

University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

**A Thesis Submitted for the Degree of PhD at the University of Warwick**

<http://go.warwick.ac.uk/wrap/55941>

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it. Our policy information is available from the repository home page.

**Parental Brain Injury:  
Children's Relationships and the Role of  
Systemic Family Therapy**

**by**

**Kathryn Lloyd-Williams**

**A thesis submitted in partial fulfilment of the requirements  
for the degree of Doctor of Clinical Psychology**

**Coventry University, Faculty of Health and Life Sciences and  
the University of Warwick, Department of Psychology**

**May 2012**

**Total Word Count: 19873**

## CONTENTS

---

	<i>Page Number</i>
<b>Contents</b>	iii
<b>List of appendices</b>	vii
<b>List of tables</b>	viii
<b>Acknowledgements</b>	ix
<b>Declaration</b>	x
<b>Summary</b>	xi

## Chapter 1 - Literature Review

### A critical evaluation of the efficacy of systemic family therapy in neurorehabilitation

---

	<i>Page Number</i>
<b>1.0 Abstract</b>	<b>13</b>
<b>1.1 Introduction</b>	<b>14</b>
<b>1.2 Aims of the Review</b>	<b>15</b>
<b>1.3 Incidence, Prevalence &amp; Outcome of Acquired Brain Injury (ABI)</b>	<b>15</b>
<b>1.4 Familial Impact of ABI</b>	<b>16</b>
<b>1.5 Treatment of ABI</b>	<b>17</b>
<b>1.6 Systemic Family Therapy</b>	<b>18</b>
1.6.1 Systemic Family Therapy in Neurorehabilitation	20
<b>1.7 Method</b>	<b>21</b>
1.7.1 Searches in Databases	21
<b>1.8 Results</b>	<b>28</b>
1.8.1 Case Studies	28
1.8.2 Empirical Studies:	35
1.8.2.1 Systemic Family Interventions	35
1.8.2.2 Family Therapy Combined with other Modalities	41
1.8.2.3 Multifamily Group Treatments (MFGT)	44
1.8.3 Summary of Findings	45
<b>1.9 Discussion</b>	<b>46</b>
1.9.1 Methodological Considerations & Implications for Future Research	46
1.9.2 Clinical & Service Implications	49
<b>1.10 Conclusions</b>	<b>50</b>
<b>1.11 References</b>	<b>51</b>

## Chapter 2 – Empirical Paper

### A qualitative study on children’s relationships and how they change when a parent acquires a brain injury

---

	<i>Page Number</i>
<b>2.0 Abstract</b>	<b>65</b>
<b>2.1 Introduction</b>	<b>66</b>
2.1.1 Prevalence & Incidence of ABI	66
2.1.2 Impact of ABI on the Family	67
2.1.3 Impact of ABI on Relationships	68
2.1.4 Rationale for Study	70
2.1.5 Aim of the Research	72
<b>2.2 Methodology</b>	<b>72</b>
2.2.1 Design	72
2.2.2 Participant Information	73
2.2.2.1 Inclusion Criteria	73
2.2.2.2 Exclusion Criteria	73
2.2.3 Recruited Sample	75
2.2.4 Materials	76
2.2.4.1 Interview Schedule	76
2.2.4.2 Heartstrings	77
2.2.5 The Procedure	78
2.2.5.1 Procedure & Service Context	78
2.2.6 Pilot Study	78
2.2.7 Data Analysis	79
2.2.7.1 Positionality of Researcher	79
<b>2.3 Results</b>	<b>80</b>
2.3.1 Discussion & Illustration of Themes	82

2.3.2	Summary of Findings	94
<b>2.4</b>	<b>Discussion</b>	<b>95</b>
2.4.1	Overview of Findings in Relation to Current Literature	96
2.4.2	Strengths and Limitations of the Research	99
2.4.3	Clinical Implications	101
2.4.4	Future Research	103
2.4.5	Conclusions	104
<b>2.5</b>	<b>References</b>	<b>105</b>

## Chapter 3 – Reflective Paper

### Reflecting on the research process using 'Heartstrings'

---

	<i>Page Number</i>
<b>3.0 Abstract</b>	<b>116</b>
<b>3.1 Introduction</b>	<b>117</b>
<b>3.2 The 'Heartstrings' Activity</b>	<b>118</b>
<b>3.3 The Research Process Whilst on Placement</b>	<b>121</b>
<b>3.4 The Relationship with Research Supervisors</b>	<b>122</b>
<b>3.5 The Relationship with Family</b>	<b>126</b>
<b>3.6 The relationship with Friends</b>	<b>128</b>
<b>3.7 Overall Reflections of the 'Heartstrings' Activity</b>	<b>129</b>
<b>3.8 Conclusions</b>	<b>130</b>
<b>3.9 References</b>	<b>131</b>

## List of appendices

---

	<i>Page Number</i>
Appendix A: Notes to Contributors	133
Appendix B: Literature Review Appendices	137
Appendix C: Research Methodology	143
Appendix D: Research Activities	149
Appendix E: Ethical Approval Documents	153
Appendix F: Participant Information	160
Appendix G: Data Analysis	180
Appendix H: List of Abbreviations	189



## List of tables

---

	<i>Page Number</i>
Table 1: Summary of Reviewed Articles	23
Table 2: Demographics of Participants	74
Table 3: Summary of Themes	81

## Acknowledgements

---

I would firstly like to thank my supervisors: I feel extremely fortunate to have been supervised by them. Thank you to my academic supervisor, Dr Eve Knight, for the support and guidance throughout the research process. I am particularly grateful for the encouragement during the more challenging aspects of the research and all the time given to me during the writing-up stage. Thank you also to my clinical supervisors, Dr Audrey Daisley and Dr Dawn Peerbhoy. I am especially grateful to Dr Daisley who gave me the opportunity to carry out this research and whose expertise in this field is insurmountable. Also, to Dr Peerbhoy for helping me make sense of the complex world of IPA, and whose knowledge and experience of this was invaluable. Thank you.

I would also like to sincerely thank all the participants who took part in the study. I am extremely grateful to them for their time and for sharing their experiences with me. I feel privileged to have met them.

Thank you to my dear family and friends whose optimism and encouragement kept me going! I'm so lucky to have you all in my life.

My final thank you goes to my husband. This would not have been possible without your unconditional support, encouragement and most importantly, your undoubting belief in me. Thank you so much.

I would like to dedicate this to my mum. You're always in my thoughts.

## Declaration

---

This research thesis was conducted under the supervision of Dr Eve Knight, Dr Audrey Daisley and Dr Dawn Peerbhoy. Authorship of the papers will be shared with them. The thesis is my own work and has not been submitted for a degree to any other university.

Ethical approval was obtained from Coventry University Research Ethics Committee, the National Research Ethics Committee West Midlands – Coventry & Warwickshire, and Nuffield Orthopaedic Centre Research & Development.

Literature review word count: 7979

Empirical paper word count: 7998

Reflective paper word count: 3896

## Summary

---

The following thesis consists of three papers; a literature review, an empirical paper and a reflective paper.

**The literature review** summarises current knowledge regarding the efficacy of systemic family therapy in neurorehabilitation. Studies investigating the impact of brain injury on the family suggest that all family members should be included in their injured relatives' rehabilitation programme due to the risk of developing relational difficulties. In view of this, family therapy has become increasingly popular amongst Clinical Psychologists and other professionals working in neurorehabilitation. This review aims to critically evaluate the efficacy of systemic family therapy within neurorehabilitation. Methodological considerations and implications for future research are discussed, as well as clinical and service implications.

**The empirical paper** explores changes in children's relationships when a parent acquires a brain injury. The findings of the study highlight the positive and negative changes children experience in their relationships as a result of their parents' acquired brain injury (ABI). Results are discussed in relation to the current literature, consideration of the strengths and limitations of the research, clinical implications and recommendations for future research.

**The reflective paper** discusses the researcher's own experience of carrying out the research. The researcher utilised the 'Heartstrings' activity used in the empirical study to help them reflect on changes in their relationships throughout the research process.

# **Chapter 1**

## **Literature Review**

**A critical evaluation of the efficacy of systemic  
family therapy in neurorehabilitation**

**Prepared for submission to NeuroRehabilitation**

**Word Count: 7979**

## 1.0 Abstract

**Aim:** To review the current literature and critically evaluate the use of systemic family therapy in neurorehabilitation.

**Method:** A search of articles was carried out using electronic gateway search engines Proquest and EBSCO to enable simultaneous searches of databases.

**Results:** A total of 11 papers were identified and are included in the review. Studies which were single and multiple cases on the use of systemic family therapy within the context of neurorehabilitation are considered first. Empirical studies on the use of systemic family therapy within neurorehabilitation are then discussed.

**Conclusions:** Anecdotal reports of positive change within the family were found in all case studies. Furthermore, empirical evidence also reported positive change in a range of domains including psychological well-being, family relationships, and a decrease in family conflict, mood related problems and carer burden. Whilst a range of positive outcomes were found, methodological issues are considered, as well as recommendations for future research and clinical and service implications.

## **1.1 Introduction**

Professionals working in neurorehabilitation are increasingly aware of the need to support the family of the brain-injured person. As a result of this, systemic family therapy (SFT) within neurorehabilitation has become a valued intervention by some clinicians who are working with families affected by brain injury (Solomon & Scherzer, 1991). Existing evidence which is based on clinical experience and practice highlights that there is very little empirical evidence for the efficacy of SFT in neurorehabilitation services. In view of the current stage of development in the knowledge base for neurorehabilitation it seems pertinent to now evaluate the evidence for the use of SFT in neurorehabilitation.

The review attempts to critically evaluate the current literature on SFT within neurorehabilitation, and whether there is any evidence for its efficacy. First, the aims of the review are given, followed by the wider issues of acquired brain injury (ABI) and neurorehabilitation to give context to the review. A detailed account of the systematic search of peer-reviewed articles is provided, followed by critical evaluation of the individual papers which matched the inclusion criteria. Finally, the work will discuss the findings of the review, methodological considerations, clinical, service and future research implications, and will end with concluding comments.

The ambiguity of different terminology used for SFT made it difficult for the researcher to establish a definition for this type of intervention. In view of this,

the studies identified were judged on whether the intervention included all possible family members and if it followed; family, systemic (i.e. systems orientated) or narrative models of therapy.

## **1.2 Aims of the Review**

The aims of carrying out the current review were; 1) to critically evaluate the current literature for SFT in neurorehabilitation, 2) to consider methodological implications and inform future research of the use and development of SFT in neurorehabilitation and 3) to inform clinical practice. It is hoped that by reviewing existing studies in this way we can learn more about the efficacy of such approaches and expand the cognitive rehabilitation focus of Clinical Psychologists, thus, providing valuable information for service delivery and contributing to the evidence base.

An outline of ABI literature will now be discussed to give context to the review.

## **1.3 Incidence, Prevalence and Outcome of ABI**

ABI is an injury to the brain which is caused by events after birth by external physical forces (such as a blow to the head) or metabolic derangement. ABI includes non-traumatic brain injuries (e.g. strokes, tumours, infectious diseases) and open or closed traumatic brain injuries (TBI), which can be as a result of an accident, fall or assault. Reports on incidence rates suggest 300 per 100,000 per



year, of which 50% are caused by road traffic accidents (UKABIF, 2011). The consequences of ABI are complex and extensive resulting in problems with physical abilities, cognition, behaviour and personality (Headway, 2011). The aftermath of the incident can cause long-term complications as the injured person may have to come to terms with significant loss of; independence, income and potentially fragment family and social life. The impact of the injuries may also lead to difficulties for family and friends who have to adjust to the changes. The wider implications for the family are now considered.

#### **1.4 Familial Impact of ABI**

ABI not only affects the individual but can also have a devastating impact on the family. Families have to come to terms with the loss of their loved one as they know them, and are expected to accept and cope with significant personality and behavioural changes. It is well documented that changes within the family system occur when a family member acquires a brain injury (Carnes & Quinn, 2005; Gan, Campbell, Gemeinhardt & McFadden, 2006; Golombok, 2000; Oddy & Herbert, 2003; Sinnakaruppan & Williams, 2001). Family members may have to adopt new roles in order to cope with the demands of living with someone who may have become a 'stranger' to them.

The transition of adapting to new roles is a difficult one and this may cause conflict and relationship difficulties as the family attempt to acclimatise to the changes (Engström & Söderberg, 2011; Serio, Kreutzer & Gervasio, 1995). The

main caring role is often taken up by the spouse resulting in older children becoming carers to their younger siblings. The impact of the changing family can lead to carer burden and high levels of stress for the uninjured partner (Low, Payne & Roderick, 1999; Webster & Daisley, 1999; Tepper, Beatty & DeJong, 1996), whilst children are at risk of developing emotional and behavioural difficulties including running away, truancy and peer relationship difficulties (Butera-Prinzi & Perlesz, 2004).

The work will now highlight the various treatment interventions within the field of ABI.

### **1.5 Treatment of ABI**

Recovering from a brain injury is slow and often painful, requiring extensive input from various disciplines including; neurology, neurosurgery, physiotherapy, speech and language, occupational therapy and psychology. Previous efforts at formal neurorehabilitation have focused on medical models of intervention to alleviate impairment (Oddy, Yeomans, Smith & Johnson, 1996). The aim of this model is to concentrate on preventing secondary complications which may occur as a result of the primary injury (Rose & Johnson, 1996). After the acute phase of treatment, the focus of rehabilitation is then to restore social and occupational integration using a multidisciplinary team approach (Groswasser, 1995).

Various models of rehabilitation have been proposed such as cognitive (Gianutsos, 1991; Wilson, 2002) and neuropsychological rehabilitation (Wilson, 2003). However, almost all agree that an important component to any neurorehabilitation programme is the inclusion of family support (Kreutzer, Sander & Fernandez, 1997). This arose due to recognition of the wide body of literature that came out of the 1980s which attested to the potentially devastating impact of ABI on family relationships.

Many models of family intervention can be found in the literature ranging from; community-based programmes (Fraas, Balz & Degrauw, 2007; Smith et al, 2006), marital counselling (Tyerman & Booth, 2001), peer/carer support programmes (Brumfitt, Atkinson, & Greated, 1994; Wiles et al, 1998), psycho-education interventions for primary caregivers (Carnevale, Anselmi, Busichio, & Millis, 2002; Morris, 2001) and skills training for caregivers (Rivera, Elliott, Berry, Grant, 2008). In this study we chose to focus on SFT as these are seen to have face validity in addressing the much talked about relational impact of ABI.

## **1.6 Systemic Family Therapy (SFT)**

Family therapy began in the 1950s with the central aim of focusing on the relationship between the person with the presenting problem and other significant family members (Bateson, Jackson, Haley, & Weakland, 1956). The idea being that in doing so, this would promote healthy family development and facilitate a resolution to the problem (Carr, 2000).

Systemic family therapy grew out of Bateson et al's (1956) model of family therapy, and in 1971 the Milan Systems Model was proposed by Luigi Boscolo, Gianfranco Cecchin, Mara Selvini Palazzoli and Giuliana Prata. This involved the use of five-part therapy sessions. co-therapy and the use of a reflecting team behind a screen, hypothesising, neutrality and circular questioning as a way of altering the family belief system to end symptom-maintaining interactional patterns (Carr, 2000). The family is considered as a self-regulating system which, although changes occur over time through life-stages, the style of relationships and 'rules' for interacting with one another remains stable (Jones, 1993). Family therapists aim to communicate in a way that allows family members to begin to see the problem as a family and not an individual problem. This enables the family to consider different solutions to problems, helping them to move forward rather than feeling stuck with options they may have already tried (Jones, 1993).

Variations of SFT exist, including Multifamily Group Therapy (MFGT) which was developed from the principles of SFT. MFGT has been used for a number of years by various specialist health and social care professionals. It combines family therapy and group therapy whereby groups of families come together rather than each family being seen separately. Laqueur (1976) was one of the first to evaluate the use of MFGT with hospitalised schizophrenic patients. Results found that MFGT was time and cost efficient and elicited change in families much faster than individual family therapy (Laqueur, 1976). Studies have also shown the efficacy of MFGT with; adolescents diagnosed with anorexia nervosa (Marner & Westerberg, 1987), obsessive compulsive disorder (Black and

Blum, 1992), bi-polar disorder (Brennan, 1995), dual diagnosis substance abuse with young people (Kymissis et al, 1995), substance dependence for adults (Cwiakala & Mordock, 1997) and brain injury (Charles, Butera-Prinzi & Perlesz, 2007).

#### 1.6.1 Systemic Family Therapy within Neurorehabilitation

When someone acquires a brain injury, the whole family system is affected as other family members find it hard to adjust and accept the 'new' family member (Webster & Daisley, 2007). The family's reaction can influence the course of events for all members left trying to deal with these difficulties (Maitz & Sachs, 1995). Jones (1993) argues that SFT with families of ABI survivors helps all members to potentially adopt new roles and consider changing the family's rules which existed before the brain injury. In support of this, Webster & Daisley (1999) explain how the family system goes through a period of adjustment as it starts to accept the changes. Roles change considerably within families who are caring for an injured relative, with partners and spouses taking on the role of main caregiver and subsequently suffering carer burden (Low, Payne & Roderick, 1999; Tepper et al, 1996).

Systemic family therapy focuses on repairing the fragmented relationships, enabling the family to move forward in accepting and adjusting to the changed roles. Furthermore, it allows the injured relative an opportunity to re-negotiate

their pre-injury role in order to develop a new one, as well as new relationships with their family (Yeates, Henwood, Gracey & Evans, 2007).

The following provides a detailed account of the search of peer-reviewed articles for SFT in neurorehabilitation.

## **1.7 Method**

### **1.7.1 Database Searches**

A search of medical and psychological databases was carried out during the final year of the training programme, between November 2011 and March 2012 using the main gateway search engines; Proquest and EBSCO. Both search engines enabled thorough searches of databases; ASSIA, PILOTS, CINAHL, MedLine, PsychInfo, PsychArticles, Social Services Abstracts and Sociological Abstracts. Search criteria included any article with the words; brain injury, stroke and neurorehabilitation, followed by family therapy, family intervention(s), systemic therapy, systemic intervention(s) and systems orientated therapy.

The range of interchangeable terminology used to describe systemic or family therapy became apparent whilst carrying out the search. Careful inspection was carried out of each article which referred to any element of family intervention. This was to ensure that articles which were ambiguous in their title were not discounted.

The studies were selected by using predefined criteria based on the current aims of the literature review and study question. The electronic search produced 406 references. Refinement of the search criteria using options of; peer reviewed articles, English language, and omitting paediatric and brain injury as key words from the search produced 276 references which were then examined by their title. The decision to remove paediatric brain injury was made firstly, to complement the empirical research which was based on parental brain injury. Secondly, the majority of papers described web-based family interventions and therefore did not meet inclusion criteria. The decision to remove brain injury was due to the vast amounts of articles retrieved whereby the emphasis was on neuropathy, drug interventions and surgical procedures. Upon examination of these titles, references (n= 105) based on paediatric brain injury, web-based family interventions, and any which did not include SFT were excluded. Of the remaining abstracts, 27 references met the criteria for empirical studies and their full articles were obtained. From inspection of these articles 29 additional references were identified as potential inclusions to the review (n=56). Full articles were obtained which resulted in 45 being excluded for not meeting review criteria of adult brain injury which incorporates some elements of SFT, leaving a total of 11 articles to review. Appendix B provides a map of the search strategy.

Table 1 overleaf summarises the papers included in the literature review and the quality criteria for which they were evaluated against.

**Table 1. Summary of Reviewed Articles**

Author & Year	Participants	Methodology	Family members other than spouse/ carer included?	Did therapy follow a systemic model?	Were session by session frameworks clearly outlined for ease of replication?	Were formal outcome measures used to evaluate intervention/ programme?	Were the outcome measures used valid and reliable?	Was statistical analysis carried out on the measures?	Independent evaluation versus therapist evaluation
Chenail, Levinson & Muchnick (1992)	62yr old female BI survivor, husband and sister	Case Study	Yes	Yes	No details of session numbers provided – although study was over a two year period	'In-house' Family Status Assessment Interview upon admission and Family Status Discharge Summary.	None reported	No	Therapist evaluation
Larøi (2003)	36yr old father of three & wife; 22yr old male & parents	Case Studies (x2)	Yes	Yes	No details of session numbers provided	None reported	N/A	No	Therapist evaluation
Maitz & Sachs (1995)	31yr old married father of four; 37yr old divorced mother of 2	Case Studies (x3)	Yes.	Yes. Family Systems Perspective	No details of session numbers provided	None reported	N/A	No	Therapist evaluation



	sons; 47yr old married father of three								
Yeates, Luckie, de Beer & Khela (2010)	Mother, adult daughter, maternal grandparents	Case Study	Yes	Yes. Post-Milan systemic family therapy	No details of session numbers provided	None reported	N/A	No	Therapist evaluation
Zimostrad (1989)	31yr old married father of four	Case Study	Yes	Brief solution- based family therapy combined with behavioural interventions.	No details of session numbers provided	None reported	N/A	No	Therapist evaluation
Charles, Butera-Prinzi & Perlesz (2007)	N = 6 (survivors and their families)	Empirical study - mixed methods design	Yes. Partners and 1-3 children included with each family.	Yes. MFGT is from a process and multidimension al systems	12 two hour sessions over a period of six months. Six weekly session initially, five	GHQ-28, The Dyadic Adjustment Scale (DAS), FAD, Behavioural Assessment Systems for Children (BASC)	All reported to have good reliability and validity	T-tests for all measures completed computed any change over the course of the intervention.	Independent evaluation

				perspective	fortnightly session and one follow-up session at three months				
Kreutzer et al (2009)	N = 53 (survivors including their families)	Empirical study. Repeated measures mixed models used to obtain means for of each outcome measure over time.	Yes – included siblings and adult children.	Family Therapy from a systems perspective combined with other modalities.	Five 90-120 minute sessions	Family Needs Questionnaire (FNQ), Service Obstacles Scale (SOS), Family Assessment Device (FAD), Brief Symptom Inventory-18 (BSI-18), Satisfaction With Life Scale (SWLS)	All reported to have good reliability and validity	Descriptive statistics and means calculated for all outcome measures. Autoregressive variance-covariance structure used to model correlations of observations. Unstructured variance-covariance used to account for correlation between multiple scales (e.g. FNQ, BSI)	Independent evaluation
Nichols, Varchevker &	N = 2 (survivors and	Empirical study using	Yes	Study employed techniques of	Five sessions - the first lasted approx. 1	Personal Questionnaire Rapid Scaling Technique	Multiple presentations of symptoms act as a	Yes. Means were obtained for all	Independent evaluation

Pring (1996)	their families)	time-series design		family therapy and included a family therapist working alongside the speech and language therapist.	½ hrs. No report of length of subsequent sessions	(PQRST)	validity to check for responses.	assessments off each family member. A Wilcoxon test computed change over time.	
Perlesz & O'Loughlan (1998)	N = 15 (survivors and their families)	Empirical study using repeated measures design.	Yes	Undefined family therapy	Sessions ranged from 1 -22, length of therapy ranged from 1 to 18 months. Two families continued therapy beyond 24 month follow-up stage	General Health Questionnaire (GHQ-28), Profile of Mood States (POMS), Subjective Burden Scale (SBS), The Social Adjustment Scale –Self Report (SAS-SR), family Environment Scale (Form-R, FES)	All reported to have good reliability and validity	Paired samples t-tests computed patterns of change for all measures completed over the course of the programme.	Independent evaluation
Söderström, Fogelsjö, Fugl-Meyer & Stenson (1992)	N =73 (patients and their families)	Empirical study of programme including a case example	Unspecified 'significant others'	Family Therapy and Crisis Intervention	No details of session numbers provided	Eysenck's Personality Inventory (EPI) completed by significant other, Psychosocial Functioning	EPI; reported to have reliable psychometric properties to measure personality dimensions.	None reported	Independent & Therapist evaluation

						Questionnaire completed by patients and significant others	None reported for the Psychosocial Functioning Questionnaire		
Wahrborg and Borenstein, (1989)	N = 22 (survivors and 37 family members)	Empirical Study	Undefined family members	Yes. Based on systems theory, communication theory and process theory.	Minimum of two and maximum of six sessions over a short time – does not give overall time.	Family interviews covered emotions, behaviour, social life, communication & medical problems. Participants' rated each domain on 5 point likert scale.	None reported	Descriptive statistics provided medians of grouped data for pre and post family therapy. Proportions of high scores (4 and 5) computed degree of change.	Therapist evaluation

## 1.8 Results

The eleven papers were critically discussed and for coherence have been grouped together dependent on the design of the study (case studies and empirical studies) and type of intervention (systemic family interventions, family therapy combined with other modalities and MFGT).

### 1.8.1 Case Studies

Of the eleven papers identified five were case studies, of which three provided multiple cases. These will now be critically reviewed.

Chenail, Levinson & Muchnick (1992) described their rehabilitation family therapy programme which aimed to identify families' own resources and their ability to cope with brain injury trauma. The authors provided a case of a female stroke patient, her husband and sister. The family therapist met with the patient and family to discuss noticeable changes in mood and loss of motivation to cooperate in the rehabilitation programme. The family therapist helped improve family relations by suggesting ways in which each family member could communicate their concerns to one another rather than apportion blame to each other. The patient's relatives were helped to construct a new understanding of the needs and rehabilitation process which enabled them to provide support which was more consistent with rehab goals. Positive change was reported in the patient's relationship with her husband, and as interactional patterns changed within the family, the patient's mood and motivation improved.

The case provides a tentative overview of the utility of SFT within a rehabilitation setting, and a rich insight into family dynamics and how change can occur as a result of family therapy techniques. Within this example, denial, blame and unrealistic goals for recovery were impeding the progress of rehabilitation (Rosenthal & Young, 1988). Reactive blaming and guilt are frequently found in families and this has a tendency to contribute to splitting amongst family members (Pasnau, Fawzy, & Lansky, 1981). Strengths of this study included the joining of all family members in sessions and it followed a systemic family approach to intervention. The long-term aspect of the project provided the researchers with the opportunity to evaluate as well as modify the model. However, the omission of details for the number of sessions and lack of formal outcome measures or empirical data potentially compromised the reliability of findings and made it impossible to generalise the effectiveness reported in this case.

Larøi (2000) provided two cases of adults who had sustained brain injuries. The first was of a father who, post-injury, experienced difficulties disciplining his children. Family therapy sessions included all members of the family which allowed the therapist to observe family interactions. The loss of power and authority the father had experienced as a result of the brain injury was re-established, enabling the father to be re-positioned as a parent by jointly making decisions with his partner. In addition to this, generational boundaries between the children and parents were introduced which allowed the parents to develop a parental coalition.

The second case example (Larøi, 2000) was of a young male ABI patient living with his parents who reported communication and relational difficulties with his family and friends. The therapist formulated that some of the difficulties were due to cognitive impairment but also there were secondary effects on the way the family communicated with one another. The therapist explored areas of curiosity in relation to family dynamics, and also helped the son to communicate more effectively with his parents. Sessions were structured to allow the therapist to form an alliance with the son and encourage him to speak clearly, enabling his parents to understand him. This helped the parents to gain insight into the changes in their son and how this affected their interaction with each other.

The cases reported by Larøi (2000) demonstrated the effectiveness of family therapy with families who have a member with a brain injury. The re-establishment of roles and help for family members to be re-positioned within the family helped to restore family cohesion. Maitz & Sachs (1995) indicate that strengthening the parental sub-system by re-establishing power and authority are fundamental goals of family therapy. The authors suggest that the injured individual is encouraged to resume parental responsibilities with their partner's support, ultimately strengthening the parental partnership. The examples indicated that the intervention followed a systemic family approach, however, key information within the paper was missing in relation to the regularity and number of sessions completed. The lack of formal outcome measures and statistical analysis prevents any generalisation of the reported positive change

within the families. Additionally, follow-up evaluation of the cases would have demonstrated whether change was retained over time.

Maitz & Sachs (1995) presented three cases of individuals who had sustained brain injuries. The first was a married man with four children who experienced difficulties relating to his children and wife. His children were starting to display behavioural difficulties in school. Family therapy focused on improving the parental sub-system by re-establishing the father's role as a parent in the family. The therapist encouraged both parents to support each other and work together, whilst also encouraging the father to take up some of the parenting responsibilities. Therapy was reported to be successful in helping the children identify with the father as their parent, whilst their father was able to improve his parenting skills with the support of his wife. The strengthening of the parental sub-system resulted in remedying the children's problems at school.

The second case study focused on a divorced mother of two teenage sons who was finding it difficult to resume responsibility for daily household chores and activities. The therapist helped the mother to gain insight into her difficulties and how unrealistic it was for her to manage given that she was still in the stages of recovery. The therapist also helped the children to make sense of the impact of their mother's brain injury, resulting in them helping to re-define family roles by agreeing to help.

The final case study presented by Maitz & Sachs (1995) was of a father of four who was finding it difficult to reintegrate back in to the family home. The family



therapist formulated this was a result of the father's loss of position and power within the family system. The therapist helped the family to redefine the father's role by identifying jobs he could do. They were discouraged from being overprotective to enable their father to gain a sense of purpose and pride. To instil a sense of hope and motivation in their father, the family also identified jobs he could take on, resulting in an end to the father's aggression.

The authors have demonstrated how redistribution of family roles can lead to family members' needs being met and reducing the burden from one member of the family on to a more available member of the family. The rigidity of some family hierarchies and power imbalances prevent families moving from ineffective family structures to effective ones. Positive aspects of the cases were that all family members took part in therapy, and interventions followed a systemic approach using family systems theory. A weakness of the cases was the absence of the number of therapy sessions or the use of robust outcome measures and lack of empirical data, preventing any generalisation of data.

Yeates, Luckie, de Beer & Khela (2010) presented a case study of a family who were referred to their service as a result of a mother and daughter's injuries sustained in a car accident. In particular, the mother was experiencing difficulties which were consistent with post-concussion syndrome (PCS). Sessions were made up of a combination of family members including the maternal grandmother and on one occasion the maternal grandfather. The family therapy team reflected upon the narratives the family provided and held in mind the concept of PCS as the most likely explanation for the mother's

difficulties. Problem formulations using a family genogram helped to improve the family's understanding of PCS. Prejudices held within the family and wider systems were reflected upon throughout sessions, helping to legitimise PCS. Curiosity was held around the family supporting one another and issues of meaning, sense-making and validation helped to re-establish the mother's position within the family.

The study highlighted the complexity of cases seen within a family therapy service and the utility of systemic techniques, e.g. the use of a therapeutic genogram to help elicit a non-blaming culture within the family system. This in turn created an understanding of the family's needs which aided family cohesion and empathy towards the difficulties experienced by family members. Additional strengths of this case were that all family members were included in therapy and it followed a post-Milan systemic model of therapy. The limitations of this case are in situ with the previous case studies reported, in terms of the lack of empirically driven evidence to support the current case study's findings. Details of number of sessions were also omitted.

Zimosttrad (1989) outlined a form of brief SFT based on a solution-focused approach. The model follows principles where metaphors and suggestions are given to trigger change, whilst also providing more structured behavioural interventions to the injured individual. The following case study provided by Zimosttrad (1989) was of a father who suffered from a number of cognitive and emotional difficulties as a result of a car accident. The family were struggling to cope with the father's volatile outbursts, and were encouraged to look at

examples where the father might have showed control during crises. This provided an opportunity for family members to reflect on their own behaviour and when things could have been done differently, to prevent potential problems in the future. Therapeutic metaphors were used as a way of endorsing the family's emotional sensitivity towards each other. During follow-up, the family reported encouraging progress and were being seen on a 'needs only' basis.

The reported structure of the current programme would appear to fit comfortably into a neurorehabilitation system. The bi-dimensional components of using both systemic and behavioural interventions demonstrated relational change within the family and behavioural change with the injured relative. The intervention could also be considered as relatively inexpensive due to the brief nature of the overall number of interventions. A further strength of this case was that it included all family members in therapy. Once again, the number of therapy sessions was omitted, and there was a lack of outcome measures and empirical data. The combined use of brief solution-focused family therapy with behavioural techniques prevented any suggestion of the effectiveness of therapy being based purely on brief solution-focused family therapy.

This section has critically reviewed the evidence provided by case studies for the effectiveness of SFT within a neurorehabilitation setting. All cases reported positive change within the family system through re-defining and re-establishing roles, using systemic techniques such as metaphor and curiosity. However, one case lacked systemic theoretical underpinning and was not purely systemic. The

absence in all papers of the number of sessions, or a robust methodology or empirical data also prevented generalisations being made to the ABI population.

## 1.8.2 Empirical Studies

Six of the eleven papers identified were empirical studies. Four of these were SFT; one was SFT and utilised other modalities; and one was SFT within a multifamily group format. These papers will now be critically reviewed.

### 1.8.2.1 Systemic Family Interventions

Nichols, Varchevker & Pring (1996) explored the use of family therapy with aphasiac stroke patients. The study used a time series design, and was a collaborative approach between the Family Therapist and Speech and Language Therapist. Family therapy techniques of exploring previous and existing family patterns and interactions were adopted. Five families were initially identified. Of the families, four patients had suffered a stroke and the fifth had sustained a head injury. Two families completed the course of therapy. All aphasiac family members were considered to have sufficient language ability to take part. Qualitative data taken from in-depth interviews of all family members' pre-therapy provided goals for change and quantitative baseline measures using the <sup>1</sup>Personal Rapid Scaling Technique (PQRST; Mulhall, 1978) assessed symptoms 3 months prior to therapy, just before starting therapy, immediately at the end of therapy and at 3 months follow-up.

---

<sup>1</sup>Full details of the reliability & validity of outcome measures can be found in Appendix B

Families attitudes were monitored over a nine month period, with sessions taking place every three months. All family members were encouraged to attend all sessions. The goal of therapy was to provide a space for the families to reflect upon the impact of aphasia in the family and to explore their patterns of relationships and roles. Therapy provided an opportunity for family members to express difficult emotions in a safe place, freeing up any feelings which would potentially hinder the promotion of change. The therapist helped the family to construct a genogram identifying family patterns, beliefs and attitudes. Therapy sessions were taped to enable the therapists to review each session and identify areas for future exploration. A positive change was reported in the family's identified difficulties over the course of the study. Improvement for patients during, and change after therapy was also reported. No change was found with family members during therapy, however a slightly change was reported post therapy.

The authors report that overall, change across the phase of the study did reach statistical significance, however, given the number of participating families (n=5) it is difficult to accept this interpretation of statistical power. The mixed methods repeated measures design adopted provided a more robust method of research and allowed for changes to be tracked over time. However, change was not measured at the mid-point of the therapy. The ideographic nature of the PQRST enabled the authors to access the feelings and attitudes of participants with language difficulties to a degree of reliability (Mulhall, 1978).

Statistical analysis provided more reliable data to interpret, however the small sample size and the absence of a control group prevented any generalisation of the data being made. The duration of therapy was limited and did not take into account other family members concerns. Furthermore, changes reported by participants could be a result of increased familiarity with the measure used or with the therapist.

Perlesz & O'Loughlan (1998) carried out a small pilot study over a two year period to evaluate changes in psychosocial outcome for families following brain injury to a family member. Fifteen families took part in the study. The average number of therapy sessions was 8.4, with the average length of therapy being 9.5 months. The General Health Questionnaire (GHQ-28, Goldberg, & Williams, 1988), Profile of Mood States (POMS, Lorr, McNair, & Droppleman, 1971), Subjective Burden Scale (SBS, Zarit, Reever, & Bach-Peterson, 1980), The Social Adjustment Scale – Self Report (SAS-SR, Weissman & Bothwell, 1976) and Family Environment Scale (FES Form-R, Moos & Moos, 1981) were used to profile individuals' psychological well-being and family adjustment. Results indicated an improvement in family cohesion and a decrease in family conflict and psychological distress. Results also indicated an improvement in healthy adjustment and a reduction in the burden and strain experienced providing care for the injured family member which was sustained at the 24 month follow-up. Self-reported anger was more complicated with a reduction within the first 12 months of therapy. However, levels of anger subsequently rose, and at the 24 month follow-up were at the level recorded pre-therapy. In terms of marital adjustment, no change was found overall.

The study highlights a number of positive changes in terms of a reduction in distress, burden and strain for the injured individual and their family members. The inclusion of all family members and the use of reliable and valid standardised measures provided substantial statistical outcome data. The measures used are considered in terms of their reliability and validity. The FES Form-R is considered to have relative consistency with test-retest reliability (Moos & Moos, 1981). The GHQ-28 is reported to have good reliability and validity (Goldberg & Williams, 1988). The POMS has been found to have high internal consistency, a reasonable level of test-retest reliability and content validity (Lorr et al, 1971). Finally, the SAS-SR and SBS are reported to have robust psychometric properties with test-retest reliability (Weissman & Bothwell, 1976; Zarit et al, 1980). The range in number and length of therapy sessions, including follow-up post therapy, allowed changes to be tracked over time and replication of the study to be carried out.

Limitations to this study included the small heterogeneous sample therefore limiting the statistical power to detect clinically significant and meaningful change. A large amount of data was also reported to be missing as participants did not return all the measures used and some did not take part in all sessions. The absence of a control group prevents any definitive conclusions to the effectiveness of the therapy. Furthermore, the type of intervention was defined as family counselling, however, a caveat described how the authors used the terms counselling and therapy interchangeably. This created ambiguity around the model and questioned whether it was in line with SFT which prevented its comparison with other studies.

Söderström, Fogelsjö, Fugl-Meyer & Stenson (1992) presented their crisis intervention and family therapy programme based on object-relations theory and transactional analysis. 14 patients and family members attended a psychotherapeutic programme which was facilitated by two psychotherapists; one to work with the patient and one to work with family members. The programme involved initial assessment of the patient using Eysenck's Personality Inventory (EPI; Eysenck, 1964) and a psychological functioning questionnaire developed by the authors of the study. This aimed to track changes and how these were appraised in relation to; interpersonal relationships, perceived cognitive and behavioural changes, sexuality, leisure and overall adjustment. Therapy was structured with patients and family/significant others, which provided the opportunity to reflect on inter-relational patterns and how family interactions were perceived and interpreted. Ways of communicating different opinions were also explored. Within the first two years, post trauma patients and their families gave their views in relation to trauma related changes.

Söderström et al (1992) reported results taken from the five married patients. Interpersonal changes from discord to harmony were reported in relation to; roles and decision making, socialisation outside the family and sexual adjustment. Furthermore, behavioural and personality changes were reported to be as a result of; the patient adapting to their new life, being more optimistic, increased coping strategies, ability to express emotions, increased empathy and better understanding of the consequences of brain injury. Tentative conclusions to the project were made in terms of facilitating ways of coping after brain injury.



The study highlights the changes elicited using a transactional systems theory approach to intervention. The use of a standardised outcome measure is a strength, with the EPI considered to have acceptable psychometric properties which measure dimensions of personality. However the lack of statistical analysis or reported statistical data compromised the reliability of the findings of the study. The frequency and number of therapy sessions was also absent from the report, making it impossible to replicate the study.

Wahrborg & Borenstein (1989) presented their family therapy programme offered to aphasiac patients and their families. The aim of the study was to evaluate change in family members' attitudes towards each other. The model of family therapy followed systems, communication and process theories. Emphasis was placed upon reinforcing cooperative attitudes amongst the family (Wahrborg & Borenstein, 1989). Thirty-seven families took part in the programme, and therapy was provided over a minimum of two and maximum of six sessions. All participants with aphasia were able to respond to interview questions. Interview questionnaires designed by the authors evaluated; emotions, communication, behaviour, social life and medical problems. The questions are rated from 0 (indicating that the problem does not exist) to 5 (indicating the problem occurs on a daily basis and is a great problem). Participants were interviewed pre and post therapy to elicit data on change. Results found that the aphasiac member of the family reported more change than other family members, post therapy. Pre-therapy data reported by family members found a number of problems with their injured family member in each of the categories particularly, social and communication problems. Post-therapy

analysis of the data found that the frequency in which high scores were reported had decreased as well as the problems themselves. An increase in knowledge about the aphasia was found to be the most prominent change reported. Positive change was also found in relation to; depression, emotional isolation, impatience, social isolation and dependency. The members of the family with aphasia reported fewer problems post-therapy in relation to their family. Those areas which were reported as continued difficulties were; irritation, decreased quality and quantity of communication.

The study was based on systemic principles and demonstrated the clinical utility of family therapy, albeit, the length of therapy was brief (2 to 6 sessions). In comparison to other studies, this study had a relatively large number of participants which provided a fuller description of the utility of this therapy. The reliability and validity of the interview questionnaire devised by the authors is questionable. It is plausible to assume that methodological problems existed in relation to the reliability of data extracted from interviews by aphasiac family members. Furthermore, post therapy assessments which indicated change were taken 6 months later. This change could be as a result of time rather than due to the carry-over of any gains made therapeutically.

#### 1.8.2.2 Family Therapy Combined with Other Modalities

Kreutzer et al (2009) developed the Brain Injury Family Intervention Programme (BIFI) - a programme for survivors of brain injury and their families. The programme utilised family therapy techniques, relying on; reflections, validation,

reframing and normalising as a way of strengthening the family system. The sessions were delivered over a ten week period and included all family members. The programme was evaluated using the following standardised measures to assess family functioning and life satisfaction; Family Needs Questionnaire (FNQ; Kreutzer & Marwitz, 1989), Service Obstacles Scale (SOS; Marwitz & Kreutzer, 1996), Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983), Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000) and Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). Data was obtained at baseline, the initial intake session, at the end of each session, and post therapy after the final session. A three month follow-up was also carried out in-between the 10th and 14th week of the programme ending.

Fifty-three families took part and the results found significant increases in family needs being met over time for; health information, professional support and care. No significant change was found in needs met for instrumental or community support. Comparisons of data pre-therapy and 3 months follow-up revealed a significant increase for all domains within the family needs questionnaire, including; health information, emotional and professional support and care. In terms of family functioning, no significant difference was found between scores obtained over time. For service obstacles, a significant decrease was identified pre-therapy to the 3 months follow-up and pre to post-therapy. Results from this also suggested that family members of participants with longer lengths of inpatient acute care showed fewer improvements than those where the individual had a shorter in-patient stay. Evaluation of families' distress and life satisfaction reported no change.

In comparison to the studies described earlier, a methodological and statistical rigour was employed which provided a number of statistically significant findings in relation to the efficacy of BIFI. The reliability and validity of measures used is considered. The BSI-18 is reported to be a robust psychometric measure of psychological distress (Meachen, Hanks, Millis, Rapport, 2008). The FAD is reported to have internal reliability for general functioning in a non-clinical population (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990), and is considered to be an effective ABI measure after ABI (Kreutzer, Gervasio, & Camplair, 1994; Zarski, DePompei & Zook, 1988). The FNQ has been demonstrated to have reliable and independent needs factors, as well as construct validity. Meanwhile, Kolakowsky-Hayner, Kreutzer, & Miner (2000) reported on the validity of the SOS, whilst the SWLS has been found to be valid and sensitive in detecting change (Pavot, Diener, Colvin, & Sandvik, 1991). Comprehensive details were given for the number of sessions required to enable replication of the study.

Overall strengths of the study are the robust design and the inclusion of standardised measures to evaluate outcome. Disappointingly, the results do not appear to reflect the reported efficacious nature of the programme. This could be due to a number of limitations which are now considered. Although the study recruited a much larger sample size in comparison to other studies on family therapy, the number was small relative to other quantitative studies and therefore raises questions over statistical power. The single centre recruitment of participants and small sample size limits the statistical sensitivity and increases the likelihood of Type II error. Additionally, the omission of a control group prevents conclusions being made in relation to the underlying benefits of the

therapy. Furthermore, it is difficult to ascertain the level of understanding from relatives with a brain injury, and whether their self-report is a reliable source of measuring outcome.

### 1.8.2.3 Multifamily Group Treatments (MFGT)

Charles et al (2007) carried out a pilot project to evaluate MFGT from a multidimensional systems perspective, using a mixed methods design. Sessions were audiotaped and transcriptions were thematically analysed, whilst the following self-report measures pre and post group, and 3 months follow-up were also completed; GHQ-28 (Goldberg, & Williams, 1988), The Dyadic Adjustment Scale (DAS, Weiss & Perry, 1979) and the Behavioural Assessment Systems for Children (BASC, Reynolds, & Kamphaus, 1992). Six families attended 12 two hour MFGs over six months. The unique focus of MFGT sees the family system as multidimensional and aims to improve families understanding of illness and communication patterns (Anderson et al, 1986).

High levels of family dysfunction and poor marital adjustment were reported throughout the pilot project, however, 73% of adult participants found a reduction in psychological distress after participating. Scores obtained from the BASC indicated no psychological distress for child relatives, although this was felt to be attributed to children answering in a socially desirable way, reluctance to disclose conflict within the family, not wanting to be disloyal, fear of family disintegration, or being convinced that things were ok.

Qualitative findings reported a number of benefits, including; creating a context for mutual support and reduced feelings of isolation, realisation of shared unique experiences of ABI, increased knowledge and understanding of brain injury, opportunities to reflect upon difficult experiences, support in moving the family from a blaming to compassionate position and re-organisation and adjustment within the family. The current study does offer some positive findings with the use of standardised outcome measures (BASC, DAS and GHQ) which have all been reported to have high reliability and validity (Flanagan, 1995; Farrington, 2004; Kalpakjian, 2001; Goldberg, & Williams, 1988). However the small sample size prevented any inferential statistical analyses of the data. Therefore, statistical significance of attending the group could not be obtained. The inclusion of information relating to the model of intervention and number of sessions does allow for replication of the study.

The critical review of empirical studies has demonstrated that positive change occurred within all families as a result of the use of SFT such as exploring relational patterns and family roles. However, the lack of control groups, small samples and omission of some measures being completed by some participants reduces the reliability and validity of some of these studies.

### 1.8.3 Summary of Results

Of the eleven papers reviewed, all reported positive changes within the family system, in a range of family members. Furthermore, positive change was also reported in a range of domains, including; marital harmony, psychological well-

being, family relationships, behaviour of children, and a decrease in family conflict, mood related problems and carer burden and strain. Whilst a range of positive impacts were found, they need to be considered within the context of methodological strengths and weaknesses.

## **1.9 Discussion**

The current review identified and critically reviewed the methodology and results of eleven papers relating to systemic family interventions within neurorehabilitation. The strengths and weaknesses, along with suggestions for future research will now be considered.

### **1.9.1 Methodological Considerations and Implications for Future Research**

Of the studies reviewed, nine reported the inclusion of all family members, however, two failed to define individuals included in the intervention (Söderström et al, 1992; Wahrborg & Borenstein, 1989). This brings in to question whether those studies followed principles of systemic practice which includes all family members in sessions (Minuchin, 1974; Carr 2000). Seven papers reported the use of at least one measure to inform the course of intervention or evaluate the outcome (Chenail et al, 1992; Charles et al, 2007; Kreutzer et al, 2009; Nichols et al, 1996; Perlesz & O’Loughlan, 1998; Söderström et al, 1992; Wahrborg & Borenstein, 1989). Three studies employed ‘in-house’ interview or self-report measures which raised questions as to the reliability and validity of these measures (Chenail et al, 1992; Söderström, et al, 1992;

Wahrborg & Borenstein, 1989). Five studies used different formal measures (Charles et al, 2007; Kreutzer et al, 2009; Nichols et al, 1996; Perlesz & O'Loughlan, 1998; Söderström et al, 1992), which provides independent evaluation, rather than therapist evaluation which could be scored more favourably. Given the variation in measures used, it is therefore difficult to make any comparisons across studies due to the lack of consistency. The use of statistical analysis does provide some evidence to suggest the interventions prompted some change within the family.

Seven studies used SFT (Chenail et al, 1992; Charles et al, 2007; Larøi, 2000; Maitz & Sachs, 1995; Söderström et al, 1992; Wahrborg & Borenstein, 1989 and Yeates et al, 2010) whilst one study combined family therapy with behavioural interventions (Zimostrad, 1989). Another study used SFT combined with other modalities (Kreutzer et al, 2009) and the model of family therapy used in one study was not defined (Perlesz & O'Loughlan, 1998). In addition to this, one study did not claim to be family therapy (Nichols et al, 1996). The inclusion of this study was decided on the basis that the authors reported that techniques of family therapy were used and a family therapist worked alongside a speech and language therapist. Given the varied methods of family therapy employed by the studies, it is difficult to assume that any family change over time is purely a result of family therapy. It is possible that the intervention used adjunct to family therapy may have played a part in influencing change.

From the literature reviewed, it is evident that nearly fifty per cent of studies are limited for the following reasons; a lack of consistent use of homogeneous



empirically endorsed standardised measures, the absence of a methodologically robust design and biased sampling. However, the studies provide a rich and in-depth insight in to family difficulties and strong anecdotal evidence of the clinical utility of SFT within neurorehabilitation. From all of the studies which were reviewed, some positive change within the family system was reported. Newly established roles and a new shared meaning for all families is demonstrated throughout the studies. These findings are consistent with de Schazer's (1985) argument that in meeting families' needs this will help them to reach an acceptable level to continue living together.

The government document 'Organising and Delivering Psychological Therapies' (Department of Health, 2004) emphasises the importance of measuring routine outcomes. Measures designed to provide information on family relationships and functioning are not routinely used for clinical purposes in family therapy clinics in the UK (Stratton, Bland, Janes & Lask, 2010). In the absence of a 'gold standard' benchmark for assessing SFT in neurorehabilitation, it is becoming increasingly important that services employ the use of standardised outcome measures to evaluate the efficacy of their interventions (i.e. family interventions), whilst not compromising the nature of systemic interventions (Boschen, Gargaro, Gan, Gerber & Brandys, 2007).

Services should employ the use of standardised outcome measures consistently to provide replicable, reliable and valid statistics. This would generate an evidence base for the use of SFT in neurorehabilitation, which as this review has demonstrated, is severely lacking at present. Services should be encouraged to

publish their data as a way of providing evidence towards the increasing demand for family interventions, and to support bids to commissioners for increasing service resources. Research may then lead to meta-analyses of literature which would provide a more powerful estimate of the true effect size of SFT, as opposed to the less precise effect size derived from single case studies.

### 1.9.2 Clinical and Service Implications

The findings of the current review make tentative conclusions regarding the efficacy of SFT in neurorehabilitation. This form of family intervention can provide help in supporting the family to shift the problem and burden of causality from the brain injured relative to the dysfunctional parts of the whole family system (Rosenthal & Young, 1988). It focuses on the strengths of the family and provides conflict-resolution strategies as a way of helping families adjust to change within the system. SFT can help the family to reframe behaviours positively to allow new options to emerge for the family and the rehabilitation team. This provides space to allow change to occur (Shoham-Salomon & Rosenthal, 1987; DePompei & Williams, 1994). This method of intervention is effective as it encourages the whole family system to take responsibility for symptoms and therefore does not rely solely on the psychological capacity of the injured person for the intervention to be effective (Griffith, 1985).

A review of family systems measures was carried out by Sanderson et al (2009) found that out of 274 outcome studies, 480 outcome measures were used, of

which only 26 were family systems measures. The majority of studies used more than one measure, and 15 per cent failed to use any. This highlights the inconsistency of measures used across services and emphasises the need for a reliable and valid method of assessing service outcome. The current validation of a shorter version of the SCORE 40, namely the SCORE 15 (Stratton et al, 2010), is reported to have reliable psychometric properties and a structure that can be easily interpreted clinically. It is also considered user-friendly and would therefore be a good starting point for services to consider using to evaluate service provision.

### **1.10 Conclusions**

The absence of consistent treatment goals and the breadth of outcome measures reflect the wide-ranging and generic nature of peer-reviewed research publications. This allows only general statements to be made regarding the efficacy of SFT. Furthermore, given that some of the studies combined SFT with other interventions, and some only loosely followed systemic techniques, it is impossible to decipher the actual benefits that are a direct result of SFT. However, there is sufficient evidence to endorse the notion that SFT is effective in assisting families. This review has highlighted the need for neurorehabilitation services to carry out empirically driven research to evaluate the efficacy of SFT. By contributing to the evidence base, this would help to inform neurorehabilitation services of the clinical utility of SFT, and provide a strong argument for its inclusion within neurorehabilitation.

## 1.11 References

Anderson, C.M., Griffith, S., Rossi, A., Pagonis, I., Holder, D., & Treiber, R. (1986)

A comparative study of the impact of education vs process groups for families with affective disorders. *Family Processes*, 25, 185-205.

Bateson, G., Jackson, D., Haley, J., & Weakland, J. (1956) Toward a theory of

schizophrenia. *Behavioural Science*, 1, 4, 251-264.

Black, D., & Blum, N. (1992) Obsessive-compulsive disorder support groups: The

Iowa model. *Comprehensive Psychiatry*, 33, 65-71.

Boschen, K., Gargaro, J., Gan, C., Gerber, G., & Brandys, C. (2007) Family

Interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. *NeuroRehabilitation*, 22, 19-41.

Brennan, J. W. (1995) A short-term psychoeducational multiple-family group for

bipolar patients and their families. *Social Work*, 40, 737-743.

Brumfitt, S., Atkinson, J., & Greated, G. (1994) The carer's response to written

information about acquired communication problems. *Aphasiology*, 8, 583-90.

Butera-Prinzi, F., & Perlesz, A. (2004) Through children's eyes: children's experience of living with a parent with an acquired brain injury. *Brain Injury*, 18, 1, 83-101.

Carnevale, C.J., Anselmi, V., Busichio, K., & Millis, S.R. (2002) Changes in ratings of caregiver burden following a community-based behaviour management programme for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 17, 2, 83–95.

Carnes, S.L., & Quinn, W.H. (2005) Family adaptation to brain injury: coping and psychological distress. *Family Systems and Health*, 23, 186–203.

Carr, A. (2000) *Family Therapy: Concepts, Process and Practice*. Chichester: John Wiley & Sons Ltd.

Charles, N., Butera-Prinzi, F., & Perlesz, A. (2007) Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation*, 22, 61-76.

Chenail, R.J., Levinson, K., & Muchnick, R. (1992) Family systems rehabilitation. *The American Journal of Family Therapy*, 20, 2, 157-167.

Cwiakala, C. E., & Mordock, J. B. (1997) The use of multi-family play groups for families with a parent in addiction recovery. *Alcoholism Treatment Quarterly*, 15, 1, 15-28.

Diener, E., Emmons, R.A., Larsen, R.J., & Griffin, S. (1985) The satisfaction with life scale. *Journal of Personal Assessment*, 49, 71.

Department of Health (2004) *Organising and Delivering Psychological Therapies*. Department of Health Publications: London.

DePompei, R., & Williams, J. (1994) Working with families after TBI: A family-centred approach. *Topics in Language Disorders*, 15, 1, 68-81.

Derogatis, L.R. (2000) *Brief Symptom Inventory 18*. Minneapolis, MN: NCS Pearson.

de Schazer, S. (1985) *Keys to Solutions in Brief Therapy*. New York: W. W. Norton.

Engström, A., & Söderberg, S. (2011) Transition as experienced by close relatives of people with traumatic brain injury. *Journal of Neuroscience Nursing*, 43, 5, 253-60.

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

Eysenck, H. (1964) *Manual of the Eysenck Personality Inventory*. London, UK: University of London Press.

- Farrington, D. (2004) Parental perception of marital and family functioning following paediatric traumatic brain injury: a multiple case study approach. *Dissertation abstracts international: Section B: The sciences and engineering*, 64, 4034.
- Flanagan, R. (1995) A review of the Behaviour Assessment System for Children (BASC): Assessment consistent with the requirements of the Individuals with Disabilities Education Act (IDEA). *Journal of School Psychology* 33, 177–186.
- Fraas, M., Balz, M., & Degrauw, W. (2007) Meeting the long-term needs of adults with acquired brain injury through community-based programming. *Brain Injury*, 21, 12, 1267-81.
- Gan, C., Campbell, K.A., Gemeinhardt, M., & McFadden, G.T. (2006) Predictors of family system functioning after brain injury. *Brain Injury*, 20, 6, 587–600.
- Gianutsos, R. (1991) Cognitive Rehabilitation: A neuropsychological specialty comes of age. *Brain Injury*, 5, 363-368.
- Goldberg, P., & Williams, P. (1988) *A User's Guide to the General Health Questionnaire*. Windsor, UK: Nfer-Nelson.
- Golombok, S. (2000) *Parenting: What really counts?* London: Routledge.

Griffith, J. L. (1985) Multilevel Patterns: Family Therapy with Neuropsychiatric Patients. *Family Systems Medicine*, 3, 2, 151-159.

Groswasser, Z. (1995) A national service: coma to community. In M.A. Chamberlain, V. Neumann and A. Tennant. *Traumatic Brain Injury Rehabilitation. Services, Treatments and Outcomes*. London: Chapman and Hall.

Headway (2011) *Key Facts & Statistics*. Retrieved on 23rd March 2012, <http://www.headway.org.uk/key-facts-and-statistics.aspx>

Jones, E. (1993) *Family Systems Therapy: Developments in the Milan-Systemic Therapies*. Chichester: John Wiley & Sons Ltd.

Kabacoff, R.I., Miller, I.W., Bishop, D.S., Epstein, N.B., & Keitner, G.I. (1990) A psychometric study of the McMaster Family Assessment Device in Psychiatric, Medical and Nonclinical samples. *Journal of Family Psychology*, 3, 431–439.

Kalpakjian, C. (2001) Psychosocial factors and quality of life after traumatic brain injury. *Dissertation Abstracts International: Section B: the Sciences and Engineering*, 61, 6709.



Kolakowsky-Hayner, S.A., Kreutzer, J.S., & Miner, K.D. (2000) Validation of the Service Obstacles Scale for the traumatic brain injury population. *NeuroRehabilitation*, 14, 151–158.

Kreutzer, J.S., Gervasio, A.H., & Camplair, P.S. (1994) Primary caregivers' psychological status and family functioning after traumatic brain injury, *Brain Injury*, 8, 197–210.

Kreutzer, J., & Marwitz, J. (1989) *The Family Needs Questionnaire*. Richmond, Virginia: The National Resource Centre for Traumatic Brain Injury.

Kreutzer, J.S., Sander, A.M., & Fernandez, C.C. (1997) Misperceptions, Mishaps, and Pitfalls in Working with Families in Traumatic Brain Injury. *Journal of Trauma Rehabilitation*, 12, 6, 63-73.

Kreutzer, J. S., Stejskal, T. M., Ketchum, J. M., Marwitz, J. H., Taylor, L. A., & Menzel, J. C. (2009) A preliminary investigation of the brain injury family intervention: Impact on family members. *Brain Injury*, 23, 6, 535-547.

Kymissis, P., Bevacqua, A., & Morales, N. (1995) Multi-family group therapy with dually diagnosed adolescents. *Journal of Child & Adolescent Group Therapy*, 5, 107-113.

Larøi, F. (2000) Treating Families of Individuals with Traumatic Brain Injury. *Journal of Family Psychotherapy*, 11, 4, 69-78

Laqueur, H. P. (1976) Multiple family therapy. In P. J. Guerin (Ed.) *Family therapy, theory, and practice*. New York: Gardner.

Lorr, M., McNair, D.M., & Droppleman, L.F. (1971) *Profile of Mood States*.  
Canada: Multi-Health Systems Inc.

Low, J. T. S., Payne, S., & Roderick, P. (1999) The impact of stroke on informal carers: a literature review. *Social Science and Medicine*, 49, 711-725.

Maitz, E. A., & Sachs, P. R. (1995) Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation*, 10, 1–11.

Marner, T., & Westerberg, C. (1987) Concomitant group therapy with anorectics and their parents as a supplement to family therapy. *Journal of Family Therapy*, 9, 255-263.

Marwitz, J.H., & Kreutzer, J.S. (1996) *The Service Obstacles Scale (SOS)*.  
Richmond, VA: Medical College of Virginia, Virginia Commonwealth University.

Meachen, S.J., Hanks, R.A., Millis, S.R., & Rapport, L.J. (2008) The reliability and validity of the brief symptom inventory-18 in persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 89, 958–965.

Minuchin, S. (1974) *Families and Family Therapy*. Cambridge, MA: Harvard University Press.

Moos, B.S., & Moos, R.H. (1981) *Family Environment Scale (FES Form-R)*. Menlo Park, CA: Mind Garden, Inc.

Morris, K. (2001) Psychological distress in carers of head injured individuals: the provision of written information. *Brain Injury*, 15, 3, 239-254.

Mulhall, D.J. (1978) *Manual for the Personal Questionnaire Rapid Scaling Technique*. Swindon, UK: Nfer-Nelson.

Nichols, F., Varchevker, A., & Pring, T. (1996) Working with people with aphasia and their families: An exploration of the use of family therapy techniques, *Asphasiology*, 10, 8, 767-781.

Oddy, M., Yeomans, J., Smith, H., & Johnson, J. (1996) Rehabilitation. In F.D. Rose and D.A. Johnson (Eds.), *Brain Injury and Afterwards. Towards Improved Outcome*. Chichester, West Sussex: John Wiley & Sons Ltd.

Oddy, M., & Herbert, C. (2003) Intervention with families following brain injury: Evidence-based practice. *Neuropsychological Rehabilitation: An International Journal*, 13, 1-2, 259-273.

- Pasnau, R. O., Fawzy, F. I., & Lansky, M. R. (1981) Organic brain syndrome and the family. In M. R. Lansky (Ed.) *Family therapy and major psychopathology*. New York: Grune & Stratton.
- Pavot, W., Diener, E., Colvin, C.R., & Sandvik, E. (1991) Further validation of the Satisfaction with Life Scale: evidence for the cross-method convergence of well-being measures. *Journal of Personal Assessment*, 57, 149–161.
- Perlesz, A., & O’Loughlan, M. (1998) Changes in stress and burden in families seeking therapy following traumatic brain injury: a follow-up study. *International Journal of Rehabilitation Research*, 21, 339-354.
- Reynolds, C.R., & Kamphaus, R.W. (1992) *The behaviour assessment system for children*. Circle Pines, MN: American Guidance Service.
- Rivera, P.A., Elliott, T.R., Berry, J.W., Grant, J.S. (2008) Problem-Solving Training for Family Caregivers of Persons With Traumatic Brain Injuries: A Randomized Controlled Trial. *Archives of Physical Medicine Rehabilitation*, 89, 931–941
- Rose, D., & Johnson, D. (1996) Brains, Injuries and Outcome. In F.D. Rose and D.A. Johnson (Eds.), *Brain Injury and Afterwards. Towards Improved Outcome*. Chichester, West Sussex: John Wiley & Sons Ltd.

Rosenthal, M., & Young, T. (1988) Effective family intervention after traumatic brain injury: Theory and Practice. *Journal of Head Trauma Rehabilitation*, 3, 4, 42-50.

Sanderson, J., Kosutic, I., Garcia, M., Melendez, T., Donoghue, J., Perumbilly, S., Franzen, C., & Anderson, S. (2009) The Measurement of Outcome Variables in Couple and Family Therapy Research. *The American Journal of Family Therapy*, 37, 239–257.

Serio, C.D., Kreutzer, J., & Gervasio, A.H. (1995) Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation*, 10, 2, 32-45.

Shoham-Salomon, V., & Rosenthal, R. (1987) Paradoxical interventions: A meta-analysis. *Journal of Consulting and Clinical Psychology*, 55, 22-28.

Sinnakaruppan, I., & Williams, D.M. (2001) Family carers and the adult head-injured: a critical review of carers' needs. *Brain Injury*, 15, 653–672.

Söderström, S., Fogelsjö, A., Fugl-Meyer, K., & Stenson, S. (1992) Traumatic brain injury crisis intervention and family therapy - management and outcome. *Scandinavian Journal of Rehabilitation Medicine Supplement*, 26, 132-141.

Solomon & Scherzer (1991) Some guidelines for family therapists working with the traumatic brain injured and their families. *Brain Injury*, 5, 3, 253-266.

Stratton, P., Bland, J., Janes, E., & Lask, J. (2010) Developing an indicator of family function and a practicable outcome measure for systemic family and couple therapy: the SCORE. *Journal of Family Therapy*, 32, 232–258

Tepper, S., Beatty, P., & DeJong, G. (1996) Outcomes in traumatic brain injury: Self-report versus report of significant others. *Brain Injury*, 10, 575-581.

Tyerman A., & Booth J. (2001) Family interventions after traumatic brain injury: A service example. *NeuroRehabilitation*, 16, 59-66.

United Kingdom Acquired Brain Injury Forum (UKABIF): Retrieved on 2nd September 2010, <http://www.ukabif.org.uk/information>

Wahrborg, P., & Borenstein, P. (1989) Family therapy in families with an aphasic member. *Aphasiology*, 3, 1, 93-98.

Webster, G., & Daisley, A. (1999) Relationship and family breakdown following acquired brain injury: the role of the rehabilitation team. *Brain Injury*, 13, 8, 593-603.

Weiss, R.L., & Perry, B.A. (1979) *Assessment and treatment of marital dysfunction*. Marital studies program.

- Weissman, M.M., & Bothwell, S. (1976) Assessment of social adjustment by patient self-report. *Archive of General Psychiatry*, 33, 1111-1115.
- Wiles, R., Pain, H., Buckland, S., & McLellan, L. (1998) Providing appropriate information to patients and their carers following a stroke. *Journal of Advanced Nursing*, 28, 4, 794-801.
- Wilson, B. A. (2002) Towards a comprehensive model of cognitive rehabilitation. *Neuropsychological Rehabilitation*, 12, 97-110.
- Wilson, B.A. (2003) *Neuropsychological Rehabilitation: Theory and Practice*. The Netherlands: Swets & Zeitlinger Publishers.
- Yeates, G., Henwood, K., Gracey, F., & Evans, J. (2007) Awareness of disability after acquired brain injury and the family context. *Neuropsychological Rehabilitation*, 17, 2, 151-173.
- Yeates, G.N., Luckie, M., de Beer, Z., & Khela, P. (2010) Elucidating the psychosocial context of 'post-concussion syndrome' (PCS): A case study from post-Milan systemic family therapy. *Journal of Family Therapy*, 32, 186-202.
- Zarit, S. H., Reever, K.E., & Bach-Peterson, J. (1980) Relatives of impaired elderly: correlates of feelings of burden. *Gerontologist*, 20, 649-655.

Zarski, J. J., DePompei, R., & Zook, A. (1988) Traumatic head injury: Dimensions of family responsiveness. *Journal of Head Trauma Rehabilitation*, 3, 4, 31-41.

Zimostrad, S. W. (1989) Brief Systemic Therapy for Families of the Closed Head Injured: Therapy With Two Hands. *Cognitive Rehabilitation*, 7, 3, 26-28.



## **Chapter 2**

### **Main Research Paper**

**A qualitative study on children's relationships  
and how they change when a parent acquires a  
brain injury**

**Prepared for submission to**

**NeuroRehabilitation**

**Word Count: 7998**

## **2.0 Abstract**

**Aim:** To explore how children's relationships change when their parent or caregiver acquires a brain injury.

**Design:** A qualitative approach using Interpretative Phenomenological Analysis (IPA) to analyse data was adopted. A semi-structured interview was based around 'Heartstrings' - a clinical activity used frequently in Child and Adolescent Mental Health Services (CAMHS).

**Participants:** 8 children and young people aged between 8 and 18 years of age took part in the study. All participants had a parent/caregiver with an acquired brain injury (ABI).

**Results:** 3 superordinate themes, including corresponding subordinate themes, were identified to capture the shared experience of participants' accounts of changes in relationships. These 3 main themes reflected participants' accounts of their experience of; 1) Acceptance of changed relationships, 2) Significant loss 3) Understanding the lived experience of the family system.

**Conclusion:** The study highlighted the positive and negative changes children experience in their relationships with family and friends, as a result of their parents' ABI. The findings are considered in the context of methodological strengths and limitations. Finally, recommendations for future research and clinical and service implications are discussed.

## **2.1 Introduction**

Children are born as social beings unable to survive or develop normally without significant relationships (Siegel, 1999; Stern, 1986). One of the most significant relationships children have is with their parents, whose role it is to provide foundations for learning human interaction and to act as primary support figures to their children (von Salisch, 2001). For most children, the parent-child relationship is a particularly special one as the child experiences a fundamental sense of support and security (Kirova, 2003). When something happens to disrupt this (i.e. when a parent becomes ill) significant changes can occur in the child's patterns of relationships. The current study will endeavour to address the impact parental brain injury has on children's relationships in an attempt to redress the balance of current acquired brain injury (ABI) research bias on family burden, stress and adjustment. It is perhaps useful to put in to context the area of current research by giving an outline of ABI, its prevalence and the implications for the individual and the family.

### **2.1.1 Prevalence & Incidence of ABI**

ABI is the most prevalent neurological condition among those under the age of 50 years. Current statistics by Headway (the UK's national brain injury association) report that in England and Wales each year approximately 1.4 million cases are reported to Accident and Emergency departments (Daisley, Tams and Kischka, 2009). While the majority of these cases are minor head injuries, around 10% are moderate or severe. The most common causes of head

injuries are road traffic accidents, falls and assaults, with incidence rates particularly high in men under the age of 30 (McGregor and Pentland, 1997). The road to recovery is a lengthy and often painful one; both physically and psychologically. However, neurorehabilitation can produce extensive sustainable improvements throughout the life of an ABI survivor with the initial financial cost offset by savings in support, in the longer term (Worthington, Matthews, Melia and Oddy, 2006). Furthermore, increasing the hours of weekly therapy accelerates the rate of recovery, resulting in a shorter hospital admission (Shiel et al, 2001).

#### 2.1.2 Impact of ABI on the Family

The potential consequences of an ABI survivor are wider than just financial ones. The loss for identity, personality, mobility and independence, as well as potential loss of relationships can be devastating. The quality of the relationships between family members pre-injury influences how well the family will cope with adjusting to the inevitable changes (Golombok, 2000). Nevertheless, the majority of partners who take on the role of carer experience carer burden due to the significant levels of stress (Bowen, Tennant, Neuman and Chamberlain, 2001; Low, Payne & Roderick, 1999; Tepper, Beatty & DeJong, 1996; Webster et al, 1999). Research on marital conflict has provided extensive evidence of the impact this conflict has on a child's emotional and behavioural well-being (Davies & Cummings, 1994; Fishman & Meyers, 2000; Hakvoort, Bos, Van Balen & Hermans, 2010; Jenkins, Simpson, Dunn, Rasbash, & O'Connor, 2005).

### 2.1.3 Impact of ABI on Relationships

The psychosocial difficulties people with brain injuries experience (e.g., financial, social isolation, personality changes, mental health problems and physical disabilities) often lead to strained relationships (Katzlberger & Oder, 2000; Oddy, 1995; Webster et al. 1999). Injuries may present themselves in various forms; disinhibition, impulsivity, memory deficits and dysexecutive syndrome which can have a severe impact on the person's ability to socially interact. The ripple effect of this can then spread across all aspects of the injured person's life in terms of social aspects, employment and being able to continue with their role as partner, parent and friend. Research on adult brain injury and its relational impact has highlighted many changes and losses (Howes, Benton, Edwards, Lexell & Söderberg, 2005; Jumisko et al, 2005). ABI survivors have reported sadness at the loss of close relationships and difficulties in forming new relationships (Bamford, 2007) as well as changes in family relationships (Lezak, 1986). However, some ABI survivors have reported positive changes on relationships as they begin to value family and friends more (Bamford, 2007; Linley & Joseph, 2004).

The relationship between the injured person and their spouse has come under scrutiny with research highlighting the distress experienced by both parties. In particular, disturbances in their relationship such as the loss of intimacy (Blake, 2008; Bowen, 2007) which can result in divorce (Webster et al, 1999). Caregivers have reported that caring for their partner severely impacted on the amount of contact they had with friends (Blake, 2008; Engström & Söderberg, 2011).

The relationship between a parent and child, in the context of ABI, has been less studied. Research suggests that both the injured and non-injured parent experience difficulties in their parenting relationship (Uysal, Hibbard, Robillard, Pappadopulos & Jaffe, 1998) – i.e. parents with ABI were said to show less warmth towards children and less nurturing. Difficulties between the non-injured parent and child are also reported (e.g. spending less time together). The consequence of a weakened relationship between the parent and child could lead to additional child behavioural difficulties (Hakvoort et al, 2010; Pessar, Coad, Linn & Willer, 1993). Research has also reported that although parents with ABI expressed great love for their children, they had difficulty redefining their relationships and feared they would deteriorate (Charles, Butera-Prinzi & Perlesz, 2007). Harris & Stuart (2006) described the pervasiveness of change in adolescents' relationships and their experiences of parental brain injury. They reported the most disruptive changes were related to the parent's changed personality, which consequently changed the parent-child relationship.

Studies have also highlighted positive experiences for children with a brain injured parent. Resilience and the consistent presence of a 'healthy' figure (i.e. teachers/friends) are protective factors for children. Furthermore, children report of positive relationship changes with their injured parent as they feel more connected to them due to an increased presence at home (Butera-Prinzi & Perlesz, 2004).

Children's relationships with friends and peers are also important. Peer friendships are often valued as they provide emotional support and play a

central role in providing young people with a sense of normality and stability (Kirova, 2003). The provision of supportive relationships is a vital coping strategy for dealing with their parent's brain injury (Moreno-Lopez, Holttum & Oddy, 2011). Westbury (2011) looked at child adjustment in relation to personal construct theory (Kelly, 1955). In contrast to Moreno-Lopez et al (2011), the author found that child relatives (and their parents) felt peers did not appear to understand their situation. This may be due to the experience of having a parent with a brain injury being outside of their friend's range of understanding, resulting in the child feeling isolated or misunderstood as their peers are unable to relate to them.

#### 2.1.4 Rationale for Study

Children's relationships are vital for influencing the development of knowledge, language, social skills, problem-solving skills and behaviour (Parker, Rubin, Erath, Wojslawowicz & Buskirk, 2006). The devastating impact on relationships with family and friends after brain injury is well documented in the literature (e.g. Oddy, 1995). However, research regarding the impact of parental brain injury on child relatives is somewhat limited (Daisley and Webster, 2009; Pessar et al, 1993; Tyerman, 2009; Urbach, Sonenklar, and Culbert, 1994) as few studies include children (Blake, 2008).

Quantitative studies of child adjustment to parental ill-health including ABI have been under-researched with just a handful of studies looking at children relative to those with adults (Butera-Prinzi & Perlesz, 2004; Heiney et al, 1997; Visser-

Meily et al 2005; Westbury, 2011). However, Graue & Walsh (1998) report quantitative research has insufficiently addressed children's perspectives and experiences. Furthermore, Oakley (2000) reports that children's experiences are often filtered through parents, denying them the opportunity to speak about situations concerning them. The National Service Framework (NSF) for long-term conditions (Department of Health, 2005) recognises that children of parental ABI need to be included within the family needs, in order to maximise the rehabilitation of the injured person. In view of this, children should be included in research to help families, services and professionals understand their needs in coping with the changes as a result of their parents' brain injury.

There are currently only a handful of qualitative studies looking at children's experience of relationships in the context of ABI. The most comparable study to the current one, using a phenomenological approach with data, looked at children's experiences of living with a brain-injured parent (Butera-Prinzi & Perlesz, 2004). This work highlighted how family interventions improve family cohesion, although used a small sample size. Children are at risk of behavioural and emotional difficulties with conflict, parental illness or injury. In terms of interventions to help children cope with the changes within their family, resources are limited or non-existent.

The literature to date suggests that many changes occur for the injured person and their family; loss of close relationships (Bambford, 2007), loss of intimacy (Uysal et al, 1998), difficulty in redefining roles within the family (Charles et al, 2007), parenting difficulties (Uysal et al, 1998) and consequences of these



changes such as children of brain injury parents presenting with behavioural difficulties (Havkoort et al, 2010; Pessar et al, 1993). Given the extent of these difficulties, and in view of the above literature and lack of evidence to demonstrate the impact of ABI on children's relationships, the decision was made to carry out this research.

#### 2.1.5 Aim of the Research

The aim of the research project was to explore how children's relationships change when their parent or caregiver acquires a brain injury. It was anticipated that the research would contribute to the growing literature around parental brain injury and the impact on children.

## **2.2 Methodology**

### 2.2.1 Design

The current study utilised a qualitative approach using Interpretative Phenomenological Analysis (IPA) to analyse data (Smith & Osborn, 2003). A semi-structured interview was based around a clinical activity used frequently in Child and Adolescent Mental Health Services (CAMHS).

## 2.2.2 Participant Information

Participants were children and young people aged between eight and eighteen with a parent or main caregiver who had sustained a brain injury. In order to meet the aims of the study the following inclusion/exclusion criteria were set:

### 2.2.2.1 Inclusion Criteria

- Children aged 8 to 18 years with one parent/caregiver with an ABI
- Willingness and interest in taking part in the research

### 2.2.2.2 Exclusion Criteria

- Participants unable to provide written consent to participate
- Not proficient in spoken English

Table 2 overleaf provides demographic details of participants and their injured parents.

**Table 2. Demographics of Participants**

<b><i>Code &amp; Pseudonym</i></b>	<b><i>Age</i></b>	<b><i>Parent with BI</i></b>	<b><i>Type of BI</i></b>	<b><i>Residency of injured parent</i></b>
P01 'Jamie'	17	Mother	Stroke & Brain Tumour	Family home
P02 'Kate'	10	Father	Subarachnoid Hemorrhage (SAH)	Nursing home
P03 'Vicky'	8	Father	Stroke	Family home
P04 'Adam'	13	Father	Viral/cerebral infection	Family home
P05 'Jenny'	15	Mother	SAH	Family home
06 'Sarah'	12	Mother	SAH	Family Home
P07 'Ben'	10	Father	Stroke	Family home
P08 'Harry'	Male	Mother	Stroke	Family home

### 2.2.3 Recruited Sample

Purposive sampling methods were used to recruit children and young people who fitted criteria relevant to the research topic (see 2.2.2.1 & 2.2.2.2). 22 families were initially identified, all of whom were familiar to the clinical psychologists. 3 were excluded immediately on the basis of not meeting the inclusion criteria; one family had a parent with a spinal cord injury, the children of the second family were too young and the third family, the injured relative was not the parent or caregiver. Of the remaining 19 families, all injured parents had at some point, or were currently an in-patient or out-patient at the centre for rehabilitation.

The families were approached by their clinical psychologist and details of the study were given to them in the form of a participant (and where applicable parent) information sheet and opt-in slip (see Appendix F). Prospective participants who expressed an interest in the study were asked to return the opt-in slip to the researcher. The researcher contacted the person by phone or email to discuss the study with them. Every effort was made not to pressurize prospective participants during the phone/email communication. The researcher discussed any questions that participants had prior to arranging an interview time. Eight families expressed an interest in taking part in the study and returned their opt-in slips. Age dependent consent forms (see Appendix F) were sent out and pre-paid envelopes provided to return them to the researcher. Participants who were under the age of 16 were contacted via their parents and their parents' consent was obtained on a separate consent form (see Appendix

F). The researcher made contact with the family using the details they had provided on the opt-in slip and arranged an interview time convenient to the participant (and parent, if applicable).

#### 2.2.4 Materials

No formal tests or questionnaires were used for the study, a semi-structured interview was followed. A clinical activity called 'Heartstrings' (Hobday & Ollier, 1998) was used to aid participant engagement. This acted as a novel vehicle to allow the participants to talk about how they experience their relationships with their family, peers and other significant people (see Appendix D for an example).

##### 2.2.4.1 Interview Schedule

An interview schedule was devised based on the current literature regarding brain injury and the impact on the family, the research question, conversations with the research team, and recommendations made by the National Research Ethics Committee, West Midlands – Coventry & Warwickshire (see Appendix D). This gave a flexible structure to the interviews and acted as a prompt for the researcher to ensure key areas of interest were covered. With the consent of the participant and their non-injured parent, each interview was audiotaped. IPA requires that interviews are not rigorously followed, but are led by the participant's own contributions. The interview schedule provided a framework for discussion, in line with IPA philosophy (Smith, 2003).

Questions focused on evoking the personal thoughts, feelings and meaning attributed to the experiences of participants. Secondary questions and prompts were prepared to elicit further information, if needed. The questions were prepared in a set format, however, the order varied across interviews and was in accordance with the participants' train of thought. The researcher made sure that all of the main questions were asked during the interview in order to limit researcher bias. Different types of questions were used to gain an understanding of the participants' experiences (Willig, 2001). These included; descriptive questions to provide a general account, structural questions, contrast questions and evaluative questions.

#### 2.2.4.2 Heartstrings

Heartstrings (Hobday & Ollier, 1998) was originally used by the researcher in a Child and Adolescent Mental Health (CAMHS) setting and was found to be a successful way of engaging with children and young people. The data from completed activity was not analysed, the activity was used solely for the purpose of developing engagement during the interview process. The decision was therefore made by the researcher to use the activity as a way of encouraging participants to talk about their relationships (Appendix D gives a step-by-step guide of the process).

## 2.2.5 The Procedure

### 2.2.5.1 Procedure and Service Context

The research was carried out within a clinical research team from a national centre of excellence for neurorehabilitation. The centre offers in-patient and out-patient care, as well as family support (including the only dedicated child relatives' service in the UK). Five interviews were conducted at the rehabilitation centre and three were conducted in the participants' homes.

### 2.2.6 Pilot Study

The initial interview also acted as a pilot study in order to check the suitability of using 'Heartstrings' as a way of interviewing children, and that the information elicited from this was relevant. Recruitment of the interviewee was carried out in the same way as subsequent participants. A debriefing took place with one of the clinical supervisors to reflect on the session and to receive feedback. This allowed the researcher space to identify any changes for subsequent use of the 'Heartstrings' activity. The data collected from the pilot study interview has been included with the main research interviews and the same analysis of IPA has been applied.

## 2.2.7 Data Analysis

Tape recorded interviews were transcribed verbatim, and as recommended by McLellan et al (2003), transcripts were proof read and checked for accuracy against the original recording. Transcripts were then coded and analysed thematically by the main researcher, in accordance with IPA procedures (Smith and Osborn, 2003). All identifying information, including names, were anonymised to maintain confidentiality. A full account of the IPA process, including independent coding of themes, credibility checks and ethical considerations is located in Appendix C.

### 2.2.7.1 Positionality of the Researcher

The researcher of this study was in their final year of a clinical psychology doctorate programme and had just completed a six month clinical placement working with a Family Therapy Service. Previous to this, the researcher had worked as an Assistant Psychologist at the study's research site, working with patients and their families within the field of neurorehabilitation. It is from this experience the researcher developed an interest in neurorehabilitation with particular emphasis on working with adult and child relatives of patients. It is acknowledged that these experiences are likely to have influenced the research in relation to the structure of the interviews and consequent biases towards the interpretation of the data. Other researchers would have perhaps constructed a different meaning to the interpretation of the data.



## 2.3 Results

From participants' accounts, 3 superordinate themes, including corresponding subordinate themes, were identified. Themes captured the shared experience of the participants' accounts of changes in relationships. Superordinate themes reflected; 1) Acceptance of changed relationships, 2) Significant loss, 3) Understanding the lived experience of the family system. <sup>2</sup>Subordinate themes were divided into sub-categories (Howitt, 2010) and can be found in Appendix G.

---

<sup>2</sup>Engaging with young people meant discussing the critical event and the impact of the brain injury, however, this research has focused on relationship themes which emerged throughout the interview.

The underlying thematic structure of the results is provided in Table 2 below.

**Table 3. Summary of Themes**

Superordinate Themes:	Subordinate Themes:
1. Acceptance of changed relationships	<p><i>1.1 Relationship changes 'inside' and 'outside' the family</i></p> <p><i>1.2 A more meaningful relationship</i></p>
2. Significant loss	<p><i>2.1 Absent parents</i></p> <p><i>2.2 The lost 'teacher'</i></p> <p><i>2.3 Deteriorating family relationships</i></p> <p><i>2.4 Our quality of life has been shattered</i></p>
3. Understanding the lived experience of the family system	<p><i>3.1 Loosening the structure of the family system</i></p> <p><i>3.2 A desire for routine and structure</i></p>

### 2.3.1 Discussion & Illustration of Themes

Validation of superordinate themes was embedded in transcripts, a selection of supporting quotes will now be presented in order to ground the interpretations in the raw data.

#### Superordinate Theme 1: Acceptance of Changed Relationships

This superordinate theme conveys how participants experienced relationships, both inside and outside the family, and how some of these changed after their parent's injury. Some relationships which were relatively insignificant prior to the parents' injury became much more meaningful as the bond became stronger and contact more frequent. Some relationships had become much more strained and contact was less frequent, as individuals' responsibilities and priorities changed.

#### *Subordinate Theme 1.1: Relationship changes 'inside' and 'outside' the family*

Six participants differentiated between those individuals who belonged 'inside' the family and were regarded as the close family members who dealt with the more personal issues and those 'outside' of the family who were there on more formal occasions when pleasantries were exchanged:

*“so inside... there was sort of sensitive issues, crying or talking to them about different things, but then outside (the family), there’s the more formal stuff like at family gatherings when you don’t really know them but ‘cos they’re kind of family you feel you have to make the effort” (Jamie, P19, L395-397)*

For six participants there was a strong emerging theme of closeness to their parent. In particular, there was a sense of ‘being with’ and sharing time. Seven participants reflected on the past and growing up:

*“...well when I was younger I sort of remember all the good memories going to the cinema with them...When I look back at that, all the happy memories, it’s nice” (Jamie, P5, L89-136)*

Subordinate themes of receiving emotional and practical support or having felt emotionally supported were also evident. All participants described scenarios whereby, before the injury, they had felt emotionally and practically supported by their parent:

*“He was really funny. He always made me laugh...and would tell jokes, and then because I’m really ticklish he would tickle me...he was always really kind and I could always trust him, so like not to be late for school...and he got me more confident... like in my dancing” (Kate, P10, L192-206)*

There was a sense of very little or no time of ‘being with’ or sharing time with some parents in four participants’ narratives:

*“Before ... she really didn't have much time for me...we'd probably go for walks but my brother would always come as well and she would always spend her time with him” (Vicky, P8, L151-156)*

Seven participants made reference to changes in their relationship with the injured parent and the 'old' and 'new' parent. They reflected how they were more mindful of their parents' needs and how they experienced the changed parent:

*“It wasn't as bad as I thought it would be because she can still go (to the shops) but she gets tired a lot more easier, so we just have to tone it down a little bit.” (Kelly, P1, L13-14)*

Furthermore, two participants spoke about the positive changes they had experienced since their parents' injury, with themes emerging which captured their sense of new found closeness:

*“We, well it's just, I feel a lot closer to him now because I feel like he's more himself, even if a bit more vulnerable, even though he's not, and so I feel he is closer to me now.”(Vicky, P4, L64-66)*

In terms of relationships 'outside' the family, there was a sense of people being physically present but less emotionally present with reduced emotional and practical support. Seven participants felt that some people 'outside' the family

were there on a 'needs only' basis. For example, Kate spoke about her relationship with her Uncle:

*"... before I didn't really spend time with him because we didn't really need him. We only saw him once in a while...." (Kate, P18, L371-372)*

*Subordinate Theme 1.2: A more meaningful relationship*

This subordinate theme reflects the positive changes participants experienced in their relationships with family and friends. Changes in sibling relationships were reported by five of the participants who experienced a positive change and narratives captured the essence of the sub-category of changed sibling relationships, in which greater bonds and reciprocal support was cultivated:

*"... we used to argue quite a lot before but we don't really as much anymore...Probably because we have to do things more together so you have to work tighter and help each other." (Sarah, P6, L113-117)*

Six accounts reflected how outside family members and friends had moved closer inside the family since their parents' brain injury. Participants described how they felt more connected and comfortable with those individuals and the increased support they provided in terms of helping to care for their injured parent, creating a more meaningful relationship:

*"...I didn't see her much but then, but I see her nearly every day now...I can talk to her a lot now, whereas before, I did know her because we are kind of related through marriage, but I didn't really talk to her that much. Now, I go around there a lot... I can talk to her. Mum being ill, she was there a lot, for us 'n that... It's good because then I know that it's not just me that has to look after my mum, that other people will help her, so she's never actually on her own." (Jenny, P5, L88-102)*

Six participants reflected on the increased presence of extended family in that they felt a greater sense of being supported and cared for from extended family members:

*"I've got to know her (grandma) better. She cares about me and Ben quite a lot more than she used to...I can trust her. If I want to tell her something I don't want to tell mum, then I know I can trust her not to tell mum." (Kate, P8, L162-167)*

Seven narratives captured an emerging theme of tightening of friendships. The majority of participants shared a sense of containing difficult feelings, trusting and confiding in friends:

*"...if like, I look really sad she always comes and comforts me...before...she would come to me but we wouldn't play as much and now we play a lot together...Even if we don't play we're always together... if I am sad at school then I don't need to keep it to myself if there is another person I can trust." (Kate, P20-21, L410-424)*

## Superordinate Theme 2: Significant Loss

Significant loss was evident from all accounts participants gave about their experiences. Absence of either or both parents due to changing roles, loss of closeness and intimacy, and loss of a role model were all themes which indicates the destructive nature and ripple effect which occurs when a parent acquires a brain injury.

### *Subordinate Theme 2.1: Absent parents*

This subordinate theme captured lost experience. Participants made reference to how they had previously felt a sense of love and affection from parents:

*"If I couldn't get off to sleep he would sit at the end of the bed and he would stroke my nose and forehead to help me sleep...he doesn't do that anymore"*

*(Jamie, P14, L288-290)*

Furthermore, participants spoke about their relationship in terms of how they would often just spend time together with their parents, being with each other:

*"She was a lot calmer then (before the injury). She'd spend a lot more time with me and we'd sit and talk about things and she was just always there"* (Ben, P7,

*L123)*

Participants also reflected on their relationship in terms of how they spent time bonding and playing together:



*“... we did a lot more things together then, because he could do all the stuff...  
Apart from teaching me the piano, we used to go and play tennis, well, he was  
kind of tennis coach I suppose” (Adam, P6, L92-93)*

#### *Subordinate Theme 2.2      The lost teacher*

As well as parenting experiences, six participants shared similar experiences in terms of the lost learning opportunities which their injured parent had once provided. There was a sense of how participants had previously been encouraged and supported in trying new things:

*“...he would always encourage me to do my best and have a go at some competitions and even if I did come last or even fifth, he would always encourage me to do better next time... and would give me advice of what I could do...”  
(Kate, P11, L211-221)*

#### *Subordinate Theme 2.3:      Deteriorating family relationships*

This subordinate theme reflects participants' feelings towards the way their parent behaved as a result of their brain injury. There was a sense of the parent being a 'stranger' and the participant feeling quite bewildered by some of their unpredictable behaviours, such as forgetting things. This resulted in participants not being able to make sense of their parents' injuries which left them feeling unsure about their relationship with their injured parent:

*“... sometimes she completely forgets she's had a stroke and her left side is paralysed, and says oh I'm just going to pop upstairs to go for a nap ... she sort of says it as if she's fine and it's a bit peculiar... I don't know it's a bit strange that she's not herself anymore. I don't know her anymore.” (Jamie, P8-9, L167-178)*

A distinction was made between good days and bad days; good days seemed to be when the injured parent was able to engage with participants and interact in some way. Bad days would be when the parent disengaged from any activity and left the participants feeling unnoticed and ignored. The following narratives capture the essence of these two themes embedded within the narratives, starting with good days:

*“We would, if he was in his wheelchair, and it's sunny we would be able to take him out in the garden. Um, and like he would, if we went to kiss, he would puff his lips as if trying to give us a kiss.” (Kate, P16, L20-22)*

Whereas on a bad day:

*“...if you saw her in the street you wouldn't know, but live with her, then you can understand what she's like. She has off days when she's really forgetful and you gotta laugh about it...sometimes you've got to be a bit careful because she leaves the cooker on, things like that. Leaving keys in the doors, then other things, words get jumbled.” (Jenny, P25-26, L507-515)*

The loss of the 'old' parent was a strong theme which emerged from all participants' accounts. They reflected on aspects of the parent which had been lost as a result of the brain injury; lost emotional and practical support, lost time being with and 'doing' together and the loss of new experiences:

*"Sometimes I think, what I could be doing if he hadn't been brain damaged. Like what I could be doing now...All the things that we were doing before, I would say...It's quite frustrating... I would have had a lot more to do." (Adam, P7, L112-119)*

Two participants relayed how they found the changes had impacted on them in a negative way and were more critical about their changed relationship:

*"... it's made us really far apart, me and dad... It's really annoying because I told him I had a project and then all he could talk about was that... He doesn't say hi how was school?" (Ben, P18, L365-370)*

Participants made reference to changes in their relationship with their non-injured parent. There was difference within this emerging theme as some participants described positive experiences and others more difficult experiences. Most felt that their non-injured parent provided emotional and practical support and felt closer than they had previously:

*“Well we talk about, she asks me what school is like now and then I tell her and then she tells me what her day’s like. We have these little times together and I really like it. It’s like she has more time for me now” (Vicky, P8, L144-146)*

However, a few participants experienced more difficult interactions as their non-injured parent became less available to be with due to their own changed responsibilities and new role as carer to their injured parent. This left some participants feeling unsupported and careful to approach their parent for help, as they sensed a state of emotional fragility and became hyper vigilant to their non-injured parents mood state:

*“I don’t want to go to her saying that I’m upset because I think it might make her upset...I really don’t want to like upset her more than what she is already upset...I go to mum when I know she is in a good mood...” (Kate, P5, L85-95)*

*Subordinate Theme 2.4: Our quality of life has been shattered*

Embedded within this theme was a sense of how difficult things had become and how some participants noticed family members’ strain since their parent’s brain injury. Five participants reported how worried they were for their family and their insight in to how hard times were, financially:

*“Well, it’s all changed since dad collapsed... She is always struggling with like work, 'cos we haven’t got enough money...And, um I try to support her... Like, I try and spend more time with her and if she, I ask her if she feels alright ‘cos*

*sometimes she looks a bit sad and lonely...And I always try and comfort her."*

*(Kate, P2-3, L42-55)*

Superordinate Theme 3:      Understanding the lived experience of the family system

This reflected all participants' accounts of what it was like being in their family. Participants described their family routines and the roles members played within the family system.

*Subordinate Theme 3.1:      Loosening the structure of the family system*

The impact of the brain injury on family life was evident from all of the participants' accounts. The subordinate theme of loosening of family routines emerged from a sense of things having to be done differently:

*"When that happened it shattered everything and everything became a mess and things just... Well we just didn't know what to do and so we had to try to set up a new regime of doing things..." (Jamie, P17, L343-345)*

Narratives also reflected the changing roles within the home, with participants carrying out domestic chores and also caring for their injured parent:

*“She forgets things, so we have to look after her, and like she can’t do as many things as she used to be able to that’s why we’ve had to start helping around the house more because she can’t do it all on her own.” (Sarah, P2, L66-68)*

There was a sense that some families were busy with everyday commitments and had very little time to all come together as a family. Participants described situations where their parents had different roles before the injury. One parent was responsible for the day to day running of the home whilst the other parent went out to work:

*“I didn’t get to spend time with mum because my dad always used to pick me up and take me to school and mum always had to leave really early in the morning to go to work.” (Kate, P4, L64-66)*

### *Subordinate Theme 3.2      A desire for routine and structure*

Embedded within the theme was the notion that participants craved structure and the security of knowing that certain things happened at certain times of the day or week. Participants reflected on the past and how they had enjoyed having a routine whereby they had activities planned throughout the week and knew what they would be doing:

*“Before I had lessons every morning, before he was ill....It got a bit annoying when I had to get up every morning to practice.... Luckily not on the weekends*

*though....I wish it was still like that though. I liked having things planned for me”*

*(Adam, P5, L69-76)*

Participants also described how routines lead to a sense of familiarity and they found this comforting:

*“Well at about six o’clock every morning, I slept through it, he would get up and go jogging. He used to coach a rowing team...Sometimes he would go out and then come back for breakfast, and we would spend as long as we could with him, when he came in we would run and hug his wet coat...It’s different now because he doesn’t do those things anymore so mornings are different...I don’t like it. I preferred it before it just felt better. (Ben, P5, L176-190).*

### 2.3.2 Summary of Findings

The first superordinate theme conveyed participants’ accounts of their experiences of changing relationships within the family and social circle. Two subordinate themes emerged from participants accounts. The first subordinate theme reflected the changes in relationships ‘inside’ the family and ‘outside’ the family. Those inside were experienced more intimately than those on the outside. The second subordinate theme focused on relationships which had changed and become more meaningful since their parents brain injury.

The second superordinate theme of significant loss was organised around accounts of how participants experienced loss. Four subordinate themes

emerged from the accounts. The first conveyed how participants experienced the absence of parents. The second of 'the lost teacher' reflected the role parents played in their child's development and learning prior to the injury. The third subordinate theme was generated from participants' accounts of how their relationships had deteriorated since their parents brain injury. The fourth subordinate theme reflected the changes in quality of life for the family.

The final superordinate theme related to the lived experience of being in a family. Within this theme, participants reflected on the loosening of the family system since their parents injury, and the desire for routines and structure.

These will be further explained in relation to the existing literature within the next section.

## **2.4 Discussion**

The present research focused on the changes in children's relationships when a parent sustains a brain injury, which to the author's knowledge, has not been extensively researched. The findings provided a rich, and at times moving, account of children's experiences of parental brain injury and how these impacted on their relationships with family and friends. This section will now consider the results of the research in relation to the research question, and the existing clinical and theoretical literature.



#### 2.4.1 Overview of Findings in Relation to Current Literature

The current research posed the question of how children's relationships change after a parent sustains a head injury. The findings provide a rich and complex portrayal of the positive and negative changes which occur in children's relationships in the context of their parents' brain injury. The even ratio of mothers and fathers with an ABI means that findings can be drawn from both genders, with no bias towards either one. The current research supports existing literature which highlights the changes which occur within families as a result of ABI (Howes et al, 2005; Jumisko et al, 2005; Lezak, 1986).

Participants described their family as previously being an established structure with each member having a specific role to play whereby one parent would provide emotional support, in comparison to other parent who provided opportunities for children to learn and develop new skills (for example, playing tennis or learning to play the piano). This demonstrates the different roles parents play in their child's development, as per Vygostky's (1978) zone of proximal development.

Children experienced positive and negative changes within their relationships. Children whose parents were no longer together experienced positive changes in their relationship with the estranged parent. There was a greater sense of closeness and provision of support and care through increased contact with this parent. However, the study also supports existing research on conflict within the parenting relationship suggested by Charles et al (2007), Harris & Stuart (2006)

Lezak (1978) and Uysal et al (1998). Some children felt more distant from both of their parents: distant from their injured parent as they were unable to provide the emotional and practical support they had showered them with pre-injury, and distant from their non-injured parent as their time was now taken with caring for their spouse.

Children's relationships with their siblings also changed: sibling relationships were much more significant and were a supportive source for one another. This appears to contradict Golombok's (2000) suggestion that the quality of relationships pre-injury will influence how well the family will cope with adjusting to change. The current study highlights relationships which developed into more meaningful relationships. Harris & Stuart (2006) also found that relationships with the non-injured parent and with siblings in the family were strengthened, post-injury.

Individuals who were previously regarded as family acquaintances, and were seen at more formal gatherings, were reported to become much more part of the family providing practical and emotional support to the parents and also the children. Children also felt that their relationships with their friends had become stronger with a tighter bond. They also felt that their peers provided vital support to them and were people they could confide in. This is in contrast to research where children have reportedly pushed their friends away even though they wanted to talk to them (Harris & Stuart, 2006). The study also supports research which suggests geographical distance leads to emotional and practical distance (Degeneffe, & Burcham, 2008; Gill and Wells, 2000; Pruchno, Patrick, &

Burant, 1996). Family and friends who lived further away participants were not considered as close to those who lived nearby.

In conclusion, there is no doubt that children's relationships change in many ways when a parent sustains an ABI. The study highlights the upset children experience at losing the relationships they once had with parents. However, the research also demonstrates the positive experiences children have in forming new relationships with family and friends, as a result of their parents ABI.

#### 2.4.2 Strengths and Limitations of the Research

The study interviewed child relatives about their relationships with family and friends and looked at changes pre and post-injury – something which other research has failed to do (e.g. Uysal et al, 1998). The current study was unique in that it used a clinical activity regularly used in CAMHS as a way of carrying out the semi-structured interviews. Given the fact that participants would only be interviewed once it was important to create a relaxed and comfortable environment to put them at ease so helping them to engage in the research process. One way of engaging children to discuss topics is through interviews. However, as the interviewer is an adult and the interviewees were children and young people, it is possible that this created a power imbalance (Kirova, 2003). By using the heartstrings activity the intentions were fourfold: (1) to circumvent any adult concept and understanding of relationships being imposed on participants, 2) to avoid using a standardised measure that asked questions that were only important for the current research without giving participants the

opportunity to say what they meant, 3) to create an environment which would be safe and comfortable for children and young people to open up about their experiences and 4) to create a uniqueness to the design of the research which would also act as an effective vehicle for participants to open up and talk about sensitive issues in a supportive and safe way. The activity also helped participants to look back and reflect which gave access to their past experiences. Furthermore, participants were happy to be interviewed on their own rather than in the presence of their parent - something which other research has been unsuccessful with (e.g. Westbury, 2011). In view of this, it was hoped that participants were able to give open and honest accounts of their experiences.

However, it is important to consider the limitations to this study. Social desirability may have influenced participants' expressed accounts of their experiences. Some participants may have felt uncomfortable expressing their true feelings. This may have prompted participants to give more positive accounts (Fisher & Katz 2000). In fact, one participant did refer to the position they had placed their mother in the diagram and asked was this ok. They went on to ask if they should change the position, however, the researcher reassured them that there was no right or wrong answer, and this information would remain confidential. On this occasion the participant was upfront and honest about how they felt about this, however, other participants might have felt differently, and censored their answers.

The small sample size of the current study prevents any generalisations being made for all children who have a parent with an ABI. The children and young

people who took part in the study were already in the service system when they volunteered and so it is possible that they had other reasons for taking part, such as giving something back to the service which had looked after their parent. In addition to this, the methodology does not allow for the generation of a theoretical model of relationship changes experienced by children. However, as Smith, Flowers & Larkin (2009) suggest, the findings from this small sample can offer a direction for future qualitative research and theoretical developments in this area.

Upon reflection on the research process and what may have influenced this, the researcher's developing clinical skills whilst on placement at the Family Therapy Service may well have contributed to the style and interview technique with participants. It is hypothesised that this would have a positive effect on the interviews. It was hoped that participants would feel comfortable and at ease with the style of interviewing, given the issues being discussed were of a sensitive nature. In contrast to this, it is also acknowledged that there may also have been some therapeutic property to the style of interview as it was difficult for the researcher to listen to participants talk about difficult relationships without being empathic. The researcher's interpretation provides just one interpretation and is most likely to be different to other researchers who have different experiences of family. It is likely that the researcher's own experience of personal and professional relationships and their own family script influenced the analysis. In view of this the researcher was mindful not to make assumptions about participants' own experiences.

### 2.4.3 Clinical Implications

The current research adds to the growing literature of parental ABI and child relatives and the potential risk of psychological difficulties if left unsupported (Hakvoort et al, 2010; Pessar et al, 1993). The current research highlights the need for neurorehabilitation services to provide interventions to support children and their families in helping them to make sense of their families' changes. Interventions which are considered efficacious in ABI include; education, counselling, therapy, support groups, networking and advocacy (Rosenthal & Young, 1988).

Given the implications surrounding the impact of parental ABI on children, a systemic approach to family interventions would help the child and their family adapt to the changes and establish new roles within the family system. Families should be facilitated to discuss the changes in family roles and relationships, much in the same way as the heartstrings activity encouraged. This would enable families to examine the losses and gains and help them to see strengths, enabling them to move forward by identifying their own resources and strengths (Rivera, Elliott, Berry & Grant, 2008). Furthermore, helping the family to adjust by using their own resources may also help in the recovery of the injured relative (Sander et al, 2002).

Interventions which focus on strengthening family resilience may also be of benefit to children and their families in neurorehabilitation services. Developing family resilience would focus on strengthening family communication, cohesion,

connectedness and time together (The National Network for Family Resiliency, 1996) – all of which emerged as themes from participants’ accounts of relationship changes, as a result of their parent’s injury. By developing family resilience, McCubbin & McCubbin (1988) suggest this would help families to adapt to crisis (Hawley, 2000) resulting in improved family relationships and therefore affirming their capacity to self-heal (Walsh, 1996). Additionally, strengths based interventions such as solution-focused and narrative therapy are deemed to have clinical utility in helping families to overcome difficulties (de Shazer, 1985; Freedman & Coombs, 1996).

Services also need to consider the importance of the therapeutic alliance between the injured relative, their family and the service. They may need to address any potential anxieties staff may have about working with families by providing appropriate staff training and resources (Bowen, Palmer and Yeates, 2010; Webster & Daisley, 2007). Ideally, services should include a designated child relatives’ clinician who can support children in coming to terms with their parents’ brain injury.

#### 2.4.4 Future Research

The limitations of the current study should be considered in terms of helping to inform future research. A larger sample size could look at the difference between having a mother with an ABI and a father with an ABI combining qualitative with quantitative measures to tease out the differences. More detailed consideration could be given to gender differences between sons and

daughters, and the different roles they take on within the family as a result of their parents' ABI. Furthermore, studies could differentiate between injured parents living in the family home compared to those living in a nursing home. The research could also be extended to look at the impact on relationships with another injured family member, i.e. siblings or grandparents, to examine whether the changes are as marked and the themes are the same or different. This would offer a much broader relational perspective on the family after ABI.

#### 2.4.5 Conclusion

The current study explored the lived experience of children and parental brain injury, and how this impacted on the child's relationships. Superordinate themes of; acceptance of changed relationships, significant loss and understanding the lived experience of the family system emerged from participants' accounts and highlighted positive and negative relationship changes as a result of parental brain injury. Based on the current findings the study suggests implications for service delivery.



## 2.5 References

Bamford, C. (2007) Living with a severe acquired brain injury as an inpatient in a neuro-rehabilitation unit: An interpretative phenomenological analysis. *Unpublished thesis*. Psychology Department: University of Hertfordshire, Hatfield.

Blake, H. (2008) Caregiver Stress in Traumatic Brain Injury. *International Journal of Therapy and Rehabilitation*, 15, 6.

Bowen, A., Tennant, A., Neuman, V., & Chamberlain, M.A. (2001) Neuropsychological rehabilitation for traumatic brain injury: do carers benefit? *Brain Injury*, 15, 1, 29-38.

Bowen, C. (2007) Family therapy and neuro-rehabilitation: Forging a link. *International Journal of Therapy and Rehabilitation*, 14, 8.

Bowen, C.M., Palmer, S., & Yeates, G.N. (2010) *A relational approach to rehabilitation: Thinking about relationships after brain injury*. London: Karnac Books Ltd

Butera-Prinzi, F., & Perlesz, A. (2004) Through children's eyes: children's experience of living with a parent with an acquired brain injury. *Brain Injury*, 18, 1, 83-101.

Charles, N., Butera-Prinzi, F., & Perlesz, A. (2007) Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation*, 22, 61-76.

Daisley, A., Tams, R., & Kischka, U. (2009) *Brain Injury: the facts*. Oxford: Oxford University Press.

Daisley, A., & Webster, G. (2009) Familial brain injury: Impact on children. In A. Tyerman & N. S. King (Eds.), *Psychological approaches to rehabilitation after traumatic brain injury*. Oxford: BPS Blackwell.

Davies, P. T., & Cummings, E. M. (1994) Marital conflict and child adjustment: An emotional security hypothesis. *Psychological Bulletin*, 116, 387–411.

Degeneffe, C.E., & Burcham, C.M. (2008) Adult Sibling Caregiving for Persons with Traumatic Brain Injury: Predictors of Affective and Instrumental Support. *Journal of Rehabilitation*, 74, 3, 10-20.

Department of Health (2005) *The National Service Framework for Long Term Conditions*. London: Crown Copyright.

de Schazer, S. (1985) *Keys to Solutions in Brief Therapy*. New York: W. W. Norton.

Engström, Å., & Söderberg, S. (2011) Transition as Experienced by Close Relatives of people With Traumatic Brain Injury, *Journal of Neuroscience Nursing*, 43, 5, 253-260.

Fisher, R.J., & Katz, J.E. (2000) Social-Desirability Bias and the Validity of Self-Reported Values, *Psychology & Marketing*, 17, 2, 105–120.

Fishman, E. A., & Meyers, S. A. (2000) Marital satisfaction and child adjustment: direct and mediated pathways. *Contemporary Family Therapy*, 22, 437–452.

Freedman, J., & Coombs, G. (1996) Narrative Ideas for Consulting with Communities and Organizations: Ripples from the Gatherings. *Family Process*, Vol. 48, No. 3, 2009.

Gill, D. J., & Wells, D. J. (2000) Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing*, 25, 2, 48-53.

Golombok, S. (2000) *Parenting: What really counts?* London: Routledge.

Graue, M. E., & Walsh, D. J. (1998) *Studying children in context: Theories methods and ethics*. Thousand Oaks, CA: Sage.

Hakvoort, E.M., Bos, H.M.W., Van Balen, F., & Hermanns, J.M.A. (2010) Family Relationships and the Psychosocial Adjustment of School-Aged Children in Intact Families. *The Journal of Genetic Psychology*, 171, 2, 182–201.

Harris, D., & Stuart, A.D. (2006) Adolescents' experience of a parental traumatic brain injury, *Journal of Interdisciplinary Health Sciences*, 11, 4, 46-56.

Hawley, D.R. (2000) Clinical Implications of family resilience. *The American Journal of Family Therapy*, 28, 2, 101-116

Headway (2011) *Key Facts & Statistics*. Retrieved on 23rd March 2012, <http://www.headway.org.uk/key-facts-and-statistics.aspx>

Heiney, S.P., Bryant, L.H., Walker, S., Parrish, R.S., Provenzano, F.J., & Kelly, K.E., (1997) Impact of parental anxiety on child emotional adjustment when a parent has cancer. *Oncology Nursing Forum*, 24, 4, 655-61.

Hobday, A., & Ollier, K. (1998) *Creative Therapy: Activities with children & adolescents*. Leicester: British Psychological Society.

Howes, H., Benton, D., & Edwards, S. (2005) Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology and Health*, 20, 1, 129-142.

Howitt, D. (2010) *Introduction to Qualitative Methods in Psychology*. Essex, England: Pearson Education Ltd.

Jenkins, J., Simpson, A., Dunn, J., Rasbash, J., & O'Connor, T. G. (2005) Mutual influence of marital conflict and children's behaviour problems: Shared and nonshared family risks. *Child Development*, 76, 24-39.

Jumisko, E., Lexell, J. & Soderberg, S. (2005) The meaning of living with traumatic brain injury in people with moderate to severe traumatic brain injury. *Journal of Neuroscience Nursing*, 37, 1, 42-50.

Katzlberger, F., & Oder, W. (2000) Psychosocial sequelae after severe head injury: Interviews of patients and their relatives in comparison. *Psychotherapie, Psychosomatische Medizinische, Psychologie*, 50, 5, 209-214.

Kelly, G. (1955) *The psychology of personal constructs*. New York: Norton Vols.

Kirova, A. (2003) Accessing children's experiences of loneliness through conversations. *Field Methods*, 15, 1, 3-24.

Lezak, M. D. (1978) Living with characterologically altered brain injured patient. *The Journal of Clinical Psychiatry*, 39, 592-598.

Lezak, M. D. (1986) Psychological implications of traumatic brain damage for the patient's family. *Rehabilitation Psychology*, 31, 241-250.

Linley, P.A. & Joseph, S. (2004) Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, 17, 1, 11-21.

Low, J. T. S., Payne, S., & Roderick, P. (1999) The impact of stroke on informal carers: a literature review. *Social Science and Medicine*, 49, 711-725.

McCubbin, H.I., & McCubbin, M.A. (1988) Typologies of resilient families: emerging roles of social class and ethnicity, *Family Relations*, 37, 247-254

McGregor, K. & Pentland, B. (1997) Head injury rehabilitation in the U.K.: an economic perspective. *Social Science and Medicine* 1997, 45, 2, 295-303.

McLaughlin, A. M. (1992) Addressing the psychological needs of children with brain injured relatives: An activity group model. *The Journal of Cognitive Rehabilitation*, 10, 12-18.

McLellan, E., MacQueen, K.M., & Neidig, J.L. (2003) Beyond the Qualitative Interview: Data Preparation and Transcription. *Field Methods*, 15, 1, 63–84

Moreno-Lopez, A. Holttum, S., & Oddy, M. (2011) A grounded theory investigation of life experience and the role of social support for adolescent offspring after parental brain injury, *Brain Injury*, 25, 12 , 1221-1233.

National Network for Family Resiliency (1996) *Family Resiliency*. Retrieved on 27th April 2012, <http://www.ces.ncsu.edu/depts/fcs/pdfs/fcs-508.pdf>.

Oakley, M.W. (2000) Children and young people and care proceedings. In A. Lewis, & G. Lindsay (Eds.) *Researching children's perspectives*. Buckingham: Open University Press.

Oddy, M. (1995) He's no longer the same person: How families adjust to personality change after head injury. In N. Chamberlain (Ed.) *Traumatic brain injury rehabilitation*. London: Chapman and Hall.

Parker, J.G., Rubin, K.H., Erath, S.A., Wojslawowicz, J.C., & Buskirk, A.A (2006) Peer Relationships, Child Development, and Adjustment: A Developmental Psychopathology Perspective. In D. Cicchetti (Ed.), D. J. Cohen, *Developmental Psychopathology, 1, Theory and Method* (2nd Ed), Chichester, UK: John Wiley & Sons Ltd.

Pessar, L.F., Coad, M.L., Linn, R.T., & Willer, B.S. (1993) The effects of parental traumatic brain injury on the behaviour of parents and children. *Brain Injury, 7*, 231-240.

Pruchno, R.A., Patrick, J.H., & Burant. C.J. (1996) Aging women and their children with chronic disabilities: Perceptions of sibling involvement and effects on well-being. *Family Relations, 45*, 318-326.

Rivera, P.A., Elliott, T.R., Berry, J.W., & Grant, J.S. (2008) Problem-Solving Training for Family Caregivers of Persons with Traumatic Brain Injuries: A Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation, 89*, 931–941.

Rosenthal, M., & Young, T. (1988) Effective family intervention after traumatic brain injury: Theory and Practice. *Journal of Head Trauma Rehabilitation, 3, 4*, 42-50.

Sander, A. M., Caroselli, J. S., High, W. M., Becker, C., Neese, L. & Scheibel, R. (2002) Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Injury*, 16, 8, 649-657

Shiel, A., Burn, J.P.S., Henry, D., Clark, J., Wilson, B. A., Burnett, M. E., & McLellan, D. L. (2001) The effects of increased rehabilitation therapy after brain injury: results of a prospective controlled trial. *Clinical Rehabilitation*, 15, 501–514.

Siegel, D. (1999) *The developing mind: How relationships and the brain interact to shape who we are*. New York: The Guilford Press.

Smith, J.A., Flowers, P., & Larkin, M. (2009) *Interpretive Phenomenological Analysis*. London: Sage.

Smith, J.A. & Osborn, M. (2003) Interpretative phenomenological analysis. In J.A. Smith (eds) *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage.

Stern, D. (1986) *The interpersonal world of the infant*. New York: Basic Books.

Tepper, S., Beatty, P., & DeJong, G. (1996) Outcomes in traumatic brain injury: Self-report versus report of significant others. *Brain Injury*, 10, 575-581.



Tyerman, A. (2009) Facilitating psychological adjustment. In A. Tyerman & N. S. King (Eds.), *Psychological approaches to rehabilitation after traumatic brain injury*. Oxford: BPS Blackwell.

Urbach, J.R., Sonenklar, N.A., & Culbert, J.P. (1994) Risk factors and assessment in children of brain-injured parents. *Journal of Neuropsychiatry*, 6, 289-295.

Uysal, S., Hibbard, M.R., Robillard, D., Pappadopulos, E., & Jaffe, M. (1998) The effect of parental traumatic brain injury on parenting and child behaviour. *Journal of Head Trauma Rehabilitation*, 13, 57-71.

Visser-Meily, A., Post, M., Meijer, A.M., Maas, C., Ketelaar, M., & Lindeman, E. (2005) Children's adjustment to a parent's stroke: determinants of health status and psychosocial problems, and the role of support from the rehabilitation team. *Journal of Rehabilitation Medicine*, 37, 236–241.

von Salisch, M. (2001) Children's emotional development: Challenges in their relationships to parents, peers, and friends. *International Journal of Behavioural Development*, 25, 4, 310–319.

Vygotsky, L. S. (1978) *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Walsh, F. (1996) The concept of family resilience: Crisis and challenge. *Family Process*, 35, 261-281

Webster, G., Daisley, A., & King, N. (1999) Relationship and family breakdown following acquired brain injury: the role of the rehabilitation team. *Brain Injury*, 13, 8, 593-603.

Webster, G., & Daisley, A. (2007) Including children in family-focused acquired brain injury rehabilitation: a national survey of rehabilitation staff practice. *Clinical Rehabilitation*, 21, 1097–1108.

Westbury, H. (2011) Young persons' constructions prior to and following parental brain injury. *Unpublished thesis*. Psychology Department: University of Hertfordshire, Hatfield.

Willig, C. (2001) *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Buckingham: Open University Press.

Worthington, A.D., Matthews, S., Melia, Y and Oddy, M. (2006) Cost-benefits associated with social outcome from neurobehavioural rehabilitation. *Brain Injury*, 20, 9, 947–957.

## **Chapter 3**

### **Reflective Paper**

**Reflecting on the research process using  
'Heartstrings'**

**Word count: 3896**

### 3.0 Abstract

**Aim:** The reflective paper aims to provide an account of the research process, in relation to the researcher's own relationships and how these changed over the course of the research. Relationships with supervisors, family and friends are considered.

**Method:** The reflective process is carried out utilising the Heartstrings activity the researcher used in the current study. This is a clinical pen and paper activity which helps to facilitate discussions around relationships and the closeness of people.

**Conclusions:** The 'Heartstrings' activity is considered an effective method in helping to reflect on the research process, and in particular, to facilitate discussions around changes in relationships during the research process. The researcher provides an account of the changing nature of relationships, and the impact of carrying out research on significant relationships.

### **3.1 Introduction**

This paper aims to provide a reflective account of one specific area related to the process of the current research. The 'Heartstrings' activity (Hobday, & Ollier, 1998) which was completed by participants of the research study has been completed by the researcher and an account is given of the changes which the researcher noticed in their relationship with their supervisors, family and friends, over the course of the research process. Three diagrams were produced to reflect the different stages of the research; prior to starting the research, during the research process and towards the end of the research (see Appendix D for an example of 'Heartstrings'). The researcher also reflected on the experience of completing the activity, as a way of understanding how the participants of the study may have felt completing it in the presence of the researcher. The work will be organised in sections dependent upon the type of relationship. First the work will look at the experience of completing 'Heartstrings'. The work will then move on to look at the experience of the research process whilst on placement at the Family Therapy Service. The relationship with supervisors will then be considered, moving on to then look at relationships with family and finally with my friends.

The rationale for reflecting in this way is to try to mirror the research process and to capture the researcher's relationship changes over the course of the research.

### **3.2 The 'Heartstrings' Activity**

Firstly, I will introduce the rationale for my decision to use 'Heartstrings' in my research. I will then follow this by describing my own experience of completing the activity.

As a way of trying to help participants engage in the research process, I felt it was vitally important to create a relaxed and comfortable environment for them. It has been proposed that in order to access children's culture and experiences this requires "an equal, confidential, and open interaction, and co-operation between the researcher and children" (Kyronlampi-Kylmanen & Maatta, 2011, p87). Many difficulties have been noted by researchers carrying out research with children, e.g. the burden of adult-centrality whereby research interviews are adult-centred making it difficult to access a child's world (Kyronlampi-Kylmanen & Maatta, 2011). Power imbalance is another obstacle for researchers to overcome, whereby the researcher is an adult and the participants are children, (Kirova, 2003).

One way of engaging children in research is through interviews, however, I was aware that as an adult, interviewing children and young people might have created an unequal power balance (Kirova, 2003). In using 'Heartstrings' it was hoped that this would reduce the possibility of power imbalance. I anticipated that by using the activity, firstly, it would avoid adult concepts being imposed on participants, which might alienate them from me. Secondly, it would create an environment which would be safe and comfortable for children and young

people to open up about their experiences. Finally, the activity would also help participants to look back and reflect on their diagram, giving them access to their past experiences.

As I began to draw my own 'Heartstrings' I noticed how I pondered over certain relationships with people and where I would position them. I felt a sense of importance around putting people in the 'right' position, whilst also feeling unsettled about placing some people further away from me – even though in my heart I knew this was the true position. Strangely, it was as if I felt under pressure to answer in a 'socially desirable way' (Fisher & Katz 2000) which, given that this was my activity I would only be pleasing myself. Or would I? Perhaps the thought of who was going to read this and what they might think had more of an effect than I anticipated. This made me wonder if this was the case for the children and young people who took part in my research. I am curious to know to what extent they felt under pressure to also put people in the 'right' position given that I was observing. I had stressed to them at the beginning that there was no right or wrong answer and that the important thing was to be true to their self and answer honestly. I now see how difficult this was.

Social desirability is something that, as a researcher, you are aware of and make every effort to try to reduce the likelihood of this occurring. I had given the issue considerable thought during the planning stage of the research, and recognised that the environment I created was going to be fundamental to participants feeling safe enough to share their experiences with me. Although I made every effort to address the issues of social desirability, burden of adult-centrality and

power imbalance, it is possible that some participants may have felt uncomfortable expressing their true feelings. This may have resulted in participants reporting their experiences in a more positive way (Fisher & Katz, 2000). When I reflect back, I was given a snapshot of one participant's concern at the position they had put their mother. They asked if they should change the position they had put their mother in, as it didn't feel right to them. They felt they had positioned their mother further away than what they thought they should have. I explained that I was not going to judge them on this, and reiterated the confidential nature of the research, which seemed to reassure them. I restated that there was no right or wrong answer, just 'their' answer. Fortunately, the participant was upfront about how they felt about this, and gave me the opportunity to try to put them at ease. Other participants, on the other hand, might have felt differently and possibly censored their answers. Upon reflection, given the strong sense I had of who 'should' be close to is possibly far greater for the participants who completed this in the presence of an adult.

One difference between completing the activity myself and the participants completing it was the reassurance they had from me that no one outside of the research team would see their diagrams. These would remain confidential and anonymous. Whereas mine, on the other hand, would be viewed by many people, some whom I would continue to see in a professional and personal capacity. I spent some time thinking about the prospect of sharing this information with my readers and subsequently made the decision that this was something I preferred not to do. As with my participants, I felt that by giving



myself the opportunity of certain aspects remaining private, I was able to be more open and honest in my answers when completing the 'Heartstrings'.

On completion of the diagram I began to consider where I had placed my supervisors, colleagues, family and friends and the change in positions over the course of the research process. These changes will now be discussed.

### **3.3 The Research Process whilst on Placement**

My placement at the Family Therapy Service provided me with the opportunity to work clinically in a field closely related to my research but separate enough to give me a new experience of being immersed in SFT. This complemented my research as the literature I was reading for my placement tied in with some of the background material I later used in my research. My placement supervisor was also very interested in my research and so I was able to draw upon her knowledge and experience of SFT and current research in this area. This helped me to develop my own understanding of the model and therefore enabled me to identify the different approaches within the literature reviewed on systemic family interventions.

Carrying out research in an area where you are currently on placement, or working in a similar environment to, is something which other Trainee Clinical Psychologists recommend as a way of conserving energy and reducing cognitive fatigue (David, 2006). In addition to this, having a supervisor who had been through a similar process was incredibly helpful. The placement supervisor was

extremely understanding of the draining effect of carrying out research whilst on placement, and on occasions, gave me time out of my placement to attend research meetings and interviews, given that they were some distance away from my placement.

It must be acknowledged that in view of the therapeutic skills I developed from this placement, there may have also have been some therapeutic property to my style of interviewing. It was incredibly difficult for me to listen to participants talk about difficult relationships without using therapeutic techniques of sensitive listening and empathically responding (Greenhalgh, 1994).

As the placement finished, contact with my placement supervisor understandably reduced significantly and this was reflected in my diagram. The position I had originally placed them in became more distant towards the end of the research process. I feel this is a natural process which happens in all placements: as one finishes another starts, and so as one relationship ends another one develops.

### **3.4 The Relationship with Research Supervisors**

The decision to carry out the research at an organisation where I had once worked as an assistant, and where I was going to be a trainee on my final placement, had to be given thoughtful consideration. There were many reasons to do it but also some reasons not to do it. I had developed a close professional relationship and friendship with both clinical supervisors and was thrilled at the

prospect of working with them again, although the risk of how this might affect the dynamics of our relationship was something we were aware of. After talking through the pros and cons with my appraisal tutor and clinical supervisors, we all agreed this would be a great opportunity. I was confident that my mature attitude towards the working relationship would enable the working relationships to be juxtaposed to our friendships. My relationship with my academic supervisor was far less frequent and much more of a professional relationship, but I felt equally comfortable in their presence and felt that they would provide me with the support and guidance I knew I needed to help me complete my research.

Prior to starting the research I saw both clinical supervisors relatively often for social gatherings, although due to the distance between where we lived, this was becoming less frequent. As the research started to develop and the recruitment began, the contact increased with one clinical supervisor slightly more than the other. The contact with my academic supervisor also increased at this point as we met regularly to review the progress of the research. This reflected the different roles each supervisor took on: one took on the role of supervising most aspects of the research process, continually reviewing my progress, one took on the role of supervising the analysis stage of the research, whilst the other focused on the content of the thesis and reviewing the literature and drafts of work. This worked really well and helped me to compartmentalise different aspects of the research, which made the task feel less overwhelming. Once the recruitment was completed, the increased contact with one supervisor continued as we began the arduous task of analysing the data. I feel extremely

lucky to have been supervised at this stage by a supervisor who is incredibly knowledgeable on IPA and who really enjoys the analysis stage of research. The pace of research gathered momentum at this point, and frequent meetings were organised to help me focus on completing the different stages of research. I found the analysis complex and slow, but realise now this was fundamental in helping me to become familiar with my data, thus, enabling me to find “a higher level of abstraction” at the more interpretive stages of analysis (Smith & Osborn, 2003, p68). As the research moved in to different stages, so did the relationship with my supervisors.

Towards the end of the research, as it moved in to the writing up stage, the contact with one clinical supervisor and my academic supervisor increased dramatically as drafts started to be passed back and forth. This was reflected in the ‘Heartstrings’ diagram. Both supervisors had very different approaches, but both worked towards the same goal, to provide me with the learning opportunity to improve my work, ultimately reaching my true potential. This corresponds with Vygostky’s (1978) scaffolding and zone of proximal learning theory – a theme which was also evident in the research within the parent-child relationship. The relationship between supervisor and doctoral student has been described as one whereby the supervisor provides ongoing feedback on writing, ideally providing a role model as an active researcher and publisher (Brown, 1994; Diezmann, 2005). Diezmann (2005) goes on to suggest that this approach assumes a cognitive model of learning in which the teacher scaffolds and coaches the student to aid the development of knowledge – something which

was very much evident in my supervisors' style of supervision, and I found to be a positive experience.

The task of juggling lots of different components of the research and meeting deadlines given to me by all supervisors was overwhelming at times. Looking back, I am now glad of the constant support and encouragement I was given by all supervisors as this gave me the motivation to keep going, and ultimately complete the research on time. The anticipation I experienced waiting for feedback on each draft engulfed me at times as I wondered if what I had spent long days and nights on was going to be good enough. At times the feedback knocked me (and my confidence), and I noticed a definite correlation between my motivation when I received positive feedback compared to a significant demotivation when negative feedback was given. This was to the extent that one afternoon I found myself sitting on the sofa drinking tea and eating cake whilst watching my husband watch his arch rival football team on the television - the title challenge was back on. This is not something I would normally be interested in!

As I write this reflective paper, the final stage of writing up the research is coming to an end and I have mixed feelings towards my research. I feel very protective of it, so much so that the thought of it being critiqued or criticised is quite unsettling. I also have great respect for my research supervisors and want the research to be a success not only for myself, but as a way of showing my appreciation and gratitude for all the support, encouragement and guidance they have given me throughout the research. When I reflect on the whole process

and the impact it has had on my relationships, there have been difficult conversations and times when I have worried if our relationships would be intact at the end of it. I am pleased (and relieved) to say that the relationships have stood up to the rigour and at times, trauma, of the research process. I feel this demonstrates that it is possible to have dual relationships as supervisor-supervisee and friends. My admiration and respect for my supervisors has if anything increased, because of the openness and honesty we shared and the ability to get through difficult times without it jeopardising valued friendships.

### **3.5 The Relationship with Family**

As I considered the heartstrings diagrams I noticed the positioning of some members of my family change noticeably over the course of the research. My husband has always been a stable source of support over the years and I am fortunate that he is extremely understanding, particularly when it has come to the pressures of me being on a doctoral training programme. At the time of my research, my husband was also carrying out his research for his Master's degree, and so we were both in our own 'research bubbles'. Having a husband go through a similar process at the same time was on the most part, very positive. We often talked about each other's research and gave each other advice about different elements of our research. He also gave me the encouragement to continue working during those occasions when I was demotivated. However I did find myself at times becoming overly concerned with his more relaxed take on the methodology of his own research which only seemed to amplify my own neuroses about my research. Towards the end of the research, I noticed a

tightening of our relationship as the pressure mounted to get things completed. When I reflect on our relationship I feel that the research process has increased our sense of closeness, and I feel a sense of pride as to how much we have achieved, particularly given that we are both in the slightly more 'mature' stages of life (in comparison to other students!). The tightening of our relationship during a stressful period in our life is something which mirrors the reflections of participants who also reported the strengthening of some of their significant relationships.

Changes with other family members were also noted in the diagrams. As I started my research and my placement in the Family Therapy Service I began to notice a change in how I viewed my own family. As I read more of the literature on families and observed family patterns within therapy sessions I noticed that my focus on my own relationship with my family became more intense. I also was given the opportunity of completing a cultural genogram (Hardy & Laszloffy, 1995) whilst on placement which was facilitated by supervisor and another family therapist. As I became aware of my own family's patterns this had a profound effect on my understanding of my family. This coupled with the fact that I was interviewing children about their relationships with their family and friends had a profound impact on the amount of time I spent reflecting on my own family.

One relationship which did surprise me was the closeness to which I felt my brother was to me. My brother lives thousands of miles away and we only see each other once a year (if we're lucky), and we talk every month or two; yet I feel

a great sense of closeness towards him. This is in contrast to the findings of my research and also that which is suggested by other research (Degeneffe, & Burcham, 2008; Gill and Wells, 2000) who reported geographical distance leads to emotional and practical distance. Further analysis of this goes beyond the scope of the reflective paper, however this is something which I find fascinating and will consider looking at in the future.

### **3.6 The Relationship with Friends**

When I looked back at the diagrams and the different positions of friends over the course of the research, I noticed that majority of my friendships grew further away from me. I believe there are a number of reasons for this; firstly, I moved from my home town three years ago and, previous to the research, I had spent the majority of weekends since then either visiting friends or vice versa. Since starting the research, I have used most weekends to either work or to try and rest to conserve my energy (as per David, 2006) and so the physical contact has reduced significantly. Secondly, my friends are incredibly supportive of what I do and they understood that this research was something which was going to take up most of my time and energy. However, they still 'checked-in' with me via text or email with words of encouragement. Kirova (2003) advocates the need for friendships, which are often highly valued as they provide vital emotional support. Furthermore, friendships have been reported to play a central role in providing a sense of normality and stability during difficult times, and a vital coping strategy (Moreno-Lopez, Holttum & Oddy, 2011).



The reported changes in friendships also support the research on geographical distance and emotional distance, as those who lived further away from me were more emotionally distant towards me. I feel that I positioned myself closer to the people who were involved in my research as this was my priority for eight months of the final year of the course. I believe this is a natural process of aligning with peers, friends and those people who have something in common with you. This is demonstrated by the increased closeness during the research process which I had with two fellow trainees. We had peer support and also organised research meetings to help with the rater-reliability of themes (Smith & Osborn, 2003). The closeness with one trainee remained constant and to the end of the research process as we kept in regular contact checking in with each, thus far, advocating Kirova's (2003) theory that peer relationships are valued as significant sources of emotional support.

### **3.7 Overall Reflections of the 'Heartstrings' Activity**

Completing 'Heartstrings' has been an extremely thought-provoking and effective method of helping me to reflect on the research process and the impact the research has had on my relationships. I wonder if I had completed 'Heartstrings' before I interviewed participants, or before analysing the data, if this would have had an impact on research findings. There is no denying that the process has helped me to evaluate the relationships that I have had with supervisors, family and friends over the course of the research. If this evaluation had taken place prior to interviewing participants then it might have increased my knowledge of ways in which to increase participation during the interview,

and helped me to get the most out of the activity. Alternatively, the fact that I hadn't completed it beforehand means this reduced the likelihood of any bias, as I had no preconceptions about whether the diagram should have been completed a certain way. This may have enabled participants to create their own personal version of the activity without feeling restricted or influenced in any way.

### **3.8 Conclusions**

The activity has shown that it has research as well as clinical utility in helping children and young people to engage in discussions of a sensitive nature. Reflections on the research process using 'Heartstrings' has highlighted some significant changes in relationships, particularly those with peers who are geographically more distant.

Overall, 'Heartstrings' is a useful and reliable method of helping to reflect on relationships. As a trainee clinical psychologist I am an advocate of reflective practice and believe that the reflective process is an integral part of emotional growth (Greenhalgh, 1994) and learning. I also feel very strongly that, given the expectations clinicians have on clients' developing self-awareness, it is only fair that we continually self-reflect as a way of developing our understanding of our own beliefs which may influence our clinical practice (Lavender, 2003).

### 3.8 References

Brown, R. (1994) The 'big' picture about managing writing. In O. Zuber-Skerritt & Y. Ryan (Eds.) *Quality in postgraduate education*. London: Kogan Page

David, C. (2006) Reflections on the research process as a trainee clinical psychologist: is it feasible to be a scientist-practitioner? *Reflective Practice*, 7, 2, 193-196

Degeneffe, C.E., & Burcham, C.M. (2008) Adult Sibling Caregiving for Persons with Traumatic Brain Injury: Predictors of Affective and Instrumental Support, *Journal of Rehabilitation*, 74, 3, 10-20

Diezmann, C.M. (2005) Supervision and scholarly writing: writing to learn – learning to write. *Reflective Practice*, 6, 4, 443-457

Fisher, R.J., & Katz, J.E. (200) Social-Desirability Bias and the Validity of Self-Reported Values, *Psychology & Marketing*, 17, 2, 105–120

Gill, D. J., & Wells, D. J. (2000) Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing*, 25, 2, 48-53

Greenhalgh, P. (1994) *Emotional Growth and Learning*. London: Routledge

Hardy, K. & Laszloffy, T.A. (1995) The cultural genogram: Key to training culturally competent family therapists, *Journal of Marital and Family Therapy*, 21, 3, 227-237

Hobday, A. & Ollier, K. (1998) *Creative Therapy: Activities with children & adolescents*. Leicester: British Psychological Society

Kirova, A. (2003) Accessing children's experiences of loneliness through conversations. *Field Methods*, 15, 3.

Kyronlampi-Kylmanen, T., & Maatta, K. (2011) Using children as research subjects: How to interview a child aged 5-7 years. *Education Research and Reviews*, 6, 1, 87-93.

Lavender, T. (2003) Redressing the balance: the place, history and future of reflective practice in clinical training. *Clinical Psychology*, Issue 27, 11-15 (2003)

Moreno-Lopez, A. Holttum, S., & Oddy, M. (2011) A grounded theory investigation of life experience and the role of social support for adolescent offspring after parental brain injury. *Brain Injury*, 25, 12 , 1221-1233.

Smith, J.A. & Osborn, M. (2003) Interpretative phenomenological analysis. In J.A. Smith (eds) *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage.

Vygotsky, L. S. (1978) *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

## Appendices

### Appendix A: Notes to Contributors

---

*Page Number*

NeuroRehabilitation

134

STM Publishing House | Impacting the World of Science  
Books & Journals, Online & Print

Shopping cart 0 items € 0

Home News Books & Journals Service About IOS Press Contact Search this site... Catalogue

#### Books & Journals

New releases  
Browse by subject  
Books  
Journals  
Book Series

Home Catalogue Journals NeuroRehabilitation

SHARE THIS JOURNAL

## NeuroRehabilitation

An Interdisciplinary Journal

IMPACT FACTOR 2010 **1,692**

ISSN 1053-8135  
Volume 30-31, 8 issues  
Status Last issue (30.2) online on 19 March 2012  
Next issue 30.3 scheduled for April 2012  
Back volumes 3-27  
Subject Neurosciences, Rehabilitation & Assistive Technology

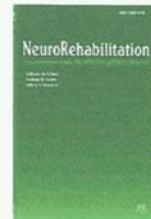
INSTITUTIONAL SUBSCRIPTION FOR 2012

€810 / US\$1132

Incl. postage and handling

Subscribe now

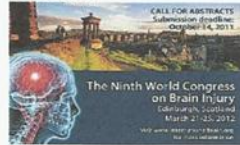
Free Sample Copy



Contents  
Current issue  
Recommend this title to your librarian

20th Anniversary Year - Celebrating 20 years of Excellence

IOS Press supports:



Aims & Scope Editorial board Submission of Manuscripts Abstracted/Indexing in Conferences News

Manuscripts should initially be submitted electronically using [the submission system](#). Please include figures and tables as separate pages at the end of the manuscript file.

#### Required files

The following electronic files are required:

- a word processor file of the text, such as Word, WordPerfect, LaTeX (If using LaTeX, please use the standard article.sty as a style file and also send a pdf version of the LaTeX file)
- separate files of all figures (if any), see "Preparation of manuscripts" for the required file formats.

#### Colour figures

It is possible to have figures printed in colour, provided the cost of their reproduction is paid for by the author. See Preparation of Manuscripts for the required file formats.

#### PREPARATION OF MANUSCRIPTS

##### Organization of the paper and style of presentation

Manuscripts must be written in English. Authors whose native language is not English are advised to seek the advice of a native English speaker, before submitting their manuscripts.

You can also visit [www.international-scienceediting.com](http://www.international-scienceediting.com). International Science Editing offers a language and copyediting service to all scientists who want to publish their manuscript in scientific peer-reviewed periodicals and books.

Manuscripts should be prepared with wide margins and double spacing throughout, including the abstract, footnotes and references. Every page of the manuscript, including the title page, references, tables, etc., should be numbered. However, in the text no reference should be made to page numbers; if necessary, one may refer to sections. Try to avoid the excessive use of italics and bold face.

Manuscripts should be organized in the following order:

- Title page
- Body of text (divided by subheadings)
- Acknowledgements

<http://www.iospress.nl/journal/neurorehabilitation/>

22/03/2012

- References
- Tables
- Figure captions
- Figures

Headings and subheadings should be numbered and typed on a separate line, without indentation.

SI units should be used, i.e., the units based on the metre, kilogramme, second, etc.

#### Title page

The title page should provide the following information:

- Title (should be clear, descriptive and not too long)
- Name(s) of author(s); please indicate who is the corresponding author
- Full affiliation(s)
- Present address of author(s), if different from affiliation
- Complete address of corresponding author, including tel. no., fax no. and e-mail address
- Abstract; should be clear, descriptive, self-explanatory and not longer than 200 words, it should also be suitable for publication in abstracting services
- Keywords

#### REFERENCES

1. APA style uses author-date citation system where the author's surname and year of publication are listed. If using a direct quote, include page numbers. Only articles published or accepted for publication should be listed in the reference list. Submitted articles can be listed in the text as (author(s), unpublished data). See [www.apa.org](http://www.apa.org) for more information.

2. All authors should be listed in the reference list.

3. References must be listed in APA style (alphabetically):

Anderson, A. K. (2005). Affective influences on the attentional dynamics supporting awareness. *Journal of Experimental Psychology: General*, 134, 258–281.

Anderson, A. K., Christoff, K., Panitz, D., De Rosa, E., & Gabrieli, J. D. E. (2003). Neural correlates of the automatic processing of threat facial signals. *Journal of Neuroscience*, 23, 5627–5633.

Armony, J. L., & Dolan, R. J. (2002). Modulation of spatial attention by fear-conditioned stimuli: An event-related fMRI study. *Neuropsychologia*, 40, 817–826.

Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56, 893–897.

Calvo, M. G., & Lang, P. J. (2004). Gaze patterns when looking at emotional pictures: Motivationally biased attention. *Motivation and Emotion*, 28, 221–243.

Carrette, L., Hinojosa, J. A., Martin-Loeches, M., Mecedo, F., & Tapia, M. (2004). Automatic attention to emotional stimuli: Neural correlates. *Human Brain Mapping*, 22, 290–299.

#### Tables

Tables should be numbered according to the sequence in the text. The text should include references to all tables.

Each table should be provided on a separate page of the manuscript. Tables should not be included with the text content.

Each table should have a brief and self-explanatory title.

Column headings should be brief, but sufficiently explanatory. Standard abbreviations of units of measurement should be added between parentheses.

Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.

Any explanations essential to the understanding of the table should be given in footnotes at the bottom of the table.

Table captions should be provided all together on a separate page.

#### Footnotes

Footnotes should only be used if absolutely essential. In most cases it is possible to incorporate the information in the text.

If used, they should be numbered in the text, indicated by superscript numbers and kept as short as possible.

#### Figures

Figures should be numbered according to the sequence in the text. The text should include references to all figures.

Each figure should be provided on a separate sheet. Figures should not be included in the text.

Colour figures can be included, provided the cost of their reproduction is paid for by the author.

For the file formats of the figures please take the following into account:

- Line art should have a minimum resolution of 600 dpi, save as EPS or TIFF
- Grayscales (incl photos) should have a minimum resolution of 300 dpi (no lettering), or 500 dpi (when there is lettering); save as tiff
- Do not save figures as JPEG, this format may lose information in the process
- Do not use figures taken from the Internet, the resolution will be too low for printing
- Do not use colour in your figures if they are to be printed in black & white, as this will reduce the print quality (note that in software often the default is colour, you should change the settings)
- For figures that should be printed in colour, please send a CMYK encoded EPS or TIFF

Figures should be designed with the format of the page of the journal in mind. They should be of such a size as to allow a reduction of 50%.

On maps and other figures where a scale is needed, use bar scales rather than numerical ones, i.e., do not use scales of the type 1:10,000. This avoids problems if the figures need to be reduced.

Each figure should have a self-explanatory caption. The captions to all figures should be typed on a separate sheet of the manuscript.

Photographs are only acceptable if they have good contrast and intensity.

Each illustration should be provided on a separate page. Illustrations should not be included in the text. The original drawings (no photocopies) are required. Electronic files of illustrations should preferably be formatted in Encapsulated PostScript Format.

Footnotes should be kept to a minimum, and they should be provided all together on a separate page.

#### COPYRIGHT

##### Copyright of your article

Authors submitting a manuscript do so on the understanding that they have read and agreed to the terms of the [IOS Press Author Copyright Agreement](#).

##### Quoting from other publications

An author, when quoting from someone else's work or when considering reproducing figures or table from a book or journal article, should make sure that he is not infringing a copyright. Although in general an author may quote from other published works, he should obtain permission from the holder of the copyright if he wishes to make substantial extracts or to reproduce tables, plates or other figures. If the copyright holder is not the author of the quoted or reproduced material, it is recommended that the permission of the author should also be sought. Material in unpublished letters and manuscripts is also protected and must not be published unless permission has been obtained. Submission of a paper will be interpreted as a statement that the author has obtained all the necessary permission. A suitable acknowledgement of any borrowed material must always be made.

#### PROOFS & PURCHASES

##### PDF Proofs

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.

##### How to order reprints, a pdf file, journals, or IOS Press books

For each contribution the corresponding author will receive a complimentary Author's Copy (watermarked) pdf of their published article. This pdf is for personal use only. Free copies will not be provided for conference proceedings and abstract issues. An order form for reprints, additional journal copies or a pdf file will be provided along with the pdf proof.

If you wish to order reprints of an earlier published article, please contact the publisher for a quotation. IOS Press, Fax: +31 20 6870039. Email: [editorial@iospress.nl](mailto:editorial@iospress.nl).

An author is entitled to 25 % discount on IOS Press books. See [Author's Discount \(25%\)](#) on all IOS Press book publications.

---

#### Contact

[North America](#)  
[Europe](#)  
[Asia](#)

#### IOS Press Copyright 2012

[Disclaimer](#) [Sitemap](#) [FAQ](#)

[FOLLOW US  
ON TWITTER](#)

[Expand](#)  
[next/previous](#)  
[Close](#)

[Previous](#)

[00](#)

[Next](#)

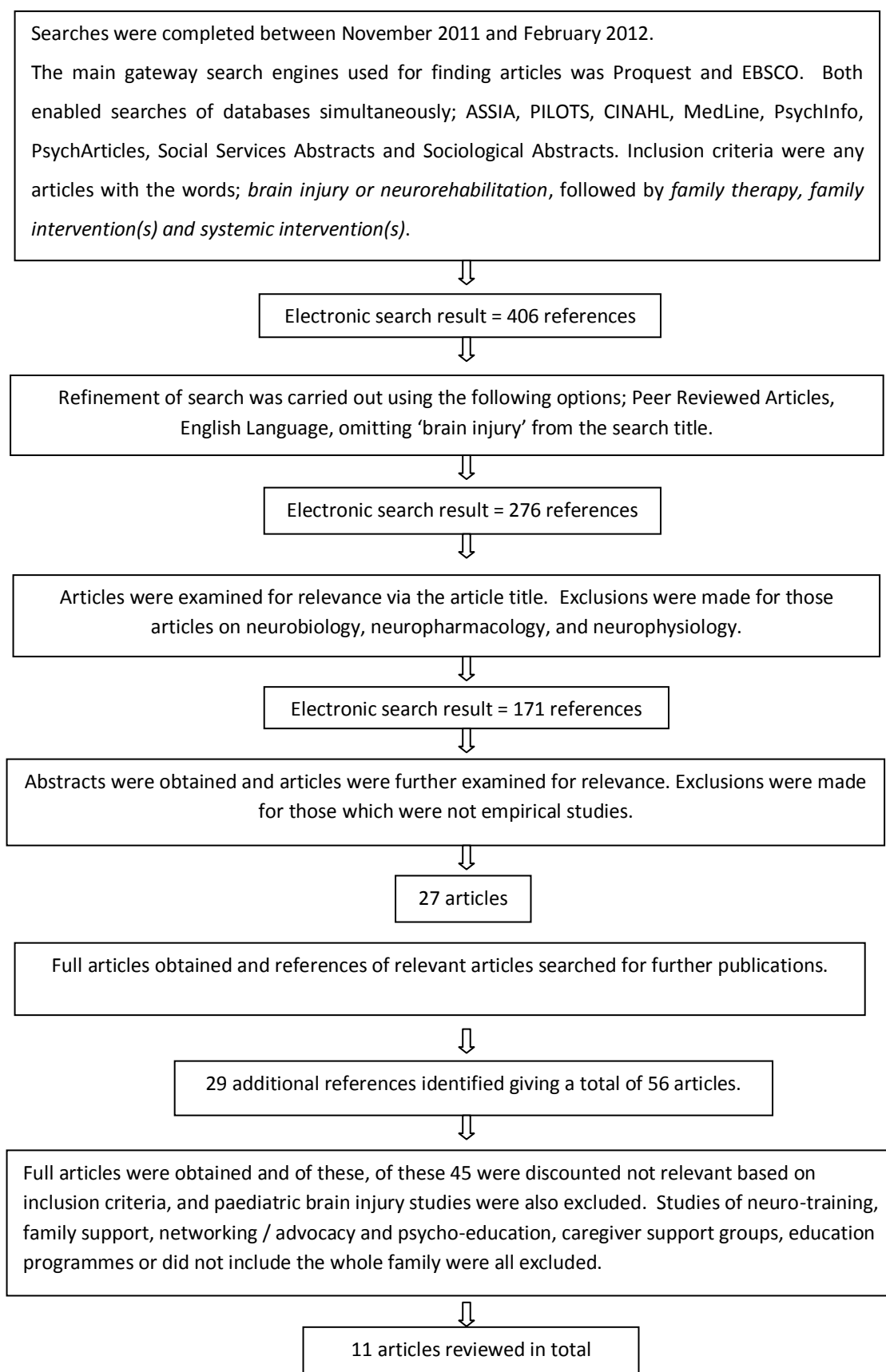


## Appendix B: Literature Review Appendices

---

	<i>Page Number</i>
Map of search strategy for literature review paper	138
Reliability & validity of measures used in studies reviewed	139

## Map of Search Strategy for Reviewed Articles



## **Reliability & Validity of Measures used in Studies Reviewed**

A. Behavioural Assessment Systems for Children (BASC; Reynolds, & Kamphaus, 1992): A multidimensional measure evaluating children's behaviour and emotional distress from the parent and child's perspective. The BASC has been found to have high reliability and validity (Flanagan, 1995).

B. Brief Symptom Inventory-18 (BSI-18; Derogatis, L.R., 2000): 18 item self-report measure to assess psychological distress in the general population, and more recently family members' distress after ABI (Kreutzer, Gervasio & Camplair, 1994). Reported to have robust psychometrical properties (Meachen, Hanks, Millis, Rapport, 2008).

C. Dyadic Adjustment Scale (DAS; Weiss & Perry, 1979): Measures couples' functioning. T scores below 30 indicating dysfunction. The DAS has been used with ABI populations [Farrington, 2004; Kalpakjian, 2001].

D. Eysenck's Personality Inventory (EPI; Eysenck, 1964): A self-report personality inventory which measures two pervasive, independent dimensions of personality: Extraversion-Introversion and Neuroticism-Stability. Considered to have acceptable psychometric properties which measure dimensions of personality.

E. Family Assessment Device (FAD; Epstein, Baldwin & Bishop): A self-report scale designed to measure six areas of family functioning; Problem Solving;

Communication; Roles; Affective Responsiveness; Affective Involvement; Behaviour Control and General Functioning. Cronbach's alpha for internal reliabilities of the 60 item version ranged from 0.57 for Roles to 0.83 for General Functioning in a non-clinical population of 627 (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). Reported to be an effective ABI measure after ABI (Kreutzer et al, 1994; Zarski et al, 1988).

F. Family Environment Scale (FES Form-R, Moos & Moos, 1981): Provides clinicians with a measure for assessing family members' perceptions of the way the family is: the real, the ideal and the expected way. Includes ten subscales measuring; Family Relationship, Personal Growth, System Maintenance and Change. Reliability rates for internal consistency range from 0.61 to 0.78. Inter correlations among these 10 sub-scales range from - 0.53 to 0.45 suggesting relative consistency for measuring characteristics of family environment. Test-retest reliabilities for sub-scales for 2, 3 and 12 month intervals range from 0.52 to 0.91, suggesting estimates of the scale are reasonably stable across time.

G. Family Needs Questionnaire (FNQ; Kreutzer & Marwitz, 1989): Assesses perceptions of; the importance of needs; and the extent to which each need has been met. 40 item analytically derived factors of: Community Support Network, Emotional Support, Health Information, Instrumental Support, Involvement with Care and Professional Support. Alpha reliability coefficients for the six subscales ranged from 0.78 to 0.89 demonstrating reliable and independent needs factors.

H. General Health Questionnaire (GHQ-28; Goldberg, P. & Williams, P., 1988): Scored on a Likert scale 0 – 3 and assesses; mood related symptoms, somatisation & social dysfunction. Reported to have good reliability and validity

I. Personal Rapid Scaling Technique (PQRST; Mulhall, 1978): The absence of numerical scoring and simple language enables individuals with some language difficulties to complete it. The ideographic nature allows participants' to identify feelings and attitudes using adjectives. These are incorporated in to assessment procedures to monitor progress and change. Multiple presentations of symptoms act as a validity to check for responses.

J. Profile of Mood States (POMS; Lorr, M., McNair, D.M., & Droppleman, L.F., 1971): Self-report measure to assess mood states on a 5 point adjective rating scale: Anger-Hostility, Confusion-Bewilderment, Depression-Dejection, Fatigue-Inertia, Tension-Anxiety and Vigour-Activity. Alpha coefficients have found the POMS to have high internal consistency. A reasonable level of test-retest reliability using product moment correlations reported. Factorial and content validity for each mood state also reported.

K. Satisfaction with Life Scale (SWLS; Diener et al, 1985): Measures global life satisfaction and comprised of five statements scored on a Likert scale of 1¼ (Strongly disagree) to 7¼ (Strongly agree). Lower scores indicate lower levels of life satisfaction. Normative data suggests sound convergent validity with other scales and subjective well-being assessments, as well as sufficient sensitivity to detect change and has good discriminant validity (Pavot et al, 1991).

L. Service Obstacles Scale (SOS; Marwitz & Kreutzer, 1996): Six item scale which evaluates brain injured survivors and caregivers' perceptions of quality and accessibility of ABI services in the community. Rated on a seven-point Likert-type scale from 1¼ (strongly disagree) to 7¼ (strongly agree). Lower scores indicate greater satisfaction and access to services. A recent study by Kolakowsky-Hayner et al (2000) evidenced the validity of the SOS.

M. Social Adjustment Scale – Self Report (SAS-SR, Weissman & Bothwell, 1976): 42 questions on a 5 point scale assessing psychological and social adjustment to ABI survivors and their families. Reported to have internal consistency, test-retest reliability, and standard error of measurement as three kinds of reliability.

N. Subjective Burden Scale (SBS; Zarit et al, 1980): Assesses perceived or subjective burden experienced by relatives living or caring for a brain injured survivor. 0 (no perceived burden) to 7 (severe burden or strain) point scale. Robust psychometric properties with reliability alphas ranging from 0.80 to 0.95 (Sisk, 1999).

## Appendix C: Research Methodology

---

*Page Number*

IPA procedures:	144
• Coding of transcripts and identification of emerging themes	
• Clustering of themes	
• Integrating themes across all transcripts	
• Credibility steps	
Consent & withdrawal	146
Anonymity and confidentiality of data	146
Support	147

## **Interpretative Phenomenological Analysis (IPA)**

IPA is a qualitative idiographic method (Shaw, 2010) used to explore how participants make sense of their personal and social world. It is concerned with the individual's personal perception or account of an event, as opposed to an attempt to produce an objective statement of the event (Smith & Osborn, 2003). The process of IPA moves from the particular to the general by descriptively and experientially coding first, and then moving towards a more interpretative, contextual account, using a 'bottom up' rather than a 'top down' approach to develop themes (Larkin, Watts & Clifton, 2005).

### *Coding of transcripts and identification of emerging themes:*

Each interview transcript was read and read several times to gain a general 'sense' of the overall description of the participants' experience. Transcripts were then descriptively coded in the left column and interpretively coded by identifying and labelling themes in the right-hand margin (Smith, 2003). An example is shown in Appendix G. Inferences about the nature, meaning and context of the participants' experiences were recorded.

### *Clustering of themes:*

The emerging themes from the right-hand column were listed, and those themes that seemed to have shared meaning were grouped into 'clusters'. As themes emerged, the researcher regularly checked the clusters of themes to ensure that



they accurately represented what participants had expressed. An example of this is shown in Appendix G.

*Integrating themes across all transcripts:*

The vast number of initial themes which emerged from the clustering stage of analysis warranted further sub-categorising to enhance the level of interpretation, as per Howitt (2010). See Appendix G for the list of sub-categories. Clustered themes were then integrated into a table of super-ordinate and sub-ordinate themes and excerpts were arranged and re-arranged to organise relationships between themes. Themes at this stage which were not well represented and did not add to understanding the participants' experiences were abandoned, as recommended by Smith & Osborn (2003). The final super-ordinate and sub-ordinate themes were explored through discussion with the research supervisors, to reflect on the proposed structure of the themes and check that all themes were sufficiently grounded in the original text.

*Credibility steps:*

Several steps were taken to increase the methodological rigour and 'credibility' of the interpretations and conclusions, as suggested by Elliot et al (1999) and Smith & Osborne (2003). To increase the study's integrity, the researcher undertook credibility checks by discussing the data with peer researchers and supervisors. One of the research supervisors' read through two of the transcripts and coded them, in addition to the analysis conducted by the researcher. This

process aimed to highlight points of agreement and disagreement and to promote inter-rater reliability. Excerpts of the analysis were also shared to ensure that identified themes or interpretations were grounded in the data. Individual supervision with one of the research supervisors experienced in using IPA provided an additional audit of the researcher's interpretations. Final themes were checked by the research team and discussed and feedback to the researcher to highlight alternative ideas regarding interpreting the data and endorse existing themes.

### **Consent and Withdrawal**

In view of the detailed information given to participants and the opportunity to discuss the study with the researcher, it was deemed that informed consent was obtained. Written consent was obtained from the participant (and the parent or caregiver if under the age of 16 years) prior to the interview. Participants were informed that the interview would be audiotaped and transcribed verbatim. Participants were also informed that they were free to withdraw from the study, before, during or after the interview (up to two weeks after data has been collected) with no adverse consequences. This information was discussed and clearly stated in the participant information sheet.

### **Anonymity and Confidentiality of Data**

Participant information and data collected was anonymised and stored in a locked filing cabinet located at the rehab hospital. Participants' identities were

protected by the allocation of an identification number on transcripts. Participants were informed that excerpts from their transcribed interviews may be used in the write-up but with any identifying information removed. Participants were informed of the above prior to the interview. Participants were also informed that the researcher was responsible for reporting the disclosure of information which caused concern for the safety of the participant or others to one of their supervisors initially. This information would then be passed on to relevant third parties if it was considered necessary by the supervisor. Additionally any illegal activity disclosed would need to have been reported to the police.

### **Support**

The interviewer (a Trainee Clinical Psychologist) has clinical experience of working with children and distress and is familiar with the protocols involving working sensitively. Participants were given the opportunity to stop the interview or take a break. Time was used at the end of the interview to allow for general discussion of the experience of participating. If a participant was to become distressed at any time during the interview, a break would have been offered and they would have been given the option to discontinue. If any participant had experienced any distress, they would have been encouraged to talk to their parent or contact one of the Clinical Supervisors. Contact details for the Supervisors were included on the Information Sheet. If the participant disclosed information that suggested either they or somebody else may be at imminent risk, the researcher would have considered whether it was necessary

to breach confidentiality (in accordance with the BPS Code of Ethics and Conduct, 2006 and the Health Professions Council Standards of conduct, performance and ethics, 2008). The researcher would have discussed this with the Clinical Supervisors and the participant if appropriate. If any participant wished to submit a complaint regarding the research, they have been given details of PALS and also Coventry University.

## **References**

Larkin, M., Watts, S. & Clifton, E. (2005) Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3, 102-120

Shaw, R. L. (2010) Interpretative phenomenological analysis. In M. Forrester (Ed.) *Doing qualitative research in psychology*. London: Sage

## Appendix D: Research Activities

---

	<i>Page Number</i>
Interview Schedule	150
Step-by-step guide to carrying out 'Heartstrings' activity	151
Example 'Heartstrings'	152

## Interview Schedule

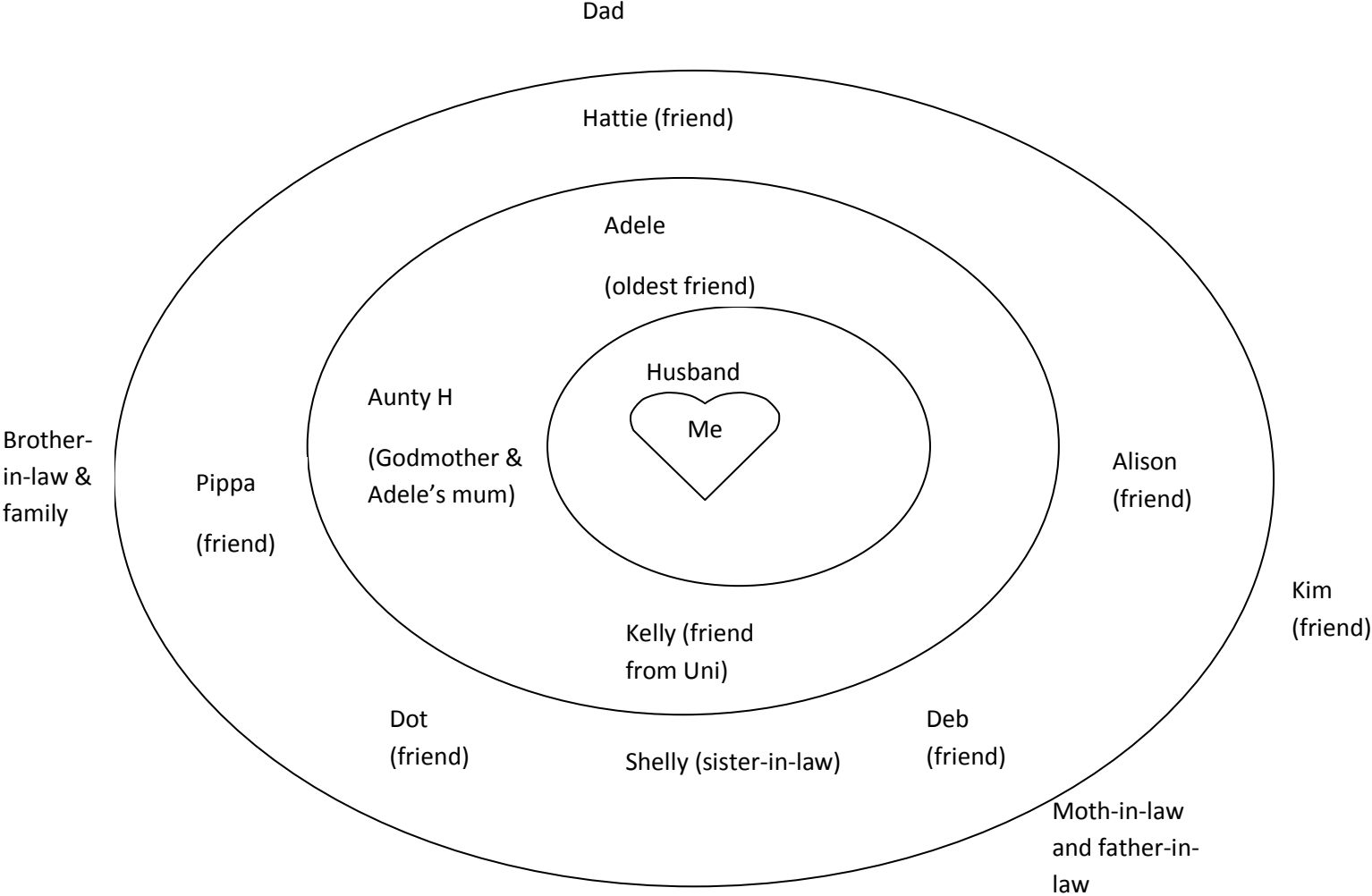
Discussions will take place around each person and may include the following questions (this may vary depending on the answers given):

- I. Tell me about (*name*) and your relationship with them.
  - a. How long have you known (*name*)?
  - b. What kind of things do you do with them?
  - c. How often do you see (*name*)?
  - d. What is it like spending time with (*name*)?
  - e. Who do you go to if you need something?
  - f. Who do you go to for comfort?
  - g. How does your relationship compare now to how it was before the brain injury?
  - h. How has this experience made you feel?
- II. Is there anyone else in your life you spend time with?
  - a. How often do you see them?
  - b. Did you spend time with them before you mum/dad was injured?
  - c. What kind of things do you do with them?
- III. When you look at the diagram, would it look any different if we started again but this time thinking about how things were before your (mum/dad) had the accident?
  - a. Tell me a bit more about how different it would be.

### **Step-by-step guide to carrying out the 'Heartstrings' activity**

The activity involved drawing a heart in the middle of the page with the participant's initial in the centre of the heart. Circles were then drawn around the heart and the participant was asked to place names of people who were closest to them near the heart. Those people who were not so close went in to the next circle and so on, until the participant included all significant people in their lives. The researcher first asked the participant to identify someone in their life who they felt closest to. Once the participant had identified someone, they were then asked to talk about their relationship with that person, the time they spend with them and the activities they do together. The participant was then asked to think about this person before their parent had the brain injury, and to consider whether that person would have been placed in a different position on the heartstrings diagram. They were then asked to record on the diagram the position of the person in a different colour and the changes in their relationship were then discussed. This process continued until the participant felt they had included all the people they would like to. The heartstrings activity took approximately 45 minutes to one hour.

Example of 'Heartstrings'





## Appendix E: Ethical Approval Documents

---

	<i>Page Number</i>
Coventry University Certificate of Employers Liability Insurance	154
Approval from Coventry University Research Ethics Committee	155
Approval from National Research Ethics Committee, West Midlands – Coventry & Warwickshire	156
Approval from Nuffield Orthopaedic Centre, Research Governance Committee	159

# Certificate of Employers' Liability Insurance(a)

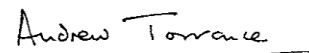
*(Where required by regulation 5 of the Employers' Liability (Compulsory Insurance) Regulations 1998 (the Regulations), one or more copies of this certificate must be displayed at each place of business at which the policyholder employs persons covered by the policy.)*

- 
1. Policy number SZ 21707594
- 
2. Name of policyholder Coventry University, Coventry University Enterprises Ltd, ACUA Ltd and Coventry University London Campus
- 
3. Date of commencement of insurance policy 01 August 2011
- 
4. Date of expiry of insurance policy 31 July 2012
- 

We hereby certify that subject to paragraph 2:-

1. The policy to which this certificate relates satisfies the requirements of the relevant law applicable in Great Britain, Northern Ireland, the Isle of Man, the Island of Jersey, the Island of Guernsey and the Island of Alderney (b); and
2. (a) the minimum amount of cover provided by this policy is no less than £5 million (c);  
 (b) ~~the cover provided under this policy relates to claims in excess of £\_\_\_\_\_ but not exceeding £~~

Signed on behalf of Allianz Insurance plc  
 Authorised Insurers



Andrew Torrance  
 Chief Executive

**Notes**

- (a) *Where the employer is a company to which regulation 3(2) of the Regulations applies, the certificate shall state in a prominent place, either that the policy covers the holding company and all its subsidiaries, or that the policy covers the holding company and all subsidiaries except any specifically excluded by name, or that the policy covers the holding company and only the named subsidiaries.*
- (b) *Specify applicable law as provided for in regulation 4(6) of the Regulations.*
- (c) *See regulation 3 (1) of the Regulations and delete whichever of paragraphs 2(a) or 2(b) does not apply. Where 2(b) is applicable specify the amount of cover provided by the relevant policy.*

MS5308

Coventry University  
Priority Street  
Coventry CV1 5FB  
Telephone 024 7688 7688

Professor Ian M Marshall  
Pro-Vice-Chancellor (Research)



## TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

Dear Sir/Madam

**Researcher's name:** Kathryn Lloyd-Williams  
**Project Title:** A qualitative study on children's relationships and how they change when a parent acquires a brain injury

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

**Professor Ian Marshall**

**Deputy Vice-Chancellor (Academic)**

Pro-Vice-Chancellor's Office  
Direct Line 024 7679 5293  
Fax 024 7688 8030

[www.coventry.ac.uk](http://www.coventry.ac.uk)



THE QUEEN'S  
ANNIVERSARY PRIZES  
FOR HIGHER AND FURTHER EDUCATION

2007



**National Research Ethics Service**  
**NRES Committee West Midlands - Coventry & Warwickshire**

Prospect House  
Fishing Line Road  
Enfield  
Redditch  
B97 6EW

Telephone: 01527 582532  
Facsimile: 01527 582540

**Date:** 16 August 2011

Mrs Kathryn Lloyd-Williams  
Trainee Clinical Psychologist  
Worcestershire Mental Health Partnership NHS Trust  
C/O Clinical Psychology Doctorate  
Coventry University  
James Starley Building  
Priority Street, Coventry  
CV1 5FB

Dear Mrs Lloyd-Williams

**Study title:** A qualitative study on children's relationships and how they change when a parent acquires a brain injury  
**REC reference:** 11/WM/0222

Thank you for your letter email of 15 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

**Conditions of the favourable opinion**

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

**Management permission or approval must be obtained from each host organisation prior to**

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in  
England

the start of the study at the site concerned.

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

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

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

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

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

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

#### Approved documents

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

Document	Version	Date
Covering Letter		12 August 2011
Evidence of insurance or indemnity		01 August 2010
Interview Schedules/Topic Guides	1	30 June 2011
Investigator CV		24 June 2011
Letter from Sponsor		27 June 2011
Other: Participant Opt-In Form	1	24 June 2011
Other: Summary CV for supervisor (Dr Knight)		17 March 2010
Other: CV - Dr Daisley		
Other: CV - Dawn Peerbhoy		10 March 2011
Participant Consent Form: Parent/Caregiver	2	05 August 2011
Participant Consent Form: Child/Young Person	2	05 August 2011
Participant Consent Form: 15 - 18 Year Olds	2	05 August 2011
Participant Information Sheet: PIS	1	24 June 2011
Participant Information Sheet: 13 - 18 Years	2	05 August 2011
Participant Information Sheet: 8 - 12 year olds	3	15 August 2011
Participant Information Sheet: Parent/Caregiver	3	15 August 2011
Protocol	1	24 June 2011
REC application	IRAS 3.1	27 June 2011

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in  
England

## After ethical review

### Reporting requirements

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

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

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

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**11/WM/0222**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

  
Dr Helen Brittain  
Chair

Email: Rosa.Downing@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Dr Eve Knight  
Coventry University

Ms Kelly Spence  
Coventry & Warwickshire Mental Health Partnership Trust

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in  
England

Nuffield   
Orthopaedic Centre  
NHS Trust

Ms Kathryn Lloyd-Williams,  
Trainee Clinical Psychologist,  
Worcestershire Mental Health Partnership  
NHS Trust, C/O Clinical Psychology  
Doctorate, Coventry University, James  
Starley Building, Priory Street, Coventry,  
CV1 5FB.

NOC Research Governance  
Nuffield Department of Orthopaedics,  
Rheumatology and Musculoskeletal Sciences,  
Nuffield Orthopaedic Centre  
Windmill Road  
Headington  
Oxford  
OX3 7LD  
Tel: 01865-737511  
**fiona.parker@ndorms.ox.ac.uk**

**Thursday 22<sup>nd</sup> September, 2011**

**CSP Study ID:** n/a  
**Ethics number:** 11/WM/0222  
**Title:** Changes in children's relationships when a parent acquires a traumatic brain injury  
(TBI)  
**Protocol code:** V1.0 24 Jun 11

Dear Ms Lloyd-Williams,

I can confirm that the Nuffield Orthopaedic Centre NHS Trust will provide management approval for the above study, as described in your application to the Research Ethics Committee and recorded in the NOC Study [or NIHR CSP Research] Governance Report.

Clinical research may be carried out in designated time within your job plan, or as additional unpaid activity in your own time if you choose. Clinical research cannot be substituted for contracted NHS activities without the prior agreement of the Clinical Director.

This letter also confirms that indemnity will be provided by the Trust for the above study, according to the information you have provided within the application form, for those study related activities that take place at the trust. This confirmation is also subject to the formal approval of the Research Ethics Committee and on the understanding that the study staff having patient contact at the Trust have a contract of employment with this Trust.

Trust management approval is ongoing and dependent upon completion of satisfactory annual reports to the Research Ethics Committee, Sponsor and the Trust. Please ensure all annual reports to the ethics committee are copied to NOC Research Governance at the above address to track study progress.

Any substantial amendments to your protocol needs to be approved by both the Ethics Committee and the Trust to NOC Research Governance, through the NIHR CSP process if used for NHS approval. This approval can be processed in parallel with each application. Non-substantial amendments also need to be reported to NOC Research Governance. Please check <http://www.nres.npsa.nhs.uk/applications/after-ethical-review> for more information.

I note that Coventry University has agreed to sponsor this study.

I wish you every success with the study.

Yours sincerely,



Mrs Jan Fowler  
Chief Executive

**Copy to Sponsor Contact: Professor Ian Marshall, AB125, Coventry University,  
CV1 5FB.**

## Appendix F: Participant Information

---

	<i>Page Number</i>
Participant Opt-In Slip	161
Parent/Caregiver Information Sheet	162
Participant Information Sheet (aged 8-12 yrs)	167
Participant Information Sheet (aged 13-16yrs)	170
Parent/caregiver Consent Form	177
Consent Form (aged 8-15yrs)	178
Consent Form (aged 16-18 yrs)	179



**PARTICIPANT OPT - IN FORM**

“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”

I am interested in taking part in the research and give my consent for the researcher, Kathryn Lloyd-Williams to contact me to discuss the research and with a view to arranging for me to take part in this study.

Signed: \_\_\_\_\_

Please print name: \_\_\_\_\_

Date: \_\_\_\_\_

Please give a contact number or email address for the researcher, Kathryn, to contact you.

Contact number:

\_\_\_\_\_

Email address:

\_\_\_\_\_

Thank you for completing this.

An envelope is provided for you to return this to the researcher, Kathryn.

## PARENT/CAREGIVER INFORMATION SHEET

### **“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”**

Hello. My name is Kathryn Lloyd-Williams and I am training to be a Clinical Psychologist at Coventry and Warwick Universities. As part of my training I am required to carry out a piece of research in order to complete the course. The area of research I would like to carry out is looking at children’s relationships and how these are affected when a parent/caregiver has a brain injury. I am asking children and young people aged between the ages of 8 to 18 if they would like to take part in this research.

I think it is important for adults to understand how much this can affect children’s relationships - not just their relationship with parents but with siblings, friends, teachers and anyone else they have a relationship with. This is an opportunity for children and young people to have their voice heard and share their experiences.

#### **What will my child have to do?**

I would like to talk to your child about their relationships with people in their life. I would like to know what these relationships were like before their parent/caregiver had a brain injury, what their relationship is like now after the brain injury, and how it has affected their relationship with other people in their life.

During the session we will do an activity called ‘Heartstrings’. This will involve drawing a heart shape in the middle of a piece of paper and putting their name in the middle of the heart. Then we will draw rings around the heart and put people’s names in between the rings. The rings represent how close people are to them so the further away from their heart the rings are, the less close these people are to them.

The purpose of this activity is to help children/young people think about people in their life, and it might make it easier to talk about their experiences. I also hope that they will find the activity interesting and fun!

**Where will the discussion take place?**

The discussions can take place at the Oxford Centre for Enablement, which is the centre where their parent might be at the moment, or they may attend as an out-patient, or might have attended in the past. If your child prefers, I can arrange for the discussion to take place at home. The session will take approximately 60 minutes and will be recorded so that I can listen to what we talk about in more detail later on.

**What will happen to the information my child gives at the interview?**

The interview will be tape-recorded and I will then listen to the recording and type everything they say on to a computer. I will not include your child's name or personal details on the recording or the information typed. This will be kept private. Once I have completed the research the recordings will be destroyed.

**Do they have to take part?**

No. Your child does not have to take part in the research and they do not have to give a reason why. They can also withdraw from the research before, during or after session, and up to two weeks after the information has been collected. This is because after this time, the information collected from their session will be anonymised and added to information from interviews with other participants. It would be difficult for me to take out their information at this point. If they do want to withdraw any time before this point, it is ok to and it will not affect the care their parent receives.

**What will happen to the results of the research?**

The results of the research will be written into a report and published in a journal that will be read by other professionals who work with people who have had a brain

injury. A written summary will be sent to all the children and their families who take part in the research, to tell them the results of the research.

**What if my child gets upset by what we discuss?**

It is completely normal for someone to get upset when talking about something personal. It is hoped that the discussion will not upset them but if it does, then they will be encouraged to talk to you, or I will arrange for a clinician in the Department of Clinical Psychology to talk to them.

**What if my child discloses something during the session?**

At the beginning of the session I will explain to your child that if they disclose something which worries me or I feel puts them or anyone else in danger, I will need to tell you and a clinician. I will always tell your child at the time that this is what I need to do.

**Are there any benefits to taking part in the research?**

There are no financial benefits to taking part, however, your child may find it helpful talking to someone who is not involved in your family, about their experiences. It is an opportunity for their voice to be heard, and to increase the awareness amongst health professionals and the public, about the impact having a parent with a brain injury has on children and young people. Furthermore, it is hoped that the data collected from this research will contribute towards the evidence base for increasing resources for families.

**What to do now**

If you are happy for your child to take part in the research please complete the parent consent form attached to this. Your child will then be able to return both consent forms and I will then contact them to discuss in more detail the research and to arrange a time to meet them.

**What if I want to know more before I decide to give consent?**

If you have any further questions I would be happy to answer them. Alternatively, you can contact my supervisors Dr Audrey Daisley, Dr Dawn Peerbhoy and Dr Eve Knight. Our contact details are:

**Research Team Contact Details:**

Dr Audrey Daisley

Consultant Clinical Neuropsychologist  
Dept. of Clinical Psychology  
Oxford Centre for Enablement  
NOC NHS Trust  
Windmill Road  
Headington  
Oxford, OX3 7LD



Tel: 01865 737365



Email: [Audrey.Daisley@noc.nhs.uk](mailto:Audrey.Daisley@noc.nhs.uk)

Dr Dawn Peerbhoy

Clinical Psychologist  
Dept. of Clinical Psychology  
Oxford Centre for Enablement  
NOC NHS Trust  
Windmill Road  
Headington  
Oxford, OX3 7LD



Tel: 01865 737365



Email: [Dawn.Peerbhoy@noc.nhs.uk](mailto:Dawn.Peerbhoy@noc.nhs.uk)

Dr Eve Knight (Academic Supervisor) / Kathryn Lloyd-Williams (Main Researcher)

Clinical Psychology Doctorate Programme  
Coventry and Warwick Universities  
Coventry University  
Priory Street, Coventry, CV1 5FB



Tel. 024 7688 8328



E-mail: [e.knight@coventry.ac.uk](mailto:e.knight@coventry.ac.uk) or [willi352@coventry.ac.uk](mailto:willi352@coventry.ac.uk)

**Thank you for reading this.**

### **Ethical Approval**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked and approved by the National Research Ethics Committee West Midlands- Coventry and Warwickshire: NRES Ethical Approval Number; 11/WM/0222  
Protocol code: V1. 0 24 June 11

### **Independent Complaints**

It is important to us that all of those involved in the research project are satisfied with the way it has been carried out. If there is something that you are not happy about please contact one of the research team as soon as possible. If you remain dissatisfied there is an independent complaints procedure. Please contact:

### **Advice & Liaison Service (PALS):**

Nuffield Orthopaedic Centre  
Windmill Rd  
Headington  
Oxford  
OX3 7LD



01865 738126



pals@noc.nhs.uk

## **PARTICIPANT INFORMATION SHEET (8-12yrs)**

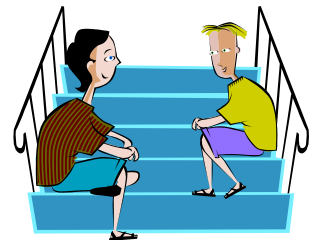
### **“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”**

Hello. My name is Kathryn Lloyd-Williams and I am training to be a Clinical Psychologist at Coventry and Warwick Universities. As part of my training I am required to carry out a piece of research in order to complete the course. The area of research I would like to carry out is looking at children’s relationships and how these are affected when a parent/caregiver has a brain injury.

I am asking children and young people aged between the ages of 8 to 18 if they would like to take part in this research. I would like to ask if you would be interested in taking part in my research.

#### **What you will be asked to do**

I would like to talk to you about your relationships with people in your life including family and friends. I would like to know what these relationships were like before your parent/caregiver had a brain injury and what they are like now.



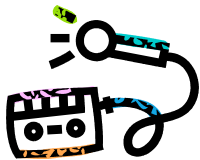
During the session we will do an activity called ‘Heartstrings’. We will draw a heart shape in the middle of a piece of paper and put your name in the middle of the heart. Then we will draw rings around the heart and put people’s names in between the rings. The activity is to help you talk about your experiences. I hope that you will also find the activity fun to do!

#### **Where will we talk?**

We can talk at the centre where your parent might be at the moment, or they may go there for appointments. It is called the Oxford Centre for Enablement.

Also, they might have been at the centre in the past, but no longer need to go. If you prefer, I can arrange for us to talk at your home. The session will take approximately 60 minutes.

**What will happen to your information from the interview?**



The interview will be tape-recorded. I will listen to the recordings later and type everything you say on to a computer. I will not include your name or personal details on the recording or the information typed up. This will be kept private. Once I have completed the research the recordings will be destroyed.

**Do you have to take part?**

No. You do not have to take part and you do not have to give a reason why. You can also stop being part of the research before we meet, or during our session. You can also decide to stop being part of the research after our session. 2 weeks after our session your information will be added to information from interviews with other children who have taken part. It would be difficult for me to take out your information at this point. If you do want to stop taking part it will not affect the care your parent receives.

**What will happen to the results of the research?**

The results of the research will be written into a report that will be read by other professionals who work with people who have had a brain injury. A written summary will be sent to all the children and their families who take part in the research, to tell them the results of the research.



**What will happen if you get upset by what we discuss?**

It is completely normal for someone to get upset when talking about something personal. It is hoped that the discussion will not upset you but if it does, then you



will be encouraged to talk to your parents, or I will find someone in the Department of Clinical Psychology for you to talk to.

**What will happen if you say something that worries me during the session?**

At the beginning of the session I will explain that if you tell me something which worries me, or I feel puts you or someone else in danger, I will need to tell your parents and a clinician. I will always tell you if I need to do this.

**Are there any benefits for taking part in the research?**

I am unable to give you anything for taking part, however, you may find it helpful talking to someone who is not involved in your family, about your experiences. It is a chance for you to have your views heard on what it is like having a parent with a brain injury. Also, it is hoped that the results from this research will help other people work in brain injury services to think about helping other families like your family.

**What to do now**

If you are interested in taking part in the research please complete the child/young person consent form attached to this and return it in the envelope provided. If you are under 16 years of age you will also need to ask your parent to consent to you taking part. Please pass on the information sheet for parents/caregivers. Once I have received the consent form(s) I will then contact you to discuss in more detail the research and to arrange a time for us to meet.

**What if you want to know more before you decide to consent?**

If you or your parent/caregiver has any questions I would be happy to answer them. Alternatively, you can contact my supervisors  
Dr Audrey Daisley, Dr Dawn Peerbhoy and Dr Eve Knight. Our contact details are:



**Research Team Contact Details:**

Dr Audrey Daisley

Consultant Clinical Neuropsychologist

Department of Clinical Psychology

Psychology

Oxford Centre for Enablement

NOC NHS Trust

Windmill Road, Headington

Oxford OX3 7LD



01865 737365



Audrey.Daisley@noc.nhs.uk

Dr Dawn Peerbhoy

Clinical Psychologist

Department of Clinical

Psychology

Oxford Centre for Enablement

NOC NHS Trust

Windmill Road, Headington

Oxford OX3 7LD



01865 737365



Dawn.Peerbhoy@noc.nhs.uk

Dr Eve Knight (Academic Supervisor) / Kathryn Lloyd-Williams (Main Researcher)

Clinical Psychology Doctorate Programme

Coventry and Warwick Universities

Coventry University

Priory Street

Coventry

CV1 5FB



024 7688 8328



e.knight@coventry.ac.uk or [willi352@coventry.ac.uk](mailto:willi352@coventry.ac.uk)

**Thank you for reading this.**

### **Ethical Approval**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked and approved by the National Research Ethics Committee West Midlands- Coventry and Warwickshire: NRES Ethical Approval Number; 11/WM/0222

Protocol code: V1.0 24 June 11

### **Independent Complaints**

It is important to us that everyone involved in the research project is happy with the way it has been carried out. If there is something that you are not happy about please contact one of the research team as soon as possible. If you are still unhappy there is someone you can contact who is not part of the research. Please contact:

#### **Advice & Liaison Service (PALS):**

Nuffield Orthopaedic Centre

Windmill Rd

Headington

Oxford

OX3 7LD



01865 738126



pals@noc.nhs.uk

## PARTICIPANT INFORMATION SHEET

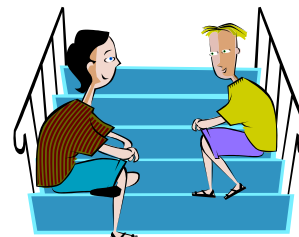
### **“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury” (13-18yrs)**

Hello. My name is Kathryn Lloyd-Williams and I am training to be a Clinical Psychologist at Coventry and Warwick Universities. As part of my training I am required to carry out a piece of research in order to complete the course. The area of research I would like to carry out is looking at children’s relationships and how these are affected when a parent/caregiver has a brain injury.

I am asking children and young people aged between the ages of 8 to 18 if they would like to take part in this research. I would like to ask if you would be interested in taking part in my research.

#### **What will you have to do?**

I would like to talk to you about your relationships with people in your life, including family and friends. I would like to know what these relationships were like before your parent/caregiver had a brain injury, and what they are like now.

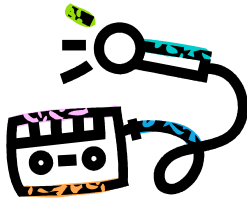


During the session we will do an activity called ‘Heartstrings’. This will involve drawing a heart shape in the middle of a piece of paper and putting your name in the middle of the heart. Then we will draw rings around the heart and put people’s names in between the rings. The rings represent how close people are to you so the further away from your heart the rings are, the less close these people are to you. The purpose of this activity is to help you think about people in your life, and it might make it easier to talk about your experiences. I hope that you will also find the activity interesting.

### **Where will the discussion take place?**

The discussions can take place at the Oxford Centre for Enablement, which is the centre where your parent might be at the moment, or they may attend as an out-patient, or they might have attended in the past. If you prefer, I can arrange for the discussion to take place at your home. The session will take approximately 60 minutes.

### **What will happen to the information you give at the interview?**



The interview will be tape-recorded and I will then listen to the recording and type everything you say on to a computer. I will not include your name or personal details on the recording or the information typed up. This will be kept private. Once I have completed the research the tape recordings will be destroyed.

### **Do you have to take part?**

No. You do not have to take part in the research and you do not have to give a reason why. You can also withdraw from the research before, during or after session, and up to two weeks after the information has been collected. This is because after this time, the information collected from your session will be anonymised and added to information from interviews with other young people. It would be difficult for me to take out your information at this point. If you do want to withdraw any time before this point, it is ok to and it will not affect the care your parent receives.

### **What will happen to the results of the research?**

The results of the research will be written into a report and published in a journal that will be read by other professionals who work with people who have had a brain injury. A written summary will be sent to all the children and their families who take part in the research, to tell them the results of the research.



**What if you get upset by what we discuss?**

It is completely normal for someone to get upset when talking about something personal. It is hoped that the discussion will not upset you but if it does, then you will be encouraged to talk to your parents, or I will find someone in the Department of Clinical Psychology for you to talk to.

**What will happen if you say something that worries me during the session?**

At the beginning of the session I will explain that if you tell me something which worries me, or I feel puts you or someone else in danger, I will need to tell your parents and a clinician. I will always tell you if I need to do this.

**Are there any benefits for taking part in the research?**

There are no financial benefits to taking part, however, you may find it helpful talking to someone who is not involved in your family, about your experiences. It is an opportunity for your voice to be heard, and to increase the awareness amongst health professionals and the public, about the impact having a parent with a brain injury has on children and young people. Furthermore, it is hoped that the data collected from this research will contribute towards the evidence base for increasing resources for families.

**What to do now**

If you are interested in taking part in the research please complete the child/young person consent form attached to this and return it in the envelope provided. If you are under 16 years of age you will also need to ask your parent to sign the parent consent form. Once I have received the consent form(s) I will contact you to discuss the research and to arrange a time for us to meet.

**What if I want to know more before I decide to consent?**



If you or your parent/caregiver has any questions I would be happy to answer them. Alternatively, you can contact my supervisors Dr

Audrey Daisley, Dr Dawn Peerbhoy and Dr Eve Knight. Our contact details are:

**Research Team Contact Details:**

Dr Audrey Daisley

Consultant Clinical Neuropsychologist  
Dept. of Clinical Psychology  
Oxford Centre for Enablement  
NOC NHS Trust  
Windmill Road, Headington  
Oxford, OX3 7LD



01865 737365



[Audrey.Daisley@noc.nhs.uk](mailto:Audrey.Daisley@noc.nhs.uk)

Dr Dawn Peerbhoy

Clinical Psychologist  
Dept. of Clinical Psychology  
Oxford Centre for Enablement  
NOC NHS Trust  
Windmill Road, Headington  
Oxford, OX3 7LD



01865 737365



[Dawn.Peerbhoy@noc.nhs.uk](mailto:Dawn.Peerbhoy@noc.nhs.uk)

Dr Eve Knight (Academic Supervisor) / Kathryn Lloyd-Williams (Main Researcher)  
Clinical Psychology Doctorate Programme  
Coventry and Warwick Universities  
Coventry University  
Coventry, CV1 5FB



024 7688 8328



[e.knight@coventry.ac.uk](mailto:e.knight@coventry.ac.uk) or [willi352@coventry.ac.uk](mailto:willi352@coventry.ac.uk)

**Thank you for reading this.**

### **Ethical Approval**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked and approved by the National Research Ethics Committee West Midlands- Coventry and Warwickshire: NRES Ethical Approval Number; 11/WM/0222

Protocol code: V1. 0 24 June 11

### **Independent Complaints**

It is important to us that everyone involved in the research project is happy with the way it has been carried out. If there is something that you are not happy about please contact one of the research team as soon as possible. If you are still unhappy there is someone you can contact who is not part of the research. Please contact;

### **Advice & Liaison Service (PALS)**

Nuffield Orthopaedic Centre

Windmill Rd

Headington

Oxford

OX3 7LD



01865 738126



pals@noc.nhs.uk



## CONSENT FORM FOR PARENT/CAREGIVER

**“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”**

**PLEASE COMPLETE THIS IF YOU AGREE FOR YOUR CHILD TO TAKE PART IN THE STUDY**

Please tick the box if you agree with the statement

1. I have read and I understand the information sheet for this research.
2. I have had the opportunity to discuss the research with Kathryn.
3. I understand that my child’s participation is voluntary. They can withdraw from the research at any time up to two weeks after the interview, without giving reason.
4. I understand that if my child does wish to withdraw, this will not affect the services we currently receive.
5. I understand that findings from this research will be written up for publication in journals read by other professionals who work with people with brain injuries.
6. I understand that quotations from my child may be used but with all identifying information removed.
7. I agree for my child to take part in this research study if they wish to.
8. I agree for my child’s session to be tape-recorded.

\_\_\_\_\_ / / \_\_\_\_\_  
Name of parent/caregiver      Date      Signature  
(Please print your name)

**Thank you for completing this form.**

**CONSENT FORM FOR PARTICIPATING CHILD/YOUNG PERSON (8-15yrs)**

**“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”**

**Please circle all you agree with**

1. Have you read about (or had read to you) this project? Yes/No
2. Has somebody else explained this project to you? Yes/No
3. Do you understand what this project is about? Yes/No
4. Have you asked all the questions you want? Yes/No
5. Have you had your questions answered in a way you understand? Yes/No
6. Do you understand it’s OK to stop taking part if you want to? Yes/No
7. Are you happy to take part? Yes/No
8. Are you happy for your session to be tape-recorded Yes/No

If you have answered yes to all the questions and you do want to take part, please

write your name below:

Print Name \_\_\_\_\_ Date \_\_\_\_\_

Please sign here \_\_\_\_\_

**Thank you for completing this form.**

---

To be completed by the researcher

Name of researcher:

Signature & date of consent:

**CONSENT FORM FOR PARTICIPATING YOUNG PERSON (16-18yrs)**

**“A qualitative study on children’s relationships and how they change when a parent acquires a brain injury”**

**Please tick the box if you agree with the statement**

- |    |   |                          |
|----|---|--------------------------|
| 1. | I confirm that I have read and understand the information sheet.  | <input type="checkbox"/> |
| 2. | I have had the opportunity to discuss the research with someone.  | <input type="checkbox"/> |
| 3. | I understand that taking part in the research is voluntary and I can withdraw any time up to two weeks after the interview, without giving reason.                    | <input type="checkbox"/> |
| 4. | I understand that if I wish to withdraw from the research, this will not affect the services my family currently receive.   | <input type="checkbox"/> |
| 5. | I understand that findings from this research will be written up for publication<br>in journals read by other professionals who work with people with brain injuries. | <input type="checkbox"/> |
| 6. | I understand that quotations from my interview may be used but with all identifying information removed.  | <input type="checkbox"/> |
| 7. | I would like take part in the study.  | <input type="checkbox"/> |
| 8. | I agree for my session to be tape-recorded.   | <input type="checkbox"/> |

---

Name of young person	Date	Signature
----------------------	------	-----------

**Thank you for completing this form.**

---

**To be completed by the researcher:**

---

Signature	Date	Name of researcher
-----------	------	--------------------

## Appendix G: Data analysis

---

*Page number*

Example transcript with descriptions and emerging themes	181
Example of clustering themes process	183
List of sub-categories of emerging themes	185

21<sup>st</sup> December 2011  
Participant 02  
R = Researcher  
P = Participant

being  
upset -  
making  
mum  
upset

not  
wanting  
to upset  
people

Grandma

Comfort

Grandma  
close

- 85 (P) I don't want to go to her saying that I'm upset because I think it might  
86 make her upset.  
87 (R) Really? It sounds like you are protecting her?  
88 (P) Yeh, I really don't want to like upset her more than what she is already  
89 upset.  
90 (R) Right. Gosh. That's really thoughtful of you to think like that. I just wonder  
91 then, who do you go to for comfort? Who is around for you?  
92 (P) My grandma. I go to her sometimes. | And then I go to mum when I know  
93 she is in a good mood 'cos something's like good happened like they've just  
94 gone to the theatre or something like that, she's really enjoyed it. I go to mum  
95 when she's like, when I know she's in a good mood.  
96 (R) OK. So, there might be occasions when you go to her for a bit of support or  
97 comfort, but it sounds like it's only when you think she's ok to deal with it?  
98 (P) Yeh.  
99 (R) Right, ok. And so I guess we've touched on grandma, it sounds like  
100 grandma is taking a bit of a role for support is that right?  
101 (P) Yeh.  
102 (R) So shall we put grandma somewhere then? Where is Grandma at the  
103 moment?  
104 (p draws on the paper)  
105 (R) That's great. So grandma is really close then?

TALKING  
ON EG SKIS

PROTECTING  
MUMS  
EMOTIONAL  
NEEDS  
WEL  
HER AN.

PROTECTING  
SCARED TO  
LOSE  
FRAGILITY

HYPERSENSITIVE  
TO GOOD STATE  
TO BEHOLD

MINDFUL  
MONITORING  
WHEN SAFE  
TO APPROACH  
MUM.

SEEKING  
SUPPORT  
MUM AS  
AVAILABLE  
FOR MUM.

CHANGING  
ATTENTION  
TO GRANDMA.

21<sup>st</sup> December 2011  
Participant 02  
R = Researcher  
P = Participant

106 (P) Yeh.

107 (R) So tell me a little bit about your relationship with your grandma now, and  
108 how often you see her. *Relationship & grandma* *INCREASES FREQUENCY INTENSITY OF CONTACT & GRANDMA.*

109 (P) I see her almost every day.

110 (R) Do you? And is this your mum's mum or your dad's mum?

111 (P) Erm, my mum's mum.

112 (R) OK. So you see her everyday?

113 (P) Yes because my mum's got to work and she can't erm always leave work  
114 early and because erm, I've seen my grandma twice as more than I used to see  
115 her. *See grandma more* *SWITCHING ROLES. MAIN ATTACHED FIGURE*

116 (R) Right.

117 (P) Because my mum can't leave work early because she needs the money to  
118 help her. *mum needs money* *FINANCIAL STRAIN/ NEEDS.*

119 (R) Yes. So grandma is coming and taking on some of the parenting role.

120 (P) Yeh.

121 (R) And what's that like for you?

122 (P) Erm, it's good 'cos I know that there is someone I can go to, like, if I'm hurt  
123 or worried about something. *Grandma's support* *DEVELOPING CLOSE ATTACHED* *BEING CARED FOR.*

124 (R) And so do you see grandma differently, and I'm thinking about when you  
125 are upset about something. So you know, where <sup>is your</sup> are with your mum you will

POI

Pre-Injury

- developing bond & dad
- establishing secure attachment to dad
- providing for the family
- sending me to sleep at night
- source of comfort and support.
- reliable "always there"
- making the environment safe
- "father-son" rels.
- shared hobbies
- attentiveness + encouragement to 2 PP, scaffolding
- teacher; learning the fun way.

- SISTER
- geographical distance
  - physical distance
  - sitting rivalry
  - constant bickering

Post Injury

Impact of The Critical Event

- Not knowing (now)
- man is a stranger
- unknown sense of past
- unknown identity
- recognition of impairment.
- not being listened to
- volatile, unpredictable environment.
- loss of social etiquette
- parent-child conflict & rules
- trying to understand severity of S.I + complexity
- parent to parent conflict

Impact on self

- Not knowing <sup>what's right</sup> from wrong.
- needing routine
- wanting familiarity
- being <sup>+ feels</sup> criticised by <sup>specialist</sup> ~~man~~ man.
- needing to feel in control
- walking on egg shells
- being critical & intolerant of impaired man.
- weakened resilience to cope & changes.

Pol

FRIENDSHIPS

- Distant friendships in close proximity.
- Detached from friends.
- identifying in someone similar "Things in common"
- Shared fun.
- Growing apart

Post Injury

- SISTER**
  - shared time together
  - absent sibling support
  - sibling support
  - positive news.
  - reciprocal support and feelings of closeness.
- MUM**
  - unpredictable routine
  - establishing new routines + roles in family.

FAMILY <sup>life</sup>

- family "putting on brave face"
- unpredictable life.
- "just a way of life"

→ Self cond.

- adjusting + accepting to changed mum.
  - making allowances
  - accepting the changed parent.
  - keeping the peace peacemaker
  - feeling bewildered by "peculiar" mum
  - trying to make sense of "peculiar" mum.
  - lost mum, changed mum.
  - increased house chores
- family trauma a heavy burden
  - escaping from burden.
  - lost hobbies & dad.
  - parent-child conflict
  - aware of carer burden & dad caring for mum.
  - impact of increased 'honourer' role.
  - overwhelmed by loss & change.
  - "just getting on & things."
  - feeling stuck.
  - conflict of own needs + needs of family.
  - desire for stability



## **Sub-categories for subordinate themes**

### **1.1 Relationship changes 'inside' & 'outside' the family**

#### ***'Inside' the family system***

- 1.1.1 Sense of closeness & trust
- 1.1.2 Being 'with' and sharing time with
- 1.1.3 Providing emotional & practical support
- 1.1.4 Playfulness & fun
- 1.1.6 Sibling rivalry & discord
- 1.1.7 Emotionally & practically distant
- 1.1.12 Moving on

#### ***'Outside' the family system***

- 1.1.13 Being present but not close to
- 1.1.14 Growing apart
- 1.1.15 'Needs only' basis
- 1.1.16 Unpredictable availability
- 1.1.17 Time limited and planned
- 1.1.18 On a 'needs only' basis

### **1.2 A more meaningful relationship**

- 1.2.1 Feeling close and connected
- 1.2.2 Greater bond and support

- 1.2.3 Sense of harmony
- 1.2.4 Shared experiences
- 1.2.5 Sense of loyalty and increased responsibility to care
- 1.2.6 Switching roles; becoming parents
- 1.2.7 Being part of and not just there
- 1.2.8 Secure emotional and practical support
- 1.2.9 Reassuring presence and familiarity
- 1.2.10 Sanctuary and escapism
- 1.2.11 Confiding, emotional containment & trusting
- 1.2.12 Understanding & validating distress & empathy
- 1.2.13 Distraction from trauma
- 1.2.14 Consistent and & reliable

**2.1 Absent parents:**

- 2.1.1 Not held in mind
- 2.1.2 Other commitments and responsibilities
- 2.1.3 Being constrained by time
- 2.1.4 Caring for my injured parent
- 2.1.5 Unable to care
- 2.1.6 Absence of affection
- 2.1.7 Lost time and intimacy
- 2.1.8 Lost identity & abilities
- 2.1.9 Lost independence

## **2.2 The lost teacher**

2.2.1 The stranger

2.2.2 We used to learn the fun way

2.2.3 We had shared hobbies

2.2.4 Being encouraged to try things

2.2.5 Opportunities to reach potential

2.2.6 Learning resilience

2.2.7 Emerging independence

2.2.8 Changed personality

2.2.9 Invisible disabilities

2.2.10 Vulnerable

## **2.3 Deteriorating family relationships:**

2.3.4 Lost social etiquette

2.3.5 Dependency on others

2.3.9 Unavailable

2.3.10 Blurred boundaries (more like a sister)

2.3.11 Overwhelmed by loss

2.3.12 Monitoring and keeping them close and protecting

2.3.13 Intolerant to others needs

2.3.14 Feeling frustrated & bewildered

2.3.15 Unpredictable

## **2.4 Our quality of life has been shattered:**

2.5.1 Absence of a reliable source of emotional and physical support

2.5.2 Witnessing fragility and emotional instability

2.5.3 Hyper vigilance to mood states

2.5.4 Reduced availability and feeling distant

2.5.5 Lost hobbies and time with each other

2.5.6 Financial burden of a lost income

2.5.7 Unpredictable chaos and disruption

## **3.1 Loosening of the family**

3.1.6 Different roles to play

3.1.7 Busy lives

3.2.5 Drifting apart

3.2.6 Close but distant

3.2.7 Absence of routine

## **3.2 A desire for routine a structure**

3.2.1 Sense of needing to re-establish a routine

3.2.2 Wanting familiarity

3.2.3 Desire for stability and continuity

3.2.4 Family demands

## Appendix H: List of Abbreviations

---

ABI:	Acquired Brain Injury
EBSCO:	Elton B Stephens Company Research Database
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
TBI:	Traumatic Brain Injury
MFGT:	Multifamily Group Therapy
ASSIA:	Applied Social Sciences Index and Abstracts
PILOTS:	Published International Literature On Traumatic Stress
RCT:	Randomised Controlled Trial
SCORE – 15:	The Systemic CORE (Clinical Outcomes in Routine Evaluation)
IPA:	Interpretative Phenomenological Analysis
CAMHS:	Child and Adolescent Mental Health Service
NSF:	National Service Framework
SAH:	Sub-arachnoid Haemorrhage