THE UNIVERSITY OF HULL

*Family adjustment after brain injury:
Understanding and intervening*

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Overview

This portfolio is made up of three sections:

Part one is a systematic literature review, in which the empirical literature relating to family-based interventions after brain injury – delivered both face-to-face by therapists and utilising new telehealth delivery methods – is reviewed and critically contrasted. It aims to explore the effectiveness of these delivery methods.

Part two is an empirical paper exploring the shared relationship of mothers and non-injured siblings of young adults who have incurred severe traumatic brain injury. This was implemented using semi-structured interviews and analysed using Interpretative Phenomenological Analysis, with consequent themes discussed in the context of established empirical and theoretical literature.

Part three comprises the appendices, including further information for parts one and two, as well as reflective and epistemological statements.

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Part One:

Systematic Literature Review

Traditional and telehealth-mediated family interventions post-brain injury: A systematic literature review

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Abstract

BACKGROUND: Technology is increasingly being used to implement cost-effective healthcare interventions. Family intervention after brain injury (BI) is often neglected due to lack of resources and the commitment required of families. Accordingly, telehealth implementation is being pursued in this area, but its relative effectiveness has yet to be compared to traditional, face-to-face interventions of the same nature.

OBJECTIVE: To compare the relative effectiveness of both telehealth-mediated and face-to-face neuro-rehabilitation interventions addressing family functioning (FF), including family-caregiver distress and burden, post-BI.

METHOD: Databases were systematically searched and studies reviewed on inclusion/exclusion criteria and quality. Lack of homogeneity necessitated narrative synthesis.

RESULTS: Eight studies were included, with differing theoretical approaches to FF. Outcome measures varied accordingly. No intervention was found to affect FF, although most reported decreased caregiver stress and/or burden. Telehealth-delivered interventions appeared as effective as traditional methods, although findings suggest this could be moderated by socioeconomic status.

CONCLUSIONS: The conceptualisation and measurement of FF should be further deliberated to allow a comparable assessment of family interventions, in BI and other clinical populations. Further exploration of demographic factors and their influence on the effectiveness of telehealth interventions should be researched accordingly.

KEYWORDS: brain injury, family functioning, caregiver, intervention, burden, stress, telehealth

Introduction

The fact that brain injury (BI) has a resounding effect on the social support network around the injured individual is recognised by both researchers and clinicians. Head injuries are a leading cause of disability and are more common than imagined, contributing notably to emergency department attendances (Yates, Williams, Harris, Round & Jenkins, 2006). Consequently, the costs to society following BI can be great, with services often needing to be provided on a long term, sometimes life-long, basis (Yates, Williams, Harris, Round & Jenkins, 2006). Exact costs to the economy in the UK are not available, but are estimated to be high, as care has been shown to cost $50 billion annually in the USA (Department of Health, 2005).

The various consequences of BI also have major implications for the family and those closest to the individual. Often, the extent and severity of deficits post-rehabilitation are unpredictable and therefore cause high levels of uncertainty regarding the future (Fleminger, 2006). Variation in the effects of BI can also mean that professionals are unlikely to be able to predict the nature of necessary care, and therefore ease this anxiety. Ultimately, relatives of those who have suffered severe BI inevitably go through a complicated process of changing emotions, roles and relationships within their family unit, which can only be somewhat tempered by the involvement of rehabilitation services (Byard, Fine, & Reed, 2011).

1.0: Family responses to BI

The unpredictable nature of BI means that family responses and coping are not straight-forward. Negative consequences are not just reserved for direct relationships with the individual; Stancin, Wade, Walz, Yeates and Taylor (2008) note effects within the inter-

parent relationship, as well as that between parents and any non-injured siblings. The severity and duration of these negative family changes can be mediated by many variables, such as type of deficit, coping strategies and family dynamics (Swift, Taylor, Kaugars, Drotar, Yeates, Wade et al., 2003). For example, family stability and availability of positive social support has been found to impact the length of time that families suffer adverse consequences up to and beyond 18 months post-injury (Stancin, Wade, Walz, Yeates & Taylor, 2008). Although the prognosis of these changes within families varies, they can be relatively long-term, with Schonberger, Ponsford, Olver and Ponsford (2010) finding that one third of relatives report poor family functioning (FF) up to 5 years post-injury. According to Anderson, Parmenter and Mok (2002), FF as a whole is made up of factors such as the family's coping strategies, roles, problem solving and affective interactions. Anderson et al propose that FF moderates distress after BI, therefore levels of distress can be indicative of FF.

Due to the varied effects of BI on family relationships, researchers have found that, ideally, interventions post-BI should include the whole family, although this is not always the case (Gan, Cambell, Gemeinhardt & McFadden, 2006; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). Family-based interventions tend to involve education, training and support, as these areas have all been identified as needs of families recovering post-BI (Ramritu & Croft, 1999), and hope to better prepare for the challenges ahead. As such, they aim to decrease distress and burden (often considered an agent of stress (Chawalisz, 1996)) and increase and support family coping (Lovasik, Kerr, & Alexander, 2001). Traditionally, interventions tackling FF, including distress, stress and burden, have been delivered face-to-face by professionals in either one-to-one or group formats, for which the individuals travel to a service base or are visited at

home. This process can extend for years post-injury, depending upon each family's needs and changing requirements of rehabilitation. For example, a child survivor of BI might demonstrate previously unreported difficulties as they mature physically and socially (National Institute of Neurological Disorders and Stroke, 2002), and so require ongoing and evolving input from services.

Unfortunately, despite supportive research, family interventions and even basic education can sometimes prove a non-viable option (Gan, Gargaro, Brandys, Gerber & Boschen, 2010). There are various reasons for this, with costs, resources, and distance from services, for example, all adding to the labour of both providing and attending further appointments upon discharge from in-patient settings. To combat this, developments in technology have allowed family interventions to reach survivors' homes by new means. The advancement of telehealth – the use of technological methods of communication to provide health services across geographical spaces – has been tested for increasing areas of intervention, as it provides an option for rehabilitation that is both more economical and wider-reaching (WHO, 2011). Telehealth utilises video-conferencing telecommunication equipment and online storage to create a comprehensive range of training and applications, which can be prescribed and accessed as needed. It can be used as a replacement for or alongside more traditional input, with the only reservation being the necessity of sometimes costly equipment (Luxton, 2012).

Telehealth has been examined and found useful across an array of health conditions, as reported in a systematic review by Kairy, Lehoux, Vincent and Visintin (2009). Although the application in the field of BI is a fairly new venture, various initial studies

report successes due to the flexibility and efficiency it lends rehabilitation (Gan, Gargaro, Brandys, Gerber & Boschen, 2010), and it has also been found to be effective in the related field of epilepsy (Rasmusson & Hartshorn, 2005). This literature has been systematically reviewed (Rietdijk, Togher & Power, 2012), with the finding that telehealth interventions are popular and reported as effective, although the evidence base is limited and somewhat lacking in quality. It is important to assess this quality as literature reviews have shown that it can be an important moderator of intervention efficacy (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007). Also, due to their recent and continuing development, family-focused telehealth interventions have not yet been reviewed comparatively alongside clinician-delivered interventions. Findings suggest that robust research is necessary to support the recommendation of telehealth-mediated interventions over more traditional systemic rehabilitation post-BI (Rietdijk, Togher & Power, 2012). Only when this research is completed can the outcomes best inform clinical decision-making and service development.

Accordingly, the objective of this review was to compare the methodological quality and relative effectiveness of both telehealth-mediated and face-to-face neuro-rehabilitation interventions addressing FF (including family-caregiver distress and burden) post-BI.

Method

2.0: Search strategy

The first step towards developing a search strategy was to decide upon keywords and main factors of interest – the research population, interventions and measure of their relationship. Scoping searches identified studies matching provisional inclusion criteria and allowed inspection of citations to explore further viable studies and to help refine inclusion criteria. These studies allowed further specification of search terms so as best to incorporate all relevant material. A limit was introduced of studies published after and including 2005 in order to include recent advances in telehealth technology and to further findings from Boschen, Gargaro, Gan, Gerber and Brandys (2007), whose review considered interventions up to this point. The final search strategy included the following terms: (("Traumatic brain injur*" OR "traumatic head injur*" OR TBI OR "brain injury" OR "head injur*") AND (famil* OR systemic OR "famil* member" OR parent* OR "family carer*" OR caregivers) AND (Intervention* OR support* OR therap* OR treat* OR program*) AND (effic* OR effectiv*)). The search was conducted between 1st November 2012 until 30th November 2012 and applied in the following databases: Medline, PsycINFO, PsycBITE, Web of Science, and Scopus. No limits were placed on language of article.

2.1: Inclusion and exclusion criteria

After initial searches it was necessary to construct exclusion and inclusion criteria to focus the pool of studies. Articles were included if they reported interventions targeting family members of any individual who had sustained a BI, with no limits on age of the injured member, family member involved, or nature/severity of the injury. To ensure that the effectiveness of the intervention on the family was the target, studies had to

have a valid measure of FF, burden or stress as one of their key outcomes. This excluded studies where rehabilitation interventions included family members but only focused on effectiveness with regards to the injured individual. There were no limits placed on the type of intervention as both the use of telehealth and more traditional interventions were of interest, although in this instance all telehealth-based interventions happened to be online resources and training rather than electronic timers or reminders.

Sources were initially included or excluded based on reviews of their titles and abstracts, and full text articles were consulted where clarity was required.

2.2: Quality assessment

Sources were assessed using an adapted version of the Downs and Black Quality Ratings Checklist (DBC; Downs & Black, 1998), with additions from National Institute for Clinical Excellence guide to public guidance Methodology Checklist (2006) (see appendix 4.1). The DBC has been found to be the most appropriate in the assessment of non-randomised intervention studies for systematic reviews (Deeks, Dinnes, D'amico, Sowden, Sakarovitch, Song et al., 2003), including those with uncontrolled designs such as single group interventions, and can also be applied to randomised control trials. It has good reliability, validity and psychometric properties, and has been widely used within reviews of BI rehabilitation literature (Cullen, Chundamala, Bayley & Jutai, 2007; Mumford & Wilson, 2009). 50% of papers were assessed by a second independent researcher to check for inter-rater reliability. There was a 90.5% level of overall agreement, suggesting good reliability.

2.3: Data extraction

Data was extracted from the final pool of included sources for the following areas: i) authors, title, journal and country, ii) details of participants – number of those with BI, ages, details of family or carers and control groups if applicable, iii) intervention detail, iv) research design, v) outcome measures used, and vi) results and findings, including those of outcome measures.

2.4: Data synthesis

Narrative qualitative synthesis was used to analyse data, because, due to the small amount of studies and varied outcomes used, quantitative meta-analysis was not appropriate.

Results

3.0: Details of included studies

Of the 41 papers identified through initial database searches and after removing exact duplicates, 27 were disregarded on assessment of their abstracts and titles. The full texts of the remaining 13 papers were reviewed, leading to the exclusion of seven further studies due to them lacking valid measures of FF, burden or stress. This left 6 appropriate articles. An additional two articles were located by reviewing references and both forward and backward citations, ultimately leaving 8 studies to be reviewed in total (Geurtsen, Van Heugten, Meijer, Martina, & Geurts, 2011; Kreutzer, Stejskal, Ketchum, Marwitz, Taylor & Menzel, 2009; Rivera, Elliott, Berry, & Grant, 2008; Sinnakaruppan, Downey, & Morrison, 2005; Wade, Wolfe, Brown, & Pestian, 2005; Wade, Carey & Wolfe, 2006; Wade, Walz, Carey & Williams, 2008; Wade, Walz, Carey, McMullen, Cass, Mark & Yeates, 2012).

An overview is presented in table 1.

	Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
1	**Geurtsen, Van Heugten, Meijer, Martina, & Geurts**. (2011). Prospective study of a community reintegration programme for patients with acquired chronic brain injury: Effects on caregivers' emotional burden and family functioning. *Brain Injury*. The Netherlands	*Injured* N: 41 Age: 18-49 (Mean (M): 23.7, SD: 6.5) 34% Female 66% Male Years since injury: 0.5–26.3 (M: 4.6, SD: 5.4) 20% mild injury 80% severe injury *Caregivers* N: 41 Age: 25-61 (M: 47.9, SD: 8.3) 68% Female 32% Male Ethnicity not reported	• Conventional intervention. • Psycho-education for injured and caregivers around injury and realistic progress, with the aim of community integration. • Delivered in residential setting, caregivers educated alongside injured and given follow-up telephone support.	• Within subjects. • T0 (point of inclusion), T1 (3 months later, start of treatment), T2 (end of treatment), T3 (12 months post-treatment).	• The Involvement Evaluation Questionnaire for Brain Injury (IEQ-BI; Geurtsen, Meijer, van Heugten, Martina, Geurts , 2010) • The General Health Questionnaire–28 (Goldberg, 1978) • The Dutch version of the Family Assessment Device (FAD; Wenniger, Hageman & Arrindell, 1993)	• Significant improvements in caregiver burden and distress. • No significant changes to FF or dynamics.	16
2	**Kreutzer, Stejskal, Ketchum, Marwitz, Taylor & Menzel** (2009) A preliminary investigation of the brain injury family intervention: Impact on family members. *Brain Injury*. USA	N: 53 families (19 at outset) *Injured* N: 53 Age M:40.73, SD: 16.52 58% Male 42% Female 83% caucasian 38.6 months post Injury (SD: 50.79) 47% mild injury 13% moderate 40% severe *Caregivers*	• Conventional intervention. • Five 90–120 minute sessions of Brain Injury Family Intervention (BIFI). Topics covered for psycho-education, support and discussion with family and doctorate level psychologists.	• Within subjects. • T0 (baseline), T1 (post treatment), T2 (10-14 week post treatment follow up).	• Family Needs Questionnaire (Kreutzer, 1998) • Brief Symptom Inventory-18 (Derogatis, 2001) • Satisfaction With Life Scale (Diener, Emmons, Larsen & Griffin, 1985) • Service Obstacles Scale (Marwitz & Kreutzer, 1996) • Family Assessment Device (FAD; Epstein, Baldwin &	• Families reported a greater number of met needs and less obstacles to care. • No change in burden or distress.	19

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
	Age: 22-72 (M: 50.22, SD: 12.52) 34% Male 66% Female Ethnicity not reported	• CBT integrated with family systems theory and self-examination for both survivor and family members.		Bishop, 1983)		
3 Rivera, Elliott, Berry, & Grant (2008) Problem-Solving Training for Family Caregivers of Persons With Traumatic Brain Injuries: A Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation.* USA.	Intervention N: 33 Age, mean: 36.5, SD: 14 79% Male 21% Female 94% caucasian 6% black *Caregivers* N: 33 Age, mean: 51.4, SD: 11.1 12% Male 88% Female 94% caucasian Control N: 34 Age: Mean: 37.2, SD: 15 71% Male 29% Female 79% caucasian *Caregivers* N:34 Age, mean: 50.8, SD: 13.3 100% Female	• Conventional intervention. • Family caregivers randomized into a problem solving training group or a control group (education-only). • Problem-solving training provided to the intervention group via 4 in-home sessions and 8 telephone follow-up calls. • Control group received written educational materials and telephone calls.	• Between subjects • Randomised controlled trial lasting 12 months. • T0 (baseline), T1 (4 months), T2 (8 months), T3 (12 months).	• The Center for Epidemiologic Studies Depression (CES-D) Scale (Radloff, 1977) • The Satisfaction With Life Scale (SWLS; Diener, Emmons, Larsen & Griffin, 1985) • The Pennebaker Inventory for Limbic Languidness (PILL; Pennebaker, 1982) • Caregiver Burden Scale (Oberst, Thomas, Gass & Ward, 1989) • The Social Problem-Solving Inventory-Revised (SPSI-R; D'Zurilla, Nezu & Maydeu-Olivares, 2002)	• Significant improvements in caregiver distress, health complaints, and dysfunctional problem solving. • No effects on well-being, burden, or constructive problem-solving styles.	20

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
	77% caucasian					
4 **Sinnakaruppan, Downey, & Morrison** (2005) Head injury and family carers: A pilot study to investigate an innovative community-based educational programme for family carers and patients. *Brain Injury.* Scotland.	Intervention N: 23 Age: 21-61 (M: 43.76, SD: 11.10) 78% Male 22% Female Months since injury: 33.12, SD: 28.61 *Caregivers* N: 23 Age: Not reported 22% Male 78% Female Control N: 18 Age: 21-63 (M: 44.63, SD: 9.17) 78% Male 22% Female Months since injury: 38 SD: 23.71 *Caregivers* N: 19 Age: Not reported 79% Female 21% Male Ethnicity: All Scottish caucasians	• Conventional intervention. • An Educational Training Program (8 x 2.5 hour sessions), addressing memory, executive functions and emotions. • Handouts, presentations, group discussion and role play. • Carer training sessions.	• Longitudinal between and within subjects. • T0 (prior to group allocation), T1 (post-intervention), T2 (3 month follow up).	The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) • The General Health Questionnaire–28 (Goldberg, 1978) • The Rosenberg Self-Esteem Scale (Rosenberg, 1989) • The COPE Scale (Carver, Scheier & Weintraub, 1989) • The Functional Independence Measure (FIM; Granger & Gresham, 1984)	• Non statistically significant reduction in caregiver psychological distress following education. • Statistically significant improvement in patient distress at follow up.	18
5 **Wade, Wolfe, Maines Brown, & Pestian** (2005)	Injured N: 6 Age: 6y 8m – 15y 9m (M: 9.4) 33% Male	• Telehealth intervention • Family Problem Solving website for	• Within Subjects. • T0 (baseline), computer training, T1 (post-	• The Family Burden of Injury Interview (Burgess, Drotar, Taylor, Wade, Stancin, Schatschneider, et al,	• Statistically significant improvements in burden, distress and parenting stress.	16

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
Putting the Pieces Together: Preliminary Efficacy of a Web-Based Family Intervention for Children with Traumatic Brain Injury. *Journal of Paediatric Psychology.* USA.	67% Female 16 months post Injury moderate to severe TBI[1] 17% African American 17% biracial 66% caucasian *Caregivers* N: 13 39% siblings 61% parents Caregiver age, sex and ethnicity not reported	family to use together – e.g. video conferencing with therapist. • 8 core sessions on problem-solving, communication and behaviour management skills. • 4 sessions tailored to family specific problems, all with interactive activities.	intervention).	1999) • The Global Severity Index of Symptom Checklist-90-R (Derogatis, 1994) • The Centre for Epidemiologic Studies Depression Scale (Radloff, 1977) • The 10-item Anxiety Inventory the Parenting Stress Inventory (Speilberger, Gorsuch, Luchene, Vagg & Jacobs, 1983) • The Home and Community Social Behaviour Scale (Merrell, Streeter & Boetter, 2001) • The Behaviour Rating Inventory of Executive Function (Gioia, Isquith & Guy, 2000) • The Children's Depression Inventory (Sitarenios & Kovacs, 1999)	• Significantly reduced anti-social behaviour in patients.	
6 Wade, Carey & Wolfe (2006) An Online Family Intervention to Reduce	Intervention N: 20 (26 on outset) Age M: 10.92, SD: 2.45 Time since injury: 13.48 m (SD: 6.86)	• Telehealth intervention • Family Problem	• Between subjects, random allocation • T0 (baseline),	• The FAD (Epstein, Baldwin & Bishop, 1983) • The Family Burden of	• Statistically significant reduction in anxiety, depression and global	20

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1   Traumatic brain injury

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
Parental Distress following Pediatric Brain Injury. *Journal of Consulting and Clinical Psychology.* USA.	64% Male 36% Female 80% caucasian Attrition: 12% Control N: 20 Age M: 11, SD: 3.93 Time since injury: 14.05m (SD: 7.54) 60% Male 40% Female 70% caucasian Attrition: 0% Total N: 40 (46 on outset) Age M: 11, SD: 3.93 Time since injury: 13.73m (SD: 7.10) 62.2% Male 37.8% Female 75.6% "European American" 24.4% African American Caregivers 10% male 90% female Most caregiver details not reported	Solving group - web-based intervention for family to use together, sessions as outlined by Wade et al (2005). • 6 family specific sessions, all with interactive activities. Internet Resources Comparison (IRC) Group – given access to web page with resources and links to web-based written information.	computer training, T1 (post-intervention follow up).	Injury Interview subscales (Burgess, Drotar, Taylor, Wade, Stancin, Schatschneider, et al, 1999) • The Social Problem Solving Index (D'Zurilla & Nezu, 1990) • The Symptom Checklist – 90 – Revised (Derogatis, 1994) • The Global Severity Scale • The Centre for Epidemiologic Studies Depression Scale (Radloff, 1977) • The Anxiety Inventory (Speilberger, Gorsuch, Luchene, Vagg & Jacobs, 1983)	distress at follow up. • Significantly increased problem solving ability, although no longer significant at follow up.	
7 Wade, Walz, Carey & Williams (2008)	N: 9 Age: 15.04 (11 years 8 months – 18	• Telehealth intervention	• Within Subjects, random allocation	• The Child Behaviour Checklist (Achenback &	• Significant improvements in	19

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
Preliminary Efficacy of a Web-Based Family Problem-Solving Treatment Program for Adolescents With Traumatic Brain Injury. *The Journal of Head Trauma Rehabilitation.* USA.	years 2 months) 55.5% Male 44.5% Female 9.33 months post injury (range: 2 – 20 months) 22% severe injury 11.1% families biracial 11.1% families African American Caregiver n: 9	• Teen Online Problem Solving Intervention (TOPS) Home visit by therapist then 10 core 45-60 minute web-based sessions covering positivity, problem-solving, planning and organization, anger management, nonverbal communication, and social relationships. Some optional sessions designed for specific family problems.	• T0 (baseline), computer training, T1 (post-intervention), T2 (follow up).	Rescorla, 2001) • The Behaviour Rating Inventory of Executive Function (Gioia, Isquith & Guy, 2000) • The Children's Depression Inventory (Sitarenios & Kovacs, 1999) • The Global Severity Index of Symptom Checklist-90-R (Derogatis, 1994) • The Center for Epidemiologic Studies Depression Scale (Radloff, 1977) • The Conflict Behaviour Questionnaire (Robin & Foster, 1989) • The Issues Checklist and Severity Scale (Glueckauf, Webb, Papandria-Long, Rasmussen, Markand & Farlow, 1992)	caregiver distress and conflict. • Improvements in adolescent's reported depressive symptoms.	
8 Wade, Walz, Carey, McMullen, Cass, Mark & Yeates (2012) A Randomised Trial of Teen Online Problem-Solving: Efficacy in Improving Caregiver	<u>Intervention</u> N: 16 (21 at outset) Months since injury: 8.75, SD: 5.51 94% caucasian *Caregivers* N: 16 Age M: 40.81, SD: 4.49	• Telehealth intervention • 6 month Intervention period. • TOPS Intervention as described by Wade et al (2008)	• Between groups randomised controlled trial. • T0 (baseline), T1 (7-8 months post-intervention)	• The Social Problem Solving Inventory – Revised – Short Form • The Global Severity Index of the Symptom Checklist – 90 – R (Derogatis, 1994) • The Centre of	• High parental satisfaction in both groups. • Caregiver problem-solving and mood measurements dependent on income – lower	20

Authors, Title, Source, Country	Participant Details	Intervention Details	Research Design	Outcome Measures	Results/Findings	Quality
Outcomes after Brain Injury. *Health Psychology.* USA.	Control N: 19 (20 at outset) Months since injury: 10.32 SD: 4.42 89% caucasian *Caregivers* N: 19 Age Range: (M: 41.58, SD: 7.31) Totals N: 35 (41 at outset) Age: 11.47 – 17.90 40% severe TBI 92% caucasian *Caregivers* N: 35 (41 at outset) Age Range: 29 - 58 (M: 41.23, SD: 6.11) 77% >secondary education Sex not reported	• Internet Resources Comparison (IRC) Group: given access to web page with resources and links to web-based written information.		Epidemiologic Studies Depression Scale (Radloff, 1977)	income reported more improved outcomes in intervention group.	

Table 1: Overview of included studies

3.1: Characteristics of Included Articles / Studies

All eight studies included in the review were quantitative in nature and used validated scales to measure aspects of FF, distress, or stress/burden. FF is widely considered to be a "stable" characteristic (Winstanley, Simpson, Tate & Myles, 2006), comprised of both physical and psychological factors. 50% of studies (Geurtsen et al., 2011; Kreutzer et al., 2009; Wade et al., 2006; Wade et al., 2008) measured FF as a whole using the Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983).

Other studies chose to define and measure FF via a combination of factors. An example of this is Wade et al. (2008), who used the Conflict Behaviour Questionnaire (CBQ; Robin & Foster, 1989) and The Issues Checklist and The Issues Severity Scales (Glueckauf, Webb, Papandria-Long, Rasmussen, Markand & Farlow, 1992) to obtain a different overall view of FF. The former is a measure of the communication and quality of relationship between injured participant and caregiver, and the latter measures identified problems within the relationship and their severity. 50% of studies used specific measures of burden (Geurtsen et al., 2011; Rivera et al., 2008; Wade at al., 2005; Wade et al., 2006), for example the Caregiver Burden Scale (Oberst, Thomas, Gass & Ward, 1989), which gauges stress and concerns about both individual and family roles and functioning. All studies considered family or caregiver stress or distress using a variety of measures.

50% of studies used video conferencing or online content as a means of delivering the intervention, leaving fifty percent that used face to face sessions with the family and a professional, as depicted in table 2.

Telehealth Interventions	Traditional Interventions
Wade et al., 2005;	Geurtsen et al., 2011;
Wade et al, 2006;	Kreutzer et al., 2009;
Wade et al., 2008;	Rivera et al., 2008;
Wade et al., 2012.	Sinnakaruppan et al., 2005.

Table 2: Intervention delivery methods

Problem solving [PS] is a key aspect of Anderson, Parmenter and Mok's (2002) model of FF, and dysfunctional PS styles have been linked to psychological and physical caregiver health in various populations (e.g. Elliott & Shewchuk, 2003). Recent studies have utilised PS training to decrease caregiver distress (Sahler, Fairclough, Phipps, Mulhern, Dolgin, Noll, et al, 2005), so it follows that five studies included in this (Rivera et al., 2008; Wade et al., 2005; Wade et al, 2006; Wade et al., 2008; Wade et al., 2012), one of which was mainly face-to-face (see table 2), involved structured interventions with the specific goal of improving PS skills. Two studies, delivered face-to-face (Kreutzer et al., 2009; Sinnakaruppan et al,. 2005), focused on wider psycho-education about BI and skills training. One study (Geurtsen et al., 2011), combined these goals, aiming to target specific outcomes in the injured individuals whilst also using psycho-education as the main intervention for caregivers. Conceptually, this study aimed to combine early family systems theory (Bertalanffy, 1968) – seeing the family as interconnected individuals who influence one another – with the education, support and skills of other approaches.

All studies sampled a population of individuals who had sustained a head injury, although the time since injury, severity and classifications of these injuries varied. Telehealth studies specified that participants had sustained moderate to severe TBI (see table 2), with 12.5% (half of traditional studies) selecting any moderate to severe head injuries (Sinnakaruppan et al., 2005) and 12.5% TBI of any severity (Rivera et al., 2008). Two studies also selected participants from a wider population of those with Acquired Brain Injuries (ABI; Geurtsen et al., 2011; Kreutzer et al., 2009), which encompasses those with TBI. Sample sizes for studies varied, from 53 (Kreutzer et al, 2009) to 6 (Wade et al., 2005), indicating varying levels of statistical power. Mean sample size of BI survivors was 19.5 (SD = 14.58). The number of caregivers was not consistently reported, although those that were varied between 41 (Geurtsen et al, 2011) and 9 (Wade et al, 2008).

Of injured participants, two papers sampled children (Wade et al., 2005; Wade et al., 2006), and two papers sampled adolescents (Wade et al, 2012; Wade et al, 2008), with the majority of papers sampling adults (Geurtsen et al., 2011; Kreutzer et al., 2009; Rivera et al, 2008; Sinnakaruppan et al., 2005). The mean age across all studies for those who had experienced BI was 24.75 years (SD = 13.74), which is representative of the overall population of those with BI as research supports the increased likelihood of BI in adolescents and fledgling adults (Kraus & McArthur, 1999). Similarly, the proportion ranged from 33-79% male participants, with only one telehealth study having a higher percentage of females than males (Wade et al., 2005), which is in keeping with previous research. Up to twice as many males experience brain injuries as females (Langlois, Rutland-Brown & Thomas, 2004), explaining the bias in this

population.

The largest ethnic group included in the studies was "white" or "caucasian", which was included in 90% of studies. It is worth noting that all of the studies took place in "western" settings – six were conducted in the USA, one in the Netherlands (Geurtsen et al., 2011), and one in Scotland (Sinnakaruppan et al,. 2005). Samples were recruited from a variety of sources, with the majority of 75% being found or referred from trauma registers of hospitals and rehabilitation centres (Geurtsen et al., 2011; Sinnakaruppan et al,. 2005; Wade et al., 2005; Wade et al, 2006; Wade et al., 2008; Wade et al., 2012). Two studies also recruited via referrals from doctors, BI groups, rehabilitation and advocacy services (Kreutzer et al., 2009; Rivera et al., 2008).

3.2: Sampling and methodological quality

All studies included thorough demographic information for the injured participants, with none finding group differences based on these factors. Only Rivera et al. (2008) reported caregiver characteristics to the same standard as with their clinical population. This study consequently scored as one of the highest for methodological quality (20/24), as it was also the only study that attempted to blind researchers to their intervention. All other studies neglected to report various aspects of caregiver characteristics. Details of control participants, for those that used them (Rivera et al., 2008; Sinnakaruppan et al., 2005; Wade et al., 2006; Wade et al., 2012), tended to be presented in accordance with those included for the clinical samples.

Sampling methods were similar across studies, with the majority of cases recruited via trauma registers and referrals from relevant professionals. Only Rivera et al. (2008)

varied, accepting self referrals from public adverts via a free telephone line. This carried the potential to create a different sample to the other studies, although Rivera et al. attempted to control for this by having the researchers meet with potential participants. Sampling was an area that all but two (Rivera et al. & Wade et al., 2006) of the studies scored low on for quality assessment, as the samples were not representative of the population they were recruited from.

All studies recognised that their small sample sizes decreased the likelihood of their findings being generalisable, and limited the statistical power of their research. Wade et al.'s (2006) telehealth study scored the lowest for this on the methodological quality checklist. This is particularly relevant given the research's interest in FF and distress, with Kreutzer et al. (2009) discussing how there is a tendency for papers using small sample sizes to report no effect on measures of this function. This leads to questions regarding the sensitivity of FF measures, and also demonstrates the poor statistical power offered by small samples. It is important to note, though, that the two studies with the largest sample sizes (Kreutzer et al., 2009; Geurtsen et al., 2011) recruited from the wider population of ABI, rather than specifying TBI, as did all but one of the remaining studies. ABI and TBI, although both a source of caregiver burden, have the potential to be very different. For example, Shah, Al-Adawi, Dorvlo and Burke (2004) discuss differences in length of hospitalisation, functional outcomes and cost of care between the two groups.

3.3: Effects of interventions on family functioning, stress and burden.
Two studies from each intervention type (Geurtsen et al., 2011; Kreutzer et al., 2009; Wade et al., 2006; Wade et al, 2008) examined outcomes on FF as a single construct

using the FAD, which is a 60-item measure of a wide range of "stable" aspects of FF with recognised validity (Miller, Bishop, Epstein & Keitner, 1985). None of these studies found significant effects post-intervention. Kreutzer et al. (2009) and previous research (Brown, Pain, Berwald, Hirschi, Delehanty & Miller, 1999) note that there have been mixed results for studies of family-targeted interventions on distress and FF. Kreutzer et al. (2009; pp. 544) described this and their current lack of effect on distress as being "unrelated to intervention delivery method, recipient or purpose". They do report that past research has demonstrated influence, although this has been with larger sample sizes, and they recommend measuring FF in different ways in order to accurately examine effects. For this reason it is important to consider sample size when interpreting these findings, as both traditional interventions (Guertsen et al & Kreutzer et al) had the highest numbers of participants (see table 2) and still found no significant effects in this area.

Geurtsen et al. (2011) give the 'stability' of FF as a reason change was not measured by the FAD. They argue that major shifts in the physical and psychological factors measured by the FAD are necessary in order for the changes to be detectable. This is perhaps less likely to occur in BI, certainly in the studies included in this review, as the majority of participants sustained injury over a year previously, and the consequences might be more settled rather than prone to major fluctuations that the FAD is designed to detect. Essentially, the use of the FAD in measuring FF as a single construct via set factors appears to be questionable, at least in these samples. Geurtsen et al did however note significant improvements in caregiver burden and distress after a traditional family intervention, although this study notably scored one of the lowest on the quality assessment (16/24).

Rivera et al (2008), using another 'traditional' intervention, take a different theoretical perspective, viewing FF factors, such as caregiver burden, as subjective and variable based on individual's perceptions of their situation, roles and how they then act. Consequently, PS has become a major area of family intervention after BI, and supports the fact that six of the studies reviewed – one traditional and all of the telehealth studies (Rivera et al., 2008; Wade et al., 2005; Wade et al., 2006; Wade et al., 2008; Wade et al., 2012) – held this as one of their targeted outcomes for caregivers. Of these studies, all found favourable outcomes for PS as well as caregiver distress. For example, Wade et al.'s telehealth intervention (2006) reported a general increase in PS ability. The findings of this study note that although both the control (internet resources) and intervention groups reported increased PS, this coincided with increased distress with the control group only. They discuss that previous studies (Wade et al, 2001) have noted an increase in distress in line with more active methods of coping, and suggest that their paper illustrates that education is necessary alongside PS skills to ensure families do not attempt active PS in inappropriate situations. This potential danger carries important connotations for further interventions in relation to PS. Further to this, Wade et al. (2012) found that treatment outcomes, including measures of PS, were moderated by socioeconomic status (SES), which suggests further complexity in this area.

3.4: Delivery method and outcome

Regarding delivery method, there did not appear to be any notable consistent difference between studies using more traditional face-to-face interventions, and those that relied on technology (see table 2). In particular, no measures of FF as a whole noted any improvement. For those that measured caregiver burden, two studies, one from each

intervention group, (Geurtsen et al., 2011; Wade et al., 2005) found significant positive changes post-intervention, whilst two conventional interventions did not (Rivera et al., 2008; Sinnakarrupan et al., 2005). The latter linked this lack of significant change to the fact that caregiver concerns are seen as "realistic", and also referred to how worries after BI are likely to be "stable" and therefore not easily influenced. All but two of the studies reported significant reduction in caregiver distress, as reported by various measures, and both of these studies were delivered by more conventional means (Kreutzer at al., 2009; Sinnakarrupan et al., 2005). Collectively, these findings suggest a potentially higher level of efficacy for telehealth methods, although lack of consistency between studies limits this observation. When considering this it is also important to note that quality varied greatly within the telehealth intervention group, with two of the studies receiving the highest awarded rating of 20/24 (Wade et al., 2006; Wade et al., 2012), and one scoring the lowest awarded score of 16/24 (Wade at al., 2005).

None of the face-to-face interventions specifically discussed delivery method (Geurtsen et al., 2011; Kreutzer et al., 2009; Sinnakaruppan et al,. 2005), whereas, due to telehealth's fledgling status, all studies using technological or online methods of delivery included further deliberation on this matter. Wade et al (2006) conclude that their findings support online interventions being "at least as effective as conventional approaches" (pp. 446), with Wade et al. (2005; 2008) both finding that their online interventions were effective for both families and patients, therefore supporting use of telehealth interventions within this population. These two studies also noted that participants described a good therapeutic relationship with their therapist, despite only meeting them on initial sessions. Wade et al. (2006) did, however, identify a sub-group of participants who said they would have preferred face-to-face interventions, so

satisfaction with this method could be variable with regards to another, so far unidentified, factor. This could also be linked to Wade et al.'s (2012) observation that although those of lower SES benefited more significantly from their online intervention, it was potentially the small portion of the intervention that included therapist contact that was the most helpful. They summarise that although web-based interventions are possibly not as efficacious when devoid of any therapeutic contact, they still allow interventions for families post BI to reach those who might otherwise have to travel long distances to access the help they need. The same can be applied to Wade et al.'s (2006) findings, as although it appears telehealth interventions might not be favoured by everyone, it is important to weigh this risk against that of the existing unmet needs and lack of requisite services.

One difference, and potential source of bias, between the telehealth and more conventional methods of intervention delivery was that participants required to access content on the Internet were provided with various items that might influence social desirability. For example, Wade et al. (2005) gave a computer, internet access and webcam in return for participation. Obviously these factors could have influenced the likelihood of those contacted taking part, either by way of adding incentive, or in increasing the risk of response bias in order to "earn" what they have been given.

3.5: Demographic characteristics

No studies reported or found ethnicity, age group, or severity of injury to moderate treatment outcomes either within or between groups. No caregiver demographics were discussed at length, although two studies, one from each intervention group, discussed marital status and had contrasting results, with Kreutzer et al. (2009) finding that

married caregivers reported more met needs both before and after traditional intervention, when compared to unmarried ones. Wade et al. (2006), however, found marital status to have no effect on treatment response.

Caregiver SES tended to be noted using a combination of both employment status and level of education. Only two papers discussed their impact on telehealth treatment outcomes, both of which had among the highest quality ratings (21/24). Wade et al. (2006), found SES to have no impact but Wade et al. (2012) found that SES significantly moderated the treatment outcomes of their online intervention group. Wade et al. (2006) concluded that their findings support the application of similar online interventions across all SES groups with the potential for successful outcomes. Wade et al. (2012), however, found that families of lower SES experienced significant improvement when in their Teen Online Problem Solving (TOPS) group, and not so in their Internet Resource Comparison (IRC) group, where participants were just given access to information and advice on the internet. Further to this, they also found that both the TOPS and IRC interventions looked to be less effective overall, but as effective as each other, for caregivers of a higher SES BI survivor. This is discussed further, with Wade at al. (2012) suggesting that perhaps those of higher SES are more familiar with seeking and applying aid for themselves, whilst families of lower SES might have found this daunting and therefore not have benefited to the same degree when in the self-driven IRC group. They also question whether one aspect of their TOPS group – regular Skype sessions with a therapist offering support and structure for interventions – was in fact the most important in this instance. This is suggestive of therapist support and contact still being influential in telehealth interventions, which is in line with other studies finding therapist involvement has lead to larger treatment effects (Spek,

Cuijpers, Nyklicek, Riper, Keyzer & Pop, 2007). This is an important consideration regarding the efficacy of pure telehealth interventions with families of lower SES, and just how big an impact therapist input – or lack of it – holds.

Discussion

This review aimed to examine the recent increase in telehealth interventions targeting the wider family and caregivers of those who have experienced BI, alongside more conventional interventions provided face-to-face by a therapist. This enabled a comparison of both effectiveness and differences between the two. A total of eight studies were systematically selected, all of which were quantitative by design and included measures of FF, caregiver distress or burden. One of the observations of the review was the variety of and theoretical disparity between outcome measures, hence the heterogeneity of results required a qualitative synthesis of findings.

4.0: Telehealth Vs conventional intervention formats

With regard to the comparative effectiveness of telehealth and conventional intervention formats, there appears to be no clear evidence that either is more effective. Telehealth studies were consistently able to reduce caregiver distress via PS interventions, but the interpretation of this effect depends on factors such as outcome measures and the methodological quality of the studies, as discussed below.

4.1: Telehealth and SES

This review indicates that families and injured individuals with a wide range of demographic characteristics demonstrated improvements in caregiver and family distress and burden when taking part in telehealth interventions, suggesting a potentially wide range of applications in this area. Previous research has identified the distress suffered by the families of those with BI, and that this can in turn effect the injured individual (Testa, Malec, Moessner & Brown, 2006). The fact that all studies demonstrated high levels of distress at baseline looks to be in fitting with this trend. As

no key differences were apparent between the effectiveness of traditional and telehealth delivery methods, there appears to be no reason the expansion of telehealth-driven services should not continue in this population. As the review highlights, however, measures of FF can be unreliable for the chronic, perceived burden that accompanies families of those with BI, and differing theoretical ideas create inconsistency.

It is worth noting that one factor found to have a moderating effect on outcome in the telehealth literature was SES (Wade et al., 2012). SES has been found to be influential in other areas of rehabilitation after BI (Hoofien, Vakil, Gilboa, Donovick & Barak, 2002), and so although this wasn't a consistent finding, Wade et al.'s (2012) suggestion that it may moderate telehealth effectiveness could be prudent. The findings suggest that families of lower SES need more guided approaches to telehealth, where a higher level of therapist input is important. This calls into question whether 'pure' telehealth interventions are effective for all. Similarly, those of higher SES reported less gains from telehealth interventions, on the same level as with basic provision of educational resources, suggesting a limit to its efficacy within this population. Prior research has found that those with low SES have limited access to technology, and therefore online resources, as well as less opportunity to make use of traditional services (Carroll, Rivara, Ebel, Zimmerman & Christakis, 2005). Accordingly, it appears that telehealth interventions including even a minimal aspect of therapeutic contact can be effective for those with lower SES.

For those of higher SES, the findings of this review suggest that there is a potential danger that more educational telehealth-mediated interventions are restricted in the amount they offer beyond that which is already available to access online. In essence, it

appears that telehealth interventions for families after BI might need to be more specifically designed with client demographics in mind, with the possibility of integrating conventional and telehealth interventions flexibly on the basis of needs and SES.

4.2: Limitations of the review and included studies

There are limitations to all of the studies included, and therefore this review itself. The low quality of preliminary studies into telehealth across all areas (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007) and in BI (Rietdijk, Togher & Power, 2012) have been noted, and was apparent in this selection. Every study recognised that samples were small, particularly in comparison to the number of measures used, which increases the chance of type 2 errors (Khamis, 1988) and constrains generalisability. In addition to this only a limited number of studies used a comparative control group, with all participants and most researchers aware of which group they were in, increasing chances of researcher bias. This was furthered by the social desirability factors of the telehealth studies, as noted above, and the high incident of self-report measures used.

Another limiting, but necessary, factor was the very specific nature of all the studies' inclusion and exclusion criteria. The relatively small population available to each sample will have limited generalisability further, made more prominent by the recruitment methods creating a likelihood of volunteer bias. It is possible that either the most confident or the most distressed families agreed to take part in the research, for example. The validity of the review was also limited by the fact that there was a possibility that fitting studies were missed due to the search strategy used, and publication bias limiting the availability of research.

As this review focused on delivery method in an attempt to consider telehealth's comparative efficacy in this area, it necessitated wide variation of included interventions, as few comprehensive studies have yet been conducted. The methodological heterogeneity necessitated the use of a narrative synthesis to review results, with the included papers reporting findings from a range of ages, times since injury, and severity of injuries. The nature of interventions was also diverse, although linked through a shared aim of measuring outcomes of caregiver and family distress. Due to this focus, the review also neglected to report outcomes for the BI clinical samples.

Another limitation imposed by the small number of telehealth studies available was that all research into telehealth-mediated interventions that matched criteria were conducted by the same group of researchers. Although quality of these studies fluctuated, and findings contrasted within this group, it is possible that these studies were biased in comparison to telehealth articles from other authors. Similar conclusions within these studies would have potentially added more support to a theory or finding favoured by the authors, although, as noted, in this particular sample their findings varied. Further bias remained, though, as more specifically the authors involved with the telehealth studies may have all come from similar backgrounds, have similar beliefs about the nature of telehealth interventions, and all of their studies might have included similar testing environments, procedures and protocols.

This pulls into question the representativeness of the selected telehealth interventions when compared to what must be a broader sample of teleheath interventions being

utilised in clinical practice but not studied or widely published about, and therefore the generalisability of findings from this review. However, unfortunately, a more diverse pool of research was not available at the time the search was conducted, as no other authors had published research of this nature, nor had any replication of the included studies been found to comment on their validity.

High variability across papers limits the interpretation of findings, and therefore constrains definitive conclusions regarding the comparative effectiveness of both telehealth and more conventional methods of family intervention post-BI. The review does, however, present an integrated summary of new research in this area, and highlights points for further consideration.

4.3: Clinical implications and further research

Despite heterogeneity, all studies found that caregivers displayed high levels of distress and burden at baseline, supporting earlier research (Byard, Fine, & Reed, 2011) and emphasising the impact of BI on family well-being. Considering this, the selection process of this review highlighted a clinical need, as research into interventions targeting families was found to be sparse.

The fact that no intervention was found to effect measures of FF as a whole – specifically using the FAD (Epstein, Baldwin & Bishop, 1983) – despite changes in distress and burden creates further support for the reconsideration of this measure, particularly in studies with small sample sizes. The FAD comprises scales on problem solving, communication, roles, affective responsiveness, affective involvement and culture (Epstein, Baldwin & Bishop, 1983). It has been used with those with BI

previously (Brown, Pain, Berwald, Hirschi, Delehanty & Miller, 1999; Ponsford, Olver, Ponsford & Nelms, 2003), although each study reviewed noted no significant effects post-intervention. As mentioned above, there is debate over the FAD's attempt to measure 'stable' factors, and the conceptualisation of FF in unitary terms.

Alternatively, Chwalisz (1996) describes the Perceived Stress Model of Caregiver Burden (PSB), based on the idea that burden is a product of the interaction between a situation and an individual's perceived coping resources. It follows, then, that FF would not be adequately gauged by only measuring 'static', objective factors, but rather subjective levels of distress and coping. Accordingly, all the studies included self-report scales, which although theoretically fitting, carry consequences for reliability and generalisability. This theoretical perspective means that FF and burden are difficult to measure, and following from this can make planning appropriate interventions difficult.

It is from Chwalisz's PSB model, and later Anderson, Parmenter and Mok (2002), that PS is identified as both a useful outcome measure and intervention point when considering rehabilitation. Anderson, Parmenter and Mok found that reports of more coping activities were positively correlated with increased perceived stress, and upon exploring this further, found that problems lay in the type of coping (Lazarus & Folkman, 1984). Problem-focused coping – working to actively change something – was actually shown to correlate with lower perceived distress, and emotion-focused coping – denying and avoiding the source of stress – increased the reported distress and burden. With these different theories all captured in this small sample of studies, it seems that the sheer variety of approaches to and measures of functioning, distress and burden limit comparability on many levels, even when the nature of interventions are

similar. Development of comparable and reliable outcome measures to be used in this area, validated for use with those who have sustained a BI and their families, provides an opportunity for further research, as it appears that there is currently no consensus.

Whilst the comparability of conventional and telehealth formats is limited by the diverse outcome measures employed, no evidence was found to suggest that telehealth interventions were any less effective than face-to-face ones. Wade et al.'s (2012) observations that SES mediated treatment effect should be further explored with regard to interventions involving a technological aspect. SES has been found to mediate other rehabilitation factors in the BI population (Putman, De Wit, Schoonacker, Baert, Beyens, Brinkmann, et al., 2007) and so this finding should not be overlooked. Further to this, Wade et al's (2006) discussion regarding the reported increase in distress in line with active PS in the control group warrants concern and further consideration of telehealth interventions tackling PS. Safeguards should be put in place against the danger that telehealth could provide families with the ability to access PS skills training without the education or guidance that should accompany it. At the very least, these findings suggest that possible demographic characteristics and the practicalities of module completion should be further researched in order to inform clinical decision-making. In this way, telehealth interventions can be designed and allocated so as to be offered to those that are likely to best utilise them, and to enable support to be provided alongside the interventions for those that are likely to struggle. Ongoing research in this area is likely to increase the cost-benefit of telehealth interventions, and ensure they effectively aid those who cannot access traditional rehabilitation services, as they were designed to do.

4.4: Conclusions

Overall, this review offers support to the expansion of telehealth-mediated interventions in the area of BI, suggesting that they can have efficacy comparable to that of face-to-face methods when aiming to reduce caregiver burden and distress. Further to this, the need for a valid and sensitive measure of FF for this population is discussed. It is important to consider interventions for families of those with BI alongside those targeting the individual, and consideration of variables that carry the potential to moderate effectiveness, such as SES, can allow for more comprehensive and targeted developments in service provision.

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Part Two:

Empirical Paper

The experiences of mother and non-injured sibling relationships post young adult traumatic brain injury

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Abstract

OBJECTIVE: This study aimed to explore the experience of role and relationship changes between mothers and non-injured siblings after a young adult in a family has experienced a traumatic brain injury (TBI). A further aim was to explore any of these experiences unique to either individual, and how both these and areas highlighted by the first aim are managed.

DESIGN AND METHODOLOGY: Seven dyads (fourteen individuals) of non-injured siblings and mothers took part in semi-structured interviews, discussing their experience of changes in relationships and roles after a young adult in their family had experienced TBI. Interviews were analysed using Interpretive Phenomenological Analysis (IPA).

RESULTS: Four superordinate themes were identified: Mothers' Prioritisation of the Injured Sibling; Isolated by the Experience; Approaches to Coping; Growing Closer.

CONCLUSIONS: Themes suggested that relationships were strengthened post-TBI, although participants noted having negotiated new roles and ways of coping, both as individuals and dyads. A lasting sense of potential emotion-focused coping and reduced flexibility was present for some dyads, balanced with more positive growth and a related clarification of values underpinning relationships. Possible consequences of these changes are discussed in line with systemic and adversarial growth literature. Implications for rehabilitation and support post-TBI are discussed, regarding application to and reception from families.

KEYWORDS: traumatic brain injury, non-injured sibling, caregiver, relationship, systemic, fledgling adult

Introduction

Brain injury is widely acknowledged to be a leading cause of disability and death around the world. A 2006 UK study found that 453 per 100 000 of emergency department attendances were due to head injury, with 10.9% of these being classed as moderate to severe [1]. The nature and consequences of brain injury can vary from brief concussion to life-long deficits and, ultimately, the effect on each individual, and the specific nature of their recovery and rehabilitation needs, differs from person to person. Accordingly, costs to society following brain injury can be great as services often need to be provided on a long term basis [1-3].

The wide range of possible deficits faced after a brain injury is not only frequently devastating for the individual, but also has major implications for their family and/or carers. The prognosis can be impossible to predict, and so the course of rehabilitation is often painful and uncertain [4]. Ultimately, families of those who have suffered severe brain injury go through a complicated process of changing emotions, roles and relationships as they adjust to the impact of injury. They face having to re-negotiate a functional relationship with the injured member, and this can have significant consequences for both their own well-being and the forecast of recovery [5].

This complicated process is sometimes referred to as ambiguous loss [6]. These are instances where a loss is more complex than usual, and the consequential uncertainty this involves can 'freeze' individuals in the mourning process [6]. Ambiguous grief associated with this is often seen in the families of those who have suffered brain injuries, as the specifics of an injury make it possible to feel as if only 'part of' a person is lost. It has been suggested its effects correlate with the breakdown of family systems

[7]. Much research has explored the relationship between family coping and rehabilitation outcomes [8, 9], so it is vital to consider the impact upon the family unit as a whole when planning services and support.

The complexity of recovery after TBI is further compounded by the fact that epidemiological research into TBI has shown that the age group which experiences the highest number of injuries is that of young adults, aged 15-24 years old [10]. 37% of these individuals are still living in their family home at the time of the injury [10], and many more have only just gained independence. This creates increased complexity post-injury as the fledgling adult and their family are forced to diverge from what is usually considered to be normative family development. For example, parents might suddenly resume a caregiving role at a stage when they had been contemplating retirement, diverging from the expected progression of the developmental family life cycle (FLC) [11, 12]. Fumiyo, Sumie, Akiko and Yasuko [13] note that the primary caregiver at this age tends to be the mother, who can then revert to a level of parenting focused more on practical care and protection, 'throw[ing] herself into caring for her son, who has regressed to the stage of a nursing infant' (p. 282). It is possible this makes it difficult for either individual to reclaim independence as recovery and rehabilitation progresses [13].

These processes and changes, which can be seen as conflicting with normative family development, can lead to mothers and families suffering adverse consequences for long periods of time post-injury, with one study finding that 47% of caregivers suffer clinically significant levels of distress [14]. However, the prognosis of this distress has been found to vary according to numerous factors. Examples of these factors include the nature of any functional limitations of the injured individual post-injury, both individual

and family coping strategies and family dynamics [15]. These have been shown to impact upon the severity and length of any negative changes in family functioning [16, 17].

These changes, especially those affecting mood, have also been found to affect family members differently, with depression and anxiety being common [17]. These have been particularly observed in parental relationships after brain injury [18, 19], yet there remains surprisingly limited research into the area of siblings. Sibling relationships are unique – the bonds they consist of are based on the individuals sharing similar backgrounds, with a higher chance of the bond lasting the entire lifetime [22, 23]. One recent key study specifically focused on the experiences of non-injured adult siblings of those who had suffered TBI [22]. General life changes were examined via a postal survey, which identified three key themes – 'caring for and about the family member', 'making sense of the experience' and 'family impacts', such as differing levels of closeness. One of the participants themselves identified siblings as 'the silent victims' of TBI, reflecting the fact that often in family studies only the views of the injured individual and their parents are included. Degeneffe and Olney's study [22] shows that siblings' lives are affected too, at least in part due to altered family relationships.

Cavallo and Kay [23] also highlighted how parental concerns and attention can become heavily focused on the injured individual, and other siblings may be given much more responsibility for their own well-being than they are used to, or ready for. Alternatively, they found that the injury can cause families to pull together, tightening bonds and emphasising closeness. Cavallo and Kay [23] note that reactions are tempered by the severity of the injury and consequential deficits; Stancin, Wade, Walz, Yeates and Taylor [16] found that severe brain injuries are more likely to result in altered inter-sibling

relationships. Clearly, the effects of brain injury on non-injured siblings (NIS) are potentially extensive as well as varied and therefore require further exploration in order to expand our understanding.

Growing research is examining the shared parent and well-sibling relationship in other clinical areas, e.g. cancer, and how this both alters and impacts further family development. Woodgate [24] explored sibling and parent experiences of a child with cancer and found that they reported a 'loss of family way of life' and the loss of the self within the family. Moreover, Rauf [25] explored this further, finding more perceived conflict in the parent-sibling relationship, causing more parental stress which then influenced the injured sibling's clinical outcomes. Rauf [25] highlights the need for consideration of increased stress and burden caused by changes in the parent-NIS relationship to be explored within this population and others, and to further assess the support offered to families for this reason.

This study aimed to tackle a particular gap in the literature around potential longer term changes in sibling-parent relationships in the years after a family has experienced young adult brain injury. There remain few studies that have examined the effects on siblings after an adolescent has sustained a brain injury, despite the fact that this is the largest demographic which do so, and the consequences on family members are recognised as potentially severe. Further to this, although it is acknowledged that wider family systems are vital in, and require support during, the rehabilitation process, Gan, Campbell, Gemeinhardt and McFadden [26] have noted the lack of studies utilising this system to conduct research with multiple members, as there is usually a focus on either the injured individual or key caregiver. In light of noted problems within the parent-sibling relationship in similar clinical populations, and potential changes to maternal

parenting highlighted post-TBI [13], the current study aimed to further the attempt made

by Degeneffe and Olney [22] to give voice to uninjured siblings, also allowing for the

lived experiences and dyadic elements of the mother-sibling relationships to be explored

and incorporated.

Accordingly, the aims of this study were:

1) To explore the experience of role and relationship changes between mothers and
   non-injured siblings, in interaction, after a sibling brain injury.

2) To attempt to explore differential experiences – those perceived by only one
   member of the dyads – within the relationship and how these and areas
   highlighted by the first aim may have been managed.

Method

Design

In an attempt to capture the lived experiences of participants' relationships post-TBI, a qualitative design was adopted, utilising semi-structured interviews. These interviews were conducted with both members of the mother-sibling dyad present in order to allow a rich, multi-perspective account of the shared relationship to be captured.

Interviews were carried out in the family home, with questions or prompts remaining open and non-directed with regards to which of the dyad should initially answer. As with individual IPA interviews, the researcher aimed to remain a 'naïve but curious listener' (p. 64) [27] where possible, allowing the dyad to fully discuss their thoughts in response to the open questions. The researcher also aimed to allow dyads to 'establish their own parameters for participation' (p. 558), as suggested in a previous discussion of dyadic interviewing [28], meaning that individuals could largely contribute however much they chose. Prompts for further explanations and clarification were used, although were often not necessary, as one member of the dyad would ask the other, for example, how they had experienced a situation, or add their own elaboration.

Although the two participants within each interview contributed at varying degrees throughout, there were no instances where an individual neglected to partake in the majority of the discussion, or where the voice of one individual drowned out the other across the interview journey. Interview transcripts were then analysed using interpretative phenomenological analysis (IPA; Smith, 2009) [27].

Applying a qualitative paradigm to dyadic research enables researchers to view two

people as 'mutually influencing partners' (p. 1577) [29] where it is possible to explore and learn from their shared meanings of experiences and collective perspectives as they occur, rather than struggling to disentangle two separate accounts [e.g. 30]. In turn, this allows for a more detailed exploration and interpretation of 'shared truths' and meanings emerging *in* the relationship, which it may not be possible to gain via separate individual interviews *about* a relationship. Epistemologically, this approach reflects the application of phenomenological and hermeneutic perspectives (e.g. Heidegger [31]), where 'truth' is seen as subjective and multi-perspectival. Please see appendix 1.2 for further details regarding the epistemological position taken up by this research.

IPA is an appropriate methodology for analysing the rich and multifaceted data elicited by dyadic interviews as it allows for the detailed consideration of 'more than the sum of two individual versions' (p. 1645) [32] with a third aspect, the relationship itself, then more amenable to analysis [28, 32, 33]. Racher [34] supports this notion, arguing that so long as the shared relationship is the unit of study, IPA analyses of conjoint interviews should not be avoided. The application of IPA in a dyadic context is becoming increasingly common, particularly regarding topics that are naturally more dyadic than individual, such as those exploring relationships or shared experiences [32]. For example, Maxted, Simpson and Weatherhead [35] recruited seven family dyads comprised of one parent and one child within families at risk of Huntington's Disease (HD) in order to explore their 'co-constructed meanings of the experience of being within a HD family' (p. 2). They then used IPA to identify key themes for these dyads. Similar procedures have been used by others [36-38].

Whilst it is possible to argue that an interview with multiple people present can restrain

candour and reduce the validity of responses (particularly where family relationships are concerned) it is also possible that conjoint interviews offer participants a valuable opportunity to disclose previously unarticulated thoughts and feelings and so create a deeper shared narrative about their shared experiences. In support of this notion, Taylor and de Vocht [29] document how interviews conducted with dyads can facilitate further disclosure and produce richer data than individual interviews, through a process where each participant prompts, supplements or even challenges the other's account and in doing so enriches the shared account that eventually emerges. Relatedly, interpretative phenomenologists emphasise the importance context has upon an experience, which previous researchers have argued extends to the context created by a dyadic relationship [29, 36]. Interviews with the dyad can be a more effective way of exploring this context and its impact in a 'live' way, compared with individual accounts. For these reasons, in this study participants were interviewed as joint dyads, rather than as individuals, as the shared experience of the maternal relationship and any changes within the context created by this were key issues the study aimed to explore.

Measures

The semi-structured interview was guided by an interview schedule constructed using open-ended questions informed by both the research questions and significant factors identified in relevant background literature (see appendix 5.5). It aimed to explore both mothers' and NIS experiences of their relationship, with prompts used to allow for further exploration and clarification. Interviews were recorded on a dictaphone, and lasted between 44 and 95 minutes (mean length: 82.6 minutes).

Recruitment

Participants were sought through the Brain Injury Rehabilitation Trust (BIRT), national NHS Neuro-rehabilitation departments, and Headway (a brain injury charity), with appropriate BIRT and NHS Research Ethics Committee approval obtained prior to this. BIRT and the NHS departments identified potential participants and then either distributed an information sheet with the researcher's contact details on (appendix 5.1), or gained the individual's consent (appendices 5.3 and 5.4) and passed their details directly to the researcher. Three Headway groups published a poster detailing the research in their online newsletter (appendix 5.2) and discussed it at regular meetings.

In total, 12 families contacted the researcher via telephone and were found to fit inclusion/exclusion criteria, four of which later withdrew their interest, one due to disagreement about participation, one because the qualifying sibling would be absent during the period of interviews, and two because they had changed their minds regarding participation. One dyad was excluded due to methodological procedures at the analysis stage, as the father-son characteristics were felt to introduce too much heterogeneity into the coincidently all-mother sample to be appropriate for IPA. This left seven dyads, four identified and recruited via BIRT, and three recruited from NHS Neuro-rehabilitation departments. Ultimately, this equated to fourteen individuals. Verbal consent (agreeing to participate and arranging the interview) was provided at least one week before written consent was gained from both the NIS and mother at the interview itself, in order to allow and encourage further consideration of participation after the opportunity to ask additional questions. No payment or reward was offered for participation. The researcher had specified a maximum of ten family dyads (twenty individuals) to take part, and although only seven came forward (fourteen individuals),

in keeping with Smith, Larkin and Flowers' [27] guidance on sample sizes when using

IPA, and participant numbers in previous dyadic studies [e.g. 35, 37, 38], the dyadic

interviews yielded a richness of data that justified the slightly reduced sample size.

Participants

Inclusion criteria necessitated each family have a male young adult member who had

sustained a head injury when they were between the ages of 15 and 24, between 2 and 5

years previously, to ensure that the injuries, functionality and family roles and

relationships were more likely to be relatively stable with regard to the TBI [39, 40].

Severity of TBI was quantified as the individual having had to spend time in

neuropsychological rehabilitation immediately after the TBI occurred. They must also

have been living at home at the time, along with a sibling who would be older than 16 at

the time of participation.

This study used a convenience sample of seven dyads. All the siblings were between the

ages of 19 and 23 (mean age: 20.6 years) at the time of interview, and consisted of five

females and two males. Mothers' ages ranged between 40 and 58 (mean age: 47.7

years). Two families were single parented, both by the mother. Mothers confirmed that

the injured sibling (IS) was between the ages of 15 and 24 at the date of injury (mean

age at injury: 20.4 years), that the injury had been severe enough to require a stay in a

rehabilitation facility, and that it had occurred between 2 and 5 years previously (mean:

3.9 years since injury) (for participant and dyad details see appendix 6.1).

Analysis Procedure

The seven audio-recorded interviews were transcribed verbatim by the interviewer to

allow immersion in the data, and were allocated pseudonym codes to ensure anonymity. Transcripts were reviewed as discussed by Smith [41] on the use of multiple participants in IPA, to ensure it was felt that each individual participant had not obviously been deterred by having another present. These transcripts were then printed and analysed using the IPA methods outlined by Smith, Larkin and Flowers [27]. This involved re-reading and familiarisation with the data, before noting descriptive, linguistic and conceptual observations in the margin of each paper. Descriptive and linguistic comments focused on the content and delivery of the pure data, whereas conceptual comments allowed further reflection and interpretative questioning from the researcher. For the purpose of this study, following a method discussed by Van Parys [42, 43], a fourth observational area – processes/interactions – was noted, focussing on the nature of any exchanges within the dyad, both verbal and non-verbal, for example elaboration, interruption or silence. This was in keeping with previous IPA dyad studies, [e.g. 28, 32, 33, 38], and also Smith's [41] suggestion of 'pushing the [IPA] analysis further' (p. 46) through the use of various analytical skills and approaches to better understand an experience. It allowed for a more experiential analysis but also worked to include some of the co-constructed aspects of the mothers' and NIS' experiences of their relationships.

After this process was completed for all transcripts, themes were re-read in order to identify emergent themes which were again noted in the opposite margin. These themes were entered into documents, and on review of all emergent themes within each interview, and then across interviews, further themes were elicited which were then organised and synthesised into super- and sub- ordinate themes. Themes were considered recurrent if they occurred in five or more interviews, in an effort to balance the preservation of perspectives of individual relationships with more sample-wide

accounts. Throughout this iterative process, a peer validation system was in place alongside the use of supervision, whereby extracts of interviews were independently annotated, and emergent and final themes were discussed to ensure validity. (For a worked example of IPA please see appendix 6.2).

As with all qualitative approaches, the researcher's biases and previous understandings – characteristics and assumptions – are influential in the analysis and interpretation of participant data. Consequently, the construction and strengthening of themes and conclusions are effectively a re-interpretation of the participants' own interpretation of their experiences [27]. Reflective processes were highly important with regard to this process in the present study as, for example, the researcher was a white British female with an interest in existential models of therapy, who had worked as a trainee clinical psychologist within two brain injury services leading up to and during the research. This included work with families in distress, and the researcher also had a male sibling falling within the included age bracket of the research.

These characteristics might have led to pre-conceived ideas and assumptions about the research. For example, it was recognised that there was a danger of predicting parental reactions to adolescent brain injury in line with previous experiences of the families the researcher had worked with, or indeed expectations of families drawn from the researchers' own experience of family. Ongoing actions were taken to be reflexive in order to acknowledge, separate off, and limit the impact that these factors might have on the study. This was achieved through the use of a reflective diary to note any initial thoughts/ideas in order to prevent them from unknowingly influencing the analysis, and to document processes the researcher was aware of and utilised, as well as the peer

validation system noted above. Two forms of academic supervision were also regularly undertaken throughout this process.

The extracts below were selected as they were thought to present the 'essence' of themes, as well as illustrations of divergence therein.

Results

The process of analysis led to the generation and organisation of a number of themes which appeared fundamental to understanding the shared lived experience of mother and NIS relationships after another young person in the family had experienced TBI. Eight themes were identified, grouped into the super-ordinate themes of 1) Mothers' prioritisation of the injured sibling (IS); 2) Isolated by the experience; 3) Approaches to coping; and 4) Growing closer. (Sub- and super- ordinate themes displayed in table 1)

Super-ordinate themes	Sub-ordinate themes
1. Mothers' prioritisation of the IS: '*He comes first because of the way he is*'	1.1: Mothers' sacrificed roles 1.2: Sibling responsibility: '*Step up*'
2. Isolated by the experience	2.1: Need for validation vs doubt that needs can be met: '*You'd never understand*' 2.2: Professional support unreliable: '*trying to find your way through mud*'
3. Approaches to coping	3.1: Coping as doing: '*just get on with it*' 3.2: Humour: '*you have to laugh about it*' 3.3: Social support
4. Growing closer	4.1: Shared awareness of mortality

Table 1: Super- and sub- ordinate themes

Super-ordinate theme 1: Mothers' prioritisation of the injured sibling (IS) - 'He comes first because of the way he is'

Mothers' described the somewhat automatic prioritisation of the IS both immediately after the accident, and, for a minority, thereafter. Almost exclusively, every mother prioritised the IS in the orientation and allocation of their physical and emotional attention. This prioritisation appeared to be led by the mother, with them raising it in the interviews, although there did not seem to have been any explicit discussions between mothers and NIS about how this would work at the time of their son's injury. The prioritisation itself, however, was openly and matter-of-factly acknowledged by mothers in the interviews:

'Well you see he's never had to fight for my attention with my daughters, because my daughters have always known that [X] comes first. Bec... not because he comes first because he's a boy, whatever, he comes first because of the way he is, and they come down second, and then my husband's right at the bottom. He comes last.' (Mother 1, line 356-359)

'And er, and he was for the first, for two years, he was, he was my priority.' (Mother 3, lines 1046-1047)

'I think you concentrate, to tell you the truth, you concentrate solely on the person that's hurt, you don't think about anything else.' (Mother 4, lines 374-375)

The majority of siblings did not disclose their feelings on this process, how it had affected their relationship, and consequential altered maternal attention, although across interviews there was a sense of acceptance. One of the NIS voiced their thoughts on

this, accrediting it to a sense of understanding.

'...I think considering the time frame and the, kind of, out of the blue kind of thing, we were all just absolutely ok with what happened, and fully expected, you know, the lengths that [Mother] had to go to, because, you know, I think anyone would.'

(Sibling 7, lines 445-448)

Only two siblings spoke of finding this prioritisation negative in some way, with suggestions of feelings of exclusion or unfairness. These statements were not presented as accusatory, but rather as part of a discussion about negative implications of the necessary changes that had taken place following the injury. In both of these instances, the mothers acknowledged these feelings in an unapologetic way. There was a sense for both individuals that this was an accepted consequence of the requisite shift in the mothers' attentions.

'...you accept it but it is difficult at times, because sometimes you feel like you...you get left out.' (Sibling 1, line 609)

'Don't treat one different to the other they all get the same, but, it, the circumstances that you're in, erm, the dynamics do change.' (Mother 1, lines 620-621)

'Sibling: But at the time I didn't. Me, personally, at the time, I didn't see it as this important. Like, more important.

[Interviewer: Hmm?]

Sibling: You think your parents are just being unfair. You do, yeah.

Mother: Of course you do.' (Dyad 5, lines 919-922)

Although this prioritisation was widely accepted by both individuals across dyads, further consequences for both mothers and siblings and their relationships were acknowledged. Most notably for mothers, this included becoming immersed in the prioritisation of the IS to the exclusion of other roles. For siblings, this involved an acceptance of unfamiliar tasks and responsibilities.

1.1: Mothers' sacrificed roles

The majority of mothers noted the fact that the necessary devotion to and prioritisation of the well-being of the IS meant that they ultimately sacrificed roles or projected roles in their lives that had previously been important to them. For most mothers this was their role as an employee, as they had given up work, but for one this included ambitions to foster children in the future. Consequently, there was a sense that their lives took an unexpected yet profound change of direction post-TBI, which, developmentally, they felt somewhat unprepared for. For example, one mother had predicted their son might have moved out of the family home at an earlier point in time, and, faced with having him staying there for the foreseeable future post-TBI, was having to adjust her plans accordingly. At the same time this was consistently accepted without resentment, with the sacrifices discussed as a necessity.

'...I mean, I can't work like I worked. So, I don't work, which in a way is good cause it helps them out now.' (Parent 1, lines 260-261)

'I like, liked my job, but it was between my job and my son, so... And, and, like, I, we were told we didn't know how long we had him so I thought I need to spend as much quality time with him as I possibly can, d'y'know, work comes second to being with my son.' (Parent 2, lines 1149-1151)

Despite this acceptance, half of the mothers showed some regret over having lost ambitions or aspects of their lives.

'Yes, and mind he's 24 years old, y'know, it's that kind of bit of I want to get on with my life, but obviously he'll still be there...' (Parent 4, line 1011)

'Yeah, yeah, so because I, I, um, want to become a foster mother, and that's not going to happen because I haven't got a spare room, basically. So, what we, yeah, our life is been put on hold, hasn't it, really. (Parent 5, lines 662-663)

Interestingly, only one mother discussed having chosen, at the time of the injury, to continue with a role she felt she ought to give up. Although she was ultimately happy with this choice as it had worked out well, she admitted to feelings of guilt for not sacrificing this personal ambition in order to spend more time with her son after injury. At this point she was comforted and reassured of the decision by her daughter, showing support with this struggle.

'Mother: I still feel guilt about it now [...] Not, not, not now, because if I didn't have my job, but, um, at the time, I could have, you know...or, or put it on hold, I, cause I think they would of, if I'd have said, you know, I can't work for the next six months. But I didn't, I didn't want to, no.
Sibling: No but I think that's also what helped you, cause it was a bit of normality, so, like somewhere you could, not forget about it, but, put it to the back of your head.'
(Dyad 5, lines 1686-1697)

This perhaps indicates the struggle felt by all of the mothers in the decision to sacrifice personal roles in order to prioritise their injured son in a time of crisis. This was the only instance where a NIS directly commented on the mothers' change of roles within interviews.

1.2: Sibling responsibility: 'Step up'

A key consequence of mothers' increasing priority of the IS was that siblings across interviews identified the fact that they felt that they now had to do a lot more both for themselves and for their mothers and families. All siblings saw these additional roles as something they 'just got on' with, tempered with an understanding of the necessity of their tasks, undertaking practical requirements without apparent further reflection on an emotional level. These new responsibilities seemed to revolve particularly around household tasks and caregiving, both for other siblings and the IS, even in families with another parent present. This seemed to convey a marked change in the mother-NIS roles within their relationship, with the siblings appearing to help to fill any maternal positions left not fully fulfilled due to the shift in the mothers' attention.

'Then I started doing more care with [X], and then I think I just sort of went for it, because I think...bearing in mind I was only sort of, 19.' (Sibling 1, lines 380-382)

'And I just, just, it was one of the things that made me think now I've gotta step up to this, and do what I've gotta do' (Sibling 3, lines 803-804)

'No, didn't seem like a responsibility it just seems like something you have to do.

[Interviewer: Okay so it felt like-]

Sibling: Just normal' (Sibling 4, lines 169-173)

'I do more for you. Like, not, like I try to make sure the house is tidy enough for when you get home because I want less for you to do, because you're tired and then you've got to deal with [X], and then me, and do the cooking, and deal with dad, and... So I just, I try and help more.' (Sibling 5, lines 1584-1586)

No siblings reported any negative implications tied to this process of helping, with some instead commenting that the undertaking of these largely unfamiliar tasks and responsibilities, and their increased independence necessitated by this role change, had positive connotations for their future. These included a sense of learning, development and growth, particularly with regard to the aforementioned maternal roles required.

''cause I had to learn how to do it for [X], I learnt a lot of responsibilities as well like how to do washing, how to cook. Being here has helped me quite a lot, especially for my independence later on in life. It does help.' (Sibling 2, lines 572-574)

'Yeah, probably learned a lot.' (Sibling 4, line 1198)

'I think it's made me mature a lot more, his accident' (Sibling 5, line 1704)

The majority of mothers did not comment regarding their opinion of this role change for the NIS, as, again, there was a sense of accepted necessity. Three did, however, comment on the strength of the NIS for taking on their new roles with a sense of respect and appreciation.

'She's really strong willed and strong-minded...' (Mother 2, line 378)

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'Y'know, he's a very strong-minded person. She can, I wish I had her mind with him.'
(Mother 3, line 1255-1256)

'I think he's absolutely amazing, to take on all that responsibility at that age.' (Mother 4,
line 214)

Super-ordinate theme 2: Isolated by the experience

Participants from every dyad expressed their thoughts and opinions on a struggle to feel
understood, independently highlighting two main factors that they felt had either helped
or hindered this. This was most strongly conveyed by mothers, perhaps due to their
larger organisational role in the practicalities of care and rehabilitation, but was strongly
supported by each corresponding NIS. The first of these factors was the benefit felt
from connecting to others who had also experienced brain injury, which, crucially,
helped to validate the experiences but also encompassed a doubt that others could really
understand. The second was a feeling of disappointment regarding the adequacy of the
information and support provided by medical and rehabilitation professionals
throughout the recovery process.

Both of these aspects were experienced with a sense of isolation from others, with the
dyads seeming to doubt others could, or were willing to, understand and support them,
effectively leaving them to continue alone. This sense was strong within interviews,
presented as a shared phenomenon, with dyads struggling to articulate exactly how
incomparable the experiences had been. Although 'Isolated by the experience' did not
immediately spring to mind as the name for this superordinate theme when considering
purely descriptive data, upon reflection, each of the quotes within the two subordinate
themes conveys a sense of isolation. Forms of this included either wishing for a rare and

idealised connection with someone in a similar position, or despairing at the inability to connect with others or be understood and supported, even by those they felt should best be able to provide this understanding.

2.1: Need for validation vs doubt that needs can be met: 'You'd never understand'
The majority of dyads, although more mothers than siblings, as noted above, expressed the view that the best support that could be offered was by those who had experienced similar brain injuries. This was something that was both wanted by those who had not experienced it, and valued by those who had. The reasoning for this was that the experience of TBI is unique and has no similar points of reference, so the ability to talk to others with a shared understanding was discussed as offering hope, guidance, validation and reassurance that could not be provided by others elsewhere.

' Sibling: And you've got that connection there, you've been through the same thing, you can...the best thing was she turned round and said 'it's rubbish isn't it?' and I said yeah, it's rubbish. And that's just how you do it.
M: You can sympathise cause you know how it...you know all the feelings, all the emotions, you know everything. But you see because there was nobody in there, when [X] went in to that unit it was quite new. There was nobody in there as bad as [X]. So you couldn't see anybody else. I had no reference to see anybody.' (Dyad 1, lines 1200-1207)

"Mother: That's an area that needs, families need, I was always told with wherever he went that was new – well there's plenty of people here, the families understand this area, but we never met them, did we?
Sibling: Yeaah, we never met anybody

Mother: we never met-

Sibling: even, even just being offered, y'know, when parents are going through, y'know,

not going through it as such but as, y'know, as...it's just y'know, to be offered somebody's

phone number that's been through it

Mother: Yeah!

Sibling: Would have been probably one of the best things

Mother: Best, yep.

Sibling: We would have got, because

Mother: I've always, I've always...

Sibling: Everyone's always said, those that don't know

Mother: Yeah

Sibling: They've never been through it

Mother: Yeah.' (Dyad 3, lines 1886-1914)

'*Sibling: I think it helps to hear other people's stories*

Mother: Yeah

Sibling: especially if you were like, in hospital, and you're going through it at the time,

it gives you a bit more hope.' (Dyad 5, lines 1809-1814)

This need for validation, guidance and support from specific others was problematic because dyads also doubted that others who had not been through a similar experience, and even those who had, could understand their experiences and therefore help them. This led to some dyads expressing a shared sense of isolation – a separation of themselves from others through an experience that was incomprehensible, therefore beyond empathy.

'That's why you can't, you can't help people that are going through it, they've got to go through it themselves. You can't help them, they've gotta go through it.' (Mother 1, lines 1182-1183)

'you could read it and cry as you read it, but you'd never understand what you felt like. I don't understand what she felt like or what she felt like, you can only guess by how you feel yourself.' (Mother 3, lines 2365-2367)

'Sibling: like our grandma still to this day probably doesn't even understand what we've been through.

Mother: No, I don't think she does.

[Interviewer: Right.]

Sibling: Urm, and like, I think it was more because we were the only ones who saw it on a first hand basis, wasn't it?

Mother: Yes, it was.' (Dyad 6, lines 1108-1126)

2.2: Professional support unreliable: 'trying to find your way through mud'

Following on from this, all mothers, yet only a minority of siblings, perhaps due to their reduced organisational role, noted that they had found the information, guidance and support provided by professionals in both acute and post-acute community settings as vague and lacking. This perceived paucity of support, perhaps in part due to the ambiguous nature of TBI, was discussed as leading to and deepening what often felt like a sense of abandonment or isolation, both within and by the situation, together with a strong feeling of uncertainty. There was a sense of mothers having to go to great effort for little gain with regards to planning the best approach to rehabilitation and care, fighting for progress with little guidance or clarity. Some dyads noted that the lack of

required support increased their shared sense of having to 'cope through doing' via trial and error.

'Sibling: They didn't know what was gonna happen, and we didn't know what was gonna happen so it was just kinda like, where do we go, what do we do, do we just talk to each other and just carry on with what we were doing anyway?
Mother: Exactly.' (Dyad 3, lines 1916-1920)

'Just the realisation, just to be told what to expect, it... y'know' (Mother 4, line 1061)

'Mother: No, well we didn't get that support, but I, I just think, looking back now, I would have liked someone. I mean, we're all intelligent people, I would have liked someone to have sat down with me and just say, look, he's frustrated, don't be angry with him, you know, don't do this.
Sibling: Yeah, no one ever actually told you, at all. They only thing we kept on being told, is it's long recovery, don't know how long it's gonna take. Well, those were the only thing we kept on being told.' (Dyad 6, lines 750-756)

'And it's you know, it's not been easy, because it is like sort of trying to find your way through mud, sort of thing, and trying to sort things out...' (Mother 7, lines 453-454)

The use of *'we'* in the quotes above helps to illustrate that although the mothers might have had more contact with professional bodies of support, the consequences of its perceived inefficiency was felt by the dyad, and impacted on their approaches to coping, as a pair. The final mother's quote uses simile to convey a sense of an exhausting struggle to find this support, emphasising a feeling of solitude within the experience

expressed by others. Only one mother discussed finding a positive stance from the ambiguity, choosing to find hope in the uncertainty.

'That's the thing, I think that's the strength that anybody can take from something like that happening, is the fact that you haven't got the foggiest idea what's gonna happen. Even doctors don't know nothing. Nobody knows what's gonna happen. So if you look at it...look at it from the perspective that although its bleak, there's, while they're breathing, there's hope.' (Mother 1, lines 269-273)

Super-ordinate theme 3: Approaches to coping

Across and throughout interviews, participants consistently shared their thoughts on a number of factors that the dyad explicitly felt were important to their shared ability to cope with the TBI and manage its consequences on their relationship. It is notable that although mothers were the ones to initiate discussion of lack of guidance within interviews noted above, the consequences of coping alone and the approaches it fostered appeared to be felt, used and conveyed by both individuals. These shared approaches to coping focused on three areas: an automatic acceptance and a practical approach, the use of humour, and the strength gained from social support.

3.1: Coping as doing: 'just get on with it'

Mothers and siblings described a journey of trial and error through the process of rehabilitation and coping. Almost every individual participant referred at least once to the necessity of just being able to cope and very suddenly adapt after the sibling was injured, simultaneously finding it hard to describe exactly how they coped. This, in part, seemed to be prompted by the sense of isolation experienced due to the struggle over validation and professional support, with dyads perceiving families as having to 'make

do' alone. An emphasis on 'doing' as a means of coping communicated a strategy based around managing instrumental tasks and practical issues, for example household chores and care of the IS, rather than a fuller consideration of more support or emotion-based needs. It was also applied to the situation as a whole, with a sense of perseverance and simultaneous commitment to the IS.

'You don't realise you're doing owt, to be honest. You don't realise, you just get on with it." (Sibling 1, line 898)

"... you just think, get on with it.' (Mother 1, line 1083)

'You sort of...I don't know, you just go into mental override and you just...do it. You, your body feels mentally drained but you know you've got to do it.' (Mother 2, lines 502-503)

'...just get on with it, you do, you do what you've gotta do.' (Sibling 3, line 1312-1313)

'I think when there's a sort of crisis, I just do it, and go like that [head down, focus]' (Mother 7, lines 440-441)

This method of coping was indicated as still present for some mothers, with the use of similar phrases in the present tense. Here there was a continued sense that particularly difficult things just had to be accepted and worked with rather than deliberated upon, as they deemed there to be no other option.

'And we wa'n't expecting what he'd got, but, tough, we've got it now and we're getting on w' it' (Mother 4, line 230-231)

'But, I think that we can't, we can't worry about it. We have, we have to get on with it,

because, he did, didn't he.' (Mother 5, lines 1553-1554)

'...so you thought oh my god I can't live like this! But we'll just keep going, just keep

going, we just keep going.' (Mother 6, line 1214-1215)

3.2: Humour

In all but two dyads, mothers and NIS explicitly noted that humour had been an

important coping mechanism for them to share in both immediately after and since the

TBI. They felt that it was necessary to help deal with the negative emotions during

particularly difficult times, and there was a sense of humour being utilised in order to

avoid becoming overwhelmed. Examples of this include laughing preventing them from

crying, grounded them in reality when dealing with a crisis, and as a way they could

maintain a sense of their family's identity in the clinical world of hospitals.

'So you find your humour 'cause we was laughing about a bad situation! That's what

you do, find the funny bits.' (Sibling 1, lines 1259-1260)

'It's like, hang on a minute, reality check, they still need feeding. So, you know, it does,

humour does get you through those situations' (Parent 1, lines 1271-1272)

'Mother:...making a laugh and a joke about this that, and of course we were sat there

killing ourselves laughing, y'know, and I thought, we were absolutely crying our eyes

out

[Interviewer: Yeah, yeah?]

Mother: and I thought god this is sick, y'know, we're sat in, in this place, y'know, and

there's people and they're dying and we're making jokes, but that's how we've got

through it, the first thing-

Sibling: And only, and, we always said was, that was the way [X] would've wanted us to

be.' (Dyad 3, lines 1702 -1714)

'So yeah, humour! Humour does help!' (Mother 5, line 1158)

'I think you have to laugh about it' (Sibling 5, line 1101)

Humour and laughter also appeared to unite the mothers and siblings during the interviews, as they reminisced about particularly upsetting times and noted how it had helped them to stay strong and manage. In discussing difficult events the dyads would share in-jokes, notably hard to capture in verbal terms using extracts of the interviews, which then inspired laughter and a sense of them being connected, which perhaps illustrated the function of humour within the context of their relationship in other situations. An additional dyad used this kind of humour without explicitly acknowledging humour in their interview, describing a dilemma that had come about by the IS' plans now being unattainable, which was diffused with humour.

'Mother: [on how they console each other] *she tells me to shurrup! She tells me to*

shurrup! [Laughs]

Sibling: [Laughs]' (Dyad 2, lines 327-328)

'Mother: I know what helps us! [Laughs]

Sibling: Oh god!

Mother: I'm sorry! Remember when...[laughs]...he was just..banging on...

Sibling: Oh, when you! [laughs]' (Dyad 5, lines 1143-1149)

'Mother: I thought it would be a good idea for him to find himself, that sort of thing, rather than try to serve a stupid university course he's never gonna be a pilot at, or sort of thing, but- [laughs]

Sibling: [Laughing] It seems so backwards, that, doesn't it? Her going, no, go to India, don't, don't go do your degree!

[All laughing]'

(Dyad 7, lines 732 -737)

3.3: Social support

Lastly, mothers, and to a lesser extent, siblings, across a majority of interviews named social support as important to their coping. This included in practical ways during crises, as a source of emotional support, and also to allow a sense of respite from stress, away from both the other member of the dyad and the family situation as a whole. There was a feeling of valuing someone external to their experience, and drawing strength to continue coping from this. There was a corresponding appreciation and gratitude for those who had helped and offered support during the time. It could be hypothesised that this was more appreciated by mothers rather than NIS due to their immersive role in caregiving.

'So you do need outside influences cause you can't use all your family as well. I mean it's not so bad now, because it's easier as time goes on, but at the beginning you need an outside vent... (Mother 1, lines 1001-1002)

'Sibling: Yeah, but we had a lot of support from even neighbours, though, we even had, though, checkin, y'know, [neighbour] was really good wasn't she?

Mother: Yeah, now I can't believe, I, yeah, she was.' (Dyad 3, line 564-567)

'Sibling: Even like, my friend, we didn't, I hadn't spoken to for about 4 years, her

parents offered their car, didn't they, for you two to drive.

Mother: Yeah – if you need a car backwards and forwards to the hospital, you know, do

do do do, yeah. But yeah, so amazing strength, and that was what we drew on, we did,

really drew, draw on their strength.' (Dyad 5, lines 237-242)

'…when others have said let me know if you need any help, she was the one physically

did, you know, you know, so I've got a lot of pals, but friends wise, you know who...

[Interviewer: Yeah?]

and I'm happy with that, it's it's got me through, you know, I can see light at the end of

the tunnel.' (Mother 6, lines 1593-1595)

Super-ordinate theme 4: Growing closer

All of the dyads reported that their relationships had been strengthened since the injury and that the shared experience had involved increased trust and understanding between the two individuals. This was based in the perception that relationships within the whole family had been strengthened.

'Sibling: I actually think we're closer now than before the accident

Mother: Mm, it's brought us all closer.' (Dyad 4, lines 458-460)

'Sibling: Like, we're probably all a lot closer as a family, aren't we?

Mother: Yeah

Sibling: I mean the thing is it's hard because we've always been close, so it's hard to

compare, but, like, compared with my, like friends, like their families would never do

things together, whereas we do do quite a lot of stuff together.' (Dyad 6, lines 1087-

1094)

'...I think, as a whole unit of seven people we are closer. We enjoy each other's

company.'

(Mother 7, lines 711-712)

'If anything, like, I dunno, yeah probably we're all closer, and to [X] certainly, than

before it.' (Sibling 7, line 450-451)

Although causation for this was not explicitly expressed, a new found importance of

family and value of time spent together was discussed as playing a key part in this. This

was noted as being instilled by a shared realisation of mortality post-TBI, which had

also, in some cases, led to an increase in anxiety.

4.1: Realisation of mortality

Mothers and siblings repeatedly referenced what is comparable to a 'realisation of

mortality' brought about by the accident, with them describing becoming more aware of

the fragility of life post-TBI and the fact that anything could happen at any moment to

upset their predicted lives and plans. These realisations were noted to cause the

individuals to reconsider their priorities in life, with the majority of key examples being

to value family more, or material items less.

'...it puts life into perspective. What you would have fallen out over years ago you

wouldn't fall out over now because it's not worth it. And if you look into other people's

lives...like, my sister doesn't have anything to do with her daughter and grandkids, and

you think, ohh...it's so sad, it's not worth it. It makes you looks at life differently.'

(Mother 1, lines 1050-1054)

'Sibling: ...just realising life's too short, probably. I don't really know.

Mother: Well that's for me as well. [...] I'd give em my last penny, and I would've before but I, I'm worse than ever now cause, cause I think, especially with what's happened to [X], like, they will come to me and I'll go out of my way to help, yeah. Yeah, 'cause like I said you never know what's round the corner.' (Dyad 2, lines 560-566)

'Sibling: Well I just saw my, it's it's made me realise that you don't, you don't have as much time with the people as you think, so like, with my grandma, I'd like, what, see her when she'd take me to school and that was about it, and now-

Mother: We go out with your grandma, don't we' (Dyad 5, lines 1506-1510)

Notably, in a minority of mothers, the realisation of mortality and its associated re-appraisal of life also caused increased anxiety and involvement in the physical well-being of their other children, discussed within the context of mother-NIS relationships. In each case, the mother was reassured by the sibling that any changes to parenting had not been overbearing, suggesting that shared experiences of the TBI had often led to an increased sense of understanding. One dyad suggested that the realisation increased anxiety in general for both individuals, introducing a new fear of fragility into unspecified aspects of their lives. For these dyads, there was a sense that the clarification of values caused by the realisation of mortality on the one hand drew them closer, but it also instilled a sense of fear and protectiveness.

'Mother: Because again you've got a situation that...you realise nobody ever realises

how fragile you are, until something like that happens.

Sibling: And when you do realise how fragile you are, it makes your life a nightmare.'

(Dyad 1, lines 830-833)

'Sibling: ...my phone was off for two days, and then when I turned my phone back on it was this big hunt all over Facebook, you know, my phone, like, mum just presumes I'm dead, ha! So I dunno, maybe that's got something to do with, um, with what happened with [X], or it could just be natural parents.

Mother: It's a bit of both, it's a bit of both, because you know, we have been through it, and my thing is I don't wanna go through that ever again. Erm, cause that was just the worst, just seeing your son, like, completely dead like, on a hospital trolley. And that, that would apply to any of them, you know. But hopefully we don't lay it on any of you too heavily.

Sibling: No, I don't think so, cause you know, I understand, you know, any parent is gonna have, gonna have a certain thing in the back of their mind, you know, making sure they're checking up. And I wouldn't say that it's restricting at all, I never feel like it's too much, or, or anything.' (Dyad 7, lines 386-399)

Discussion

Summary of findings

This study examined the lived experiences and shared relationships of NIS and mothers of young male adults who had experienced brain injury. It aimed to 1) explore any role and/or relationship changes, and 2) to explore any differential experiences unique to either individual and how they are managed.

With regard to the first aim, both members of the dyads perceived their roles to have changed within both the relationship, and, as they perceived, the wider family context, with mothers having lost roles in order to be able to prioritise the care of the IS, and siblings accepting extra caregiving responsibilities in response to this. The dyads also noted a number of relationship changes post-TBI, revolving around a shared sense of isolation from others due to and since the experience, but also a strong feeling that they were closer to one another, and valued the idea of family more.

Differential experiences mainly revolved around these role changes and individual reactions to them, as they were each discussed solely from the perspective of one half of the dyad. This was also influenced by the fact that mothers' more organisational roles in the rehabilitation of the IS allowed them a greater insight into the support available. Management of these different experiences, and the other consequences to roles and relationship, were strongly conveyed through the explicit discussion of shared approaches to coping.

Roles and Relationship

Changes in roles within the context of the examined relationship were prominent themes for both mothers and NIS post-TBI (Theme 1). Frequently, the dyads made sense of these changes not just in the context of their relationship but also that of the family as a unit, i.e. the meanings they placed on their experiences as a dyad were heavily influenced by the way they understood and experienced changes in their family in the months and years following the brain injury. Although the degree to which dyads' experiences do actually represent a 'true' picture of the experiences of the family at large post-TBI is arguable, models of family functioning and adjustment could still be very useful in integrating the current findings and formulating questions that further research should seek to answer.

Reiss's Family Paradigm model [44], for example, suggests that after crisis, in this case TBI, ineffective parts of families' paradigms (e.g. putting selves before the family unit) will have become obsolete and replaced with a new shared focus. In the current study this could be seen in terms of participants putting the IS first, starting with prioritisation of medical treatment. Reiss suggests that, if successful, these new paradigms become embedded in each family's organisational structure, until they are negated by another crisis (p. 218) [44]. This could be linked to findings of mothers and NIS working with a new shared, automatically accepted, goal within their relationship (Theme 1). This finding was born out of the insight dyadic interviews allows, for example the mothers' unapologetic acceptance of instances of the NIS initially finding the prioritisation 'unfair', and the NIS' own acceptance despite these feelings. It could also help to explain the fact that new responsibilities were undertaken by the majority of NIS interviewed, with no obvious differences between dyads with or without another parent in the home. Additionally, the ongoing nature of the changes experienced by dyads could be viewed

as new effective paradigms, potentially remaining in operation until challenged by further events and changes.

Conceptually, if the dyads' experience of shared acceptance could be understood in terms of an adapted paradigm of living, the construct of the FLC may help to address why a sense of regret over lost roles/ambitions was suggested for some mothers (Theme 1.1). These could be seen to represent a response to a disrupted progression of personal development within a predicted FLC [4, 45], (e.g. '*life is*[sic] *been put on hold*' Mother 5, line 663), where expected milestones had changed or were perhaps no longer attainable. This, and the more anxious parenting noted by some dyads (Theme 4.1), can be further conceptualised from a systemic theory perspective. Fryer [45] notes that initial attempts to compensate in the face of traumatic events such as brain injury can be unhelpful, leaving families 'stuck in rigid styles of responding, e.g. showing "protectiveness"' (p. 6). This can increase the difficulty of balancing the demands of chronic care and resources for individual family members' development, making rigidity more likely [4, 46, 47]. This risk is greater with illnesses experienced in a developmental stage they were not expected in, having an 'inward pull' (p .471) [47] on families, preventing flexible development. This is particularly problematic for those with children ready to leave the home and involving illnesses with uncertain prognoses [47], as in the present study, so it is possible that the increased anxiety experienced by dyads could represent signs of this developmental rigidity.

Further changes in the shared dyadic relationship can also be considered with reference to concepts represented within TBI literature. For example, the dyads' shared sense of being isolated, both from and by others (Theme 2.1), is in line with previous studies that have found chronic illnesses to cause a sense of isolation within families who feel cut

off from their communities, by, for example, duty of care or lack of understanding [46, 48]. Degeneffe [48] notes that this then places importance on the support offered by the TBI professional community. What adds complexity is the ambiguous nature of TBI and consequential difficulties medical professionals can face when asked to give a prognosis for recovery [49]. This has been marked as a problem in previous studies [7, 50, 51], although the perceived dismissal of families by professionals appears to be ongoing, certainly for these mothers and siblings (Theme 2.2), and could understandably emphasise dyads' sense of just having to cope together however they could, establishing a new family paradigm [44] in a context of uncertainty and perceived lack of support (Theme 2.2).

To further consider this sense of individual isolation expressed by the dyads (Theme 2), it appears to reflect Broderick's [52] reasoning that a 'family' cannot have the same feelings towards an experience – it is a system and as such only the individuals who comprise it can have a true understanding of the experience they are having. Despite this, Gilbert [53] suggests that individuals 'attribute greater similarity in beliefs within the family than might actually exist' (p. 273). This perspective perhaps helps to clarify the dyads' somewhat confusing quest for validation despite adamance that not even others within the family can understand, as a united perception of the TBI within their shared relationship might then help them to fully process it, and its repercussions.

Coping and support in TBI

In this potentially difficult situation of coping in the face of altered roles, perceived isolation and family adjustment processes, TBI literature can perhaps help to explain a number of approaches that were highlighted by the dyads as important. Within the context of the relationship, mothers identified social support as more helpful than NIS

did (Theme 3.3), which is in keeping with Hanks, Rapport and Vangel's finding that perceived social support was the strongest factor in the perception of caregiving mastery for primary caregivers of those who had experienced TBI [54]. Certainly this could aid in understanding the participating mothers' appreciation, gratitude and valuing of support sourced externally from the family, from which they could draw strength to continue with their new or intensified caregiving roles. This is also in line with a previous study considering mothers of young adult sons who experienced TBI, in which a continued social connection was found to ease the reclamation of both individuals' independence at later stages of rehabilitation [13].

Beyond this, the importance humour played for both mothers and NIS was notable (Theme 3.2). Although from a psychodynamic standpoint humour can be an example of a defence mechanism [34, 55], in-jokes and light-heartedness clearly had experiential value within the relationships of those who took part in this study. Literature supports this, with early theorists seeing humour as an approach to create healthy distance from problems [56]. This idea was perhaps illustrated by the dyads' shared jokes uniting them and preventing them from becoming overwhelmed at critical moments – both anecdotally and within interviews. Further to this, coping humour – humour used to help manage stress – is being increasingly explored as a factor impacting upon a family's ability to remain flexible and adapt successfully to ongoing stressors [57]. The fact it was explicitly present for dyads in the current study suggests that they may have found it a shared, useful and adaptive coping mechanism that contributed to a shared sense of resilience in the face of stressors incurred on the path of rehabilitation. This, in turn, suggests successful approaches to coping had been fostered within the dyadic relationships despite perceived isolation, which echoes previous research into family coping over time [58].

In order to understand the processes represented by the 'Just get on with it' theme (Theme 3.1), models of coping could be considered. These highlight two approaches: emotion- and problem- focused coping [59]. Emotional coping is seen in the acute stages of trauma, involving avoidance, distraction and forced acceptance, whereas problem-focused coping aims to build knowledge and resources with which to deal with stress, and is usually linked to more positive psychological outcomes. Although some dyads had fought for support, the wider sense of forced acceptance is suggestive of emotion-focused coping. Within the context of TBI, brain injury literature reports that problem-focused coping decreases over time as emotion-focused coping increases, despite possible negative consequences to well-being [60]. This is especially so in situations over which individuals have little control, e.g. having to care for an adult child [61, 62], which could be reflected in the experiences of the dyads. An explanation of this is that, over time, families accept the limitations of their injured member, decreasing their search for wider solutions [63]. The family systems model [23] suggests that this coping is an attempt to find and maintain homeostasis [64] after a crisis, with the risk of further securing this as a family paradigm for regulating responses [65].

Positive experiences and outcomes

Many of the positives reported by the dyads in the face of the challenges to role change, adjustment and coping described above could be understood through the concepts related to growth in the face of adversity. An example of this is 'posttraumatic growth' (PTG), defined as 'the positive effects that result from a traumatic event' (p. 1461) [66] relating to coping and adjustment [67]. This can be useful to consider in families of those who have experienced TBI as those around an individual who has experienced

trauma can experience 'vicarious trauma' [68]: the experience of trauma through indirectly being 'confronted' with a traumatic event. Vicarious trauma has been found within those close to individuals who have experienced TBI [69], and as such, aspects of positive growth, such as bonding, have also been reported [69]. Tedeschi and Calhoun [70] describe the process of PTG as a traumatic event shaking an individual or group's world view, necessitating new and often initially negative coping responses. Lengthy cognitive processing of this trauma and testing of new paradigms by which to live eventually lead to new, more resilient approaches being adopted [70].

Elements of PTG that could be seen to emerge from interpretation of the dyads' accounts imply this vicarious traumatisation. Despite supportive findings of research in this area [69], this does not necessarily mean TBI is inherently traumatising for families in the same way it can be for the individual, or indeed in every instance. It cannot be assumed that all dyads perceived it as a trauma and reacted as such. Although PTG could be seen as adding one potential explanation of aspects of positivity experienced by dyads post-TBI, the concept of benefit-finding (BF) – reporting positives from negative experiences – can provide further interpretations of positive growth in the absence of 'trauma', both in isolation of and in addition to the concept of PTG. BF is a quicker process whereby cognitive adaptation allows individuals to better accommodate changes post-adversity, and is considered a more 'superficial' change (p. 3), as individuals re-assign positive value rather than initiating 'core' changes [67]. It adds a further useful frame with which to consider the dyads' positive experiences as it has been more widely linked to better psychosocial and health-related outcomes in both caregivers of and those with chronic illness and disability [71], with increases in resilience, 'wisdom' and perceived efficacy commonly reported [72, 73].

There are potential overlaps in PTG and BF within the literature – indeed, the terms are noted as often having been used interchangeably [74, 75]. Despite this, the concepts of PTG and BF are distinct constructs representing different processes that can co-occur in those who have experienced adversity [67, 74]. BF is conceptualised as starting immediately, and PTG as developing in the years post-trauma [67, 76], and they may therefore both aid in understandings and interpretations of the positive growth suggested within relationships by dyads within this study.

PTG can help to add explanation to the dyads' experiences as they could be considered to have directly or indirectly experienced a trauma that is ongoing, with initial stress reactions as described by the participants being linked to its development [70, 77]. PTG is also suggested to be particularly encouraged when a personal identity or purpose related goal becomes unattainable [70], which is echoed in the experiences of the mothers in the current study (Theme 1.1). PTG has been described as affecting more existential changes than BF does [78], with altered priorities in life and appreciation of aspects previously perceived as more trivial [67, 70]. The literature on PTG in TBI, although limited, has further identified the existential concepts of 'meaning' and 'purpose' as relevant [79], with two key areas of psychological PTG thought to be greater appreciation for life and development of meaningful interpersonal relationships [70, 77]. This could be argued as a frame through which to view the positive aspects represented by 'Realisation of mortality' (Theme 4.1), as participating individuals expressed a reappraisal of what matters to them (meaning) and consequently how best to spend their time (purpose), having understood that life is limited and unpredictable.

With further regard to the concept of PTG, the process described by Tedeschi and Calhoun [70] can potentially help to account for the anxiety encountered by mothers

when negotiating family adjustment (Theme 4.1), whereby trauma causes anxiety but ultimately cognitive processing aids in the development of being 'better able to accept some of the paradoxes of life' (p. 21) [76]. Accordingly, it could be considered that these instances of positivity might be suggestive of PTG within the sample, expressed within the examined relationship. Although these positives appear somewhat contradictory to the isolation and forced coping described by dyads (Theme 2), PTG literature suggests that this contradiction may in fact be necessary for positive developments post-trauma. It is generally unclear as to whether PTG is a process or an outcome [77], however it is agreed that extended exposure to and cognitive processing of stressors post-trauma facilitate its presence. In line with this, PTG does not occur removed from negative coping strategies and struggles such as those displayed by the dyads, but rather alongside them – their existence is necessary to facilitate cognitive processing and therefore growth, which develops over great lengths of time [70].

Certain aspects of the dyads' experiences could be more appropriately considered with regards to BF. For example the maturity and future gain cited by NIS (Theme 1.2) could represent a reappraisal of a potentially negative consequence of the TBI and change in the mothers' priorities, in order to allow more positive coping [67, 80]. A similar positive outcome has been found when considering the gained roles and maturity amongst children of those who had sustained head injuries [81]. Although overwhelming negatives cannot be ignored, such as potential for burden and role strain [82], it has been suggested that positive outcomes of brain injuries for those around the individual are potentially overlooked and undervalued [4, 66]. BF is also widely attributed to individuals gaining 'a positive change in relationships, a greater appreciation of life and a change in life priorities' (p. 584) [74] via a process of individuals re-evaluating existing relationships [67, 80] and so perhaps could be

considered a more accurate frame of reference in expanding interpretations of the dyads' shared reports of being closer post-TBI, with increased appreciation of family relationships, and focused priorities (Theme 4). Certainly, aspects of positivity expressed by the participants in the current study support the potential occurrence of this in the specific sample.

Following from this, social support is also a key influence on the development of qualities of both PTG and BF. Studies suggest that consistent support allowing self-disclosure enables the trial and establishment of new and adapted paradigms of living [83] as well as increasing the likelihood of BF and its related positive outcomes in caregivers of those with chronic illness [73]. Instances of BF have been linked to greater perceived social support [73], which could add a frame of reference when considering Theme 3.3. This adds possible explanations as to why the mothers found ongoing social exchanges beneficial, illustrating further how both PTG and BW can potentially be drawn on to add reference to the dyadic experiences.

Accordingly, these experiences of both ongoing changes to coping, and indications suggestive of PTG and/or benefit-finding within the examined relationships, may be representative of a more holistic process of continuing adaptation for the participating dyads in the years post-injury, both as individuals and pairs. These experiences could be regarded as a shared journey through the years post-TBI, negotiating ways of coping with altered roles and struggles for support, as well as the potential risks of developmental rigidity, in order to grow from the experience with shared strengths. It could be considered that this ongoing process at the time of exploration ultimately ensures the balancing of the evolving demands of the IS and movement towards the new normal of post-TBI homeostasis [64] in the context of their dyadic relationship.

Clinical implications

This study is strongly indicative of the potential for role-strain in both mothers and NIS due to the changes they must quickly adapt to post-TBI (Theme 1). In other clinical populations, sibling adjustment and consequential conflict within this relationship has been linked to increased parental burden and therefore detrimental outcomes for the injured individual [25], so it is important to reliably monitor any conflict and role strain within this population. This study is unique in that it considers changes within a relationship, and from this a number of other clinical implications can be highlighted.

Firstly, although individual counselling is often offered to parents, it is important that other individuals within the system and the family as a unit in itself are considered in clinical settings. TBI represents more than the ambiguous loss of one individual – it can represent loss of roles, relationships and a predicted future, which is something each member of the family potentially must contend with. Certainly this challenge was apparent for both mothers and NIS in the present study, although more research would be necessary to look into the experiences of the wider family.

Depending on this, systemic theory suggests that family therapy could be beneficial in helping families construct more meaningful and helpful narratives and paradigms in relation to brain injury [45]. This may help in reducing indirect burden, processing any guilt and allowing the emergence of resilience alongside the preservation of flexibility, which was possibly limited in some of the dyads participating in this study. Considering this, however, it is important for professionals not to reinforce the idea that family members should be suffering *equally* through an experience, but rather be supportive of individual losses and challenges and help manage how they come together to form a

functional whole [53].

To aid this, a family's development in terms of the FLC is important to consider post-TBI, and this includes individual positions within it. The sense that mothers in this study felt, to some degree, held back from their projected goals (Theme 1.1), and also perhaps that NIS had gained roles that they accepted but might not previously have deemed necessary or appropriate for their current stage in the FLC (Theme 1.2), makes sense considering a TBI's effect on systems [4, 45]. These findings, and research into these systems, support the notion that clinicians' help can be needed to ensure that the often ongoing rehabilitation needs of the IS can be met without limiting the developmental growth of both the family system and individuals within it [46, 47]. This in turn rests on flexibility, with clinicians potentially needing to tackle the protectiveness and rigidity that, if lasting, might make it difficult for individuals within families to access external resources and move forward developmentally whilst at the same time supporting the IS effectively [47].

The theme of perceived lack of support (Theme 2.2) – a serendipitous finding owing to the qualitative methodology of the study [84] – suggests that the ability to be able to share experiences with others who have also suffered the consequences of a family member incurring a TBI was seen as a valuable source of support for mothers and NIS. This suggests that peer support schemes for families need to be considered as more integral components of care and rehabilitation pathways post-TBI. The value of peer support to mothers should not be undervalued (Theme 3.3), either, and has also been shown to aid development of PTG [83] and linked to BF [73]. Further to this, research suggests disclosure of emotions by any means which encourage cognitive processing can increase PTG, such as journal-writing regarding trauma-related experiences [71,

85]. This represents a low-resource and easy-access intervention that could potentially be advisable to all those affected by TBI reliant on further research into PTG in this population.

Continuing with the theme of support, the perception amongst participants that medical professionals throughout the rehabilitation journey were non-committal and offered vague, limited information and guidance is problematic (Theme 2.2). Considering the complex nature of TBI, professional prognoses can appear unreliable, meaning the feedback from participants is, on the one hand, understandable. This makes it all the more important that professionals provide families with feedback on a frequent basis – to best support validity, comprehension and retention of information through what is likely to be an intensely stressful time.

Further to this, entering into a regular exchange with families is recommended, as various sources have identified the clinical benefits of involving families in rehabilitation [26]. To enable this, professionals must be aware of how they communicate with families, with higher perceived empathy leading to increased satisfaction [86]. It is worth noting that previous studies having highlighted a mismatch between clinicians own empathy ratings and patient ratings [87]. This emphasises the need for professionals to be aware of barriers to communication, e.g. limited resources, and to employ the Rogerian principles [88] in order to convey a position of supportive understanding as opposed to the sense of detachment and disinvestment perceived by participants in this study.

Limitations

The current study has a number of limitations. Firstly, the number of participants

recruited for this study was relatively small and not representative of the wider population of family members affected by TBI. However, the sample size is commensurate with similar studies of dyads which have utilised IPA [e.g. 35, 37, 38]. Moreover, the epistemological and methodological approach taken by this study places more emphasis on idiography and detailed lived experiences rather than external validity in the quantitative or statistical sense. Interviews generated rich transcripts of textual data, created together by and with dyads, helping to convey and allow exploration of their in-depth descriptions of shared, contextualised, subjective experiences.

In keeping with an IPA approach, efforts were made to keep the sample group as homogenous as possible, with all ISs being male (a gender bias also prevalent in brain injury statistics [89]), and limits placed upon the gender of parent, age at injury, type of brain injury, time since injury, and having a sibling living at home, as outlined by the inclusion criteria.

The sample retained a level of heterogeneity, however, in a number of areas. These included the gender of NIS, a number of the families having more than one NIS, families originating from a variety of areas of the UK, and two of the families being single-parented. All of these factors could result in very different perspectives on experiences of TBI, as, for example, coping resources might have altered with a different number in a family, single-parented families may have altered experiences, and expected roles within families might vary depending on the gender of NIS. Age ranges of both mothers and NIS also allow room for variation in perspective that comes with life experiences and developmental stages, e.g. older mothers might have been more likely to find a return to caregiving more out of line with their expected development in

regards to a FLC. These variations and possibilities comprise a limitation of the current study.

However, it is hoped that what homogeneity was achieved provides a strong basis for the themes and conclusions of the data. Data saturation was reached within the interviews, meaning that similar themes were being communicated across dyads despite heterogeneity, suggesting important aspects of a shared experience. This heterogeneity was also considered throughout. For example, the two dyads with male NIS could have been excluded from the study. However, detailed analysis and comparison of their themes showed them to be in line with those of the other dyads – an approach used in other IPA studies facing heterogeneity within their sample, [e.g. 90]. Similarly, the age ranges of mothers and NIS were within the bounds of heterogeneity exemplified in published explorations of dyadic parent-child experiences [35, 38].

Chapman and Smith also note that in using IPA there is no prescriptive approach to the level of homogeneity that should be aimed for [91]. They add that most researchers are only able to achieve a 'fairly homogenous sample' (p. 127), with valid samples ranging between being 'based on people attending a particular clinic or centre, in other cases it may be according to more standard demographic variables' (p. 127) [91]. In line with this, and in comparison with the samples of similar, published, dyadic IPA studies [e.g. 35] it is proposed that the current study remains a valid and coherent account of these dyads' shared experiences.

Another potential limitation linked with interviewing mothers and NIS simultaneously was the risk that one would coerce the other into taking part. An attempt was made to deal with this by obtaining individual written consent from each of the two family

members separately, and also by allowing a week between verbal and written consent, to encourage discussion. This aimed to help encourage full consideration of whether or not to participate and allow discussion both between the dyad and through consulting others, should they wish. This time could have allowed any individual to voice concerns away from the pressure of the researcher, and, as noted, families did withdraw at this stage, suggesting this was effective.

With regard to one individual controlling or biasing the conversation, or either individual's willingness to talk openly about their experiences, the use of dyads with IPA allows the subjective nature of a dynamic, fluid relationship, including any power-imbalances or secrets, to be played out within interviews. It is hoped these can then be noticed and observed, and these and the respective levels of openness within the interview are, within the bounds of qualitative interpretation, viewed as being a factor present in the relationship rather than as having been caused by the interview itself [32]. In essence, the study aimed to explore the shared cognitions and emotions of participants – those played out in their relationship – as opposed to purely those of the individual [28, 92].

Despite these measures, the possibility that individual openness could have been limited within the interviews remains a limitation [27], although previous dyadic studies [35-38] have not noted this to limit outcomes. Prior [93], in a dyadic IPA study of mothers and adolescents, found richness of interviews to in fact be enhanced by the 'double perspective' (p. 739) allowed by the mother and child discussions and 'joint meaning making' (p. 739), a process echoed in the current study. Further to this, the feeling within the room during interviews remained one of open dialogue, with mothers or the NIS frequently encouraging the other to share their thoughts and experiences rather than

impeding personal contributions. As a basic measure, the interview schedule (appendix 5.5) was also constructed so as to begin with less threatening topics that would ease initial anxieties and encourage shared discussion, aiming overall to encourage flowing, open conversation style with and between the participants.

The benefits of interviewing as a dyad and the co-constructed view of the relationship it allows [42, 93] were also apparent. For example, with the exploration of the NIS' acceptance of the mothers' increased anxiety in parenting, or the two mothers' matter-of-fact acceptance that the NIS had felt their prioritisation of the IS as unfair in some way. Without both members of the dyad present, these perspectives would be unknowable. In this study the dyadic element helped to truly illustrate their shared sense of acceptance and commitment to the changes necessitated by the TBI.

The use of IPA also imposes limitations that characterise all qualitative approaches, in that the researcher's biases and previous understandings are influential in the analysis and interpretation of participant data [94]. The researcher attempted to tackle this through the use of a reflective diary to comment on the process and note any potential assumptions as they arose, through two sets of academic supervision, and also used a validation group of three other independent researchers for considering the coherence and consistency of both themes and supportive anonymised quotes. Ultimately, it is important to remember that this study, as with all others of this nature, comprises a subjective interpretation of the dyads' perceived experiences, and so generalisability to the wider population is neither intended nor supported.

Future research

Further research in this area could consider different perspectives of family experience,

for example by focusing on differing experiences of fathers, families of female ISs, and also exploring differences in response from single-parent families. It is noted that the inclusion criteria when considering fledgling-adult TBI with siblings living at home limits participant numbers, and so from this initial research it is predicted that recruitment would need to be extensive and widespread if a larger sample size was required. In this case, quantitative measures could be utilised with families of TBI in assessing the effect on family structure, coping and well-being. This is timely as more traditional measures of family functioning, although previously used in attempts to gauge effects post-brain injury, are being found to be lacking in sensitivity [95], and so progression of assessments on this basis is ongoing (e.g. the SCORE [96]).

Aspects of intervention for families of TBI could also be considered further, such as the effectiveness of elements highlighted as important in the current study, e.g. social support. Further to this, the potential for positive growth for family dyads post-TBI is apparent, so depth could be added to literature in this area to expand what is currently a very limited resource. More longitudinal research into the process, development and ongoing monitoring of instances of BF and PTG is acknowledged as necessary [70] to shed further light upon more specific contributing factors and the balance of positive growth with negative consequences of adversity within this population.

Conclusions

This study sought to explore the subjective experiences of participating mothers and NIS of young male adults who have experienced TBI, particularly regarding their shared relationships and consequential role changes. Findings suggested that dyads showed potential signs of divergence from normative projections of the FLC, with individual roles being suddenly adopted or suspended within the context of their

relationship due to perceived necessity and lack of support. A level of consequential developmental inflexibility was perhaps encompassed in this, which, when coupled with qualities of ongoing emotion-based coping [59], is suggestive of rigidity and the danger of potentially stifled individual development within a family setting, due to adapted family paradigms.

Despite this, dyads also showed what could be considered signs of PTG and/or BF within the examined relationship, altered existential values, and positive adaptive coping strategies. Capacity for PTG in families is noted as somewhat overlooked in extant TBI literature [66], and the shared suggestion of this and BF within dyads relationships alongside ongoing struggles is perhaps indicative of a continuing process of the negotiation of the noted changes post-TBI, with the potential for adaptation and growth. Beyond this, findings carry implications for systemic rehabilitation support post-TBI, regarding both its application to and current reception from families, particularly mothers and NIS.

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Part Three:

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Appendix 1.1: Reflective Statement

This reflective statement intends to trace my journey through the process of conceptualising, implementing and producing this piece of research, including both rewarding and challenging aspects. On initiation of this project I was aware from an ongoing interest that I wanted to work with the brain injured population, but my ideas were rooted in measuring decision-making ability comparatively through psychometric tests and brain scans. Although the rationale for this research was supportive, funds and resources were not, so at a relatively late stage I had to reformulate my ideas. This was a frustrating time, as I felt the need to balance time pressure enforced by the course with the need to conduct research that was both useful and something I could commit to being passionate about.

In my research up to this point it had become apparent that families of those who had incurred brain injury were often paradoxically both vital to the rehabilitation process and overlooked. I was working in a systemic-based child placement at the time, and the importance of supporting families was really emphasised, which lead to consideration of family support in brain injury. On finding that siblings were recognised as being so overlooked within the literature this confirmed that additional research would be clinically relevant in this area, and I noted that although a number of sibling studies had been conducted, no studies I was aware of focused on the consequential change in relationship between non-injured sibling and caregiver, further than to state that brain injury effects the whole family. I chose to focus on injuries sustained by young adults as this is the most prominent group of this population, and a fledgling adult injury might have different consequences than those incurred in childhood or later adulthood. Incidentally, a later neuro-rehabilitation placement confirmed to me that this research

was necessary and cemented my belief in it, as I was working overtime in order to meet with family members of brain injury survivors who would otherwise have been neglected due to lack of recognised need for support and resources.

The decision of *how* to measure any effect on this relationship was difficult, as upon research many family functioning measures lacked validity in small sample sizes or were not flexible enough to capture all the potential changes. My initial intention had been to utilise a quantitative methodology, however the paucity of research in the area and the potentially small sample size meant that a qualitative approach appeared more fitting. I have had experience in both quantitative and qualitative methods before, so committing to the decision was not too daunting. After consulting with others with more experience than my own, it seemed that IPA was the most appropriate approach to use in order to capture the shared experience of a dyad, rather than contrast opinions or explore a pre-established theory.

During this time I also built up the question for my strategic literature review. I was aware of the increasing application of telehealth into various fields of work, and was interested in examining this within brain injury literature. At a late stage, once again, this intention had to be altered twice as my planned review question was published, however nowhere were conventional and telehealth methods in this area contrasted, so this felt like a natural progression of research.

The recruitment for my study was the biggest challenge I faced, as although each recruiting party was supportive and enthusiastic, they had trouble locating potential participants that fitted my inclusion criteria. This was a particularly hard time, as recruitment consequentially extended for months longer than planned, and caused me to

feel extremely anxious and disheartened regarding the potential of my research. I felt disillusioned with the research process, as I again was desperate to balance time pressure with passion and belief in my work as well as ensuring the research was meaningful and valid. It was frustrating that I knew that my luck could change in a matter of hours, as it was the case of having to wait for interested parties to contact me the majority of the time. In retrospect I would have designed my recruitment process so that I had more involvement, if only to ease the feeling of powerlessness! This was an important lesson, both about myself and about the research process, as each study involves a certain amount of reliance on others and waiting. I think this was made particularly difficult by my inexperience, and is now something I could handle and plan for better having survived it. Supervision at this stage was a really big support, with guidance and constant reassurance that the appropriate potential population did exist. Looking back with insight, the population I targeted was probably too small for such a time-limited study. In one sense allowing more time for recruitment for small populations is something I would now consider for future research and advise to others, although in another sense I forgive myself for overlooking this as it was due to naïvety and inexperience from which I have now learnt, and I am pleased that I managed to stay true to my research question despite the struggle.

During this time I wrote up all I could and put a lot of energy into completing my SLR. The findings confirmed my initial thoughts around measures of family functioning and also potentially informed the nature of future support. In the meantime I extended my potential participants by gaining R&D approval to recruit through a local neuro-rehabilitation unit, attended meetings and sent repeated email reminders to all involved. I initially felt awkward hassling professionals that I knew were busy and had much more to worry about, but each individual I spoke to was supportive which I feel allowed

me to remain firm and persistent with my communication. This is one thing I feel really helped my research to progress where it could, and is something I would carry forward in future. Eventually enough participants were recruited, and this long metaphorical journey paralleled itself in an exhausting 24 hour dash up and down the country as a number of participants arranged interviews in quick succession.

Any worries I had were swept aside for the periods I met the families who took part in this research. I was humbled by their accomplishments and buoyed by their willingness and interest in the area. I think this was what made transcription and analysis of my data an enjoyable process; it was easy to remember participant voices and develop a sense of their experiences, and my disillusionment vanished when faced with the enthusiasm and experience they offered. I had been wary that my initial reactions to families or interviews might overly influence the analysis process, so wrote a reflective diary in order to 'park' these ideas and aid a more objective outcome. In retrospect, although I cannot comment on exactly how effective this was as IPA will always acknowledge input from the researcher as present, I am glad I took this precaution as it allowed me some distance from my original theories, which was especially helpful considering my long-standing interest in the area and the extended time I had in which to ruminate on possible outcomes! Taking part in a IPA group of independent researchers was also invaluable at this stage and further progression through the work.

Another aspect I found difficult was selecting quotes, as I felt "attached" to families and wanted to include extended dialogue to illustrate shared opinion and the processes by which these were reached. Again, supervision and independent opinions were the most useful resource here, in order to ensure the written text remained meaningful yet more concise. I did struggle with knowing when I was 'finished' with analysis, as I was

anxious to put together an accurate representation of experience, but reviewing IPA literature and online IPA groups helped to abate this fear.

For my SLR, both the *Journal of Rehabilitation Medicine* and *NeuroRehabilitation* were appropriate to submit to, as they publish literature relevant to rehabilitation after brain injury. I decided on the latter, however, as the former notes that it does not tend to publish narrative reviews, whereas *NeuroRehabilitation* does, and has also published other qualitative reviews of intervention after brain injury. Regarding the empirical paper, the decision of which journal to submit to seemed a natural choice. *Brain Injury* had published a number of papers I had cited, including the few qualitative sibling studies, and so this appeared to be the most relevant. I wanted my research to be presented in context, and I felt that this was appropriate. It is notable that whilst I was struggling for participants the idea of publishing seemed ridiculous and incomprehensible, but after meeting families and obtaining meaningful results it now feels like a disservice to both them and myself to not at least try.

There are changes I would make to both papers if I were to do them again. I would ideally have liked a larger sample size for my empirical paper, and if I were to re-conduct the study or do similar research I would allow for an extended recruitment period and be firmer in my communication with participating professionals. I would also have liked to spend more time researching new measures of family functioning to quantitatively support the qualitative findings. With regard to my SLR I might have refined my inclusion/exclusion criteria or altered my question so as to allow for more papers to be included. The process of completing this research has illustrated just how difficult the implementation can be, no matter how well-thought-out the question. The necessary but more bureaucratic aspects of research application, such as awaiting ethical

approval, can feel as though they undermine the aim of a study (I remember at the time thinking that they "suck the soul" out of it), but having been through this and then gathered results I am both more aware of the process and reassured that the experience is worthwhile, which has supported my interest in research projects in the future, especially those that might not be as time-restricted.

Ultimately, despite the fact this research was undertaken as a necessity of doctoral training, it has become something that I continue to have belief in and that has granted me increased skill and understanding to take forward. The implementation of study itself has challenged me, but fortunately the findings can be used to inform future research and clinical application in order to support progression for the participants and professionals that formed it.

After VIVA, obviously I was disappointed that it was felt that more work was needed on the empirical study, and the length of time that this would take. I quickly realised that to stay true to the journey described above, the changes were necessary to make the study the best it could be, something that carried great importance for me when considering the families that had taken part. It was also good to have the opinion of experts – the examiners – guiding the changes, which helped me to feel that committing to the thesis and time it required was worthwhile. Going back to recruitment was difficult – this was the most frustrating time originally, and was no less so the second time around. Three more dyads were eventually recruited, however, and when their interviews reflected many of the themes in the original analysis it reaffirmed to me that the study was viable and had the potential to add insight to the experience of these individuals. My ongoing hope is that all the effort I have put in to fulfilling the required corrections is apparent, and that these consequently aid the study's validity and coherence.

Appendix 1.2: Epistemological Statement

Epistemology is the study of knowledge and how we arrive at the belief that something is true, acknowledging our presuppositions and the validity of what we believe to be real (BonJour, 2002). Different research methods hold different epistemological stances, which are operationalised by their chosen methodological approach.

Qualitative research methods, as selected by the researcher, very much differ from the positivist stance of quantitative researchers, which view knowledge, or 'evidence' , as being logical, testable and existing independent of subjective human experience (Scott-Findlay & Pollock, 2004). In contrast to this, qualitative approaches take more of a critical realist stance, which is more in fitting with the researcher's personal standing point, believing aspects of knowledge to be subjective and unique to an individual's experience.

In acknowledgement of these assumptions, qualitative approaches were deemed to be the most appropriate for both the researcher and the research question, which aimed to explore the subjective experiences of a shared mother-sibling relationship after brain injury. Given the focus on individuals perception of their own relationships, and the lack of research into this population, this seemed fitting. Interpretative Phenomenological Analysis (IPA) takes this critical realism – accepting differing experiences and meanings for each individual – alongside the social cognition paradigm, which suggests that these differences in meaning and experience are conveyed through speech and communication, making semi-structured interviews an appropriate research tool (Fade, 2004).

The philosophical areas of phenomenology, hermeneutics and idiography all influence

IPA (Smith, Flowers & Larkin, 2009). The inclusion of both phenomenology and hermeneutics allows the acceptance of individual experiences but also further interpretation of these, in an effort to describe inner processes. Further to this, idiography allows the exploration of a particular, individual experience, rather than necessitating the use of a group or wider population. This allowed an exploration of both the mother and siblings experiences of their specific relationship, the interplay of these, and further interpretation.

The researcher's role in this is a tool of analysis – they are used to interpret and therefore combine their 'knowledge' (Scott-Findlay & Pollock, 2004) and subjectivity with that of the participants, in order to create a co-constructed truth. Although this is accepted, the awareness of our influence as researchers is important, and the use of supervision and independent researcher groups to validate and discuss themes and interpretations was utilised for the current study in order to ensure it reliably captured the lived experiences of participants.

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The corresponding author will receive a PDF proof and is asked to check this proof carefully (the publisher will execute a cursory check only). Corrections other than printer's errors, however, should be avoided. Costs arising from such corrections will be charged to the authors.

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Brain Injury
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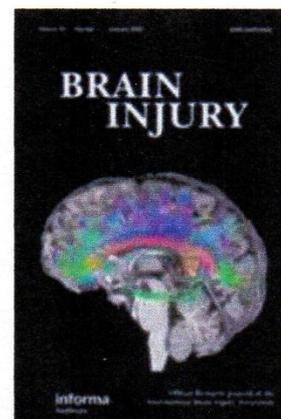
Manuscript Preparation

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author(s) should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

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Brain Injury considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to **Brain Injury**, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which **Brain Injury** incurs, and their papers will not be published. Copyright will be transferred to the journal **Brain Injury** and Informa UK Ltd., if the paper is accepted.

General Guidelines

Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence.

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

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Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).

Ethics of Experimentation: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

Abstracts are required for all papers submitted, they should not exceed 200 words and should precede the text of a paper. See below for further information.

Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

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Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (on separate pages); figures; figure captions (as a list).

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing your article. The title page should be uploaded separately to the main manuscript and designated as "title page – not for review" on ScholarOne Manuscripts.

Abstract

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title and author's name and address, preceding the main text.

For papers reporting original research, state the primary objective and any hypothesis tested; describe the research design and your reasons for adopting that methodology; state the methods and procedures employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central experimental interventions; state the main outcomes and results, including relevant data; and state the conclusions that might be drawn from these data and results, including their implications for further research or application/practice.

For review essays, state the primary objective of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the main outcomes and results of your review; and state the conclusions that might be drawn, including their implications for further research or application/practice.

The abstract should not exceed 200 words.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0.

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The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. Tables and/or figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

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Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

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Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously.

Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.

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All authors are asked to take account of the diverse audience of *Brain Injury*. Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience.

Some specific points of style for the text of original papers, reviews, and case studies follow:

- *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
- *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.

- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.
- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- *Brain Injury* is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.
- Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.
- All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
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- The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.
- Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.
- n (not N), % (not per cent) should be used in typescripts.
- Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

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Click for more information on the presentation of mathematical text.

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Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. Science 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. The pharmacological basis of therapeutics. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. Brain Injury 23(11):853-865. http://www.informaworld.com/10.1080/02699050903283221. Accessed 2009 Oct 06

Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: http://bmj.bmjjournals.com

Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: http://www.cdcnpin.org/

Appendix 3.1: Confirmation of NHS Ethical Approval

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Appendix 3.2: Confirmation Extension of Study

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Appendix 3.2: Confirmation Extension of Study

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HARD BINDING

Appendix 3.3: BIRT R&D Approval

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Appendix 3.4: HEY R&D Approval

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Appendix 3.4: HEY R&D Approval

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Appendix 3.5: Leeds Community Healthcare Trust R&D approval

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Appendix 3.5: Leeds Community Healthcare Trust R&D approval

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Appendix 3.6. Gloucestershire Hospitals R&D approval

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Appendix 4.1: Adapted quality assessment checklist and ratings

	Item	Possible Answer	Geurtsen at al. (2011)	Kreuter at al. (2009)	Rivera et al. (2008)	Sinnakarrupan et al (2005)	Wade et al. (2005)	Wade et al. (2006)	Wade et al. (2008)	Wade et al. (2012)
1	Is the hypothesis/aim/objective of the study clearly described?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
3	Are the demographic characteristics of the patients included in the study clearly described ?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
4	Are the interventions of interest clearly described?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
5	Are potential confounders clearly described?	Yes(1)/No(0)/ Unclear(0)	0	0	0	0	0	0	0	0
6	Are the main findings of the study clearly described?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
7	Does the study provide estimates of the random variability in the data for the main outcomes? (e.g. SD)	Yes(1)/No(0)/ Unclear(0)	0	1	0	1	1	1	1	1
8	Have the characteristics of patients lost to follow-up been described?	Yes(1)/No(0)/ Unclear(0)	0	1	1	0	1	1	1	1
9	Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes(1)/No(0)/ Unclear(0)	1	1	0	1	0	1	1	1
10	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Yes(1)/No(0)/ Unclear(0)	0	0	1	0	0	1	0	0
11	Were those subjects who were prepared to participate representative of the entire	Yes(1)/No(0)/ Unclear(0)	0	0	0	0	0	0	0	0

	population from which they were recruited?									
12	Was an attempt made to blind study subjects to the intervention they have received?	Yes(1)/No(0)/ Unclear(0)	0	0	0	0	0	0	0	0
13	Was an attempt made to blind those measuring the main outcomes of the intervention?	Yes(1)/No(0)/ Unclear(0)	0	0	1	0	0	0	0	0
14	If any of the results of the study were based on "data dredging", was this made clear? **If none reported- yes**	Yes(1)/No(0)/ Unclear(0)	1	1	1	0	1	0	1	1
15	Were the statistical tests used to assess the main outcomes appropriate?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
16	Were the main outcome measures used accurate (valid and reliable)?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
17	Were study subjects randomised to intervention groups?	Yes(1)/No(0)/ Unclear(0)	0	0	1	1	0	1	0	1
18	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	Smallest: $<n1=0$; $n1-2=1$; $n3-4=2$; $n5-6=3$ $n7-8=4$; $>n8=5$	5	5	5	5	3	5	5	5
19	Did the discussion address limitations to the study?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
20	Have implications been discussed?	Yes(1)/No(0)/ Unclear(0)	0	1	1	1	1	1	1	1
21	Have future areas for research been described?	Yes(1)/No(0)/ Unclear(0)	1	1	1	1	1	1	1	1
		Totals (/25)	**16**	**19**	**20**	**18**	**16**	**20**	**19**	**20**

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Appendix 5.1: Participant information sheet

Information Sheet

UNIVERSITY OF **Hull**

Parent-sibling relationships post-TBI

Charlotte Valentino, University of Hull

You are invited to take part in a voluntary research study, being completed as part of a doctorate PhD programme. Before you decide whether to take part or not, it is important that you understand why the research is being done and what participation would ask from you. This information sheet should do this, as well as giving you further information about the study.
Please ask the researcher if there is anything that is not clear. Please feel free to talk to others about the study if you wish.

Introduction
You are invited to take part in a research study on how head injury in a family affects relationships between parents and non-injured brothers or sisters. It is designed to explore any changes in this relationship from both points of view, between 2 and 5 years after the head injury happened. This research should hopefully help to inform and improve services for other affected families in the future.

Why me?
Families taking part in the study must have a young adult member who had a head injury between 2 and 5 years ago when they were between the ages of 15 and 24, and spent time in neuro-rehabilitation because of this.

You have been invited to take part either because you identified yourself as being interested in taking part by contacting the researcher. Alternatively, a BIRT or healthcare worker at Castle Hill who works directly with you thought that you may be interested in taking part. If this is the case, he or she should have asked you to sign a consent form before giving us your details and may have already given you a little information about the study.

What would it involve?
It will take about 1 -2 hours of your time to complete this study. Before the beginning of the study you will be given a choice of where to meet, and a chance to ask any questions about the study itself. During the interview you and your chosen family member will sit together in a private room with the researcher and a semi-structured discussion will take place. This means the researcher will start off asking some specific questions, but you are both free to follow the natural direction of the conversation. You should try not to worry about what you say during the interview, as an honest and realistic account of family relationships is what the study aims to explore. The interview would be

recorded on a Dictaphone so that the researcher can go over it later and make full sense of what has been said. The aim is to look for 'themes' in how different people talk about their relationships and things that have happened because of the head injury.

After the interview, you will not be contacted again, or asked for any more information. If you wish to know the findings of the study you can add your preferred method of contact on the consent form and these will be emailed to you.

Voluntary Participation
You are free to choose whether to complete the study or not. You will be given a copy of this information sheet to keep. If you choose to take part in the research you will be asked to sign an informed consent form. This means that you understand what you are taking part in and what you will have to do. After this, you may stop taking part for any reason at any time by telling the researcher. After the study, you may also withdraw your results should you so choose. This would not affect the standard of any care or support you later receive.

Anonymity
Names will not be recorded during this study (the consent form being an exception). Codes will be given to each participant (e.g. AA), which will then be used to identify data. The interviews will be recorded using a dictaphone. These recordings will be kept securely on an encrypted memory stick, will not be transferred off this memory stick, and will be deleted once the data has been anonymously written up.

Data from this study and quotes from the interviews may be used in published research papers but no names or identifying information will be included.

Risks and Benefits
This study involves very little risk, although that there is a chance that you may find the issues raised in the interviews upsetting. If you do become aware of this, breaks can be taken, or the interview can be stopped early, by telling the interviewer how you are feeling. The interviewer will be a trainee clinical psychologist and will be able to respond to help you with any emotional distress you feel. If this happens you might be encouraged to seek further help from your doctor. If, during the interview, the interviewer feels that you, or anyone else are at risk, they will have to break confidentiality to inform relevant others. Should this happen, they will discuss this with you at the time.

At the end of the interview the researcher will talk you through what the study aims to find out and what will happen next. There will be a chance to ask any more questions at this point.

Your participation will help us to learn more about the wider effects of brain

injury within families, and hopefully will help to shape future services for neuro-rehabilitation. It is intended that this research will be published in a peer-reviewed journal, which is accessible to the public. If you would like to be informed of the results of the research, we will keep your personal details on file, and send you information once the results have been found.

Contact
The researcher will be happy to answer any questions that you may have about taking part, or the nature of the study itself. Similarly, any complaints or problems regarding the research can be discussed with the researcher on 07927 321599.

Funding
The chief investigator is being paid to carry out this research by the Humber NHS Foundation trust as part of their job. However, this piece of research is receiving no external funding, and there are no identified conflicts of interest.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by Yorkshire & The Humber – Leeds Central Research Ethics Committee and given a favourable opinion.

If you would like more information on taking part in research you can to look at the NHS Choices website: http://www.nhs.uk/Conditions/Clinical-trials/Pages/Introduction.aspx or the National Research Ethics Service: http://www.nres.npsa.nhs.uk/

For further information, you can also contact the primary researcher by post, telephone or e-mail with any questions:

Charlotte Valentino
Trainee clinical psychologist
Department of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
HU6 7RX

Telephone number:
    07927 321599

E-mail: Charlotte.Valentino@hey.nhs.uk

Thank you for your interest in completing this study, and for taking the time to read this information sheet.

UNIVERSITY OF **Hull**

Parent-sibling relationships post-TBI

Charlotte Valentino, University of Hull

I am looking for participants for a doctoral research study on how head injury in a family affects relationships between parents and non-injured brothers or sisters. It is designed to explore any changes in this relationship from both points of view, between 2 and 5 years after the head injury happened. This research should hopefully help to inform and improve services for other affected families in the future.

Could you help?
Families taking part in the study must have a young adult member who had a head injury between 2 and 5 years ago and spent time in neuro-rehabilitation because of this.

What would it involve?
It will take about 1 -2 hours of your time to complete this study. During the interview the sibling and chosen parent will sit together with the researcher and a semi-structured discussion will take place. This means the researcher will start off asking some specific questions, but you are both free to follow the natural direction of the conversation.

Your participation will help us to learn more about the wider effects of brain injury within families, and hopefully will help to shape future services for neuro-rehabilitation. It is intended that this research will be published in a peer-reviewed journal, which is accessible to the public.

Contact
If you are interested in participating in this research, or would just like to find out more information about the study, please contact Charlotte Valentino -

Telephone number: 07927 321599

E-mail: Charlotte.Valentino@hey.nhs.uk

Appendix 5.3: Consent form for participation

Patient Identification Number:

Consent Form

UNIVERSITY OF **Hull**

Title of Project: Parent-sibling relationships post-traumatic brain injury

Name of Researcher: Charlotte Valentino

Please initial

- I confirm that I have read and understand the information sheet dated 26/07/2012 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

- I am aware of the potential risks and benefits of taking part

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

- I agree to take part in the above study.

- I consent to my participation being audio-recorded.

- I would like to be informed about the results of this study.
Please contact me at the address below:

    Address:_____

    Postcode:_____

    E-mail address:_____

    Telephone number: _____

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

This information will be stored securely, in a different place to any confidential data that you submit as part

of this research study. There are two copies of this form: one for you to keep and one for the researcher.

Appendix 5.4: Consent form for contact

Patient Identification Number:

Consent Form

UNIVERSITY OF **Hull**

Title of Project: Parent-sibling relationships post-traumatic brain injury
Name of Researcher: Charlotte Valentino

Please initial

- I confirm that I have read and understand the information sheet dated 03/10/2012 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

- I confirm that I agree to my contact details being passed to the researcher (Charlotte Valentino) and to her then contacting me with further information regarding the study and potential participation

- I understand that my participation is voluntary and if I agree to take part I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

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

- I am aware of the potential risks and benefits of taking part

- I would like to be contacted with further information on the study.

Please contact me at the address below:

Address:_____

Postcode:_____

E-mail address:_____

Telephone number: _____

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

This information will be stored securely, in a different place to any confidential data that you submit as part of this research study. There are two copies of this form: one for you to keep and one for the researcher.

Parent-sibling relationships post-TBI
Charlotte Valentino, University of Hull

Interview Schedule

1) Tell me about your family before the injury happened

   Prompt: - individual roles, alliances or bonds, perception of family as a unit, view of family from outsiders

2) Tell me about your family after the injury happened

   Prompt: - individual roles, alliances or bonds, perception of family as a unit, view of family from outsiders

3) Please describe your relationship before and after the injury?

   Prompt: -Trust, authority, who's in charge, responsibility, closeness, perceptions of one another and selves as a pair, future relationship – hopes, predictions, fears

4) Tell me about trust and independence in your relationship

   Prompt: - closeness, openness, secrets, feelings, autonomy, individuality

5) How do you view and manage responsibilities in your relationship?

6) Tell me about how you supported each other through the accident, and the nature of this support now

   Prompt: - Individual struggles and impact on relationship, nature of support, how do you feel about it? Has this continued?

7) Tell me about how you view family roles now

   Prompt: - Has this changed? Most important things? Why?

Appendix 6.1: Dyad demographic information

Dyad number	Parent/caregiver		Non-injured Sibling		Injured Sibling		
	Age (years)*	Gender	Age (years)*	Gender	Age (years)*	Gender	Time since Injury (years)*
1	48	Female	23	Female	26	Male	5
2	47	Female	19	Female	24	Male	5
3	41	Female	20	Female	24	Male	3
4	40	Female	21	Male	26	Male	5
5	46	Female	19	Female	23	Male	3
6	54	Female	22	Female	23	Male	3
7	58	Female	20	Male	24	Male	3

* at time of interview

Appendix 6.2: Worked example of IPA

This is an example, using a short section of transcript from the interview with Dyad 6, of the methodological process of IPA, step-by-step, as described in the methodological section of the empirical paper.

Step one: Immersion in data and notes

Transcripts were read and re-read, initially to ensure that individuals were not obviously deterred from sharing by having another family member present. Notes were then made in the left hand margin. These initial notes comprised of descriptive comments, regarding the content of what was said, linguistic comments, how it was said and delivered, and conceptual comments, adding a level of interpretation to the raw data. Any interesting aspects of interactions and exchanges were also noted, focussing on the nature of these within the dyad, both verbal and non-verbal, examples including elaboration, interruption, prompting of the other, or silence. Independent researchers also completed this stage on excerpts of transcript and discussion was generated.

NIS generates idea and pauses to ask for help from mother	**S**: There was that day they did for [unit], was it...
Mother helps by generating information NIS couldn't recall	**M**: Headway, yeah.
NIS struggles to complete sentence	**S**: Headway, there was other people, like-
Mother helps NIS explain *"for us" - united? us/them?*	**M**: it was for us, wasn't it, families.

NIS found talking to other families with shared experience helpful	**S**: There was families so you could talk to other people and you heard their story, and it made you think.
"like therapy" - talking to others with shared experience as supportive, like a treatment, to mother	**M**: It was like therapy, wasn't it! Yeah.
Shared opinion.	**S**: Yeah
Mother was still actively grieving at the time	**M**: The lady, she, she, I was still crying every morning, at this time.
Prompt to continue	**I**: *Yeah?*
Sought other emotional help	**M**: And then I went and had my profound healing that night, do you remember? She, um, she said that her brother had had his injury, what, 28 years ago, she said, and I still cry now, she said, and I think I'll cry forever. So I kept thinking, oh, god, y'know, cause we were, what was it, about a year down the line? Yeah, so um, where was I going with that one? Yes, so that, that was really helpful, we talked, it was nice, wasn't it?
Other families offered support and normalisation	
Fear for ongoing grief.	
Even negative stories classed as helpful? Therapeutic?	
	S: Yeah.

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M: We sat in little groups, and-

Interruption – to summarise own experience? Hearing others experiences of TBI helpful.

S: I think it helps to hear other people's stories.

M: Yeah.

"Hope" - stories from others provide a sense of optimism? A sense of the journey ahead.

S: Especially if you were like, in hospital, and you're going through it at the time, it gives you a bit more hope.

M: Yeah.

S: Like we, we had the nurse who's son had had it.

Prompt to continue

I: *Yeah?*

Positive stories of TBI journey conveyed by those who have lived it

S: So we'd heard positive feedback.

M: Yeah.

Lack of hope provided elsewhere?

S: Which had made us think oh well we've got hope for [X].

Mother adds explanation.

M: You know, and he was living in almost a normal life.

S: Yeah.

Not enough hope?

M: Yeah, and I think, yeah, there's not enough because when, I remember when we'd gone back to the neurologist, we'd only met him once. You know, when [X] had come from [unit] to [unit], you initially see the

Consultant shocked by IS recovery.

big head man, don't you, [consultant]. Anyway, I remember [X] was out of [unit], he was back home, and

"for people to see" - consultant aware that comparison to those who have experienced TBI helpful. Sense that even the consultant unaware of recovery progression. Mother surprised that IS' recovery at that stage seen as "amazing" If amazing at that stage, what is it now? Sense of pride?

he walked in, well, he was still hobbling in, and he just went, [open mouthed action] and he was like, my god [X]! I wish we'd videoed your progress for people to see, he said, cause it's truly amazing! And at this time, he was still had a really bad tremor, his drop foot was still really bad, and he was still really, his speech was really slow, and I was thinking, gosh! And I was thinking yeah, they should have been allowed. That nurse stopped it.

Prompt to continue

I: *Hmm?*

Friends of the IS having photos with him whist he was hospitalised.

M: The boys would come in, you see, and they'd have their photo taken with him, they'd be putting their thumbs up.

Continued support from IS' friends.

NIS defends actions she feels

S: But even when he was in his coma, but, that

others disapprove of.

Humour shared with family and
friends as a connection to IS.

Mother struggles to uphold
caregiver role in hospital.

Want to record diary for IS – to
record progress? Fill in memory?
Indicates belief IS will be okay.
Activity looked down on by medic –
nurse didn't understand/
undervalued the nature of the
support

Shared sense of humour – united in in-
jokes
Humour as a source of unity and
support?

NIS defending activity because of
shared humour

Regrets being unable to record
recovery and give hope to others

wasn't...people say that's bad, but that wasn't... it was [X]'s humour as well.

M: I wish, I wish...and I'd tried to explain that to the nurse. She said those are gonna go on Facebook or something, and I said I can promise you the will not go on Facebook, they'll be totally private, I said it's like a diary for him. But she said he can't give his consent, and I said no, and I'm his mother and I would like to give consent, and she goes well I'm gonna ask you not to do it any more, she said, because the boys are taking the piss.

I: *Right.*

M: I said they're not, actually, they're actually doing exactly what [X] would be doing if it was them in the bed. You know, like they'd bought him a tiger because of the tiger blood, and they'd have the tiger on him, and-

S: And like, [X] with his shaking, Friend would be like "stop shaking, [X], you're spilling all your food!"

M: But what we've said, is if we'd done that all the way through, that progress would have been amazing for

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who experience TBI, to provide a
positive story in the face of
unpredictable prognosis.
Prevented by medics (interesting
they are seen as both unable to
provide hope and have a role in
preventing it)

someone to see, you know? From him just, just laid there with his eyes closed, then, then just, like, so it's a shame that they didn't let us. So.

Step two: Developing emergent themes

Transcripts with notes were re-read, and emergent themes were marked on the opposite margin of the page. Emergent themes aimed to capture the essence of what was said, and were again discussed with independent researchers.

NIS generates idea and
pauses to ask for help
from mother

S: There was that day they did for [unit], was it...

Mother helps by
generating information
NIS couldn't recall

M: Headway, yeah.

Dyad work
together to create
co-constructed
narrative

NIS struggles to
complete sentence

S: Headway, there was other people, like-

Mother helps NIS
explain
"for us" - united?
us/them?

M: it was for us, wasn't it, families.

United with
others who share
experience

NIS found talking to other families with shared experience helpful	**S**: There was families so you could talk to other people and you heard their story, and it made you think.	
"like therapy" - talking to others with shared experience as supportive, like a treatment, to mother	**M**: It was like therapy, wasn't it! Yeah.	*Both of dyad: Shared experiences as offering hope and support*
Shared opinion.	**S**: Yeah	
Mother was still actively grieving at the time	**M**: The lady, she, she, I was still crying every morning, at this time.	
Prompt to continue	**I**: *Yeah?*	
Sought other emotional help *Other families offered support and normalisation* *Fear for ongoing grief.* *Even negative stories classed as helpful?* *Therapeutic?*	**M**: And then I went and had my profound healing that night, do you remember? She, um, she said that her brother had had his injury, what, 28 years ago, she said, and I still cry now, she said, and I think I'll cry forever. So I kept thinking, oh, god, y'know, cause we were, what was it, about a year down the line? Yeah, so um, where was I going with that one? Yes, so that, that was really helpful, we talked, it was nice, wasn't it?	*Normalisation/ validation of feelings is offered by others*

S: Yeah.

M: We sat in little groups, and-

S: I think it helps to hear other people's stories.

M: Yeah.

S: Especially if you were like, in hospital, and you're going through it at the time, it gives you a bit more hope.

Hearing stories of recovery provides hope

M: Yeah.

S: Like we, we had the nurse who's son had had it.

I: *Yeah?*

S: So we'd heard positive feedback.

M: Yeah.

Lack of hope provided elsewhere?	**S**: Which had made us think oh well we've got hope for [X].	*Prior shared sense of hopelessness of recovery*
Mother adds explanation. Comparison to others inspires hope for IS.	**M**: You know, and he was living in almost a normal life.	
	S: Yeah.	
Not enough hope?	**M**: Yeah, and I think, yeah, there's not enough because when, I remember when we'd gone back to the neurologist, we'd only met him once. You know, when [X] had come from [unit] to [unit], you initially see the big head man, don't you, [consultant]. Anyway, I remember [X] was out of [unit], he was back home, and he walked in, well, he was still hobbling in, and he just went, [open mouthed action] and he was like, my god [X]! I wish we'd videoed your progress for people to see, he said, cause it's truly amazing! And at this time, he was still had a really bad tremor, his drop foot was still really bad, and he was still really, his speech was really slow, and I was thinking, gosh! And I was thinking yeah, they should have been allowed. That nurse stopped it.	*Medical prognosis as unreliable/ unpredictable.*
Consultant shocked by IS recovery. *"for people to see" - consultant aware that comparison to those who have experienced TBI helpful.* *Sense that even the consultant unaware of recovery progression.* *Mother surprised that IS' recovery at that stage seen as*		

I: *Hmm?*

Friends of the IS having photos with him whist he was hospitalised.

M: The boys would come in, you see, and they'd have their photo taken with him, they'd be putting their thumbs up.

Social support as ongoing at time.

Continued support from IS' friends.

NIS defends actions she feels others disapprove of. Humour shared with family and friends as a connection to IS.

S: But even when he was in his coma, but, that wasn't...people say that's bad, but that wasn't... it was [X]'s humour as well.

Mother struggles to uphold caregiver role in hospital.

Want to record diary for IS – to record progress? Fill in memory? Indicates belief IS will be okay.

M: I wish, I wish...and I'd tried to explain that to the nurse. She said those are gonna go on Facebook or something, and I said I can promise you the will not go on Facebook, they'll be totally private, I said it's like a diary for him. But she said he can't give his consent, and I said no, and I'm his mother and I would like to give consent, and she goes well I'm gonna ask you not to do it any more, she said, because the boys are taking the piss.

Medical support vs support by others with shared experience

Activity looked down on by medic – nurse didn't understand /undervalued the nature of the support

I: *Right.*

Shared sense of humour – united in in-jokes

Humour as a source of unity and support?

M: I said they're not, actually, they're actually doing exactly what [X] would be doing if it was them in the bed. You know, like they'd bought him a tiger because of the tiger blood, and they'd have the tiger on him, and-

Shared sense of humour in bad times

NIS defending activity because of shared humour

S: And like, [X] with his shaking, Friend would be like "stop shaking, [X], you're spilling all your food!"

Regrets being unable to record recovery and give hope to others who experience TBI, to provide a positive story in the face of unpredictable prognosis. Prevented by medics (interesting they are seen as both unable to provide hope and have

M: But what we've said, is if we'd done that all the way through, that progress would have been amazing for someone to see, you know? From him just, just laid there with his eyes closed, then, then just, like, so it's a shame that they didn't let us. So.

Mother wants to provide story for others in their situation – Ingroup/ Outgroup?

a role in preventing it)

Step three: Identifying themes

The emergent themes were compared, grouped and organised within transcripts at first, and then across all transcripts, in order to identify super-ordinate themes through a process of abstraction. Themes not relevant to the majority of transcripts were dismissed. This was an iterative process, and one in which time was spent in discussion with independent researchers. As themes were elicited they were synthesised into super and sub-ordinate relationships until it was felt the data was accurately represented, and multiple quotes were extracted and placed together in support of themes, an example of these processes can be seen below. Further examples of these can be seen in Appendix 6.3.

Overall Super-ordinate theme	Overall Sub-ordinate theme	Initial emergent themes	Example quote
Mother's Prioritisation of the IS	Step up	"Gotta do this" - Necessity. Filling role previously taken by mother? Taking responsibility for care of siblings.	*"it's just thinking, right, er, I've gotta do this, and this, and this, y'know like, wasn't even important things it was just, like, make sure they have something for dinner, y'know, stuff like that."*
Isolated by the experience	Professional support unreliable	Lack of support perceived by mother. Lack of support perceived as detrimental (with hindsight). Feeling of superiority experienced from medics. Info withheld?	*"No, well we didn't get that support,* *but I, I just think, looking back now, I would have liked someone.* *I mean, we're all intelligent people, I would have liked someone to have sat down with me..."*

Appendix 6.3: Supportive Quotes per Sub-theme

(Further to those included in Results section, P. 72)

**1.0 – Mothers' prioritisation of the IS: '*He comes first because of the way he is'*

'M: *Yeah, because they are second best, in a sense.*

S: *Which is difficult at times.*

M: *Not in a nasty way, but the are second best. But they accept it.'*

(Dyad 1, lines 597-601)

'S: *yeah, I was used to you (mum) being there all the time. I don't know, you was there all the time and then all of a sudden...*

M: *I was still there but the attention wasn't. So it's not particularly, it's not particularly that you're not there anymore, it's that your attention's not there anymore.*

S: *and I sort of went from all the attention to nothing, and, I'd just turned 18, so you get a lot of attention, and then all of a sudden that was it and it'd gone and I was like...oh.'*

(Dyad 1, lines 632-639)

'*I literally...especially when he was at [rehab centre], I lived at the hospital.'*

(Mother 2, line 600)

'*I think the thing was, because mum had been out of the, not out of the picture as such, but, because her priority was [X] and we all know her priority was [X]...'*

(Sibling 3, lines 1358-1359)

'S: *Cause, for a while as well, for the past few years it had to be all about him.*

M: *Yeah, it did, wasn't it.'*

(Dyad 5, lines 677-679)

'M: *...we were able to focus 100 percent on [X]. Had the other two been younger, I*

guess it would have been awful.'

(Mother 6, lines 1003-1004)

1.1 – Mothers' sacrificed roles

'I'm not bothered how seriously injured he is I'll look after him. And like, I took my redundancy last year, not last year the year before for me job, d'y'know, because I went on this job share, and and did less hours. But it was still... [X] went into hospital, like, he's had a lot of operations and different things done, it was hard, d'y'know, to be there with him all the time, and I had to give him that commitment, so like, I...it's been two years now. So I took my redundancy, so... I get that quality time with my son now.'

(Mother 2, lines 207-212)

'M: It was hard work, keeping my job going.

S: mm.

M: Yeah. And that, That was selfish of me, that was, you know, I could have given up my job, and I could of... But I kept thinking, y'know, if he gets better, I have this, my job is amazing, I, I'm an activities co-ordinator in a skills centre, and those jobs just don't come, right. And if [X] gets well, I'm never gonna get this job again, I going to keep my job, because I love my job, and...cause I don't want to give up my job. And I don't want to be at home. So we had care come in, didn't we, when he first got back.'

(Dyad 5, lines 1596-1604)

'M: Had to kind of put our life on hold, because, obviously [X] is 23 this year, he should be moving out-

[Interviewer: Right?]

M:*-or he should have moved out-*

S: He was going to.

M: Yeah

S: *Because [Friend], was in a flat and he had a spare room, and he was thinking about it.*

M: *Yeah, yeah, so because I I um, want to become a foster mother, and that's not going to happen because I haven't got a spare room, basically. So, what we, yeah, our life is been put on hold, hasn't it, really.'*

(Dyad 5, lines 653-664)

1.2 - Sibling responsibility: 'Step up'

'...as well like, if anything was wrong like a bruise or cut, whereas mum who's had kids would know what to put on that, a plaster or germolene, but I wouldn't know stuff like that, so now I've learnt about it, it's made me more, like, so when I have kids it's gonna help me in future. I've learnt quite a lot.'

(Sibling 2, lines 578-581)

'And I just, just, it was one of the things that made me think now I've gotta step up to this, and do what I've gotta do, and, like I say, like, a a lot of the time it wasn't even up to me, it was, y'know, about the girls first, and it was making sure that the girls and mum were alright, and then I'd have my time because I'd just sit upstairs and do whatever'

(Sibling 3, lines 803-804)

'S: *At that point in time it's just getting through each day I think.*

M: *Yeah.*

S: *It's just thinking, right, er, I've gotta do this, and this, and this, y'know like, wasn't even important things it was just, like, makes sure they have something for dinner, y'know, stuff like that'*

(Dyad 3, lines 773-775)

'Whenever needed I'll look after't kids. She were at hospital every day.'

(Sibling 4, line 152)

'S: *Yeah, I think it's made me mature a lot more, his accident.*

M: *Yeah, you are very mature, compared to your friends.*

S: *Yeah, but I just think because of that, it's made me – yeah.*'

(Dyad 5, line 3 1704-1708)

2.1 – Need for validation vs doubt that needs can be met: 'You'd never understand'

'And sometimes that's what you've gotta do, you've got to see it further on, to see. And that's the trouble with brain injury at the beginning, nobody shows you the further on. If somebody shows you the further on sometimes, although they might not get to that, you've got something.'

(Mother 1, lines 1193-1195)

'I know what that feeling's like. But unless you're there, and you're going through it, you can't empathise with anybody. People say, oh it must be awful. No. You don't know, you've got no idea. You've got to live through it to know what it's like.'

(Mother 1, lines 1234-1237)

'First time I sat down and talked to [other patient]'s mum, everything she said, it was what I was thinking and what I was feeling, and just to be able to speak to somebody that was going through the same emotions, same problems, d'y'know, yeah.'

(Mother 2, lines 849-851)

'One thing I would say that if, if somewhere along the line it could be pushed to put one mum, with another mum, that has actually experienced the same thing.'

(Sibling 3, lines 1867-1869)

'M:...if, if headway rang me tomorrow and said we've got a family that, y'know, this has happened to their son or daughter, blah blah blah, would you like to, y'know, would you support them in just, yeah.

[Interviewer: Mm?]

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M: Just yes, absolutely! Quite, that's the one thing that, that Headway, I believe, or some, or even BIRT, could start up.

[Interviewer: Mm?]

M: That, that support.

S: *I think it, I think what the thing is, is you want to talk to somebody that's been through it and knows what you're going through.'*

(Dyad 3, lines 1944-1955)

'M: *Yeah, it would give people amazing hope, yeah. Especially, like, when they, even when they came to, when people come up from [rehab unit] to [rehab unit], didn't they, and I'd be like, you know, it was like this for us, but you know.*

S: *Yeah.*

M: *They need someone on the ward sat there going, you know, this is my story, it's, I know at the moment it looks pretty grim, and you think this, that and the other, but actually, this might happen.*

S: *What I think, the families, when it's like a break for them to clean the room, the bedding, for the families to go and talk to the other families, and encourage it more.'*

(Dyad 5, lines 1859-1867)

'*...no one completely understands, still, like, what we did go through. They just assume like, ah.'*

(Sibling 6, lines 1130-1131)

2.2 - Professional support unreliable: 'trying to find your way through mud'

'...at that point you haven't got the foggiest idea. You trust a doctor. I would not trust a doctor as far as I could throw one now.'

(Mother 1, lines 63-64)

'There's no, d'y'know, no information out there, there's nothing. I found Headway myself, d'y'know, and like, BIRT, we we found BIRT ourself d'y'know. No nobody came to me and said these are your options, look at these places, this is what help there is for you. Nothing.'

(Mother 2, lines 1157-1159)

'...one of the things that I totally disagree with is if you read any brain injury thing, either in the brain injury rehabilitations, or he went to [outpatient unit], anything like that, the first paragraph will always say, speak to family and close friends to get to know what the person was like before their brain injury.

[Interviewer: Mmm?]

That is the biggest, you'll have to 'cuse me, pile of bullshit I've ever read in my life. Because, everywhere we went, apart from [two hospitals], they didn't wanna know. They weren't interested, were they?'

(Mother 3, lines 831-844)

'M: Gaps that we filled, that maybe someone else wouldn't be, someone else wouldn't, you know?

[I: Yes?]

M: Like, someone else, like we said, might not be so determined...'

(Mother 5, lines 1988-1989)

'We were just told, well, we weren't even prepared! Nobody prepared us....'

(Mother 6, lines 326-327)

'But certainly those first two years, when it came to psychological help, I feel that we were out on our own.'

(Mother 6, lines)

'S: *Like, it's best to have a vague idea of what we're gonna be dealing with, cause we had no idea, it was each day, if something new happened we'd be like, oh, is that is that he accident or is that him? So just to be told and like, as a like, erm, there just needs to be more family support. Like, I don't understand how we could have missed it so many times when we could have been seen once.*

M: *Yeah.'*

(Dyad 6, lines 1617-1622)

'I think the message was he has got some kind of a brain injury but we don't know what it is or what the extent of it is or how long lasting it'll be or anything like that. So, so it's all, all a bit vague really.'

(Mother 7, lines 173-175)

3.1 - Coping as doing: 'just get on with it'

'M: *where you've just sort of...*

S: *I get on with it.*

M: *She's got on with it, and d'y'know...I know it's not nice to do but if he's opened his bowels she'll deal with it, she empties his urine bag, she does injections, d'yknow, trachi and absolutely everything. And, and, you've been that hands on more or less from the beginning ain't ya?*

S: *Yeah*'

(Dyad 2, lines 172-180)

'*There's no point in crying over it, it's happened, you can't change it, so just...take him how he is now.*'

(Sibling 2, lines 984-985)

'*I'm in this situation and I've got to deal with it, d'y'know, so.*'

(Mother 2, line 1032)

'S: *At that point in time it's just getting through each day I think.*

M: *Yeah*

S: *It's just thinking, right, er, I've gotta do this.*'

(Dyad 3, lines 769-773)

'S: *...y'know, but I think, because you're in that situation, you just do it. You just get on, you don't even think about it, like I didn't even think about it really, it was just something that I had to do and it was just, y'know*'

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(Sibling 3, lines 816-817)

'Yeah you just get on with it, it all just goes over your head.'

(Mother 4, line 252-253)

'It is, from sitting in hospital just looking up at the ceiling and doing nothing, not

moving a limb, thinking right, what we've got we've got, get on with it.'

(Mother 4, lines 597-598)

'We've just got on with it and we've worked it out and learnt how to deal with [X]'

(Mother 4, line 999-1000)

'M: *It was hard work, wasn't it.*

[I: And did anything help?]

S: *I dunno, just ignoring it, and getting on with it.'*

(Dyad 5, lines 739-743)

3.2 - Humour: 'you have to laugh about it'

'That's what you do, find the funny bits.'

(Sibling 1, lines 1259-1260)

M: *...you do tend to look at the funny side, rather than the sad side of it. I mean, some of the things! The most hilarious, we was in [rehab unit] – you imagine you've got somebody near death's door, and your dad, all he was interested in was going for his dinner! It was like, are we going for dinner? Everybody couldn't care less if they didn't eat, but it was like, are we off down to the canteen to get dinner, I'm hungry!*

S: *Then again I didn't stop eating!*

M: *So you've like got me and [older sister] going, I'm not really hungry, and you've got them two going, I need my dinner! It's like, hang on a minute, reality check, they still need feeding. So, you know, it does, humour does get you through those situations'*

(Dyad 1, lines 1271-1272)

'So, y'know there was always, y'know, yeah I think each other definitely was the thing that got us through it. Again, just, like I said earlier, just humour, just making little jokes and thinking up funny memories and stuff like that -'

(Sibling 3, lines 1651-1653)

'You've got to, you, like [S] said, you were laughing as well as crying at the same time, and, y'know, you can when you sit and really think about some of the really bad times that we went though with him, one minute you can be crying, and then the next minute you can be laughing about something he's done.'

(Mother 3, lines 1781-1785)

'S: *I think you have to laugh about it.*

M: *There's lots of times we'd laugh in hospital, wasn't there?*

S: *Yeah.*

M: *Like, things would happen.*

S: *Yeah.*

M: *You just had to laugh, didn't you, yeah.'*

(Dyad 5, lines 1101-1111)

'S: *...like, he wanted to go to Africa this summer, to go volunteering, and we said it was the worst idea he'd had. But, we've been saying this to him now, last year, the year before...*

[both laughing]

M: [Laughing] *We did, yeah. Yeah, he's cottoned on!'*

(Dyad 6, lines 898-906)

'M: *I thought it would be a good idea for him to find himself, that sort of thing, rather than try to serve a stupid university course he's never gonna be a pilot at, or sort of thing, but-* [laughs]

S: *It seems so backwards, that, doesn't it? Her going, no, go to India, don't, don't go do your degree!* [all laugh]

M: *Yeah, maybe so. But, also the thought terrified me because, you know, literally, young people get lost in continents far away, and if anyone's gonna get lost and we lose track of them, it'll be [X], wouldn't it, you know!'*

(Dyad 7, lines 732 -741)

3.3 – Social Support

'You do find that, people support you – they come see him but to support you.'

(Sibling 1, line 986)

'Yeah, see, you need support...I've got 3 friends that...2 friends that always take me out and we go out once a month. We always have fun, but they take me out and they listen to things that you can't talk to people who are close to you about. So you can rant about this, that and the other, because they're different. So, although you need your family, you need someone outside of it as well...'

(Mother 1, lines 988-992)

'M: *We had a couple of friends, one somebody that I'd known for years and she said y'know, um I'd like to help you out. And we just, y'know, come home and found a lasagne didn't we, and brownies on the doorstep.*

S: *Yeah.*

[Interviewer: Ah?]

M: *Y'know, which was lovely*'

(Dyad 3, lines 1666-1674)

'But then again you do have the people that will stick by you and even now will still ask how he is.

[Interviewer: yeah?]

Um, things like that and you think, y'know, they know, because you've only seen them a week ago, and but they still will always ask.'

(Sibling 3, lines 585-591)

'See I had help most days looking after't kids. I either had me cousin or my girlfriend at time-

[Interviewer: yeah?]

- who'd help me so I always had someone to speak to, I wasn't alone.'

(Sibling 4, lines 713-715)

'We just had an amazing support from friends, didn't we?'

(Mother 5, lines 156-157)

'M: *You did go and spend time at [Friend's house] though when it got too much for you didn't you?*

S: *Quite a lot, yeah. I still do now, don't I. Like my friend, she lives round the corner, like 5 minutes away, so whenever I need her I just have to text her and she'll say, come round.*

[Interviewer: Okay.]

M: *And you know [S] can stay there anytime.*

S: *Yeah*

M: *That's where she stayed while [X] was in hospital*'

(Dyad 5, lines 746-755)

4.0 - Growing closer

'You have a different relationship with them [family members]. I think if anything, [X]'s

accident made us closer. Than we probably was before.'

(Mother 1, lines 258-259)

'M: *We're even closer now.*

[Interviewer: You feel like you're closer now?]

S: *yeah.'*

(Dyad 1, lines 321-325)

'I think as a whole, I think everybody's become a lot closer, everybody, sorry, everybody

understands there's gotta be a bit of leeway now for [X], obviously, because of't

condition, so it' brought us all a lot closer, and we all understand.'

(Mother 4, lines 249-251)

'M: [hugs S] *I'm not shy, we're not frightened to show that we love each other.*

S: *I think, as well, I like, I can show my emotions around you more, whereas like, I used*

to try to not cry or anything around you and dad'

(Dyad 5, lines 479-482)

'S: *...I dunno how to explain it. I'm happy to be around my mum with my friends, like it*

doesn't embarrass me.

M: *Yeah but all your friends love me anyway.*

S: *Yeah, but before, mum, I wouldn't have.*

M: *I know.*

S: *Do you remember? So, I think it's, I'm just closer to you'*

(Dyad 5, lines 1168-1177)

'S: *But as, yeah, I suppose the fact that it has happened, there's not harm in the fact that*

we're, that we're closer.'

(Sibling 7, lines 886-887)

4.1 - Shared awareness of mortality

'Because if you go through that situation of nearly losing somebody, you do become

protective'

(Mother 1, line 1081)

'...you live in this bubble and you know what's gonna happen to you and then when

something like this happens to one of your children there's that realisation that, God, it

could happen again. I used to ring [Other Sibling] up all the time, have you got your

seatbelt on? And even with you, don't I, I tell her that watch how you're driving and be

careful, y'know. And like when they're going abroad, if I'm booking a hotel she has to

have a low down room, I won't have her high up with balcony, d'y'know. And I don't

think, I said to them, when you're a parent, you'll realise that worry and that, y'know,

threat, that you have. And especially when it's happened to one child.'

(Mother 2, lines 352-359)

'M: I'm more, I worry more. If, if she's out she has to text me, y'know. And with [other

sib], if I ring once or twice and he aren't answering the phone-

S: She'll go mad!'

(Dyad 2, lines 363-366)

'S: it's like I said, of what happened to [X], though, she just worries, but it's frustrating

going to my phone and having loads of missed calls.

M: That is, my worst. If I can...I'll ring. They have their phones glued to them so if they

don't answer their phone, my worst nightmare starts. Have they crashed?'

(Dyad 2, lines 1067-1071)

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'M: *Life is short, a bit more precious than what they thought.*'

(Dyad 3, line 1310)

'S: *Do you feel the same?*

M: *Do you mean, what, life?*

S: *Yeah, anything can happen.*

M: *Yeah! Yeah, absolutely. I think that, erm, yeah.*

S: *I think uncle and auntie are probably appreciated.*

M: *Yeah, that's my brother*

[Interviewer: Mm?]

M: *Um, I don't, no, I don't think it's, I think we need to enjoy what...*

[Interviewer: Right?]

M: *Even if we've only got today, let's enjoy it with them.*

S: *Yeah, but you take it, I mean, you take it for granted and forget that one day they*

won't be here.

M: *Yeah.*

S: *And, like, them and [X] has made me realise.*'

(Dyad 5, lines 1527-1544)

'*So I think that my outlook on life is...and money. You know, every so often 'I'm gonna*

win the lottery' and I think to my self, d'y'know, if I won the lottery, [...] I couldn't not

have let [X] have the brain injury, so you know... Yes, it's nice to have a little bit and be

comfortable, blahblahblah, but it's not the be all and end all of everything, is it? So

yeah, my outlook on life has changed a little bit that way.'

(Mother 5, lines 1770-1774)