so maybe…'* *'Whereas now we've got a completely different…'*	Mary Melissa
	Loss of place and status in society	1. Social stigma	*'Nobody would come near you they…'* *'You know there's all these people…'*	Elizabeth Elizabeth
		2. Negative perceptions of others	*'He has been labelled as lazy…'* *'He's a naughty child, if I hear my…'* *'I think they thought he was weird…'*	Mary Elizabeth Melissa
		Hidden injury	*'You wouldn't see that…'* *'It really is the hidden injury…'* *'She found it really hard when she was in…'* *'The thing is it's the lesser of the two evils…'* *'When you look at a child that looks normal…'* *'You either go two ways you either hide…'* *'He's just trying to be normal or what's normal…'*	Elizabeth Clare Laura Melissa Melissa Elizabeth Elizabeth
		3. Not fitting in	*'What she's really struggles with is…'* *'So this is what I mean about square peg…'* *'It's a shame because we wanted…'* *'I think that's another thing that she found frustrating..'*	Laura Elizabeth Melissa Laura
Positives	Achievements are 'surprising'	1. Surprises	*'All I would say to you is everything…'* *'A lot of the time and then she'll…'* *'He's very quick thinking and this is stuff…'*	Elizabeth Laura Clare
	Friendships and relationships that survived	1. Continuity of relationships	*'He still has a very good relationship…'* *'She sees Jack, she doesn't see the lack of ability…'* *'She's got a really close knit circle of friends…'* *'Now it's a good relationship, it is a father…'*	Mary Clare Laura Elizabeth

		2. Re-establishing relationships		
	Glimpses of pre-injury child	1. Glimpses	*'Catch a glimpse of who he used to be…'*	Clare
Construction of new identity	Comparisons with pre-injury child			
	Comparison with other children	1. Positive comparison pre-injury 2. Loss of social participation 3. Comparison with peers 4. Comparisons as painful and attempts to avoid situations 5. Comparison with 'different' type of children	*'He was up there with the best of them…'* *'He was intelligent…'* *'He won't go to parties…'* *'I see other children his own age now and…'* *'You can see the difference between him…'* *'I have a constant comparison because my friends'…'* *'Every time I walked in there was a constant reminder..'* *'I suppose she's doing things that I would have…'*	Mary Elizabeth Mary Elizabeth Mary Clare Clare Elizabeth Clare Clare Elizabeth Melissa
	Childs own response	1. Aware of being different 2. Making comparisons to other children 3. Wanting to be normal and fit-in	*'He knows he's different…'* *'I think he feels comforTable around that environment'* *'The things that he wants to do now I…'* *'He will go to school today and no doubt have…'*	Melissa Melissa Clare Clare

Other parents' comparison	983	that comparison and parents get that haunted look I think when you have a child with a brain injury and have
	984	these struggles and she was saying yeah his behaviour, so she had one at mainstream and one at special school
	985	and she said now he's come on leaps and bounds because he's at a special school, because obviously the
Progress in special school	986	expectations are lower, whereas he's had nothing but trouble and now as I say he's been diagnosed with autism
	987	and you know she said I had him crying under the Table and that's what I had with Jack he didn't want to go into
Damaged?	988	the other school and you think god you have to cope with all of that on top of having a child that's damaged, coz
	989	they are, like it or not they are and it's not about uhh I think when you as soon as you are reminded of the
Reminder of things they aren't going to do	990	children, your reminded of things that they're not going to do, everything is a, every triumph yeah is nice but
	991	there is always a balance, there's always, its its not like a balance that's wrong because with children who are not
	992	compromised there is a devil and an angel scenario with everything you do in life but with kids like this there is
	993	always more of the damage, even every victory there is and for me as a positive person who is and not
Deficits prominent	994	pessimistic at all is very difficult as an eternal optimist I think we are now entering the most difficult period
	995	because we've fought to get him from where he was to where he is now and um and fought from where he is now
	996	to, to get him this far, only to have him failing on local services and having him failing on basic education and
	997	basic fundamental rights to sleep somewhere properly and somewhere to sit properly and somewhere to go to the
Lack of understanding from services	998	toilet and you think to yourself, all of that fighting and all of that battling to get him back and you, you talking
	999	about just constantly hitting a brick wall of negativity and I think that's got to have an impact on us which in turn
	1000	will have an effect on him um and I know there's not endless buckets of funds out there for services but there
Reminders of difference	1001	massively underestimating the psychological effects of brain injury on the person and on the family, there
	1002	massively underestimating the daily struggles and the daily reminders you have and he has, he will go to school
	1003	today and no doubt have anything from one to a hundred reminders that he can't do what the other kids can do
Positivity from pre-injury disappearing	1004	and what worries me is when we come to our next operation and how do we get him through that, because that
	1005	positive little boy who, was there, is being chipped away at psychologically by the system and by the world in
	1006	general and that's what concerns me because if he doesn't want to wake up, he won't wake up, you know it's a
Depression?	1007	psychologically push to get you up and round from an operation, you have to mentally want to be alive and have
Split personality	1008	a thirst for life and I'm slowly seeing that being eeked, eeked away, chip, chip, chipped away on a daily basis and

Right margin codes:

Child: Comparisons from others

School: Special school-more progress? Different expectations

Abilities: Loss of ability, loss prominent? Constant reminders?

Services: don't understand? Failing

Child: reminded of difference, comparison with other children

Child: brain injury led to changes in personality