Brain injury:
The impact on family members living with a brain injured adult and implications for rehabilitation services

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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May 2005

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Acknowledgments

I would like to thank Dr Eve Knight and Dr Louise Lorenc for their support and supervision throughout the duration of this research thesis. I would also like to extend my thanks to each member of staff who gave up their valuable time to participate in the focus groups conducted for the research paper presented in chapter two and those members of staff that assisted in the recruitment process for the study presented in chapter three. I would especially like to thank each of the participating children and their parents for allowing me into their homes and sharing with me their experiences. Thanks also to Dr Nicola Murphy for her continued support, advice and friendship. Finally, I would like to thank my partner Cathy for supporting me through the highs and lows of conducting this research thesis.

Declaration

This thesis was carried out under the supervision of Dr Eve Knight and Dr Louise Lorenc. Other than this I conducted all stages of the research process myself. Ethical approval was given by South Birmingham Research Ethics Committee and Coventry University (see appendix A). This thesis has not been submitted for a degree at any other university. Authorship of any papers published from this work will be shared with the above.

The review paper has been prepared for submission to *Brain Injury.*
The two empirical studies have been submitted to the peer-reviewed journal *Brain Injury* (see appendix A instructions to authors).

Summary of chapters

Chapter One:

This chapter reviews the relevant literature published since 1990 that has addressed the psychological impact both progressive and acute brain injury can have upon spouses of patients. The papers reviewed suggest that psychological strain or burden experienced by spouse carers is associated with a number of factors irrespective of illness type. A number of methodological limitations of the studies reviewed are discussed along with implications for clinical practice. Further research is required that explores the experience of family members to ascertain the best way forward for rehabilitation services in terms of providing family orientated interventions and support.

Chapter Two:

Chapter two presents a study that explores the views, beliefs and experiences of brain injury rehabilitation professionals on working collaboratively with families. Using a qualitative research approach, two focus groups were conducted with a total of 12 professionals from a range of disciplines. Focus groups were analysed using thematic analysis. A number of salient themes emerged that reflected the narrative collected. Implications for brain injury rehabilitation services and suggestions for further research are made.

Chapter Three:

Chapter three presents an empirical study that explores children's experiences of parental brain injury. Using a qualitative research approach interviews were conducted with twelve participants aged between 11 and 18 years living at home with a brain-injured parent. Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA). A number of themes emerged that reflected the narrative collected. A preliminary model of adaptation to parental brain injury is proposed. Implications for brain injury rehabilitation services in terms of addressing the needs of children and suggestions for further research are discussed.

Chapter Four:

This chapter documents the first author's experience of conducting the two empirical papers presented in chapters two and three. Specifically it highlights a number of ethical and methodological concerns associated to conducting focus groups and interviewing children. The first author's personal account and reflections in relation to each of the two research studies are also presented.

CHAPTER ONE

Spouse caregivers of partners with brain injury: Factors that impact on the caregiving experience

Word count: 7021

Abstract

Primary Objective: This article aims to review the relevant literature published since 1990 that has addressed the psychological impact both progressive and acute brain injury can have upon spouses of patients.

Main outcomes and results: A total of 21 papers were reviewed of which three employed qualitative approaches. The remainder used standardised questionnaires which were analysed using quantitative methods. The psychological strain or burden experienced by spouse carers was found to be associated with a number of factors irrespective of illness type. These factors related to characteristics of the illness; carer characteristics; social characteristics such as availability of social support; and relationship characteristics such as change in relationship status.

Conclusions: A number of methodological limitations of the studies reviewed are discussed along with implications studies may have for clinical practice. Further research is required that explores the experience of family members to ascertain the best way forward for rehabilitation services in terms of providing family orientated interventions and support.

Introduction:

When a family member acquires a brain injury, whether a progressive or sudden onset, it is often other family members who bare the burden of providing care for their injured loved one [1-4].Over the last two decades there has been a growing interest in the literature base that has focused on the experience and needs of family members following brain injury. Such research has sought to gain insight into the experience of family caregivers. More specifically studies have concentrated on the impact injury has upon primary caregivers.

Primary caregivers are often expected to take on the new role of carer with little prior knowledge or experience [5, 6]. The main or primary caregiver may be expected to provide personal care such as toileting, dressing and bathing [7]. They may also be required to provide physical support in terms of assisting their loved one to walk or to eat [7]. The caring role may often involve the carer making many personal sacrifices such as giving up work and social activities [8]. Carers often report that they provide support 24 hours a day seven days a week [9]. In addition to this carers also report receiving little outside assistance or respite [5, 10]. Spouses are more likely to adopt the role of main caregiver to brain injured partners than other family members [3, 11-14] and have therefore been considered a group at risk of experiencing high levels of stress and strain [7, 11, 15].

Brain injury can have a progressive or sudden acute onset [16]. The estimated lifetime prevalence rates of neurological disorders have increased over the last ten years [17]. Survival following acute brain injury has also improved due to recent advances in surgical, neuropsychiatric and rehabilitative care. This has led to an increase in the number of people who are living with any number of impairments as a result of injury to the brain [18].

Progressive Onset

Progressive neurodegenerative diseases include Multiple Sclerosis (MS), Parkinson's disease (PD) and dementia, the most common form of which is Alzheimer's disease (AD). Such disorders are characterised by slow irreversible decline of functional and cognitive ability [19]. Incidence rates for such disorders increase with age. MS is most commonly diagnosed between the ages of 20 to 40 years [12]. The incidence rate of PD rises after the age of 50 increasing sharply in old age [20]. The onset of AD can be in middle adult life but the incidence is higher in later life [20]. Therefore, it is likely that individuals suffering from such diseases would have been in long term stable relationships prior to onset [12]. The patient's partner has to adjust and adapt to the uncertain and unpredictable course of the disease. In addition, given the predominately late onset of such diseases, Spouse carers may also have to cope with any health related problems they too are experiencing in later life. The 'well' spouse may eventually be faced with the prospect of no longer being able to care for their loved one. The patient may eventually have to move away from the family home to residential nursing accommodation. As a result the 'well' partner may find themselves living alone.

Acute

Acute neurological damage most commonly occurs following Stroke or Traumatic Brain Injury (TBI). These types of neurological events can result in sudden loss of cognitive and functional ability with the prospect of a degree of recovery, most of which will occur during the first six months post injury [19]. Although stroke is the third largest killer in the developed world, many people do survive but experience persisting impairments [21]. Strokes predominately occur late in life, with the average age of stroke victims being 75 years [21]. In contrast, TBI is predominately a problem that occurs amongst younger people [22]. In particular males aged between 15 and 30 years are more likely to suffer head injuries as a result of car and motorcycle accidents [20]. Given the early incidence of TBI, partners are often faced with the prospect of providing life long care to a loved one who would otherwise have been independent over a much greater period of time.

Scope of Review and Aims

This paper will review the relevant literature that addresses the psychological impact neurological illness or injury can have upon spouses of patients. Research interest in this area has grown over the last two decades, this paper will therefore primarily review work conducted during this period. It is the aim of this paper to identify what research has so far discovered in relation to the impact brain injury, both progressive (degenerative) and acute (non-degenerative), can have on spousal caregivers. Brain injury can take either course but are the experiences of spouse carers different? If so should family based interventions from rehabilitation services differ dependent upon the type of injury? The limitations of studies and recommendations for future research will also be discussed.

Search Strategy

A review of the literature using Psycinfo, Medline and the Cochrane library was conducted. Combinations of key words were used to search for relevant material such as *Spouse, husband, wife, marital, brain injury, stroke, neurodegenerative, progressive, and carer.* Initially the search strategy focused upon factors that impact on spouse caregiver strain. The information obtained from these studies led to further literature searches to identify papers that addressed these specific factors. Only studies conducted since 1990 and where participants were spouses of brain injured patients were considered. Twenty one papers were found that fitted the search criteria. Three tables have been compiled to illustrate the factors investigated, findings and demographic information of each paper. Table one, presents studies on spouse caregivers of patients with progressive brain injury. Table two, presents papers on spouse caregiving of patients suffering acute brain injuries. Table three, presents comparative studies on spouse carers of patients with progressive and acute brain injuries. The reference sections in papers were also examined to identify other key papers.

Main findings of literature review

Factors that influence spouse caregiver strain or burden

An initial search of the literature found three studies that have sought to determine the factors that may influence caregiver strain or burden. Blake and Lincoln [7, 23] conducted two empirical studies that investigated caregiver strain of spouses caring for a partner after stroke. The first aimed to identify factors associated with strain in a group of co-resident spouses caring for a partner who had had a stroke. The second study aimed to test the accuracy of the initial findings in terms of predicting carer strain.

In the first study [7] questionnaires were posted to co-resident spouses of patients that measured caregiver strain, stress and mood. In addition carers assessed the level of perceived independence of the patient in the realms of mobility, domestic and leisure activities. Correlation coefficients between each of the questionnaires and the measure of strain were then obtained. The results suggest three factors that were significantly associated with caregiver strain; carer mood seen as an impermanent emotional component and responsive to therapeutic intervention; level of disability of the patient in terms of activities of daily living; and negative affectivity seen as a stable

Table One: Studies on Spousal caregivers of patients with progressive degenerative brain injury

Research Study	Number of Participants M F	Carer Age	Years Married	Injury/ Illness Type	Time in caring role years	Factors Investigated	Control Group Y/N	Methodology	Findings
Schneider et al 1999	Total 240	55 - 79	27 - 52	AD	NR	Caregiver burden and health	N	Quantitative	Carer burden associated to four variables (across each country)
Freyne et al 1999	19 25	57.5	NR	Dementia	NR	Carer burden, social support and general health	N	Quantitative	Carers of younger sufferers report greater burden
Hooker et al 2000	68 107	68.9	41.6	AD & PD	6	Carer stress, depression and anxiety	N	Quantitative	Gender differences in reported distress
Aarsland et al 1999	Total 94	70.8	NR	PD	NR	Care stress, depression and general health	Y	Quantitative	Psychological disturbance in patients =emotional distress in partners
Miller et al 1996	Total 54	65.6	NR	PD	NR	Psychological strain/distress of carers	Y	Quantitative	Psychological distress of patient = carer distress
Leinonen et al 2001	16 27	74.6	NR	Dementia	NR	Caregiver burden and psychological distress	N	Quantitative	Combination of behavioural and psychiatric symptoms = carer burden/distress
Cheung & Hocking 2004	6 4	40 - 60	NR	MS	NR	Experience of spousal carers	N	Qualitative	Carer disconnects from marital role to carer role
Croog et al 2001	80 119	46 - 82	NR	AD	NR	Caregiver well being, emotional status and general health	N	Quantitative	Carer psychological distress mediated by age and gender
Baikie 2002	NR	NR	NR	Dementia	NR	Impact on marital relationships	N	Qualitative	Quality of relationship pre-illness
Rankin et al 2001	49 51	69	42.8	Dementia	4.28	Carer burden and quality of relationship	N	Quantitative	Marital functioning associated to carer mental health

Key: NR = not reported AD = Alzheimer's Disease PD = Parkinson's Disease MS = Multiple Sclerosis

Table Two: Studies on spouse caregiving of patients with acute non-degenerative brain injury

Research Study	Number of Participants		Carer Age	Years Married	Injury/ Illness	Time in caring role	Factors Investigated	Control Group	Methodology	Findings
	M	F				years		Y/N		
Blake et al 2003	33	83	45 - 88	NR	Stroke	NR	Caregiver Strain and General Health. Patient's ADL	N	Quantitative	Carers under sig strain 3 and 6 mths post injury.
Blake & Lincoln 2000	148	74	NR	NR	Stroke	NR	Carer strain, stress, mood, social support. Patient's mood and ADL	N	Quantitative	Mood, neg affect and patient ADL predictors of carer strain
Anderson et al 2002	17	47	22 - 74	20 mean	TBI	NR	Behavioural problems, family functioning, resources, psychological distress.	N	Quantitative	Behavioural problems strongest predictor of carer distress
Purk & Richardson 1994	15	29	NR	45 mean	Stroke	6mths to 4yrs	Morale, Functional independence	N	Quantitative	Morale of caregiver and patient positively correlated
Neiboer et al 1998	45	82	70.1 mean	NR	Stroke	NR	Depression, number of caregiving tasks and activity restriction	N	Quantitative	Increase in caregiving tasks=activity restriction and low mood
Wood & Yardakul 1997	34	97	20 - 50	13.04 mean	TBI	5.42 mean	Relationship status	N	Quantitative	Many rltshps breakdown after 5 yrs post injury
Katz et al 2005	0	40	25 - 63	2 – 45 range	TBI	1 to 32	Carer burden and coping	N	Quantitative	Longer time married =greater carer burden
Gosling & Oddy 1999	0	18	39.2 mean	5 – 40	TBI	1 to 7	Marital state and sexual satisfaction	N	Quantitative	Sexual satisfaction reduced since injury

Key:
NR = not reported TBI = Traumatic Brain Injury ADL = activities of daily living

Table Three: Comparative Studies on Spousal caregivers of patients with progressive degenerative and acute brain injury

Research Study	Number of Participant M F	Carer Age	How Long Married years	Injury/Illness Type	Time in caring role years	Factors Investigated	Control Group Y / N	Methodology	Findings
Wright et al 1999	16 26	65 mean	36.1	AD & Stroke	NR	Carer depression, physical health and background characteristics	Y	Quantitative	AD carers continued to report low mood over 12 moth period. Stroke carers low mood improved over time.
Thommessen et al 2002	Total 186	NR	NR	Stroke, Dementia, PD	NR	Psychological burden between carers of stroke, PD and dementia	N	Quantitative	Spouse carers in stroke group report concern over further illness or injury

Key:
NR = not reported

AD = Alzheimer's Disease PD = Parkinson's Disease MS = Multiple Sclerosis characteristic or personality trait of the carer. The results of Blake et al's [7] study also found that strained carers reported being in receipt of significantly less support from family and friends.

In their follow up study Blake, Lincoln and Clarke [23] tested their initial findings on a cross-sectional sample of spousal carers. Questionnaires were sent to carers at 3 and 6 months post injury. The results of this study supported the author's initial findings that mood, negative affectivity and perceived activities of daily living were strong predictors of caregiver strain after stroke. Both studies were however postal and therefore suffer the disadvantages of high non-response rates. Only 44% of the questionnaires were returned for study one and 42% returned for study two.

A number of contributory factors have also been identified that determine the level of caregiver strain and psychological well being in spouses caring for a partner with a progressive neurodegenerative brain injury. Schneider, Murrey, Banerjee et al [24] conducted a cross-national study, involving 14 of the countries in the European Union. The aims of the study were to explore factors that contributed to caregiver burden among co-resident spousal carers of partners with AD. Twenty spouses from each country were administered semi-structured questionnaires to obtain demographic information. In addition participants were asked open questions to elicit perceived difficulties and rewards associated with caring, along with their perception of any support they had received. Standardised questionnaires were also administered that measured caregiver burden and health. Carer burden was found to be significantly associated to four variables across each country. These were financial concerns; younger carer age; behavioural deficits of the patient and the negative reactions of others. However, participant selection for this study was dependent upon service pathways that may vary between countries. Therefore, the participants recruited from each country may have differed due to the configuration of services.

These studies therefore suggest that a number of factors may be associated to caregiver burden. Characteristics of the patient's illness or injury; carer characteristics; and the support and understanding of others may all contribute to caregiver burden and strain.

Review of papers exploring specific factors associated to spouse caregiver strain

Many of the specific factors that have been shown to impact on spouse caregivers, identified by the studies reviewed, are similar irrespective of whether injury was acute or progressive. These factors will now be summarised and any differences drawn out.

Illness or Injury Characteristics

A number of studies have attempted to identify the illness characteristics that cause the greatest emotional distress and caregiver stress to spousal carers. Purk and Richardson [25] investigated the relationship between the psychological wellbeing of patients who have suffered stroke and caregiver distress. The results of this study suggest that the morale of care receivers was positively related to the morale of caregivers. A positive relationship between the patient's morale and their level of functional independence was also found. The greater the functional independence of the injured partner the greater the morale of the patient, and consequently the greater the morale of the carer. This would suggest that the psychological well being of the patient can impact on the mood and level of distress experienced by their carers.

However, one should also consider that the more functionally dependent the patient is, then the more of a burden they may be to carers. Therefore, the more functionally independent the patient, then the more time the carer has to pursue their own needs. This may result in elevated carer mood and consequently this may impact on the mood of the patient.

Similar results were gained by Miller , Berrios and Politynska [26] in a study of married sufferers of PD. Multiple regression analysis was carried out on a battery of questionnaires administered to carers. The results found that measures of depression and anxiety in PD patients correlated closely to carer distress. Further stating that psychological distress experienced by patients is a far stronger predictor of carer distress than physical symptoms of the patient's injury. Miller et al [26] explain this finding by suggesting that the psychological problems presented by the patient may be harder to accept and adapt to than physical impairments, possibly as a result of the patient not being perceived as the same person they were prior to onset of injury. Alternatively one might consider that those patients with greater physical impairments may be in receipt of more outside support than those presenting with cognitive deficits. Therefore, carers of physically impaired spouses may have more access to support networks than carers of patients requiring less physical assistance, which in turn may impact on the distress reported.

The emotional and social difficulties of caring for a partner with PD have been investigated by Aarsland, Larson, Karlsen et al [27]. They found that psychological disturbances in PD patients were the strongest determinants of both emotional distress and stress in partners compared to healthy controls. This finding has important implications for professionals working in neuro-rehabilitation, given that the psychological distress of patients such as low mood or anxiety is potentially treatable. Therefore, if the patient's psychological disturbances are addressed then this may help to improve the psychological wellbeing of the primary carer as well as the patient. In addition the results of this study also found that behavioural disturbances of patients also led to greater levels of emotional distress of carers, whereas functional impairments of patients were not associated to caregiver emotional stress. These findings provide further evidence to suggest that changes in personality and behaviour that lead to the patient being perceived as a different person since time of injury are stronger predictors to caregiver distress than physical impairments suffered.

Leinonen, Korpisammal, Pulkkinen et al [28] conducted a study comparing caregiver burden between spouse carers of partners with depression to spouse carers of partners with dementia. The dementia patients and their carers were divided into two groups. Group one consisted of patients admitted to hospital for assessment purposes, whereas group two consisted of dementia patients presenting with both psychiatric and behavioural symptoms. The results of this study found that spouses of demented patients with a combination of psychiatric and behavioural symptoms experience greater burden than spouses of depressive patients. Whereas spouse carers of dementia patients admitted for assessment reported similar levels of burden to the carers of depressive non-demented patients. Such findings suggest that psychological disturbance alone does not fully account for the burden reported by spousal carers of dementia patients. However, a limitation of this study is that the spouses of depressive patients were significantly younger than the spouse carers of dementia patients. Perhaps the younger the carer then the more able they are to cope and manage, especially if we consider the possible age related difficulties carers may eventually be challenged with such as their own ill health or mobility.

Anderson, Parmenter and Mok [29] explored the relationship between neurobehavioural problems after TBI and the psychological well-being of spouses. Spousal carers of partners who had sustained TBI were administered a number of questionnaires designed to provide data on neurobehavioural problems experienced by the injured partner; family functioning and resources; and psychological distress as perceived by the non-injured spouse. The results of this study found that behavioural problems presented by patients were the strongest predictor of carer distress. This would suggest that behavioural difficulties can be mediated by the resources available to family members. However, conversely such difficulties can also deplete family resources. Therefore, behavioural problems are important influential factors that can mediate family functioning and lead to psychological distress of primary carers, especially spouses.

Two studies have also suggested that the risk of relationship break down increases if the neurobehavioural consequences of the patient's injury were such that they required a period of rehabilitation. In Katz, Kravetz and Grynbaum's [30] study those wives whose husbands were attending rehabilitation services, reported experiencing greater burden and strain. Similarly, Wood and Yurdakul [31] also found that where the brain injured patients behavioural impairments had led to a period of rehabilitation as an in-patient, the risk of relationship breakdown significantly increased. However, it should be stressed that both papers refer to such findings as being rather serendipitous and secondary to the actual research questions being addressed.

There have been two studies that draw comparisons between carers of partners with progressive and acute brain injury. Wright, Hickey, Buckwalter et al [19] compared the physical and emotional health of spouse caregivers of patients with Alzheimer's disease and stroke. This longitudinal study was designed to monitor the course of caregivers physical and emotional health over a twelve month period. Face to face interviews were conducted at the onset of injury and at 6 months post injury with couples. Participants were divided into three groups these being the AD group, stroke group and a well group acting as a control for the study. At 12 months post onset of injury a follow-up telephone interview was conducted.

The results of this study found both similarities and differences between the groups of carers. In particular AD caregiver depressive mood was shown to follow a different pattern to the depression experienced by stroke carers. AD spouse caregivers reported high levels of depression in the early phases of illness. These carers continued to report significantly increased rates of moderate to severe depression over the twelve month period. In comparison to this, spouse stroke carers reported rates of depression decreased over time. The authors suggest that such results reflect the progress of each type of injury. For example in the case of stroke victims, carers will witness some level of recovery and deficits will eventually plateau. However, in the case of progressive injury as witnessed by AD carers, patients will continue to deteriorate over time. More longitudinal studies that compare injury types need to be considered as it could be hypothesised that the heightened mood of stroke carer's may be short lived once the realisation that a full recovery may not occur and consequently it may be the case that mood will again begin to decrease.

The only other study which compared illness types was conducted by Thommesson, Aarsland, Braekhus et al [16]. They explored the psychological burden experienced by spouses of stroke, dementia and Parkinson's sufferers attempting to identify patient characteristics associated to carer burden. Participants were recruited to form three groups of spouse-patient couples living with Stroke, dementia or Parkinson's disease. Questionnaires that assessed the well spouses stress and the patients Activities of Daily Living (ADL) and cognitive function, along with demographic information was collected. The results of this study found that spouse carers in the stroke group reported greater concern of further accidents occurring to their partner than participants in the other groups. This suggests that, the sudden unexpected nature of stroke may increase fears of further neurological insult.

What studies on the impact illness characteristics have on spouse carers have shown is that cognitive and behavioural disturbances will mediate the level of burden or stress experienced by carers. These studies also show that the impact such characteristics have on spouse carers is similar for those caring for patients with either progressive or acute brain injury. However, comparative studies have also shown that differences in the cause of carer burden may exist dependent upon the nature of the injury. Such studies also illustrate the fact that other factors also contribute to the stress of carers such as the resourcefulness of families and certain characteristics of carers.

Carer Characteristics

A number of studies have explored the role certain characteristics of carers may play in mediating carer psychological wellbeing and perceived burden. Freyne, Kidd, Coen et al [32] compared levels of burden and social support between carers of patients with early onset dementia to carers of late onset dementia. The results of the study found that carers of younger sufferers reported the greatest burden, further suggesting that the social, financial and occupational impact early onset dementia can have on partners may be greater than for older carers. However, the carers of the early onset dementia group in this study had been caring for an average of two years longer than the late onset carer group. Therefore length of time assuming the caring role needs to be standardised between groups before it can be more confidently suggested that age of carer contributes to caregiver burden.

Gender of carers has also been shown to be an influential factor associated with carer distress. Hooker, O'Dell, Monahan et al [33] compared reported stress, depression and anxiety between spouse caregivers of AD and PD patients. Analysis of questionnaires administered found that significant gender differences existed within the AD caregiving group but not in the PD group. The wives in the AD group reported higher levels of depression and anxiety than caregiving husbands. These authors suggest that the cognitive sequelae that presents in AD patients may lead to increased responsibility to the well spouse. Female spouses may therefore be expected to assume a role of authority previously not experienced. Subsequently, they may suffer greater mental health difficulties than their male counterparts. The lack of gender effects in the PD group may well reflect the fact that PD is characterised by slowing of emotional and voluntary movement, such as muscular rigidity or tremors, with cognitive problems occurring later in the disease. Therefore, the carer does not have to cope with and adapt to changes in personality or the cognitive sequelae often associated to greater levels of carer strain [4, 25, 27].

In a study of spouse vulnerability to caregiving stressors, Croog, Sudilovsky, Burleson et al [34] argue that the levels of psychological distress experienced by carers may be mediated by both the age and gender of the carer. In this study husband and wife caregivers of partners with AD were administered questionnaires to determine their emotional status, well being and general health. The analysis of the data collected focused upon identifying any differences that may exist between male and female carers, and if age of carer would also impact upon reported caregiver stress and wellbeing. When considering the age of carers alone the results suggest that the younger the carer then the greater the negative impact patient stressors will have. In particular behavioural problems presented by patients were shown to be the strongest predictor of psychological distress in younger carers. When considering gender differences, this study found that wife carers were more vulnerable to patient stressors than husband carers. When examining both age and gender together Croog et al [34] found that older male carers reported less burden than younger male caregivers.

The findings of these studies provide professionals with important information regarding potential carer characteristics that may indicate a greater vulnerability to the stress associated to caring. However, more needs to be understood in terms of how such characteristics of the carer inter-relate. More needs to be done to determine why different age groups or how gender of carer may lead to carers experiencing different levels of psychological well being. Does caregiver burden decrease over time? Do men or women take longer to adapt to impairments or to accept their new caregiving role? In particular these studies fail to explore the social support systems of carers.

Could it be that the older the carer then the more time they have had to build up more stable and supportive relationships with family and friends than younger carers?

Social Characteristics

Social Networks

The size of social network and amount of social support available has been shown to contribute toward carer wellbeing. In Miller et al's [26] study the size of social networks of married couples where one partner had a diagnosis of PD were assessed. The assumption of this study being that size of social network would be a good indicator of the social support available to each couple. Social support was measured by asking participants to record the number of people they had contact with over a two-week period who were outside of the carer's immediate household. In comparison to a control group of healthy couples, the couples living with Parkinson's disease had smaller social networks. However, this finding may simply reflect the carer's choice of not wanting to access support networks. More research is required that not only records number of social contacts, but also records availability and quality of support networks. This may then lead to questions regarding why do some carers access support when others choose not to?

The social support available may also be influenced by others understanding and ability to accept and cope with the illness. In Cheung and Hocking's [35] qualitative study of spousal carer experiences of MS, a number of themes emerged including the theme *loss of* support. This theme encapsulated the participants description of experiencing a distancing of friends and relatives. Participants further expressed their disappointment at the loss of support networks due to the inability of others to accept and cope with the illness, and the ease at which others had withdrawn into concentrating on their own lives.

The negative reactions of others can result in carers feeling rejected and lead to increased social isolation. Participants in the Schneider et al study [24] were asked how they felt people reacted to their partner's illness. The most frequent responses were sympathy and acceptance. However, 22% felt rejected by friends and family, with 9% stating that others showed fear of the illness. This is of particular relevance when we consider the important role social support plays in mediating carer stress and strain experienced living with a partner with a progressive neurological disorder [36, 37] and the possible social constraints caring may place on carers [38].

Activity Restriction

Nieboer, Schulz, Matthews et al [8] propose that an increase in caregiving tasks can result in restrictive activity patterns and social support networks. This can in turn increase depressive symptomology in the non-injured spouse. Baseline data was collected from eligible spouses registered on the morbidity Registration Network Groningen (RNG), a longitudinal aging study of which 99% of all non-institutionalised elderly are registered. Information collected included measures of depressive symptoms, number of caregiving tasks and activity restriction. Consent was then obtained to contact the non-injured spouse if one of the illness events under study occurred. Participants were then monitored for illness events including stroke. General practitioners registered 180 first occurrences of the illness events of which 127 spousal caregivers were available for follow-up assessment 3 months post illness event.

The results of this study found that spouse carers reporting at least 4 caregiving tasks post illness event, presented with significantly higher levels of depression. The results also found that increased care giving tasks lead to activity restriction. However when activity restriction is controlled the impact caregiving tasks has on depressive symptoms is reduced, suggesting that activity restriction plays a mediating role between caregiving and depression experienced by spousal carers. Such findings highlight the important role both professional and family support systems can play in alleviating depressed mood. Social support systems may provide relief to carers enabling them to pursue activities outside of the caregiving situation. However, a limitation specific to the findings of this study is that it does not consider the impact depressive symptoms may have on an individual's motivation to engage in activities. Could the carer's low mood itself lead to activity restriction and not necessarily the increased number of caregiving tasks?

Relationship Characteristics

The impact brain injury has upon the marital and relationship status of spouse carers has received a lot of research interest. Rankin, Haut and Keefover [39] present a model of spousal caregiving that suggests current marital functioning will influence caregiver mental health. These authors further state that it is the loss of emotional support experienced by spouse carers that has the strongest association to carer depressive reactions as oppose to functional support. Therefore, it would seem that carers adapt better to functional deficits than they do to the loss of intimacy and companionship. A further suggestion made by Rankin et al [39] is that carers not only mourn the actual loss of marital cohesion, but may also find the anticipatory grief associated to degenerative illness emotionally painful and distressing. However, this study does not explore the relationship status of participants prior to injury, and as a result may be reporting on pre-existing marital discord or difficulties.

Three studies have used qualitative approaches to explore the experience of spousal carers in terms of the impact brain injury has on relationship status. Baikie [40] states that the quality of the marital relationship prior to onset of illness may be associated to caregiver strain. Therefore, the closer and more affectionate the pre-morbid relationship, then the burden reported by the partner providing care will be less. This raises important questions as to the voluntary nature of caring. If spouses have experienced a good pre-morbid marital relationship then they may be more willing to provide care to their partner. Alternatively, if the relationship has been unsatisfactory, carers may adopt the role of carer as a sense of duty or in line with their marriage vows. Indeed many of the woman interviewed in Paun's [41] study of older women caring for a spouse with Alzheimer's disease, justified their expressed commitment to caring by providing quotes from their marriage vows. A further issue in connection to marital relationships is the notion of consent. Baikie [40] suggests that some spouses may be unsure if their partner is consenting to sexual intercourse. This can lead to feelings of guilt in the 'well' partner.

The loss of a partner was also a theme that emerged in Cheung and Hocking's [35] study of carers of MS patients. In depth interviews were held with spouse caregivers and then analysed to identify themes that described the carer's experiences. The loss of a partner, loss of self and loss of support were all identified as important themes. The progressive nature of neurological diseases such as MS means the gradual loss of a friend, a lover, and the deterioration of the marital relationship. Carers in this study reported that the ill partner still looked like the person they married, but was a stranger in terms of their relationship status. As a result carers had eventually disconnected from the role of marital partner and assumed the role of carer, no longer seeing their spouse as a lover, but instead simply seeing them as someone they cared for.

The break down of relationships or marriages after sudden unexpected brain injury to a partner is well documented [42-44]. Wood and Yardakul [31] presented a pilot study to explore the frequency of relationship break down following TBI to a partner. Demographic information of TBI survivors including relationship status was obtained from clinical records. Follow up information regarding current relationship status post injury was obtained through postal enquiry. Only 42% of the couples surveyed had been able to maintain their relationship longer than 5 years post injury. These authors suggest several factors that may be attributed to relationship break down. The length of time the couple have been together prior to injury appears to correlate with the possibility of separation. Therefore the longer the relationship had lasted prior to injury the less likely the couple would separate. The data obtained in Wood and Yardakul's [31] study also suggests that relationships are more likely to break down at 5 years post injury or later and tend not to break down during the first two years post injury. This may reflect the current thinking that suggests very little recovery will occur beyond two years post injury. Therefore, once this time has elapsed carers may loose the optimism that had maintained their relationship up to this point.

Katz, Kravetz and Grynbaum [30] however suggest that the longer couples have been married then the greater the burden experienced by the uninjured spouse. Wives of husbands who had suffered TBI were administered questionnaires to obtain data on spouses coping flexibility and perceived burden. The term 'coping flexibility' used in this study refers to the ability of the carer to adapt their coping style to the patient's deficits. Participants were then divided into two groups on the basis of the information provided. Group one comprised wives with below medium coping flexibility. Group two consisted of wives with coping flexibility above the medium. Each group's data was then examined in relation to the time since injury and other demographic information obtained at interview. The results of the study suggest that female carers with little coping flexibility and whose partner's injury had occurred more than 7 years ago reported increased burden. Therefore, suggesting that poor coping flexibility may lead to increased burden over time. A further interesting finding of this study was that wives who reported the greater burden were those who had been married the longest time. This may go some way to supporting other studies that suggest relationships formed post injury have greater prospects than those pre-existing prior to injury [43, 45].

The sexual relationships of non-injured spouses following TBI to partners have been investigated. Gosling and Oddy [42] conducted structured interviews to obtain demographic and neurological information from couples, where the male partner had experienced a TBI. The female partners were additionally asked to complete a number of questionnaires that would provide self-report information regarding marital state and sexual satisfaction. Participants were asked to complete these questionnaires retrospectively, considering the relationship prior to injury. They were then asked to complete the same questionnaires in terms of their current relationship status. In addition, non-injured partners were asked seven open-ended questions regarding their perceptions of the current relationship.

The results obtained from the Gosling and Oddy [42] study suggested that the sexual satisfaction reported by female partners was significantly lower since injury to their partner. One of the reasons for this dissatisfaction was shown to correlate with the uninjured spouse's new responsibilities and role. Many of those interviewed suggested that they felt their role had become more maternal and therefore was "inherently incompatible with an intimate sexual relationship" (p792). A further factor voiced by participants was that it felt like their partner was a stranger leading to the feeling that sexual intercourse would be wrong. A limitation specific to this study is that all of the male injured partners had been in full time employment prior to injury. However, all of them were now unemployed. The possible impact unemployment can have on relationships is well documented [46] and needs to be considered when interpreting or generalising the results of this study.

Summary

A number of different factors have been suggested that may contribute in some way to spouse caregiver strain. These range from characteristics of the illness, such as the patient's psychological well being, behavioural difficulties and severity of cognitive impairments; characteristics of the carer such as age and gender; social characteristics, such as the level of social support available to carers and the extent at which caregiving has restricted social activities; and the impact injury has had on the marital relationship.

Methodological Considerations

In addition to the specific methodological considerations already mentioned, there are a number of more general limitations to the studies reviewed. Firstly the absence of a control group in many of the studies makes it difficult to know if similar results would be obtained from a non-carer population. Therefore, such studies are unable to confidently state that the factors seen as contributory to carer distress were not pre-existing prior to illness onset. Those studies that do incorporate control groups have reported higher levels of depression [19] and distress [26] in caregivers. Further studies using control groups will provide a clearer picture of the causal factors of psychological distress in caregivers.

Another limitation of many of the studies reviewed is that they do not report the length of time spouses have spent caring for their partner. Those studies that do report this information [25, 30, 31, 33, 42] predominantly show that the time spent by participants assuming the caring role varies considerable within studies. The length of time caring also varies considerably between studies. Does life become harder as each year passes by, or is time a healer? Does type of injury determine whether time is a factor that influences carer burden? Further research may provide the answer to such questions.

Only a third of the studies reviewed report how long couples have been married [24, 29-31, 33, 42] with the length of time married varying greatly both within and between studies. Therefore, comparisons between studies are difficult to make. With the exception of Katz et al [30], none of the studies reviewed consider time married as a factor in their analysis. A further limitation of studies is that, with the exception of Gosling and Oddy [42], they do not consider relationship status prior to injury. More needs to be found out about the impact brain injury has upon couples and whether length of time together and pre-existing marital status may determine the level of distress or burden experienced by carers. This is especially important given Katz et al's [30] finding that participants married the longest were expressing the greatest level of burden.

One further notable methodological limitation of studies in this area is the marked absence of qualitative studies, especially in the realms of acute brain injury where no qualitative studies were found that sought to gather experiential information from spouse carers. The knowledge gleaned from the three qualitative papers exploring the issues related to caring for a partner with progressive illness [34, 35, 40], have highlighted many interesting issues. Similar studies in TBI and stroke care may help clinicians gain a greater understanding not only of the issues faced by carers, but will also help identify similarities and differences between carers dependent upon injury type.

Clinical Implications

In most of the studies reviewed the ethnicity or cultural background of participants is not considered or even reported. In those studies that do outline the ethnicity of their sample, participants were predominately white [25, 29]. With the exception of one study [19] most did not investigate or comment upon cultural differences between carers. Furthermore, a prerequisite for some of the studies was that participants should be literate in English [7, 35], another factor that could lead to the exclusion of culturally diverse groups.

Studies that do consider cultural difference have identified some interesting findings. Wright et al [19] preliminarily report that black stroke caregivers initially experience higher levels of depression than white caregivers at onset of injury, but in contrast to white carers, gradually this depressed state decreases and stabilises over time. Paun [41] also found differences in the way the African American participants in her study formulated meaning. This study found that African American carers of PD patients reflected more on their spiritual beliefs in attempting to find the ultimate meaning for their loved ones illness. Furthermore, Haley, West, Wadley et al [47] in a comparison of black and white dementia carers, found that black carers were more resilient to the psychological effects of the stress of caregiving, compared to their white counterparts. This suggests not only a methodological limitation of studies in this area, but also identifies a clear need for future research to consider the impact culture and ethnicity may have on the caring role.

Although it is important to recognise and understand the difficulties faced by primary carers such as spouses, we must not ignore the fact that caring takes place within a family context. Therefore it is important to place what we believe we know about the primary carers experience within the context of their environment and family network. The studies reviewed in this paper do not consider such factors as living conditions, the size of family, or who else is living at home with the injured relative. However, studies that investigate the caring experience of other family members such as children or parents have found that they too experience increased burden and strain

[9, 15, 48]. Similarly illness characteristics [49, 50] and carer characteristics [51, 52] have all be shown to correlate with the burden reported by family members including siblings, extended family members and friends.

It is particularly important for healthcare professionals working in this field to understand the commonalities that may exist between family member's ability to adapt and cope with brain injury. Similarly it is just as important to understand any differences individual family members may experience before developing services that provide input to families. Some areas of difficulty for individuals may require treatment in isolation, such as specific carer characteristics. Whereas the impact illness characteristics may have on family members may be addressed more generally within the family unit.

Summary and Conclusion

This paper has sought to identify what is currently known about the impact brain injury to a spouse can have on partners. Studies have concentrated on patients with either progressive neurological illness or acute brain injuries. These studies have found that similarities exist regardless of injury type in terms of the factors that are associated to carer psychological wellbeing, coping ability and perceived burden. Such contributory factors are related to illness, carer, social and relationship characteristics. The small number of studies that have compared the carer experience of both progressive and acute injury have identified differences between carer experiences. Such differences appear to be related to the onset of illness and future prognosis.

In terms of the implications such research studies have for practitioners, it can be seen that adopting the role of primary carer can have a number of negative consequences for the individual. What these studies do not consider is the impact other family members may have on the caring experience. Nor do these studies consider cultural diversity or individual belief systems. More research is required that identifies similarities and differences in coping styles and expressed burden between other family members living with brain injury. In particular clinicians need to be aware of the context within which the carer is attempting to provide care. Who else is around? What are the well partner's beliefs about injury? What was life like prior to injury? Finding the answers to such questions will undoubtedly help inform the best way forward in terms of carer needs and involving families in the rehabilitation process.

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CHAPTER TWO

Working with families affected by Brain Injury: The views, beliefs and experiences of professionals providing rehabilitation services for acquired brain injury.

Word count: 3706 (excluding tables, figures, references and raw data)

All identifying features have been removed from this paper to ensure anonymity and confidentiality of participants.

Abstract

Primary objective: The purpose of this study was to explore the views, beliefs and experiences of brain injury rehabilitation professionals on working collaboratively with families.

Research design: A qualitative research approach was conducted using focus groups.

Methods and procedures: Two focus groups were conducted with a total of 12 professionals who provide brain injury rehabilitation at a regional outpatient and inpatient service. Focus groups were analysed using thematic analysis.

Main outcomes and results: A number of salient themes emerged that reflected the narrative collected. Such themes addressed the barriers to working with families; the understanding family members held about brain injury; the importance of support networks; and the impact belief systems and cultural diversity could have on rehabilitation services and provision. Implications for brain injury rehabilitation services and suggestions for further research are made.

Conclusions: It is concluded that the results of this study may help guide professionals working in this field in terms of recognising the barriers to family work and the needs of patients and family members.

Introduction

Brain injury often occurs without prior warning at a time when the individual still has many years ahead of them [1]. Upon discharge from hospital many patients will return home to live with partners, parents and/or other family members [2]. It is these family members, friends and loved ones who will play a crucial part in supporting and shaping the quality of life the patient will have post injury [3]. Close family members are often expected to, and indeed assume the responsibility of, providing life long support and care to the brain injured relative [4, 5].

The impact of acquired brain injury (ABI) on the patient and primary caregivers has been well documented [6-11]. Researchers widely acknowledge the long term consequences of ABI for both the patient and family members [12] and much has been published that explores the consequences of ABI for family members in terms of stress, coping and specific needs [4, 12, 13].

In a review of the literature Sinnakaruppan et al [4] identified lack of knowledge and understanding about brain injury as a key contributory factor leading to carer stress, with carers often identifying a high level of need for information regarding consequences of brain injury, referral sources and prognosis [2, 12]. Furthermore it has been suggested that the negative effect of inadequate knowledge due to poor information provision can be devastating for the family [5]. However, patients and their main carers often report poor satisfaction with the information they have received [14] and as a result are more likely to form misconceptions about recovery from brain injury which can be detrimental to the rehabilitation process [15].

The brain injured relative may experience any number of physical and cognitive impairments. However, the literature suggests that it is the cognitive deficits or invisible disabilities that cause the greatest distress to carers. Such deficits are often difficult for carers to understand given their lack of prior knowledge or experience with brain injury [1, 2, 5]. Studies have therefore suggested that the provision of relevant information may facilitate more positive family adaptation and in turn provide a more therapeutic home environment for the injured family member [12]. This is of particular importance when one considers the contribution families can make toward the generalisation of cognitive strategies from the rehabilitation unit to the home [16]. This has led to the recognition that family members need to be included in the rehabilitation process.

Carers are a core ingredient in the process of recovery and maintenance of compensatory strategies. However, traditionally rehabilitation programmes have focused on the patient's needs and have adopted an approach that does not always consider the important role carers play and the impact brain injury may have had on family members, with the emphasis of such programmes being placed on the person who had experienced the traumatic event [17]. However, it is important to recognise that family members have also experienced a trauma themselves, with the family's ability to cope having a direct impact on the patient's ability to accept and come to terms with their injury [5].

Professionals or specialist therapists have been viewed as playing significant roles in influencing family adaptation and problem solving after injury [1]. This has led to recommendations for more collaborative work between rehabilitation professionals and family members [1, 17]. However, for collaborative work to be achieved professionals need to first consider the emotional state of family members and attempt to get to know families in terms of adaptation, beliefs and pre-injury family dynamics [5]. A sensitive approach toward sharing possibilities about recovery and the realistic goals of rehabilitation is also essential to ensure good working relationships between members of the rehabilitation team and families [1].

One of the limitations of existing research conducted in this area is that it concentrates on gaining the patient or main carer's perceptions about brain injury and their needs [14, 17]. Therefore, such research fails to recognise the reciprocal relationship that exists between family members and professionals. Recommendations for family work have primarily stemmed from patient and family feedback to the exclusion of staff views. Studies have neglected to consider the views and experiences of professionals on collaborating with families and the difficulties that may arise when trying to involve families in rehabilitation programmes.

Aims of study

The aim of this study was to investigate the experiences of therapists working at a regional brain injury rehabilitation service in terms of family involvement in the rehabilitation process. It was hoped that by exploring professionals experiences and beliefs about collaborative work with families, a greater understanding of the potential pit falls and barriers to such work would be obtained. The primary aim is to identify areas of concern that may be addressed by brain injury services to ensure higher quality service provision to patients and their families.

Method

Design

A qualitative non-experimental design was adopted for this study, allowing the researcher to explore the experience of the participants as seen through their eyes as oppose to testing preconceived hypothesis or predictions. Focus groups were conducted using a semi-structured interview schedule and later transcribed for analysis [18]. Thematic analysis was used to inductively identify themes that emerged from the data [19, 20]. Thematic analysis is a process for encoding qualitative data that provides the researcher, participants and the research audience with an insight into events or situations under observation. Data obtained is described and organised into themes that provide a foundation from which further qualitative or quantitative analysis may be conducted.

Participants

Participants were all members of inter-disciplinary teams working on a hospital site providing inpatient and outpatient regional brain injury rehabilitation. Each participant had worked in the service for at least 6 months prior to focus groups taking place. Sixteen members of the outpatient team and 12 members of the inpatient team were provided with written information and consent forms that outlined the nature of this study (see appendix C for all correspondence). A total of 14 therapists, 7 from each team consented to take part in the study, with one from each team not attending due to unforeseen circumstances, leaving 6 in each group. The medium age of participants was 33 years with an age range of between 25 and 48 years.Tables One and Two provide information about participants.

Table One: Focus Group One (inpatient team) Participant Details

Participant Code	Age	Gender	Occupation
A	35	Female	Occupational Therapist
B	25	Female	Occupational Therapist
C	26	Female	Physiotherapist
D	36	Female	Physiotherapist
E	38	Male	Clinical Psychologist
F	28	Female	Speech & Language Therapist

Table Two: Focus Group Two (outpatient team) Participant Details

Participant Code	Age	Gender	Occupation
G	39	Female	Occupational Therapist
H	32	Female	Occupational Therapist
I	48	Female	Trainee Occupational Therapist
J	38	Male	Speech & Language Therapist
K	26	Female	Clinical Psychologist
L	26	Female	Assistant Psychologist

Interview Schedule

A semi-structured interview schedule was designed to elicit views and experiences on working with families (appendix D). The open ended questions devised for the interview schedule were created deductively through a process of crudely coding the relevant literature to obtain a list of themes that could be categorised into general areas of interest [20]. Gaps in the research or areas in need of further investigation were considered and questions developed [18]. The interview schedule was then loosely used to facilitate discussion in each of the focus groups.

Procedure

The agreement of therapy managers was secured prior to the researcher contacting potential participants. All members of the inpatient and outpatient teams were given information sheets about the study and consent forms to sign and return to the researcher should they wish to participate. Two focus groups were arranged to take place at the participants workplace at times convenient to them. It was decided that participants should join the group attended by members of their own interdisciplinary team. It has been suggested that colleagues identify with each others shared experiences [21]. Also in terms of pragmatics, it was better for staff to be seen in their teams within the work place. Focus groups lasted 60 minutes and were audio-taped. Time at the end of each focus group was allowed for debriefing purposes. The focus groups were then transcribed ensuring anonymity. Transcripts were then analysed using thematic analysis (see appendix E for transcript extract).

Coding Process

The process of thematic analysis followed the steps recommended by Boyatzis [19]. Transcripts of both focus groups were read and summarised to ensure the researcher had a good understanding of the data. Both transcripts were analysed together and then crudely coded into four core categories and descriptions of each core category along with supporting quotes from the data were written. The core categories were then refined by re-reading the transcripts and a list of seven themes was developed. These themes were further refined to produce a total of fifteen sub-themes. This process of refining themes ensured that they were reflective of the data collected [19]. Definitions of each sub-theme were written along with supporting quotes from the data (see appendix F for detailed stage by stage analysis of data).

To help ensure reliability and consistency of judgement [19] the researcher collaborated with participants. Each participant was sent a summary of the themes identified and supporting quotes from the transcripts (appendix G). Each participant was asked to provide feedback as to whether the emergent themes captured the essence of the focus group content. Any feedback that suggested disagreement with any aspect of the analysis was considered and appropriate changes made where necessary. Emergent themes were also discussed in depth with the other research collaborators.

Results

The stages of analysis are represented in Table Three along with the number of participants whose comments were used to generate the stage three sub-themes. The sub-themes will now be discussed in detail under the broad headings of core categories.

Table Three: Stages of analysis and emergent themes.

Stage One: Core Categories	Stage Two: Themes	Stage Three: Sub-Themes	n=
Barriers to Family Work	Service related	*Resources*	5
		Service philosophy	7
	Family related	*Engagement*	7
		Secondary carers	2
		Family adaptation	3
Understanding of Brain Injury Rehabilitation	Information needs	*Prognosis*	3
		Rehabilitation process	5
	Misconceptions	*Miss-information*	3
		Perceived roles	2
Support Networks	Support systems	*Support systems*	5
Belief Systems	Expectations	*Family expectations*	9
		Team expectations	5
		Client expectations	3
	Cultural differences	*Cultural awareness*	4
		Implications for rehabilitation	2

Key to transcript annotations:

F1= focus group one; p = page number; L = line number; Letter = participant code

Barriers to Family Work

The perceived barriers to collaborative work with families fell into two key areas, service related barriers and family related barriers.

Service related barriers

Resources: In terms of service related barriers to family work participants identified resource limitations such as inadequate funding, time constraints, geographical catchment area and general demands on the staff team and service as stumbling blocks to effective family orientated interventions:

> *"it depends on staff availability, demands on the service and how much time"* (F2,p6.L205.I)

Service philosophy: Service philosophy was also seen as a potential barrier to family work. Both focus groups recognised the need for increased family involvement. However, a good deal of time was spent reflecting upon how service philosophy could prevent systemic working practice leaving the therapists feeling that their hands are tied. Consequently, such limitations could lead to considerable confusion over who actually should offer and conduct the family work in terms of job descriptions and perceived roles. Therefore it is often left up to personal choice as to the level of involvement one would have with families and carers:

> *"do you know the poem, 'anybody, everybody, somebody, nobody'. So anybody thinks they can do it, everybody should do it, somebody should do it and nobody actually does"* (F1.p12.L477.A)

Family related barriers.

Engagement: A number of family related barriers were also suggested by both groups. The family's motivation, availability and life demands may all influence the level of engagement achieved. For instance family members may well have taken a lot of time off work already as a result of the injury to their loved one or may experience difficulty finding appropriate childcare provision:

> *"you are dealing with a family who may have been under an awful lot of pressure for a long time, financial, and like you say your asking them to commit to coming here on a regular basis"* (F2.p10.L375.G)

Secondary carers: The recognition that some family members may be forced into the role of secondary carers was also considered. In particular siblings, especially children, who already have a number of demands in their lives were seen to be particularly difficult to engage and at times may struggle with the responsibilities they are faced with:

> *"the teenagers a lot of them are going through so much personally, then they are reluctant or just can't handle any more emotional overload"* (F2.p4.L112.I)

Family adaptation: Family involvement may also be reliant on the co-morbid home situation and whether patients actually want their families involved. There may be a number of fears associated to the initial shock of the injury that have created high levels of anxiety for certain family members. Therefore, the level of adaptation to the situation may well influence engagement:

> *"it is almost that patients and families have to be at a certain level"* (F1.p3.L95.A)

Understanding of Brain Injury Rehabilitation

The families' understanding of injury and rehabilitation was discussed in terms of information needs and misconceptions held.

Information needs.

Prognosis: When and who should be responsible for explaining prognosis and recovery was discussed. Focus group one raised the issue of having to deal with the beliefs that had developed in the early stages of injury in the acute setting, suggesting that not enough information is provided early on leaving therapists with extra responsibility in terms of educating carers and other family members:

> *"we have a legacy of what has happened in the acute sector as well and a lack of potential education about prognosis, length of stay..."* (F1.p3.L100.C)

Rehabilitation process: This included having to deal with the lack of information and understanding family members had about the rehabilitation process in general, further suggesting that, at times it can be difficult not to take it for granted that people possess the same knowledge base as yourself:

"because we work with head injury all the time, we forget that there is little understanding amongst lay people" (F2.p1.L9.J)

Misconceptions.

Mis-information: In addition to this lack of knowledge, participants also discussed the misconceptions some family members may hold as a result of being given mis-information, either by other family members or through misinterpreting the information they are in receipt of:

*"sometimes you get 'oh well uncle **** said this' and well that isn't exactly what I said to uncle ****"* (F1.p19.L755.F)

Perceived roles: This may lead to unrealistic expectations about the level of recovery expected prior to discharge from the service. The perceived roles of family members may also be influenced by any misconceptions they may hold. Some may see rehabilitation as separate from home life and underestimate their valuable contribution to the recovery process:

" (rehabilitation) *not being something they need to be a part of*" (F2.p2.L66.J)

Alternatively, over involvement of family members was seen to be just as detrimental to the rehabilitation process. For example carers may find it difficult to stop doing everything they can for the injured family member, thus restricting the potential for increasing and encouraging independence:

> *"where the mother wants to do everything for the daughter"* (F2.p9.L323,I)

Support Networks

There was a strong recognition that at times carers' needs might outweigh those of the patient. The relationship between having good support networks and improved prognosis was also considered. Participants suggested that it is not only the family who can provide valuable support, but also benefit can be seen from patients meeting others in similar situations and sharing their experiences:

> *"the most positive thing I hear from clients here is about the support they gain from peers, you know just meeting other people who have similar experiences"* (F2.p11.L408.H)

Belief Systems

A hotly discussed area of concern focused upon the beliefs held by families, and how these may help improve or impede recovery. Belief systems were seen to be strongly influenced by the expectations held not only by the patient and their family, but also by the team. Cultural differences and implications for rehabilitation services were also raised.

Expectations.

Family expectations: The expectations held by family members can at times be unrealistic leading to inappropriate and at times punishing approaches to the patient's progress and recovery. Family members may lose patience and adopt a more blaming attitude, suggesting that patients simply aren't trying hard enough:

"a lot of it is that people don't know what's realistic, what's achievable" (F2.p12.L427.G)

Client expectations: Unrealistic expectations of clients may be fuelled by the attitude and beliefs of family members. However, beliefs may also be influenced by what the patients see going on around them. If they observe the progress of others in similar situations, then their expectations may be that they too will make the same level of recovery:

"oh I will be walking with a stick by then, I'll be eating whatever, I think they always look to the best case scenario" (F1.p4.L156.B)

Team expectations: The beliefs of patients and families may also be influenced by the beliefs of the therapists. Team expectations of clients can be high at times, which in turn can place increased pressure upon the patient and their families:

"we have got a lot of expectation about our clients and their families" (F2.p10.L349.H)

The key difficulty expressed across both focus groups was the need for patient, family and team expectations to be similar and not too far apart:

"we need to understand what they want to achieve as well as them understanding the potential they can achieve" (F1.p20.L805.C)

Cultural differences.

Cultural awareness: Belief systems may be embedded in family values and cultural background. Participants stressed the need to recognise that not everyone is the same. This raised the importance of having a wider cultural awareness:

> *"it's about finding out about that person within the family context and not making assumptions"* (F2.p9.L336.H)

Participants further stressed the importance of finding out what family values exist and where the patient fits into these, stressing the importance of not trying to change people's religious or cultural beliefs just because they differ from your own:

> *"but to modify something that's cultural, even if it doesn't work, you know we shouldn't touch it"* (F1.p20.L781.E)

Implications for rehabilitation: Participants from both focus groups suggested that cultural beliefs could have implications for rehabilitation, stating that perhaps such belief systems should take precedence over what we believe would benefit the patient. Even given what we as professionals know about brain injury rehabilitation, is it right to impose such ideals that may oppose the very cultural foundation of that family:

> *"is that putting Western medicine, idea's onto people, because who is to say how a family should operate"* (F2.p9.L320.I)

Discussion

A number of salient themes emerged from the two focus groups conducted. It is hoped that these themes reflect the narrative collected and therefore represent the personal experience and views of participants. The theme comprising "service related barriers" and "family related barriers" raises some interesting points. In particular, philosophy of the service in terms of models of practice and confusion over whose role it should be to work directly with families was explored in depth by both focus groups. Findings suggest some inconsistency between the beliefs of therapy staff working clinically and the working model adopted by service managers. This appears to have led to some confusion as to how family work can be conducted within the defined role of the therapist and who should take responsibility for such work given the expectations of service managers?

The theme "information needs" is consistent with the findings of prior research [4, 6, 12] in that it identifies that families do indeed lack relevant knowledge about brain injury rehabilitation. However, the question of when educational information regarding recovery, prognosis and the process of rehabilitation should be provided raised further concerns as to who has the time to actually sit down and educate families about such things? This theme also identifies how misconceptions can be formed either through misinterpreting information received or through incorrect information being passed on by other relatives, again supporting past studies that suggest that misconceptions can lead to unrealistic expectations, such as the belief that once the injured family member is discharged from hospital they will be back to their old selves [15, 22].

The importance of support for patients and their families addressed by the theme "support networks" is also consistent with other studies [22, 23]. This suggests that, at times the needs of family members may outweigh those of the patient, and can adversely affect recovery outcomes, highlighting the need for professionals to be aware of family functioning and specific needs to ensure they are able to provide a supportive environment for their loved one. In addition to this it can also be seen that support can be received from others in similar situations, suggesting the possible benefits of organised peer support groups.

The theme describing expectations and cultural differences highlights how difficult it can be to co-ordinate family work when the family, patient and rehab team all have differing expectations of each other regarding the rehabilitation process and recovery. Simpson et al [24] suggest that family co-operation and participation can be shaped by cultural beliefs, but equally services may be shaped in such a way that they exclude different cultures. The results of our study suggest the need for increased cultural awareness of professionals to ensure family belief systems do not have negative implications for the rehabilitation process or for the patient.

Limitations of the study

There are methodological limitations in relation to this study. Firstly, the findings reflect the experience and views of one regional rehabilitation service. Therefore it is difficult to generalise these findings to other services. It could also be argued that the qualitative design of this paper may lend itself to subjective interpretation on behalf of the researcher [25], although every attempt has been made to stay as close to the content of the narrative as possible. Furthermore, the focus groups are not truly representative of the entire staff team as no nursing staff or therapy managers participated. It could be argued that nurses, who have the most contact with families given that they work during visiting times, were unintentionally excluded from the study. It could also be argued that managers may well be the very people best placed to implement family work, but were also absent from the focus groups conducted.

A further limitation of this study is that it did not explore differences between groups. In particular the actual time of contact with families may differ between the two focus groups. The contact the in-patient group participants have with family members is often when family members are still experiencing shock and attempting to understand what had happened to their loved one. The contact professionals working in outpatient rehabilitation have with family members is at a much later time post injury. Therefore, some adjustment and level of acceptance would have taken place.

Personal reflections

It is important to recognise the influence that I as the first author may have had on the research process. I had previously worked for this rehabilitation service and therefore may have influenced the recruitment process, given that I was known to some members of staff. My familiarity with the service and staff team meant that facilitating the focus groups and throughout the process of analysis I had to be very mindful of my own views and opinions, attempting not to allow these to influence the narrative obtained or the process of analysis. I do however feel that the themes identified in this study are a true reflection of the participants experience. On a more personal note, I have come away from this study feeling frustrated by the fact that staff appear to be trapped in a system that continually prevents them from working collaboratively with families.

Clinical Implications

This current study has a number of implications for brain injury rehabilitation services. In order that collaborative family and professional work be implemented successfully, services should consider resource availability. It would appear that the participants in this study would welcome the allocation of time and resources to enable a more family focused working practice. However, at present it would appear that time has to be made between their already busy schedules. This suggests that change needs to occur at a number of levels; at a management level to ensure employment contracts outline and allow for therapist time and training to work with families; at a macro level, given that the culture and the ethos of the National Health Service has historically been to focus on the patient and not to necessarily consider their family.

The results of this study also suggest the need for teams to work closely together to ensure that any information gathered regarding pre-injury family functioning, beliefs and concerns are addressed early on in the rehabilitation process. In particular professionals need to be aware of cultural diversity and adapt services to ensure they meet the needs of a broader population of potential patients. Such considerations will not only impact upon the mental health and well being of family members, but may also directly influence recovery time and rehabilitation of the patient.

Further research

Further research in this area may consider making comparisons across services in terms of barriers to and success with incorporating more systemic collaborative family working. Further studies may also wish to explore the relationship between cultural difference and uptake of rehabilitation services, to further our understanding of how best to provide input to those holding different beliefs from service providers.

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CHAPTER THREE

Living with a brain injured parent: A proposed model of adaptation to parental brain injury.

Word count: 5127 (excluding tables, figures, references and raw data)

All identifying features have been removed from this paper to ensure anonymity and confidentiality of participants.

Abstract

Primary Objective: to investigate children's experiences of parental brain injury.

Research Design: a qualitative study conducted by means of interviews.

Methods and procedures: Interviews conducted with twelve children aged between 11 and 18 years living at home with a brain-injured parent. Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Main outcomes and results: A number of themes emerged that reflected the narrative collected. These themes address the initial shock; period of adaptation and acceptance; beliefs about recovery; information needs; understanding about injury and rehabilitation; and views of the future.

Conclusions: A preliminary model of adaptation to parental brain injury is proposed. Implications for brain injury rehabilitation services in terms of addressing the needs of children and suggestions for further research are discussed.

Introduction

McFarlane [1] describes brain injury as a "catastrophic and life altering experience" (p13). Survival following brain injury has improved due to recent advances in surgical, neuropsychiatric and rehabilitative care. This has led to an increase in the number of people who are living with any number of impairments as a result of injury to the brain [2]. Damage following traumatic brain injury can be diffuse or localised, therefore survivors may experience a range of emotional, physical, cognitive and behavioural difficulties. Such impairments can inevitably have a major impact on the injured individual's work, leisure and social life [3]. This in turn can impact upon the individual's family functioning [for reviews see 4-6], with changes in personality and emotional lability having the greatest effect on relatives [7]. The awareness of the long-term difficulties faced by both the individual and their family [8] has led to the recognition that service providers need to be considering adopting more family focused approaches to rehabilitation [for a review see 9].

Family members and friends play a crucial part in supporting and shaping the quality of life patients will have post injury [10]. Family members may spend long hours caring for the patient often with little appreciation or acknowledgment [10]. The brain-injured relative may seem like a stranger as a result of their impairments, leading to frustration and confusion for loved ones. It has also been suggested that the family's ability to cope and provide support to the injured family member may impact on the patient's rehabilitation outcomes [11].

Immediately following injury, family members may experience a period of initial shock and grief [12] and may form unrealistic expectations or beliefs regarding recovery [13]. In the long term family members may be adversely affected for many years after the occurrence of injury, especially partners [14-15]. It has also been suggested that the levels of stress experienced by family members can increase due to the patient's dependence upon them [16].

Spanbock [12] suggests that families go through five stages of adjustment following brain injury to a close family member. Initially they experience a state of *shock*. At this time they will feel angry, confused and helpless. The next stage is one of *elation*, where family members experience feelings of hope and optimism as the injured family member moves out of medical danger. The long-term consequences of the injury begin to be recognised at the *reality* stage where family members begin to realise that impairments may be permanent. The permanence of deficits can be difficult for the family to endure and can send the family into *crisis*. It is at this stage that family members begin to contemplate the future and seek professional advice. The final stage is that of *mourning* and redefining the relationship. Family members begin to accept that the patient's former self may not fully return. They then begin to mourn their loss. However, this model of adjustment is purely drawn from the author's clinical practice and not based on empirical research findings.

Powell also suggests a five-stage model of family emotional reaction to injury, describing the experience as "an emotional roller-coaster, where emotions can rise and fall as expectations soar and plummet" (p139). The five stages of emotional reaction suggested are *Shock*, *Relief*, *Hope*, *Realisation* and *Acceptance*. However, Powell stresses the cyclic nature of this model, in that relatives' emotions can change from one day to the next, given the slow and unpredictable recovery process.

During this grieving process and beyond family members will often have to take on extra responsibilities regarding household management. This can cause difficulties in assuming roles outside of the immediate care-giving situation often resulting in a reduction in work, leisure and social activities [14]. Such changes in family roles and responsibilities can lead to feelings of anger, frustration and ultimately lead to associated mood disorders such as depression. On a more practical note, families can experience serious financial difficulties as a result of either the brain-injured parent's inability to return to work and/or the non-injured parent's need to fulfil the full time carer role.

It is often the spouse or the parent(s) who take on the role of primary caregiver [7]. Consequently much of the research on family burden and coping after brain injury has concentrated on the needs of partners and parents [18-20]. In a review of the literature Perlesz, Kinsella & Crowe [6] suggest the need for further research that explores family adaptation to brain injury, in particular the impact on secondary (children or other siblings) and tertiary (friends and extended family) caregivers. In particular relatively little is known about the impact parental brain injury has on the children of the brain injured parent, and even less is known about the impact this can have on adolescents, who may well be experiencing many other challenges as they approach adulthood [21-22].

Lezak [23] suggests that parental brain injury brings a sharp reduction in the attention children receive from family members. Children may find themselves ignored or even abused by the injured parent who is becoming increasingly aware of their own dependence on others [10, 24]. Children may also find themselves neglected by the non-injured parent who may struggle to run the family single-handed. As a result, in the early stages of injury the uninjured parent may be unable to support the child in their grieving, especially as they too are still grieving themselves. In addition to this the uninjured parent is often faced with the decision whether to take on the role of carer or leave the marriage in order that a better life can be had for the spouse and for their children. Studies do suggest that the greatest disruption the child faces following injury to a parent is the increased likelihood of marital conflict, separation and divorce [10, 25, 26].

A limited number of studies have investigated the effects of parental brain injury on the behaviour of both the parent and the child. Pessar, Coad, Linn & Willer [27] explored the frequency and nature of psychological and behavioural problems that children experience following brain injury to a parent. A total of 24 married couples took part in the study representing 52 children. Uninjured parents were administered questionnaires that provided information on their perception of change in their child's behaviour and behavioural changes in the injured parent that might influence parenting ability. The results of this study found that 22 of the uninjured parents described their children as having increased behavioural, emotional or relationship problems. The study also found that negative changes in parenting performance demonstrated by the injured parent led to children being less loving and more avoidant of them. The results of this study also show that depression of the uninjured parent can lead to poorer parenting performance of both parents and correlates highly with many of the difficulties experienced by children. These researchers therefore suggest the need to consider the presence of depression in both parents when considering behavioural reactions of children. However, the results of this study are based on the parents self-reports and did not incorporate any data obtained directly from the children.

Uysal, Hibbard, Robillard et al [28] examined the parenting skills of individuals who had suffered a traumatic brain injury (TBI) and their spouses; the effects parental TBI has on children; and the effect TBI has on levels of depression reported by all family members. Assessments were administered to parents and children. The results of this study suggest that parents with TBI demonstrated differences in parenting performance compared to parents without TBI. Spouses of individuals with TBI also differed in parenting style compared to spouses of individuals without TBI. The study did not find support to suggest that children of parents with TBI would present with greater frequency of behavioural problems. However, they do suggest that these children are at greater risk of depressive symptomology compared to the control group. The study also found that both the injured and non-injured parent reported higher levels of depressive symptoms when compared with parents without TBI. The conclusion was that parental brain injury can have consequences for all family members. A limitation of this study is the broad time range since parental injury of between 2 to 39 years, with a mean time post injury of 9.3 yrs. Therefore, in some cases injury to the parent would have occurred prior to the child's birth. This makes it difficult to determine if behavioural problems or symptoms of depression presented by children were directly associated to the parent's injury and not due to other factors.

Only one qualitative study to date has attempted to address the child's experience of parental brain injury. Butera-Prinzi and Perlesz [24] adopted a phenomenological framework attempting to gain an understanding of what the experience had been post parental brain injury for a sample of four children aged between 7-12 years. Interviews with the children were conducted and themes developed that emerged from the data. Children reported feeling excluded from the information giving process and having little if any contact with professionals. The children further reported experiences of initial crisis, feelings of ongoing loss through being faced with a father who has changed and grief for a number of years post injury. This study suggests that these children were finding it difficult to mourn their loss, especially as their parent was still alive and therefore posed a constant reminder of how things used to be. As a result children had not talked openly about their own feelings, therefore prolonging the grieving process. These authors conclude that professionals and policy makers need to address the needs of dependent children as well as those of the patient and primary caregiver during the rehabilitation process. However, these findings are based on a rather small sample of children within a narrow age range whose fathers had suffered brain injury.

To date it would appear that few studies have explored the experience of children living with a parent who has suffered brain injury. To the knowledge of this author, no attempt as yet has been made to develop a model of the stages children may go through in terms of grieving, emotional reaction and adaptation. Furthermore, studies have not directly addressed the needs of children with respect of what professionals or rehabilitation services may be able to do to help them adjust to the losses and trauma experienced.

The current study: aims and research question

This study aims to address the lack of research on the experience of parental brain injury. More specifically it attempts to understand the experience of children aged between 11and18 years, classed as adolescents. The study aims to propose a preliminary model that identifies the stages children go through during and following parental brain injury. Such a model may help identify the specific stages of emotional reaction and adaptation experienced and during what stages rehabilitation services may be best suited to intervene.

The research question considered for this study was: are there identifiable stages of adjustment and adaptation that children go through following brain injury of a parent and if there are at what stage should service providers intervene?

Method

Design

A qualitative research design was used in this study in order that the researcher could gain an understanding of each participants lived experience without restricting the narrative through structured questions and answers. Semi-structured interviews were conducted with each participant that explored their experiences of parental brain injury. Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts of interviews. IPA is phenomenological in that it seeks to explore how individuals make sense of their personal and social world. IPA takes both an empathic and questioning interpretative stance in attempting to understand the view of the participant and to identify any leakage of information that may be less obvious to the participant. IPA also recognises the dynamic process of research and therefore realises that interpretations of data will be influenced by the researchers own conceptions [30].

Participants

The participants for this study were recruited through a regional brain injury out-patient unit. Inclusion criteria stated that participants should be between 11 and 18 years old; injury would have occurred at least six months prior to interviews being conducted; the injured parent would have either attended or be attending the out-patient rehabilitation service; and children should currently be living at home with the injured parent. Children were excluded from the study if the injured parent already had a disease or disorder that required care pre-brain injury; if the parent had any mental health difficulties pre-injury that meant they had been cared for in some capacity already; and if the child's first language was not English.

Fifteen children who fulfilled the inclusion criteria were approached. Out of those approached twelve agreed to be interviewed, of which nine were boys and three were girls. The mean age of those interviewed was 16 years with an age range between 13 and 18 years. The mean length of time post brain injury of parent was 26.5 months, with a range of 12 months to 4 years and 2 months. C1 + C2 and C9 + C10 were brother and sister, C5 + C6 and C11 + C12 were brothers. Six of the injured parents were fathers and three were mothers. All the injured parents were experiencing a range of cognitive deficits but were independent in self-care and mobile with mild to moderate physical impairments. Table one gives information about participants and information about time and type of injury sustained by parent. All three of the children who did not wish to participate in the study were girls living at home with an injured mother.

Semi-structured interview schedule

A semi-structured interview schedule was designed to elicit views and experiences of parental brain injury (appendix H). The open-ended questions were devised deductively from a search of the relevant literature. After the first interview was conducted and analysed to produce meaningful themes, the interview questions were then modified to reflect these emerging themes [29].

Table One: Child and Injured Parent Information

CODE	Age years	Gender	Which parent?	Age of parent	Time Since injury	Details of Injury
C1	13	F	Father	44	20 mth's	Fractured Skull
C2	18	M				
C3	18	F	Father	47	18 mth's	Subarachnoid Haemorrhage
C4	18	M	Father	51	4 yrs 2 mths	Subarachnoid Haemorrhage
C5	16	M	Father	53	16 mth's	Fractured Skull
C6	14	M				
C7	13	M	Mother	44	12 mth's	CVA
C8	18	M	Mother	44	34 mth's	Subarachnoid Haemorrhage
C9	17	F	Father	45	4 yrs	Stroke
C10	16	M				
C11	14	M	Mother	36	14 mth's	Subarachnoid Haemorrhage
C12	17	M				
Mean	16			45.5	26.5 mth's	

Procedure

The aims of the study were presented to the inter-disciplinary team working at a regional brain injury rehabilitation out-patient service. Staff were asked to consider the recruitment criteria and given detailed packs to pass on to suitable clients. These packs contained information sheets for the family to read and information sheets for the children (appendix I). The pack also contained consent forms requiring the signatures of a parent and the child agreeing to be interviewed (appendix J). Those wishing to participate were contacted by the researcher to arrange a time convenient to conduct the interview.

All interviews were conducted in the family home. Participants were given the choice of either having a parent present at interview or a chaperone (a member of staff from the rehab unit); this was in response to the local ethics committee recommendations. Interviews lasted between 30-60 minutes and were tape recorded for transcription at a later date. Participants were reminded about confidentiality and anonymity of information collected prior to interview and then again during a debriefing session after the interview.

Interviews were then transcribed and anonymised by the researcher. The taped interviews were kept in a locked filing cabinet at the regional rehabilitation centre.

Analysis

Interview transcripts were analysed using IPA. The process of Interpretation of the data followed the steps recommended by Smith et al [29-30] (See Appendix K for sample of transcript):

Step 1: Transcripts were read a number of times and the left hand margin of the transcript was used to record anything of interest about the participant's narrative.

Step 2: The right hand column of each transcript was then used to record any emerging themes.

Step 3: The emergent themes of each transcript were recorded and connections between them were identified to form clusters of themes. At this stage themes that did not cluster were dropped. Transcripts were discussed in detail between each of the authors to ensure agreement on the themes and clusters identified.

Step 4: Major themes that captured the essence of the clusters produced in step 3 were then devised.

Step 5: Each transcript was re-read to ensure the researcher had not missed any data that may fit into the major categories.

Through the process of analysis a number of recurrent themes were identified, leading to the development of nine major themes (see table two).

Table two: major themes, emergent recurrent themes and number of participants whose narrative led to development of emergent themes *(n)*

MAJOR THEMES	*RECURRENT THEMES & No of participants*
Initial Shock	*Emotional impact (2), Shock(8), Realisation(5), Initial fears(5), Turning to God(1)*
Impact on the Child	*Hopelessness(5), Bottle up feelings(8), Need to be near(6), Reliability of parent(2), Feeling forgotten(1), Shattered dreams(1), Behaviour(5), Impact on schooling(5)*
Period of Adaptation	*Strength of relationships(8), Changing roles(6), Responsibility(9), Sacrifice(7), Support from family(6), Support from school(2), Support from peers(7)*
Acceptance	*Making allowances(5), Accepting impairments(8), Take things day by day(2)*
Beliefs about Recovery	*Positive view(5), Slow process(1), Expectations(8)*
Information Needs and Provision	*Trying to forget(3), Don't want to know(1), Shielded from information(1), Information handed down(5), Input from professionals(9)*
Understanding of Injury and rehabilitation	*Prior experience/knowledge(3), Rehabilitation at home(3), Perception of rehabilitation(9), Understanding of Injury(6), Frustrated by deficits(3)*
Period of Reflection	*Life not perfect(2), reality of life(3), Feeling guilty(1), Duty(2), Regret(1), Time is a healer(2), Could be worse(2)*
View of the Future	*Giving something back(1), Future ambitions(2), Change of heart(1), Concerns(3), Make the most of life(2)*

These major themes capture the experience of those interviewed (see appendix L for detailed listing of major themes, their composite recurrent themes and supporting interview extracts). For the purpose of this report master themes will appear in bold type and abstracts from interviews will be in italics and are followed by participant identifiers and line number of transcript (e.g. C1, 57).

Initial Shock

The first major theme reflects the initial experience and impact of parental brain injury on the child. A majority of the participants described a period of initial shock:

"and it was just like, I just sat there" (C2, 121).

This shock turned to fear for some as they began to think about the severity of the injury and what the possible prognosis might be:

"I was thinking stupid stuff like is he going to come back again?" (C1, 95).

These feelings of shock and fear invariably impacted on the child's emotional state. Eventually the shock experienced settled down to allow for a slow realisation as to what had happened to their parent and of how little control they had in terms of helping them get better:

"you realise that he might not get better, might not ever drive again, might not have the same opportunities" (C10,42).

As this stage of realisation emerged children began to find ways of coping that strengthened any beliefs about recovery, for instance C3 turned to her beliefs and religion:

"the only person we could go for help is God right now, so we started praying" (C3, 248).

Impact on the Child

Specific factors that had an impact on the child were identified. Some of those interviewed experienced feeling hopeless and lost:

> *"like you can put a plaster or a bandage on, but you can't put anything on my dad's head, because there is nothing you can do about it"* (C1, 341).

One participant felt forgotten:

> *"I am constantly frustrated by certain people in the family who have forgotten who I am"* (C4, 46)

Many felt unable to share their thoughts and feelings through fear of either causing further upset to the family or drawing unwanted attention to themselves:

> *"because you get people sort of feeling sorry for you and stuff like that and that's a bit uncomfortable at times"* (C7, 43)

Some of the children expressed how hard it is to be apart from the injured parent, expressing a fear that they needed to be close in case of further complications:

> *"he would be in bed and I would think do I leave him or stay with him"* (C2, 527)

Another important issue raised by some of those interviewed was concerned with schooling and behaviour. These children reported that initially school work and attendance had been disrupted:

> *"I didn't want to go into school so I went into hospital instead"* (C7, 73)

A number of the children further suggested that their behaviour had been cause for concern,

> *"I used to mess around a bit"* (C6, 110)

However, behavioural difficulties only appeared to present at the early stages of injury and seemed to reduce as the children began to adapt to their parents injury.

Period of Adaptation

The initial trauma experienced by the family and the direct impact the injury had on the child's life, ultimately led to a Period of Adaptation. During this time many of those interviewed reported experiencing a number of changes to their role within the family and the roles of other family members:

"so instead of supporting me, now he needs support" (C4, 90)

Others remarked on how the level of responsibility expected of them had changed:

"I have to do a bit more sort of to help mum and she has to rely on us a bit more" (C7, 3)

The child's ability to cope during this period of adaptation was dependent upon the support they received from family and friends, with children often opting to talk to friends or family members as oppose to engaging with professionals:

"I didn't really want to speak about it with anyone else, just friends and family like" (C6, 189)

A greater emphasis was placed on the support gained from peers as oppose to support received from other networks:

"I spoke to a couple of my close friends about it" (C7, 188)

Schools were also mentioned as a source of support. In particular two of the children mentioned that they had been offered, and had accessed, mentoring or counselling services which they reported finding useful in terms of talking over their thoughts and feelings:

"I went to this group that they had, which was quite good really. Because I could discuss what was on my plate whatever, in confidentiality" (C10, 68)

Ultimately adaptation for many led to a strengthening of relationships with peers and family members:

"all of us got strong for my dad" (C3, 211)

However, adaptation also involved children making and accepting a number of sacrifices to ensure positive change:

"yes we do kind of need help but at what cost, it's like you got the help in exchange of freedom" (C4, 18).

Acceptance

This theme emerged as participants discussed how they have come to terms with and accepted their parent's injury and impairments:

"you have just got to learn to accept it" (C10, 35)

Acceptance involved making a number of allowances dependent on the impairments presented by the injured parent:

"we can't like talk very loud" (C1, 6)

For two of those interviewed, it was considered best to take each day at a time:

"you can't predict what he will be like everyday" (C2, 16)

This theme appears to suggest that acceptance may be dependent upon the expectations held by the child regarding speed of recovery and potential prognosis. Further implying that acceptance also relies on the child's ability to make allowances to accommodate the injured parent's impairments.

Beliefs about Recovery

A number of those interviewed held very positive beliefs about recovery:

"I do try to be more positive about things, I think she will be like a lot more back to normal" (C7, 297)

However, such beliefs appear to be strongly influenced by the expectations held by the child, with some holding realistic beliefs about recovery:

> *"not back to how he used to be, just a lot better than he is now"* (C6, 178)

Others held more unrealistic expectations that appeared to stem from assurances offered by others, in particular their close friends

> *"they* (peers) *were very supportive, they made me understand that he would be fine and he will be himself eventually"* (C3, 158).

Only one of the participants gave an indication that they recognised and accepted that recovery would be a slow process. Even then they held high expectations for the future:

> *"it's not going to change from day to day"* (C2, 67)

Information needs and provision

Beliefs about recovery were strongly influenced by the child's information needs and provision. Three of those interviewed expressed a wish to be left alone so that they could try and forget about the ongoing difficulties faced by the family:

> *"so I was actually taking, answering everyone's questions like how's dad etc, when I was actually trying to forget him"* (C2, 53)

Further stating that talking about the injury can make things worse:

> *"because it sort of makes it worse for you, because you think about it more and stuff"* (C7, 49)

This has implications in terms of information provision in that children were somewhat reluctant to engage with professionals:

> *"I don't feel like I need to know anything else"* (C9, 301)

Instead children seemingly preferred to gain information second hand from other family members:

"my dad always sort of relayed the information" (C7, 218)

However, interviewees also reported that they were seldom approached by professionals or offered any form of support directly from services:

"I got cut completely out of the loop" (C4, 290)

One participant reported that the information she did receive from family members was minimal, stating that she felt her family were trying to shield her from information that may upset her:

"my older brother didn't tell me much because he thought I would get upset" (C3, 91).

Understanding of Injury and Rehabilitation

This theme emerged as participants expressed their perception of rehabilitation. Interestingly, many of the children interviewed perceived outpatient rehabilitation as being like a school or college:

"English, computers, woodwork, so I imagine it as a school" (C1, 263)

Many also saw rehabilitation as something that was separate from home life:

"I don't want to know the specifically what he does, just as long as it works" (C2, 306)

Three of the participants also appeared to have little understanding regarding cognitive strategies that, if incorporated in the home, could assist the injured parent's day to day functioning. For example, when discussing her father's diary (a simple but effective tool to help with everyday memory problems), one of the children stated:

"I think that if it's his diary then it should be for himself" (C1, 392)

When discussing the actual injury, some did have a good understanding of brain injury:

"I already knew a bit about what he had, it was mainly like a vertebra broken and a brain damaged skull" (C5, 115)

There was even some suggestion that certain television programmes had helped them understand what had happened to their parent and gave them some insight into possible prognosis:

"I had sort of some idea, because I know it sounds silly but I have seen it on the TV and stuff" (C7, 131)

However, those with limited understanding expressed that at times they would become rather frustrated by the injured parent's deficits and therefore found it harder to be empathic toward them:

"he has gone from someone who was active and hard working to someone who is lazy" (C4, 124)

Period of Reflection

The eighth major theme describes a Period of Reflection that some of the children appear to have experienced. Adaptation and acceptance of their parent's injury sometimes resulted in a change of philosophy to life. Two of the participants described their realisation that life is not always perfect:

"before everything used to go my way in the end... we were like superheros because apart from the occasional thing that went wrong, everything went our way" (C4, 317)

Leading to further reflection on the reality of life:

"being indestructible isn't fun if your world can come crashing down around you" (C4, 337)

Some expressed feelings of guilt and regret:

"if I could wind back the clock, I sure as hell would" (C4, 182)

While others took on a more responsible role in the family due to a sense of duty:

"he's helped me so I help him" (C5, 154)

This period of reflection for two of the children resulted in an acceptance that things could have been worse:

"there was one woman there who was brought in with a stroke, and then when she was brought in she had another stroke, so I felt grateful that at least that didn't happen", (C7, 414)

And a belief that time is a healer:

"well, it's been hard, but as time has gone on it has got better" (C5, 350)

View of the Future

This theme encompasses the participants concerns that brain injury can happen at anytime to anyone:

"it can happen to anyone...just hope it don't happen to anyone else" (C6, 212)

And more specifically concerns about the injured parent's future:

"because, what's going to happen when erm, when I'm not here" (C4, 99)

The impact the injury has had upon the future ambitions of some of the children was discussed, one mentioned going to university:

"it depends how mum is and if dad can cope with it" (C7, 318)

One of the younger children felt that given the help and support her father had received from the health service, she would like to give something back:

"I want to do the same as other people, thinking that I can help them to get better" (C1, 308).

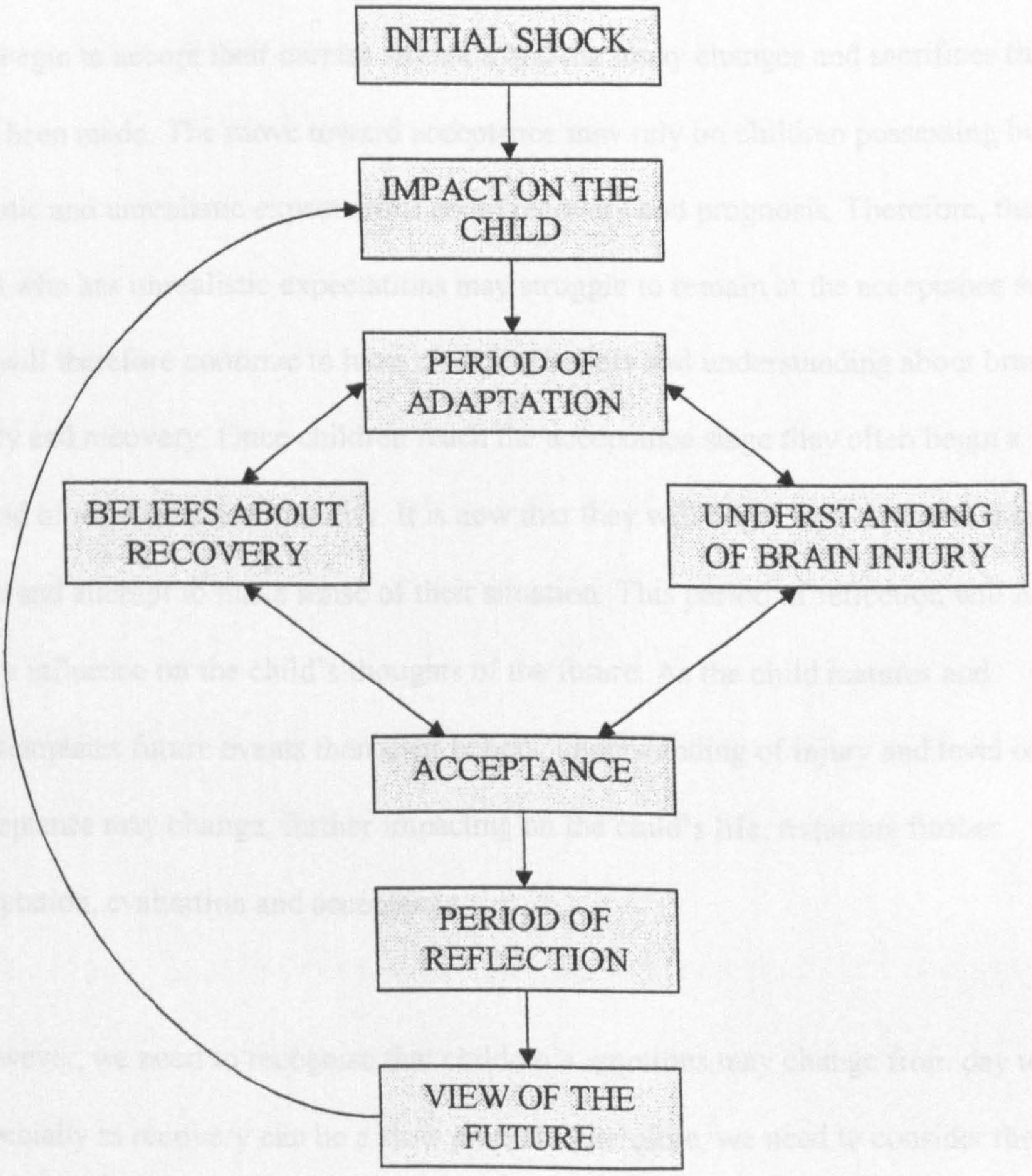
Two of the participants discussed how their parent's injury had made them reflect on how unpredictable life can be and as a result had adopted the attitude of making the most of life:

> *"you might as well make the most of it while you can. You never know you could end up the same way, so just have a good time"* (C10, 142)

Preliminary Model of Adjustment

The major themes developed from the interviews conducted suggest a pattern of adaptation that each child was either moving through or had moved through. This pattern of adaptation can be represented in a preliminary model to help identify the specific stages children experience after parental brain injury (see Figure One):

Figure One: Preliminary model of children's adaptation to parental brain injury.



The model explained

It can be seen from the analysis of the data collected that children experience a stage of initial shock. This stage appears to exist up until the injured parent is stabilised and some level of recovery has begun. Once this shock begins to sub-side the child then starts to recognise the direct impact the injury has had on the family functioning and for them personally. There then follows a period of adaptation which children may revisit dependant upon their beliefs about recovery and understanding of brain injury. Once the child is able to adapt and come to terms with the parent's injury, they can then begin to accept their current situation and the many changes and sacrifices that have been made. The move toward acceptance may rely on children possessing both realistic and unrealistic expectations about recovery and prognosis. Therefore, the child who has unrealistic expectations may struggle to remain at the acceptance stage, and will therefore continue to have changing beliefs and understanding about brain injury and recovery. Once children reach the acceptance stage they often begin a period of reflection and maturity. It is now that they will begin to re-evaluate their lives and attempt to make sense of their situation. This period of reflection will have some influence on the child's thoughts of the future. As the child matures and contemplates future events then their beliefs, understanding of injury and level of acceptance may change, further impacting on the child's life, requiring further adaptation, evaluation and acceptance.

However, we need to recognise that children's emotions may change from day to day, especially as recovery can be a slow process. Therefore, we need to consider the cyclical nature of this model.

Discussion

Recent literature that explores family functioning after brain injury has tended to focus on the needs of primary caregivers [18-20]. The results of this study recommend that service providers need to move away from seeing the patient and primary caregiver as the key parties who the injury will impact upon and begin to recognise the specific needs of secondary carers, such as children of the injured family member.

The themes identified in this study suggest a number of stages children may go through while adapting to and accepting the injury to their parent. Consistent with findings of other studies that focus on adult adaptation to brain injury [12, 17, 24] all those interviewed experienced an initial stage of shock. Following the initial shock stage the direct impact injury had on their lives was then considered. Participants reported feeling forgotten and unappreciated. Such feelings led to a level of withdrawal that caused them to bottle up their feelings, choosing only to share their thoughts with close friends. This may be seen as a reflection of the parenting performance of both parents as suggested in other studies, whereby the uninjured parent is so involved in caring for the injured parent they have little time to give to their children [27, 28]. It could also be the case that children believe they have to put a brave face on the situation, and therefore choose to remain silent.

This study also found some support for the suggestion that children of parents with brain injury will present with a higher frequency of behavioural problems [27]. However, such behaviours appear to be short lived as the child adapts to the situation; assumes a new role and responsibilities; and begins to form beliefs and increased understanding about recovery.

Studies have found that children report feeling excluded from the information giving process [24]. The children interviewed in this study however, stated that although they did feel excluded from information provision by professionals, they actually did not want any more information than what was offered second hand by close family members. This remained so even though some of this information may be censored to prevent further upset of the child leading to the formation of unrealistic expectations. Therefore, professionals need to be aware of when information provision may be appropriate and manageable for the child. There is also the need to consider the important role unrealistic expectations may have for children in terms of coping, and not immediately think such beliefs should be challenged with the facts.

Throughout each interview one could not fail to recognise the sense of positivity of each child. Participants appeared to be able to reflect upon and access their feelings to ensure a clear account of their experiences. In particular it was interesting to hear how they had seemingly re-evaluated their perspectives on life and how this had influenced their beliefs about the future and life in general.

Limitations of the study

There are a number of limitations of this study. The relatively small sample size and age range of participants makes it difficult to generalise the results to all children who experience parental brain injury. However, given the small sample it was possible to conduct in-depth interviews that may be a more accurate reflection of the experience than would have been achieved using more quantitative methods of enquiry. The qualitative method of analysis adopted may be influenced by the researchers own subjective views and agenda, although Smith et al [29, 30] does recognise that the results obtained from such enquiries are the researchers interpretation of the interviewee's interpretation of events (see chapter four for further consideration of these issues). It may also be argued that the method used may not have been appropriate given the age range, as IPA relies on the articulation and reflective ability of those interviewed. However, this was considered early on and was one of the reasons why the participant criteria only considered 11 to 18 year olds.

Personal reflections

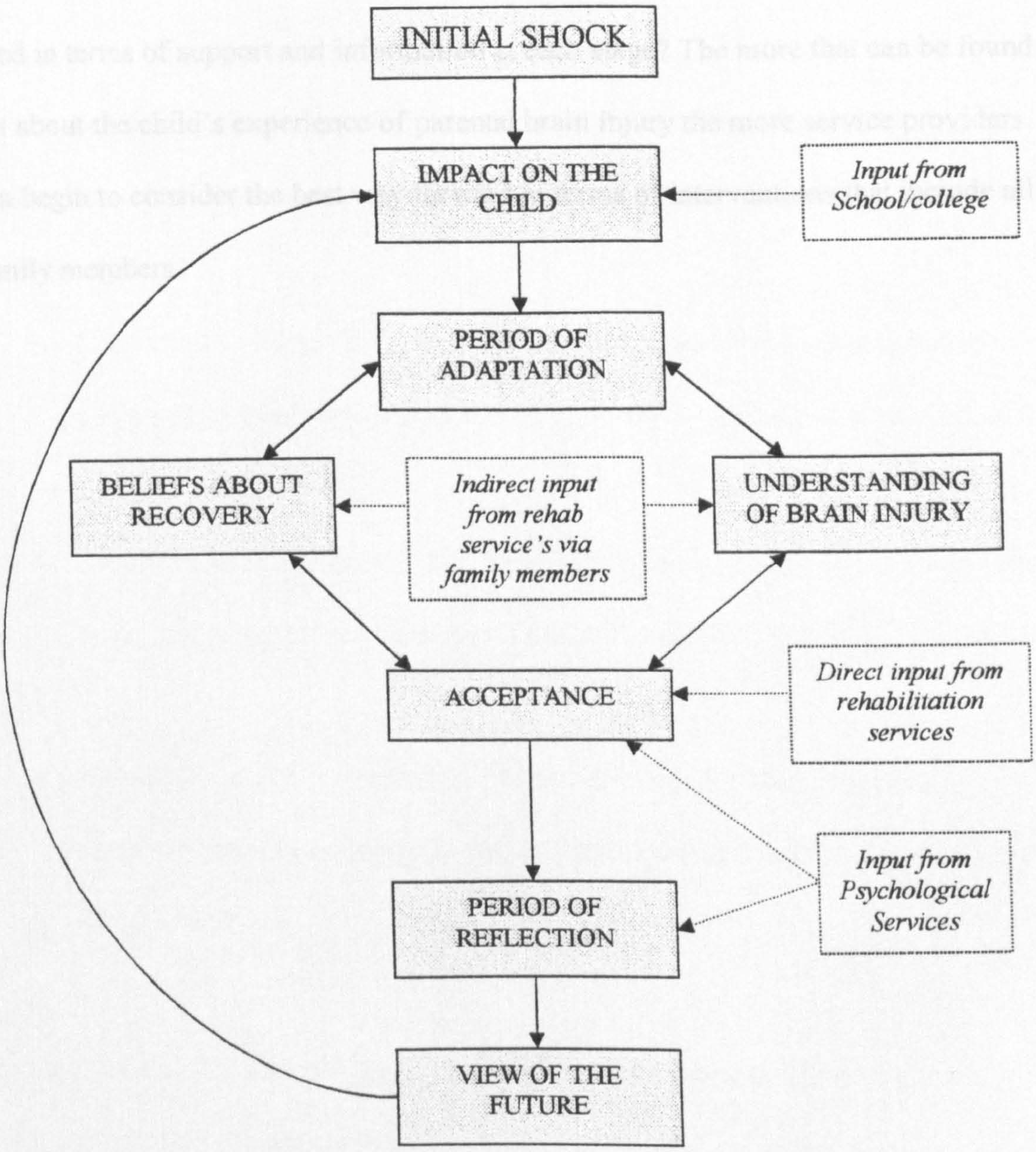
There are a number of questions that I as the first author have reflected upon in relation to this study. I feel that being male may have impacted on the process of conducting this study. I wonder if the ethics committee would have made the requirement for a parent or chaperone to be present at interview if I were female? I also wonder if more girls would have agreed to participate if it had not been a man conducting the interviews? I also wonder if my own preconceived beliefs and ideas about parental brain injury could have, at least initially, influenced the dynamics and focus of interviews. I entered into this research domain believing that the reports obtained from children would be very distressing and negative, and that these children would have been in desperate need of interventions from services. The reality was quite the opposite. In many ways the children radiated a strong sense of positivism, strength and resilience in terms of relaying their personal accounts and experiences which in turn gave me a sense of hope for their future.

Clinical Implications

The proposed model of adaptation to parental brain injury has a number of implications for rehabilitation services and the education sector. Through identifying specific stages of adaptation we can begin to understand where and when professionals may need to intervene and what support or information children actually require during each stage (see figure two).

The results of this study suggest that during the *impact on the child* stage children are more likely to experience behavioural problems and performance at school may suffer. It is at this stage that teaching staff may be best placed to intervene, in terms of offering the child a listening ear so they can express their thoughts and fears without being judged or lectured to. However, healthcare professionals may need to wait until the child reaches a level of *acceptance* before providing any direct support or information about the injury, as children appear to be content with the information they receive indirectly via close family members during the *period of adaptation.* If the child finds it difficult to move beyond the *period of adaptation* to the *acceptance* stage or becomes distressed while in the *reflective period*, then they may require further support, possibly from psychological services.

Figure Two: Proposed model of adaptation showing stages at which appropriate intervention may be most effective.



Further Research

Further research may wish to test the proposed model on different age ranges to explore validity across the age groups. To further understand the adaptive process more longitudinal studies need to be conducted to examine the impact parental brain injury has on children in the long term, especially in terms of future goals, expectations and achievements. Perhaps the most important and necessary line of enquiry future research may take is to identify the specific expressed needs of children? If the proposed stages of adaptation do indeed exist, then what do children need in terms of support and information at each stage? The more that can be found out about the child's experience of parental brain injury the more service providers can begin to consider the best way forward in terms of interventions that include all family members.

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CHAPTER FOUR

Reflective Review

Conducting Qualitative Research Interviews and Focus Groups: Ethical, Methodological and Personal Reflections

Word count: 2965

Abstract

This paper documents the first author's experience of conducting two qualitative empirical papers as part of his doctoral thesis. Specifically it highlights a number of ethical and methodological concerns associated to conducting focus groups and interviewing children. The first author's personal account and reflections in relation to each of the two research studies are also presented.

Introduction

This paper will focus on the first author's experiences of conducting two qualitative research studies as part of his doctoral thesis in clinical psychology. Its content is more honed toward personal expectation, experience and reflections. As a result I have opted to use the first person in writing this review. This reflective paper provides a space to discuss ethical and methodological concerns and considerations in greater depth than the empirical papers would permit. It also allows for a more personalised account of the data collection process and the opportunity to evaluate outcomes in comparison to original expectations held prior to conducting each research project.

The paper will be divided into two sections that discuss each of the research papers in turn. Section one will explore the experience of conducting focus groups with therapy staff for the study "Working with families affected by Brain Injury: The views, beliefs and experiences of professionals providing rehabilitation services for acquired brain injury." In particular the selection of participants and the motivation behind participation will be discussed. Section two will discuss issues relating to the empirical paper "Living with a brain injured parent: A proposed model of adaptation to parental brain injury", focusing upon ethical considerations and personal reflections around interviewing children about parental brain injury.

About the author

I worked in neuro-rehabilitation for a number of years prior to beginning my clinical training. This provided me with the opportunity to gain first hand experience working with children and adults presenting with a range of neurological injuries and associated impairments. Whilst working in this field I also completed a number of research projects, including a thesis as part of my MSc in Health Psychology. This thesis evaluated a family therapy programme set up and facilitated by me at a regional brain injury rehabilitation unit. While conducting this research it became apparent that the family members we came in contact with often received little outside help and the needs of family members other than the primary caregiver, such as children, were very seldom considered and under researched. A further outcome of this study suggested that the literature base on the impact of brain injury on families relied on data collected from family members. Consequently little is known about the pragmatics of providing families with support from the perspective of professionals working in the field. Such gaps in the existing research literature therefore inspired the two papers under discussion.

Section One: Conducting Focus Groups

This section will explore the ethical and methodological issues faced while conducting the study "Working with families affected by Brain Injury:

The views, beliefs and experiences of professionals providing rehabilitation services for acquired brain injury." In particular it will explore the arguments for and against participants being familiar with each other and the facilitator of the group.

Ethical and Methodological Issues

Focus groups have become an increasingly popular approach used by social science research (Wilkinson, 2003). However this approach is not without its methodological debates. One debate within the literature on focus group methodology concentrates on participant selection. The focus groups conducted as part of this researcher's dissertation consisted of therapy staff working on inpatient and outpatient rehabilitation wards. It was decided that two focus groups would be conducted that grouped participants together with their colleagues within interdisciplinary teams. Therefore, all those who took part from the outpatient team were invited to attend one focus group and those from the inpatient team the other group. Some researchers suggest that ideally participants should not know each other and groups should therefore be naturally occurring (Hyden & Bulow, 2003). However, others suggest that the use of pre-existing groups can be beneficial (Kitzinger, 1994). In particular colleagues can identify with each other's shared experiences within their working lives (Kitzinger, 1995). In terms of this study, it would have been extremely difficult to recruit participants to focus groups who did not know each other given the interdisciplinary approach adopted by the service. On reflection I feel that because of their familiarity with each other, participants were able to engage in the group process quickly and easily, with participants welcoming the space to discuss the issues raised by fellow colleagues. However, we cannot be sure what would have happened if I had not used pre-existing groups.

The use of pre-existing groups raises other methodological considerations. Hydon and Bulow (2003) pose the question who are the participants actually representing in the focus group? Suggesting that researchers need to be aware that participants comments may be reflective of personal views; the views they hold as part of a professional discipline; or representative of the role they have in the focus group itself. These researchers further suggest that participants may shift positions throughout the focus group discussion. This therefore needs to be considered when researchers attempt to interpret and analyse data. One needs to consider whether the views being expressed are personal or political, are they representative of the entire team or just those who belong to the same disciplines? We also need to consider our own beliefs and to what extent our role of facilitator can influence the group dynamic (Smithson, 2000).

A further methodological and ethical dilemma to consider with respect to holding focus groups is the participants' intentions, are they going to use the group for the reasons intended by the researcher? Smithson (2000) suggests that focus group participants should be seen as performers. Researchers need to be aware that group discussions are constructed within social situations and can be influenced by events unforeseen by the moderator of the group. Indeed one of the focus groups conducted for the study of staff experiences of involving families in brain injury rehabilitation, certainly became an attack on managerial decision-making and political issues that had been resonating through the unit. This emphasis on such issues almost turned the focus group away from the research agenda and subject matter toward more service related issues not particularly relevant for the study in question.

Personal account and reflections

Researchers have less control over participants when conducting focus groups than perhaps they do when using others methodologies. One can never guarantee who will show up and what direction the narrative will take. Although both the focus groups in question went rather smoothly it was interesting to me as an ex-member of the rehab team to note who did not participate. The most noticeable absentees were the therapy managers. Not one staff member in a managerial position agreed to participate. This may have been simply due to the demands of their jobs. However, the feeling I had was that managers passed on the information about the groups to staff teams, without considering that they could participate themselves? Given that managers by definition possess the authority to implement change to service provision it seems a shame that none took part in this study. Managers could have contributed to groups and witnessed the many ideas generated about how the service could be improved. Nursing staff would also have provided another perspective regarding collaborative family work. However managers chose not to extend the invitation to participate to nursing staff for reasons unknown to myself.

At the end of each focus group the feedback from participants was extremely positive to the extent that a number of them left considering using focus groups regularly as part of their clinical practice to brainstorm possible change to service provision. The focus groups left me feeling that those who had participated had found it refreshing to be given the space to voice their views and share their thoughts in a safe non-judgemental environment. However, another part of me felt that the groups had not been perceived as offering anything of importance to therapy managers and would simply be forgotten, having had little if any impact on service provision in terms of collaborative work with families.

Section Two: Interviewing Children and Adolescents

This section will reflect upon the researcher's empirical study entitled "Living with a brain injured parent: A proposed model of adaptation to parental brain injury". This qualitative research study involved interviewing participants aged between 11 and 18. Interviews sought to explore the participant's experience and interpretation of parental brain injury. This study therefore posed a number of ethical dilemmas and methodological issues with respect of the age range of its sample that will now be discussed.

Ethical and Methodological Issues

One issue specifically connected to the qualitative paradigm adopted for this study concerns the process of obtaining informed consent from participants. Larossa, Bennett & Gelles (1981) argue that the principle of informed consent may be called into question given the very nature of qualitative research studies, as the researcher cannot prepare for every eventuality given the explorative nature of such studies. Therefore, participants cannot be completely informed as to the content or direction the research interview will take. Even with an interview schedule and procedure put in place to help ensure a safe environment for disclosure, the actual content of disclosure cannot be fully anticipated. This may be especially important to consider when interviewing children.

Informed consent was obtained from each of the children interviewed for the empirical paper under discussion, along with consent from both parents. However, on reflection I wonder how much my participants really understood about the project and to what extent they simply consented because their parents told them to or assumed they would! Were children cajoled into participation or simply taking part to please others as oppose to having a genuine interest in expressing their experiences. Information packs and consent forms were initially given to the injured parent, who would take them home for the family to read. It could be hypothesised that children's participation was dependent upon how enthused and motivated parents were about the research question. If parents did not consider the research interesting or relevant to their situation then would they share the information pack with children? One of the themes discussed in this study focused upon how family members would often censor information or exclude children from discussions about injury and rehabilitation. Could this research study have been viewed in the same way, as being potentially distressing for the child and thus best kept quiet? This is not to say that there is anything wrong with the fact that parents want to protect their children from further upset or distress.

One of the recommendations made by the local ethics committee was that each interview should be conducted with a third party present. This resulted in children being giving the opportunity to either have one of his/her parents present at interview or a female member of staff from the regional rehabilitation unit, acting as the research base. Obviously this could have both positive and negative ramifications for the interview process. The need for a 'chaperone' is understandable given the age of the participants and the sensitivity of the research question. A chaperone would provide further support and reassurance for both the researcher and the interviewees. However, they would also impact upon the dynamics of the interview. Interviews were all held within the informal setting of the child's own home which can in itself impact upon the interview process (Larossa, Bennett & Gelles, 1981). Most of those interviewed chose to have the non-injured parent present at interview. To what extent this restricted the child's disclosure cannot be said. However, one of the findings of this study was that children were less likely to express themselves through fear of upsetting other family members. Therefore we might assume that children found themselves once again censoring their true feelings to protect the parent present during interview.

Personal account and reflections

Historically there has been much debate over the quality and validity of data collected from interviews with children. In particular research studies have focused on how the way questions are asked may influence the child's testimony (Poole and Lindsey 1995, Amato & Ochiltree, 1987). It has therefore been suggested that the use of open ended questions will generate higher quality narrative, or where closed questions are used one should use follow up questions to seek clarity of the answers given (Waterman, Blades & Spencer, 2001). Research studies further suggest that adolescents provide higher quality data than younger children (Amato & Ochiltree, 1987) and widely acknowledge that at the end of the day "children are the best sources of information about themselves" (Docherty & Sandelowski, 1999, p177).

Given the knowledge that adolescents provide higher quality data and considering the methodology adopted for this study, it was decided to set the age range of participant's between11 and 18 years. A semi-structured interview was constructed consisting of open-ended questions and clarifying questions to help facilitate conversation. However, even with these 'safe guards' in place, when one plays back interview tapes it is still often very apparent that at times I as the interviewer was perhaps influencing the emotional content of narrative obtained in response to my own anxiety and inexperience with interviewing children.

The anxiety I experienced as the interviewer highlights the importance of self-monitoring during the interview process. One needs to be aware of one's own anxiety, prior to and while conducting interviews. The grey cloud of ethical dilemmas that hang over researchers, especially when working with children, can and did in this case impact upon my own perceived vulnerability as a trainee clinical psychologist. In the initial interviews my anxiety was associated to not wanting to be directive but at the same time wanting to ensure the children felt safe and supported. As a result of this there is a possibility that more sensitive or emotional information may have been regulated in earlier interviews to avoid any discomfort not only for the interviewee, but also for the interviewer.

My expectations and anxieties were quite literally shattered by the end of the first two interviews. I entered into this research domain believing that the reports obtained from children would be very distressing and negative. The reality was quite the opposite. In many ways the children radiated a strong sense of positivism, strength and resilience in terms of relaying their personal accounts and experiences. Much like other researchers working in this field (Butera-Prinzi & Perlesz, 2004) I found myself overwhelmed by the maturity of responses and the openness to which each child approached each interview. In fact it felt as if these children welcomed the opportunity to voice their experience, almost as if they had been holding back from voicing their thoughts and feelings, through not wanting to upset other family members.

This to me raises the question, "what is it about those who participated that may suggest a tendency for such a sample to be more positive in their recall of events?" Studies have shown that boys are more likely to hide negative feelings (Cole, 1986). The majority of children interviewed for this study were male. Interestingly the majority of those who declined the offer of participating were female. Perhaps girls elected to not participate through fear of the process opening up old wounds, whereas those who did participate had managed their grief more effectively or were more able to mask their negative affect? Alternatively were those who declined to take part still at a stage of shock or adaptation that made talking about their current situation much harder than those more accepting of their parents injury? Therefore, do girls travel through the process of adaptation and acceptance at a different pace to boys? The other possibility for girls not participating may have been the fact that the interviewer is male? The list could possibly go on but obviously there remains a great deal of investigation to be done before we can attempt to understand the reasons behind participating in the study or not.

Concluding Thoughts

During the course of conducting these research papers I feel that I have developed as a researcher, a clinician and as a person. The qualitative approaches used to explore the research questions under investigation provided me with the opportunity to practice and grow more confident in my clinical practice. Such research methodology can limit the researcher's ability to predict and prepare for what narrative may arise during interview. This was of particular importance for the interviews conducted with the children in study two. Initially it was difficult facilitating these interviews without some level of anxiety around eliciting the data required whilst attempting not to be directive or assuming. However, as each interview progressed it began to feel more appropriate to simply begin each interview without too much preparation and to simply allow the child to take me on their experiential journey. It started to feel ok not to know what each interview would entail. Furthermore, I began to feel accepted and trusted by participants who had allowed me into their world.

Collecting data for each of the empirical studies was predominantly an enjoyable and rewarding experience. However, facilitating the interviews with the children who participated in paper two was both fun and enlightening. I feel I learnt something about how resilient the children interviewed had been during times of crisis. The resourcefulness shown and the considerate, empathic approach they adopted toward the brain-injured parent were quite overwhelming at times. If I take anything away from this experience it will be a renewed belief and faith in the youth of today. My hopes are that each of those interviewed will continue to grow strong in the face of the personal loss they have experienced as a result of their parent's injury.

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Appendix A

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This journal covers all aspects of brain injury from basic science, neurological techniques and outcomes to vocational aspects, with studies of rehabilitation and outcome of both patients and their families. It addresses both adult and paediatric issues and it embraces issues such as family and peer relationships, effects of alcohol and drugs, communication problems and management techniques and creating new programmes. **Brain Injury** uses case studies to illustrate different approaches to a subject, and provides a forum for the appraisal of theories which may influence future research. **Brain Injury** is the official research journal of the *International Brain Injury Association*.

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Contacting the Editors:

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We strongly encourage you to send us the final, revised version of your article in both hard (paper) and electronic (disk) forms. This Guide sets out the procedures which will assure we can process your article efficiently. It is divided into three sections:

1. **a guide for authors using standard word-processing software**

packages
2. a guide for authors using LaTeX mathematical software packages
3. a guide for authors using graphics software packages

There are some general rules which apply to all three options.

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For the main text of your article, most standard PC or Mac word-processing software packages are acceptable, although we prefer Microsoft Word in a PC format.

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

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Special care should be taken with mathematical scripts, especially subscripts and superscripts and differentiation between the letter 'ell' and the figure one, and the letter 'oh 'and the figure zero. If your keyboard does not have the characters you need, it is preferable to use longhand, in which case it is important to differentiate between capital and small letters, K, k and x and other similar groups of letters. Special symbols should be highlighted in the text and explained in the margin. In some cases it is helpful to supply annotated lists of symbols for the guidance of the sub-editor and the typesetter, and/or a 'Nomenclature' section preceding the 'Introduction'.

For simple fractions in the text, the solidus / should be used instead of a horizontal line, care being taken to insert parentheses where necessary to avoid ambiguity, for example, $1/(n-1)$. Exceptions are the proper fractions available as single type on a keyboard.

Full formulae or equations should be displayed, that is, written on a separate line. Horizontal lines are preferable to solidi, for example:

$\underline{6}1 + 5h + q$

$3n + 3yz^2$

But: $\underline{a/b + c/d + a/d}$

$P = (a^2 + b^2)(c^2 + d^2)$

The solidus is not generally used for units: ms^{-1} not m/s, but note electrons/s, counts/channel, etc.

Displayed equations referred to in the text should be numbered serially (1, 2, etc.) on the right hand side of the page. Short expressions not referred to by any number will usually be incorporated in the text.

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

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Journal article on Internet:
[5] Loker WM. "Campesinos" and the crisis of modernization in Latin America. Jour of Pol Ecol [serial online] 1996; 3(1). Available: **http://www.library.arizona.edu/ej/jpe/volume_3/ascii-lokeriso.txt** via the INTERNET. Accessed 1996 Aug 11.

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

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

Further examples and information can be found in the CBE style manual *Scientific Style and Format*, sixth edition.

Appendix B

NHS Trust ethics approval
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NHS

South Birmingham Research Ethics Committee
27 Highfield Road
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Birmingham
B15 3DP

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Fax: 0121 245 2535

Our Ref: RMD/02
Date: 30th March 2004

Chairman: Mr R K Vohra
Administrator: Mrs Rosa Downing

Please Quote: 2004/018

Mr C Morrell
Clinical Psychology Doctorate
Coventry University
Priory Street
Coventry
CV1 5FB

Dear Mr Morrell

REC reference number 2004/018
Parental Brain jury: Children's Adaptation to Changing Roles and Responsibilities following Traumatic Brain Injury to a Parent

Thank you for your letter of 8th March 2004 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 Vice-Chairman.

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.

The favourable opinion applies to the following research site:

Site: Moor Green Out Patients Unit Moseley Hall Hospital Alcester Rd Birmingham
Principal Investigator: Mr Christopher Morrell

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

- Revised copy of the ethics application (page 14, paragraph 4)
- Revised consent form for families
- Revised Information Sheets for families and children
- Staff consent form
- Staff Information Sheet
- Semi-structured interview schedule
- Child behaviour Checklist for ages 6-18

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

Notification of other bodies

We shall notify the Trust that the study has a favourable ethical opinion.

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.

REC reference number: 2004/018 **Please quote this number on all correspondence**

Yours sincerely,

Ros Salter.

Vice **Mr R K Vohra**
Chairman

Enclosures Standard approval conditions SL-AC2

List of names and professions of members who were present at the meeting and those who submitted written comments.

COVENTRY UNIVERSITY - SCHOOL OF HEALTH AND SOCIAL SCIENCES

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: C. B. MORRELL (BLOCK CAPITALS)

2. Course: CLINICAL PSYCHOLOGY DOCTORATE

3. Title of project: PARENTAL BRAIN INJURY: CHILDREN'S ADAPTATION TO CHANGING ROLES + RESPONSIBILITIES FOLLOWING TRAUMATIC BRAIN INJURY TO A PARENT.

4. Summary of the project in jargon-free language and in not more than 120 words:

Sample:

Research site: MOOR GREEN, MOSELEY HALL HOSPITAL, ALCESTER RD, MOSELEY, BIRMINGHAM.

Design (eg experimental): QUALITATIVE USING IPA + THEMATIC ANALYSIS.

Methods of data collection:

- FOCUS GROUP(S) WITH STAFF.
- SEMI-STRUCTURED INTERVIEWS WITH CHILDREN.

CHILDREN WILL BE INTERVIEWED IN THE HOME WITH EITHER A PARENT OR MEMBER OF STAFF FROM MOOR GREEN PRESENT TO ACT AS CHAPERONE. INTERVIEWS WILL BE TAPE RECORDED, TRANSCRIBED AND ANALYSED USING IPA.

FOCUS GROUPS WITH STAFF WILL BE CONDUCTED AT MOOR GREEN, TAPE RECORDED AND TRANSCRIBED, AND ANALYSED USING THEMATIC ANALYSIS.

LREC ETHICS APPROVAL HAS BEEN OBTAINED.

Access arrangements (if applicable):

VIA MOOR GREEN

5.	Will the project involve patients(clients) and/or patient(client) data?	Yes ☑	No ☐
6.	Will any invasive procedures be employed in the research?	Yes ☐	No ☑
7.	Is there a risk of physical discomfort to those taking part?	Yes ☐	No ☑
8.	Is there a risk of psychological distress to those taking part?	Yes ☐	No ☑
9.	Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available?	Yes ☐	No ☑
10.	Is it intended to seek informed consent from each participant (or from his or her parent or guardian)?	Yes ☑	No ☐

Student's signature: ……………………

Supervisor's signature: ……………………

Date: 30/4/04

FOR COMMITTEE USE:

Immediate approval	☑	Referral to full School Committee	☐
Referral to local Hospital Ethics Committee	☐	Decision pending receipt of further information (specify below)	☐

Committee Member's signature: David Giles

Date: 12/5/04

South Birmingham NHS
Primary Care Trust

R&D for Birmingham and Solihull PCT Consortium
R&D Department
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel 0121 442 3500
Fax 0121 442 3588
R&D_dept@southbirminghampct.nhs.uk

Mr Chris Morrell
Clinical Psychology Doctorate
Coventry University
Priory Street
Coventry
CV1 5FB

14/4/2004

Dear Mr Chris Morrell

PCT CONSORTIUM R & D REQUIREMENTS - COMPLETED

Project title:	Parental brain injury: Children's adaptation to changing roles and responsibilities following traumatic brain injury to a parent .	
Project No.:	646	
Chief Investigator:	Mr Chris Morrell	
Chief Investigator Employer:	South Warwickshire Primary Care Trust	
Principal Investigator *(Local researcher if different)*	No Local Researcher	
Start/ End dates:	14/4/2004 to 30/9/2005	
Sponsor	Coventry University	
Funding	No Funding	
PCT Registered:	South Birmingham Primary Care Trust	Yes
Service/ Directorate	Rehabilitation Services	

The above project has been registered with R&D Department on behalf of the Birmingham and Solihull Consortium (North Birmingham Primary Care Trust, Eastern Birmingham Primary Care Trust, Heart of Birmingham Teaching Primary Care Trust, South Birmingham Primary Care Trust and Solihull Primary Care Trust)

i. Researchers who have substantive or honorary contracts with the South, East, North or Heart of Birmingham Teaching and Solihull Primary Care Trusts will be covered against claims of negligence by patients of the Primary Care Trusts under the Clinical Negligence Scheme for Trusts (CNST). This scheme does not cover 'No Fault' compensation and the Trust is precluded from taking out separate insurance to cover this. Any patient or volunteer taking part in the study is entitled to know that if they suffer injury as a result of participating in the study they first have to prove negligence of law before they could gain compensation.

ii. Primary Care Trusts owe a direct and non-delegable duty of care to NHS patients; this duty exists whether those patients are being treated in a hospital or an independent GP. In these circumstances, the Primary Care Trust would have a right to require information about research being undertaken within GP's practices. However NHS indemnity does not extend to GP practitioners, if a practitioner takes part in research then the practitioner accepts personal liability for quality assurance and for any claims that may arise. If Practice Staff are part of the research team and employees of the

Primary Care Trusts, then they need to ensure/ obtain indemnity from the R&D Department.

iii. Employees of Universities may be covered for 'No Fault' compensation by the University insurance scheme. However, you would need to check whether or not everyone involved in the study is covered by this scheme.

iv. Clinical trials by a pharmaceutical company should be covered by 'Indemnity for Clinical Studies' form that can be acquired by the Trust R&D department. This form ensures that the Sponsor indemnifies and holds harmless the Trust and its employees and agents against all claims and proceedings.

If you still have a query regarding indemnity please get in contact with the Department as soon as possible.

During the project the Lead Investigator will be contacted **Six months** into the project and **Annually** to ensure Research Governance monitoring is in place. At the End of the project the R&D Office will contact you to ensure the project has finished.

Could I please remind you that all research needs to comply with Research Governance Standards (www.doh.gov.uk/research) and if projects are registered with the Department they will be randomly audited to demonstrate that the research is being monitored and the protocol is being adhered too. This step is to reassure patients, service users and care professionals of the quality of the study and to guarantee the organisations and researchers reputation for high quality research and care.

If you require any further assistance, please call the Department with your
R & D Project Number 646

Dr Peter Mayer
Trust R&D Director

Karen Hampshire
R&D Manager

Appendix C

Chapter Two:

Information sheets and consent forms

South Birmingham **NHS**
Primary Care Trust

West Midlands Rehabilitation Centre
Out-patient Brain Injury Rehabilitation Service
(Moor Green)
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel: 0121 442 3400
Fax: 0121 442 3420

Research on Parental Brain Injury:

Information Sheet – Staff

My name is Chris Morrell and I am a student at the Universities of Coventry and Warwick. I am currently researching the impact of parental traumatic brain injury on children. I am currently looking for staff members to participate in my research and would very much appreciate it if you could take the time to read this information sheet.

Why Do This Research?

The aim of this study will be to identify the level of involvement of family members other than the primary caregiver in rehabilitation services. Seeking to explore the level of contact professionals have with family members other than the primary caregiver and to what extent information regarding the rehabilitation process gets disseminated to non-professionals outside of the multi-disciplinary team. Attempting to identify both the positive and negative aspects of involving family members in the rehabilitation process.

It is hoped that the information gained will help rehabilitation services develop. In particular it will identify specific needs of young family members that are often not addressed as part of the rehabilitation program.

What will I need to do?

Participation in this study will involve taking part in a focus group. The group will be very much like a discussion group facilitated by the researcher. It is hoped that between 6 to 8 staff members will take part in the group. The focus group will last for between 60 and 90 minutes and will be audio-taped for transcription at a later date. The group will be held at Moor Green and during working hours. All identifiable information such as names and addresses will be removed to ensure confidentiality.

Do I have to take part?

You do NOT have to take part in this research and you do NOT have to give any reason for refusing. You can also withdraw from the study at any time, again without having to give any reason why. Refusing to take part in the research will NOT affect any of the services you are receiving or may receive in the future.

What will happen to the information gained?

The information gained from the focus group interview will be entirely confidential. The audio-tape of the focus group will be kept in a locked cabinet at Moor Green. The transcript of the group will be coded to ensure that they are anonymous. Once the research is completed all tapes and transcripts will be destroyed.

The results of the study will hopefully be published in a number of journals that will serve to inform other professionals of the experience of parental brain injury.

What do I do now?

Decide if you would like to take part. If you would like to take part then sign the consent form that came with this information sheet. The completed consent form should then be sent back to me.

What if I want to know more?

If you want more information or have any questions then my supervisors Louise Lorenc at Moor Green and Dr Eve Knight at Coventry University or myself will be happy to answer them, our details are below.

THANK YOU

Louise Lorenc
Moor Green
Moseley Hall Hospital
Moseley
Birmingham

0121 442 3400

Dr Eve Knight / Chris Morrell
Clinical Psychology Doctorate
George Eliot Building
Coventry University
Priory St
Coventry
CV1 5FB

02476 888328

South Birmingham **NHS**
Primary Care Trust

West Midlands Rehabilitation Centre
Out-patient Brain Injury Rehabilitation Service
(Moor Green)
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel: 0121 442 3400
Fax: 0121 442 3420

Consent Form - Staff

If you would like to take part in the focus group then please read the following information before signing the consent form:

- I have read the research information sheet.
- I understand that I can withdraw from the research at anytime, and I do not have to give reasons for doing so.
- I understand that not taking part in the study or withdrawing at anytime will NOT affect the services I receive.
- I understand that all information provided will be made anonymous, and that I will not be identifiable from any final reports written.
- I understand that findings from this research will be written up for publication in journals read by other professionals who work people with brain injury.

I have read and understand the information regarding the research project and agree to taking part.

Name .... (please print)

Signature ....

Witnessed by .... (please print)

Signature ....

Today's Date ..../............./...........

I would like to receive a summary of the research findings Y / N (circle)

2000 Commended HEALTHCARE SERVICE Sector Award
2000 Highly Commended RoSPA TRAINING AWARD

Trust Headquarters Tel: 0121 442 5600
Minicom: 0121 449 8352
E-mail: info@southbirminghampct.nhs.uk
Chair: Professor David Cox *Chief Executive:* Ms Cynthia Bower

INVESTOR IN PEOPLE

Appendix D

Chapter Two:
Semi-structured interview schedule

Semi-Structured Interview Schedule
FOCUS GROUPS

The following questions will be used as a guide to the researcher to facilitate narrative during interviews.

Focus groups will begin with the opening question:

"what are your views about involving family members in brain injury rehabilitation?"

Further questions or areas of interest that may be referred to as focus groups progress are:

What level of contact with families do you currently have?
- **What family members?**
- **Who most contact with?**
- **Who do you discuss strategies/progress/prognosis with?**

Do family members understand what has happened to their relative?
- **Facts about injury**
- **Facts about rehabilitation and the future**
- **Do they understand/practice strategies?**

What have you liked about working with families?

What difficulties have you experienced when working with families?

What problems arise in terms of engaging family members in the rehabilitation process?

Are family members other than the primary carer involved in the rehabilitation program?

What do you feel are the obstacles that get in the way of involving family members in the rehabilitation process?

Do family members help or hinder you in your work?

Do you see collaborating with families as a positive or negative? Why?

Appendix E

Chapter Two:

Sample transcript

Barriers Family Needs + Collaborative Wk Beliefs

FOCUS GROUP: IN-PATIENT UNIT

Those present:
2xOT's (OT1 & OT2), 1xSALT (ST), 2xPhysio (P1 & P2), 1xClinPsy (CP).

R Thank you for coming along today. I would like to start by asking, could you give me a general idea of what are your views about involving family members in in-patient rehab services?

Misconceptions
Barriers.

OT1 It depends, if you have a family who are very realistic and supportive it can work very well, but if you have a family that are very anxious and scared then it can make the job a lot harder.

Need for early intervention
Impact on client rehab.

CP very important to engage them, because if they are very co-operative, very on the ball it is great, but if they don't, if they are very anxious or defended then its more important to get in there at the early stage. So that you can work with them to get them to co-operate and engage in rehab. that's got to be picked up or they might throw complications or problems in the patients rehabilitation that need addressing right away, even though this is a recurrent theme.

compulsory part of work
Early interventions.

OT2 I don't know, I think for starting off when a patient first moves in you have to involve the family, I don't think it's a choice really it should be done. However, if it goes down the road, for example, of them not wanting to be involved then we need to kind of deal with that. But if you haven't involved them in the first place you wont get anywhere.

R is that what generally happens, what actually happens in terms of…?

Actual family contact
Judgement of family by Team
Lack of understanding re cog deficits

OT2 well I think what we try is that well officially on the ward is at IGP meeting, that's the official meeting that families are invited to and stuff, but we will try and involve families before that, because your suppose to go to that meeting with kinda idea's and plans erm. I think what comes out at MDT's and things erm that's kinda a private place for staff to say this family are really, really helpful, this family come across as being helpful that there not, and insight! I think is the other thing, because we have some people, I'm thinking of a particular patient on the ward whose particular relationship with this person does not have any insight into the patients condition, they have a lot of cognitive problems. And, it's a nightmare really.

Barriers
- Organisational / Managerial

Early intervention
(timing of contact)
Lack of coordination in MDT + early intervention
Barriers

CP I will talk to you later about that er…but yeah I find that 38
quite frequently when we do identify that there is going to be difficulties with the family then its like not anytime soon enough really. Or there is no sort of peer plan, like saying "ok we know this we recognise this team, what are we going to do with it, how are we going to manage the family? How are we going to er unravel the problems that they bring" and of course then what usually happens is that at some point it blows up into a spectacular problem and it's really too late to act on that because you haven't been able to establish a relationship or create an atmosphere to respond to that, erm I mean in my experience that I have been positively stopped or held back from trying to respond to families, difficult families…

R what you've been…?

Barriers

CP yeah I have been told not to do it by…er failure to co-operate, deliberate erm a deliberate decision to not to involve the team and not to work together and say "yes let's do something for this family". And then we learn later on that 56
there are problems and they do blow up and we have no adequate response to that…

R so is it generally client focused and blinkered…?

Team focused not client focused

ST I think it's quite MDT focused a lot and the client is just left out, it's how it feels coming in with quite fresh eye's it does 61
feel that a lot of the time it's what team members want rather than what the client or their family want…

CP which isn't what team members want…

ST well not always no…

Politics

CP it's more what the consultant wants really, that's what happens a lot is that the consultant whatever the team say's, you know….(inaudible)

Time constraints

OT2 it's also to do with like (ST) says you go to the MDT and explore worries and explore needs obviously of yourself so you have got the team but you got a resource problem there as well. I mean I certainly don't mind bringing things to the forum, bringing things to the team, I don't mind doing that but er if it's ignored or not kinda supported and time span is 74
focused on the patient I mean there only here for 12 weeks regardless of the family or not kinda thing, there are various issues around it really….

understanding of family

Family understanding ability to cope.

Family adaptation = better able to work with.

OT1 but if you think that patients and their families arrive here at different stages of mental preparation recovery most of them are just grateful that their child or their spouses have survived, and some are more accepting than others who have different levels of understanding what has happened, let alone understanding what this phase of rehab is. So I think it's difficult to meet that with all carers and all families because some people are just absolutely completely on board have thought about how to adapt the property, whether this person is in a wheelchair and how mentally they do it and the patients there as well. But then you get other people who are just completely in shock and don't really know what to do and then you have, I mean there are forums there is a patient link worker who meets and greets and meets with the patients on a regular basis and there are patient/carer forums at which they will bring issues but that individual catered need for that particular family, there isn't a particular pathway or a different way of accessing it. It almost that patients and families have to be at a certain level, you can help them along at that level, but if their somewhere here or somewhere there then its quite hard to adapt to the unit…

CP there is no policies or procedures for it.

Lack of information at acute stage - Prognosis

P1 don't you think its really difficult because we have the legacy of what has happened in the acute sector as well and a lack of potential education about prognosis, length of stay…

Given mis-info = misconceptions

OT2 yeah, its so true. I always feel like its not even lack of education, I think these people have been told many times by, I don't know who, that their going to come here and walk. So it's not even they not, they have been totally mis-told something in the first place, I'll go to that place and learn or walk or learn new things and it's almost like their trying to get rid of them…

R but is that what they believe…?

mis-info

OT2 yeah, well the thing is if you believe that and it's not told to you ever, but if I mean I have heard patients say that the doctor said they would walk if they came here, you know and you can kind of see that trying to get rid of people, this is a good place to go kinda thing…

Expectations placed on unit

CP there's a lot of expectation attached to this unit being called a rehabilitation unit (inaudible) people think they wont leave until they have a good level of cognitive function

ST but I think there's those other patients who have spent 6 months on a acute ward and the last place they want to be is here

OT1 you have access to family, parents, people and sometimes it can be difficult and again that may mean varying your level of contact, so if somebody isn't at work then they can come in and join in on therapy sessions and be there and carry over some of the work that's great, but for somebody for sanity or money or for whatever reason people kind of are working and mainly come on the evenings, they end up having a breakdown so that what happens is that carers aren't particularly involved with their care and input, because we do a 9 to 5 job and they can come 7 to 10...

Financial burdens — to needing work

Telephoned — out of hours contact

CP well this is a regional unit so people are going to have to come from quite a while away sometimes or they are the only parent left who is looking after the kids there, so its you know they have all those roles the last thing they can think about is coming to the hospital on a daily basis and do their bit there as well, so it does create difficulties. There have been attempts I think in the past on outpatients to have patient family support groups, but they tend to fall to pieces... because they are still at work or they have to go home and pick up the kids

Carer responsibilities away from client.

R picking up on some of the stuff about unrealistic expectations, I always heard from clients that they were told they would never ever walk, so it's interesting to hear...

PT sometimes, we do see that as well. I think because patients and families talk to each other so much, you know they expect if someone has had a stroke, you know their talking to someone else who has had a stroke, they expect to get the same prognosis not considering where the site of the stroke was or head injury, there's an awful lot of that that goes on they talk to each other and they think "oh so and so is walking with a walking aid by now, that's next week for me"..

comparison to others

misconceptions + unrealistic expectations

OT2 yeah, and even if the person by the side of them hasn't they will look, if two people are on the ward with a stroke they will look to the person who is... and they will say "oh I will be walking with a stick by then, I'll be eating whatever, I think they always look to the...

CP best case scenario

comparison to others

OT1 and they also I think it appears that at least from the feedback from the patients they make comparisons about input as well,

Appendix F

Chapter Two:
Stage by stage analysis

Themes from Literature:

Condensed to form core cats to derive semi-structured interview schedule for focus groups:

Family burden
Family perceptions of health professionals
Experience of family members
Societal understanding
Role of healthcare professional
Information provision – timing/sharing of possible outcomes
Family beliefs
Family expectations of professionals
Family inclusion
Family adaptation
Information needs
Extended family understanding
Family burden
Co-morbid functioning
Misconceptions
Beliefs
Poor understanding in society and non health professionals
Expectations of family
Information needs
Expectations on family
Rehab as respite
Effects of time limited rehab
Client centred approach
Barriers to family work
Systemic issues
Collaborative work
Resources

Stage One:
Analysis of Focus Groups:

Core categories determined through process of inductive thematic analysis and description of each category:

1 Barriers to family work

- **Service related:**

Perceived lack of resources and time, combined with confusion over who should be doing family work, further confounded by service philosophy

- **Family issues**

Engagement of families can be problematic and is dependent upon family adaptation. Family conflict either co-morbid or as a result of injury can hamper family work. Therapists need to be able to consider secondary carers as well as primary carers.

2 Understanding of Brain Injury Rehabilitation

- **Information/education**

Patient and family member beliefs about recovery, understanding of cognitive deficits and the rehabilitation process.

- **Misconceptions**

Family members may be miss-informed and consequently establish misconceptions about rehab and recovery, further influenced by their perceived roles in the process.

3 Support systems

- **Support Systems**

Carers and patients require support systems, these can be provided by others in similar situations. Those with good support systems fair better.

4 Belief systems

- **Expectations**

Expectations of family members, patients and the team of therapists.

- **Cultural differences**

Need for cultural awareness and implications for rehabilitation process.

Stage Two:
Analysis of focus group transcripts

Transcript quotes that relate to each of the core categories:

Key to annotations:

F1 = Focus group 1
F2 = Focus group 2
P = page number
L = line number
Letters e.g. A = participant

1. Barriers to Family Work

Service related barriers

F1.p16.L640.CP	"there's budget issues you know, we are not really funded by the health authority to actually work with families"
F2.p6.L205.tOT	"it depends on staff availability, demands on the service and how much time"
F2.p8.L294.OT1	"it's often time constraints, you just don't have the time for realistically to involve the family at every stage"
F2.p13.L452.SLT	"we don't necessarily think about the family when setting the goals"

Family related barriers

F1.p4.L126.OT1	"people are kind of like working and come in the evenings"
F1.p4.L132.CP	"they are the only parent left who is looking after the kids"
F1.p10.L406.OT2	"Sometimes, you get the other type, people who actually don't want the responsibility of what is entailed"
F2.p10.L371.tOT	"it can also be something as simple as they have had a hell of a lot of time off work anyway"

2. Family understanding of TBI

Information needs

F1.p5.L162.A	"I think that's the hard part is how do you explain the individually tailored therapy programme"
F1.p11.L440.B	"Some people don't realise that it can take a year to have housing adaptation"
F2.p1.L11.J	"when you talk to families you realise often how little information they have been given"
F2.p1.L17.L	"it would be quite important that they are aware of them so that they can try and incorporate them at home"

Misconceptions

F1.p3.L116.E	“people think they won’t leave until they have a good level of cognitive function”
F1.p17.L650.E	“you get them say “he hasn’t got cognitive problems, I have done a bit of psychology and I tell you he’s not got cognitive problems”
F2.p2.L66.J	“not being something they need to be a part of”
F2.p4.L129.L	“kind of see this place that she comes to as a bit of a nut house, like she would describe it as being full of mental weird people”

3. Support systems

F1.p5.L166.A	“the families themselves the patients will get the most support from the people around them the people who have been through similar experiences
F2.p3.L103.A	“the teenage section seem very reluctant, and in a way it seems harder to target them and try and look at support systems for them”
F2.p7.L241.J	“there have been situations here where the client’s carer needs more support than the client”
F2.p14.L520.I	“People with support networks seem to fair better”

4. Belief Systems

Expectations

F1.p11.L417.B	“a lot of people say they want to maintain their role as partners and not carer”
F1.p12.467.A	“expecting the parents or spouses to make, to have that decision of trying to agree or prepare or think about what’s realistic”
F2.p10.L349.H	“we have got a lot of expectation about our client’s and their families”
F2.p12.L427.G	“a lot of it is people don’t know what’s realistic, what’s achievable”

Cultural differences

F1.p20.L797.B	“but if your culture and belief are the same and so it’s not matching up with what rehab is perhaps that person isn’t suitable for rehab”
F2.p3.L74.I	“because of the nature of the head injury we are dealing with a huge cross section of society”
F2.p9.L330.H	“it is worth talking to families to find out what the family value’s are and where the client’s value’s fit into that”
F2.p9.L336.H	“it’s about finding out about that person within the family context and not making assumptions”

Stage Three:

Refinement of categories from stages One and Two. Definitions of categories and supporting quotes from transcripts.

Theme 1a- Service Related Barriers: Resources
Therapists discussed resource limitations such as inadequate access to funding, time constraints, issues regarding geographical catchment area and general demands on the service.

F1.p16.L640.E	"there's budget issues you know, we are not really funded by the health authority to actually work with families"
F1.p2.L74.B	"they're here for 12 weeks regardless of the family"
F1.p19.L747.B	"the more people that you involve the more difficult it will be as well and who is the most important to that....."
F2.p8.L266.G	"we are trying to sit here in an hour doing a session with someone then expect them to try and take that in"
F2.p11.L389.J	"your not expected to work out of hours, but on the other hand you just can't catch all the people"
F2.p14.L513.H	"it needs dedicated time, but you don't get the resources"

Theme 1b- Service related Barriers: Service philosophy/model
Service philosophy prevents systemic working leaving therapists feeling that their hands are tied and confused as to who should be doing the work with families.

F1.p6.L215.E	"the situation was just getting worse and worse and we kept saying "yes but there are more implications, there's more problems arriving on this...", and your told not to get involved"
F1.p6.L232.E	"There's no conception that this is actually going to affect this persons rehabilitation in terms of discharge."
F1.p16.L644.E	"there are also a lots of issues about our roles and being seen to do this and not to do this"
F2.p1.L23.J	"I think it depends on the therapist working...how much contact there is with the family"
F2.p7.L235.H	"who is it that is supposed to provide that"

Theme 2a- Family Related Barriers: Engagement
Do families have the resources, time or inclination to work collaboratively with therapy staff.

F1.p4.L126.A	"people are kind of like working and come in the evenings"
F1.p4.L132.E	"they are the only parent left who is looking after the kids"
F1.p9.L357.E	"they don't want them involved in this next case review because they have issues they want to talk about that are personal"

F1.p10.L406.B	"Sometimes, you get the other type, people who actually don't want the responsibility of what is entailed"
F2.p13.479.L	"for them they may be so time pressured"

Theme 2b- Family Related Barriers: Secondary carers

Difficulties faced by secondary carers such as children or parents of brain injured patient.

F2.p4.L109.I	"with teenagers and parents we have conflict with them trying to establish a role"
F2.p4.L112.I	"the teenagers a lot of them are going through so much personally, then they are reluctant or just can't handle anymore emotional overload"
F2.p8.L261.L	"they got so many other things going on, other issues in their life"

Theme 2c- Family Related Barriers: Family adaptation

The family's poor adaptation to the injury and subsequent internal conflicts, can act as a barrier to collaborative work with team.

F1.p1.L10.E	"if they are very anxious and defended then it's more important to get in there at the early stage"
F1.p3.L88.A	"then you get other people who are just completely in shock and really don't know what to do"
F1.p6.L241.B	"I heard the spouse shouting at the mum, saying "your always treating him as a child, and he's not he's a grown man, he's got a partner and a baby" and they started physically attacking each other"
F1.p10.L396.E	"they are too caught up in what they want and what they are afraid of and what they need, and that's where you get these conflicts"
F1.p12.L458.A	"you got one parent who wants the patient to come home, and then the other patient is saying "actually what is it going to mean""

Theme 3a- Information needs: Prognosis

Beliefs and hopes about recovery are affected by the family's awareness of cognitive deficits.

F1.p1.L33.B	"a particular patient on the ward whose particular relationship with this person does not have any insight into the patients, they have a lot of cognitive problems."
F1.p11.L447.C	"one question you often get asked is "will he be 100% better?""
F1.p3.L100.C	"we have the legacy of what has happened in the acute sector as well and a lack of potential education about prognosis, length of stay…"
F2.p3.L95.L	"especially for the children who really don't understand what has happened to their mum or dad"

Theme 3b- Information needs: Rehabilitation process

Lack of information provision and understanding about rehabilitation and prognosis.

F1.p5.L162.A	“I think that’s the hard part is how do you explain the individually tailored therapy programme”
F1.p19.L373.C	“the relative helps the client walk but not in the right way, so the earlier we educate them the better really”
F1.p11.L440.B	“Some people don’t realise that it can take a year to have housing adaptation”
F2.p1.L9.J	“because we work with head injury all the time we forget that there is little understanding amongst lay people”
F2.p1.L11.J	“when you talk to families you realise often how little information they have been given”

Theme 4a- Misconceptions: Mis-information

Beliefs formed through miss-information.

F1.p3.L104.B	“I think these people have been told many times by, I don’t know who, that their going to come here and walk”
F1.p19.L755.F	“sometimes you get “oh well uncle Jack said this” and well that isn’t exactly what I said to uncle Jack”
F1.p22.L865.E	“if somebody has a stroke or a cerebral bleed or, it’s like “if I have sex will it happen again””
F1.p3.L116.E	“people think they won’t leave until they have a good level of cognitive function”
F1.p17.L650.E	“you get them say “he hasn’t got cognitive problems, I have done a bit of psychology and I tell you he’s not got cognitive problems”
F2.p4.L129.L	“kind of see this place that she comes to as a bit of a nut house, like she would describe it as being full of mental weird people”

Theme 4b- Misconceptions: Perceived roles

Perceived roles of family members in the rehabilitative process.

F2.p2.L66.J	“not being something they need to be a part of’
F2.p9.L323.I	“…where the mother wants to do everything for the daughter..”

Theme 5- Support Systems

Importance of support systems and the benefit of sharing experiences with others in similar situations.

F1.p5.L166.A	“the families themselves the patients will get the most support from the people around them the people who have been through similar experiences”
F2.p3.L103.G	“the teenage section seem very reluctant, and in a way it seems harder to target them and try and look at support systems for them”
F2.p7.L241.J	“there have been situations here where the client’s carer needs more support than the client”

F2.p11.L408.H	“the most positive things I hear from clients here is about the support they gain from peers, you know just meeting other people who have had similar experiences”
F2.p14.L520.I	“People with support networks seem to fair better”

Theme 6a- Expectations: Family expectations

Expectations of family members can influence level of involvement in rehabilitation process for the good and for the bad. Perceived role in process.

F1.p5.L193.E	“who’s gonna be the main next of kin and who’s going to take the main responsible to care”
F1.p11.L417.B	“a lot of people say they want to maintain their role as partners and not carer”
F1.p12.467.A	“expecting the parents or spouses to make, to have that decision of trying to agree or prepare or think about what’s realistic”
F1.p13.L528.A	“it goes back to expectations, and that process cannot be expected by anybody to be achieved in 16 weeks”
F2.p2.L64.J	“I think sometimes people see this place as a kind of respite, it’s an opportunity for them to have a break”
F2.p14.L518.I	“We see people at the longest for a year and the family are with them possibly for 20 years”

Theme 6b- Expectations: Team expectations

Expectations of the team on clients and family members.

F1.p1.L17.B	“I don’t think it’s a choice really it should be done”
F1.p18.L693.D	“different therapists or people who intervene will be asking them to do different things…”
F1.p20.L805.C	“and we need to understand what they want to achieve as well as them understanding the potential they can achieve”
F2.p10.L349.H	“we have got a lot of expectation about our client’s and their families”
F2.p13.L489.G	“I can walk away until next week….imagine having to live with that 24 hours a day”

Theme 6c- Expectations: Client expectations

Patient’s high expectations about recovery.

F1.p4.L149.C	“you know they expect if someone has had a stroke, you know their talking to someone else who has had a stroke, they expect to get the same prognosis”
F1.p4.L156.B	“oh I will be walking with a stick by then, I’ll be eating whatever, I think they always look to *the best case scenario*”
F1.p14.L538.D	“often people feel like they are treading water before they come here”

Theme 7a- Cultural issues: Cultural awareness

Need to address cultural background prior to intervening.

F1.p20.L775.E	“because it’s cultural, that you gotta respect that not everyone is like an ordinary Joe family from, white British family”
F1.p20.L781.E	“but to modify something that’s cultural, even if it doesn’t work, you know we shouldn’t touch it”
F1.p21.L826.A	“those who have had it hard most of their lives have probably been the most rewarding, because they were really grateful for the support”
F2.p3.L74.I	“because of the nature of the head injury we are dealing with a huge cross section of society”
F2.p9.L336.H	“it’s about finding out about that person within the family context and not making assumptions”

Theme 7b- Cultural issues: Implications for rehabilitation
Need to place interventions in cultural context.

F1.p20.L797.B	“but if your culture and belief are the same and so it’s not matching up with what rehab is perhaps that person isn’t suitable for rehab”
F2.p9.L320.I	“is that putting western medicine, idea’s onto people, because who is to say how a family should operate”

Appendix G

Chapter Two:

Triangulation summary sheets

Working with families affected by brain injury: The views, beliefs and experience of professionals providing inpatient and outpatient rehabilitation for acquired brain injury.

Dear Participant

I would like to thank you again for taking part in this research study. The focus groups have now been transcribed and analysed. The analysis has involved identifying salient themes that emerged from the data. This has led to a number of themes being generated that hopefully reflect the content of each focus group.

In order to ensure that these themes do indeed capture the essence of the groups it would be helpful to collaborate the findings with those who participated in the study. I have therefore enclosed a brief overview of the themes identified along with a selection of the quotes used to devise them.

If you can spare some time reading this information and try to reflect back on the group itself, you may then be able to agree with or make comments on the themes generated. Please use the form attached to make any comments or suggestions and return using the envelope attached.

This exercise is purely voluntary and returned comments will remain anonymous.

Thank you for your ongoing support with this research project.

Yours Sincerely

Christopher Morrell
Trainee Clinical Psychologist
Warwick University

Working with families affected by brain injury: The views, beliefs and experience of professionals providing inpatient and outpatient rehabilitation for acquired brain injury.

Feedback Form:

Please write any comments regarding the themes generated from the data collected. These may be in relation to the actual labelling of themes, the focus of themes or any agreement/disagreement with themes:

Return to: **Chris Morrell, 12 Dawson St, Smethwick, West Midlands, B66 4JB**

Focus Group In-patients

Theme 1a- Service Related Barriers: Resources
Therapists discussed resource limitations such as inadequate access to funding, time constraints, issue's regarding geographical catchment area and general demands on the service.

> "there's budget issues you know, we are not really funded by the health authority to actually work with families"
>
> "they're here for 12 weeks regardless of the family"
>
> "the more people that you involve the more difficult it will be as well and who is the most important to that....."

Theme 1b- Service related Barriers: Service philosophy/model
Service philosophy prevents systemic working leaving therapists feeling that their hands are tied and confused as to who should be doing the work with families.

> "it's almost like a decision to what level the family should get involved and who should involve them"
>
> "do you know that poem, 'anybody, everybody, somebody, nobody'. So anybody thinks they can do it, everybody should do it, somebody should do it and nobody actually does"
>
> "there are also a lot of issues about our roles and being seen to do this and not to do this"

Theme 2a- Family Related Barriers: Engagement
Do families have the resources, time or inclination to work collaboratively with therapy staff?

> "if it goes down the road...of them not wanting to be involved then we need to kind of deal with that"
>
> "they are the only parent left who is looking after the kids"
>
> "Sometimes, you get the other type, people who actually don't want the responsibility of what is entailed"

Theme 2c- Family Related Barriers: Family adaptation
The family's poor adaptation to the injury and subsequent internal conflicts, can act as a barrier to collaborative work with team.

> "if you have a family that are very anxious and scared then it can make the job a lot harder"
>
> "then you get other people who are just completely in shock and really don't know what to do"

> "It almost that patients and families have to be at a certain level"
>
> "you got one parent who wants the patient to come home, and then the other patient is saying "actually what is it going to mean""

Theme 3a- Information needs: Prognosis

Beliefs and hopes about recovery are affected by the family's awareness of cognitive deficits.

> "a particular patient on the ward whose particular relationship with this person does not have any insight into the patients, they have a lot of cognitive problems."
>
> "one question you often get asked is "will he be 100% better?""
>
> "we have the legacy of what has happened in the acute sector as well and a lack of potential education about prognosis, length of stay…"

Theme 3b- Information needs: Rehabilitation process

Lack of information provision and understanding about rehabilitation and prognosis.

> "I think that's the hard part is how do you explain the individually tailored therapy programme"
>
> "the relative helps the client walk but not in the right way, so the earlier we educate them the better really"
>
> "Some people don't realise that it can take a year to have housing adaptation"

Theme 4a- Misconceptions: Mis-information

Beliefs formed through miss-information.

> "I think these people have been told many times by, I don't know who, that their going to come here and walk"
>
> "sometimes you get "oh well uncle Jack said this" and well that isn't exactly what I said to uncle Jack"
>
> "if somebody has a stroke or a cerebral bleed or, it's like "if I have sex will it happen again""
>
> "people think they won't leave until they have a good level of cognitive function"

Theme 5- Support Systems
Importance of support systems and the benefit of sharing experiences with others in similar situations.

> "the families themselves the patients will get the most support from the people around them the people who have been through similar experiences"

Theme 6a- Expectations: Family expectations
Expectations of family members can influence level of involvement in rehabilitation process for the good and for the bad. Perceived role in process.

> "most of them are just grateful that their child or their spouses have survived"
>
> "a lot of people say they want to maintain their role as partners and not carer"
>
> "they can be like (shouts) "YOU CAN SAY IT, NOW JUST SAY IT NOW, NOW, NOW SAY IT""
>
> "if ya not gonna do your best then we are gonna leave you here"

Theme 6b- Expectations: Team expectations
Expectations of the team on clients and family members.

> "different therapists or people who intervene will be asking them to do different things…"
>
> "and we need to understand what they want to achieve as well as them understanding the potential they can achieve"

Theme 6c- Expectations: Client expectations
Patient's high expectations about recovery.

> "you know they expect if someone has had a stroke, you know their talking to someone else who has had a stroke, they expect to get the same prognosis"
> "oh I will be walking with a stick by then, I'll be eating whatever, I think they always look to *the best case scenario*"
>
> "often people feel like they are treading water before they come here"

Theme 7a- Cultural issues: Cultural awareness
Need to address cultural background prior to intervening.

> "because it's cultural, that you gotta respect that not everyone is like an ordinary Joe family from, white British family"

> "but to modify something that's cultural, even if it doesn't work, you know we shouldn't touch it"

Theme 7b- Cultural issues: Implications for rehabilitation
Need to place interventions in cultural context.

> "but if your culture and belief are the same and so it's not matching up with what rehab is perhaps that person isn't suitable for rehab"

Focus group Out-patient

Theme 1a- Service Related Barriers: Resources

Therapists discussed resource limitations such as inadequate access to funding, time constraints, issues regarding geographical catchment area and general demands on the service.

> "it depends on staff availability, demands on the service and how much time"
>
> "the way the NHS works now is funding, they are funding but what do they expect from the funding"
>
> "we are a regional unit as well, so you tend to get people scattered over a huge area"
>
> "we only get to see them for like three hours here at the unit"

Theme 1b- Service related Barriers: Service philosophy/model

Service philosophy prevents systemic working leaving therapists feeling that their hands are tied and confused as to who should be doing the work with families.

> "the focus is very much on the client and their rehab needs"
>
> "it just feels more medical model what we do"
>
> "we don't necessarily think about the family when setting the goals"
>
> "I think it depends on the therapist working…how much contact there is with the family"
>
> "who is it that is supposed to provide that"

Theme 2a- Family Related Barriers: Engagement

Do families have the resources, time or inclination to work collaboratively with therapy staff.

> "because of cause they're going to be working, and there's an issue about how accessible we are to families"
> "we can't force the family to come in"
>
> "it can also be something as simple as they have had a hell of a lot of time off work anyway"
>
> "you are dealing with a family who have been under an awful lot of pressure for a long time, financial, and like you say your asking them to commit to coming here on a regular basis"

Theme 2b- Family Related Barriers: Secondary carers

Difficulties faced by secondary carers such as children or parents of brain injured patient.

> "the teenagers a lot of them are going through so much personally, then they are reluctant or just can't handle anymore emotional overload"
>
> "they got so many other things going on, other issues in their life"

Theme 3a- Information needs: Prognosis
Beliefs and hopes about recovery are affected by the family's awareness of cognitive deficits.

> "especially for the children who really don't understand what has happened to their mum or dad"

Theme 3b- Information needs: Rehabilitation process
Lack of information provision and understanding about rehabilitation and prognosis.

> "because we work with head injury all the time we forget that there is little understanding amongst lay people"
>
> "when you talk to families you realise often how little information they have been given"
>
> "They really don't have a good idea at all what (rehab) offers and the type of people are here"

Theme 4a- Misconceptions: Mis-information
Beliefs formed through miss-information.

> "kind of see this place that she comes to as a bit of a nut house, like she would describe it as being full of mental weird people"

Theme 4b- Misconceptions: Perceived roles
Perceived roles of family members in the rehabilitative process.

> "not being something they need to be a part of"
>
> "...where the mother wants to do everything for the daughter.."

Theme 5- Support Systems
Importance of support systems and the benefit of sharing experiences with others in similar situations.

> "the teenage section seem very reluctant, and in a way it seems harder to target them and try and look at support systems for them"
>
> "there have been situations here where the client's carer needs more support than the client"

> "the most positive things I hear from clients here is about the support they gain from peers, you know just meeting other people who have had similar experiences"

Theme 6a- Expectations: Family expectations
Expectations of family members can influence level of involvement in rehabilitation process for the good and for the bad. Perceived role in process.

> "I think sometimes people see this place as a kind of respite, it's an opportunity for them to have a break"
>
> "some families are told their relative will never walk again, and they walk again so they don't know what to believe"
>
> "We see people at the longest for a year and the family are with them possibly for 20 years"

Theme 6b- Expectations: Team expectations
Expectations of the team on clients and family members.

> "we have got a lot of expectation about our client's and their families"
>
> "I can walk away until next week....imagine having to live with that 24 hours a day"

Theme 7a- Cultural issues: Cultural awareness
Need to address cultural background prior to intervening.

> "because of the nature of the head injury we are dealing with a huge cross section of society"
>
> "it is worth talking to families to find out what the family value's are and where the client's value's fit into that"
>
> "it's about finding out about that person within the family context and not making assumptions"

Theme 7b- Cultural issues: Implications for rehabilitation
Need to place interventions in cultural context.

> "is that putting western medicine, idea's onto people, because who is to say how a family should operate"

Appendix H

Chapter Three:
Semi-structured interview schedule

Semi-structured interview schedule:

The following questions will be used as a guide to the researcher to facilitate narrative during interviews.

Interviews will begin with the opening question:

"Tell me about how things have changed since (name) had their injury?"

Further questions or areas of interest that may be referred to during interview, but in no particular order:

- **What has changed for you?**
- **What has been the most difficult thing to get used to?**
- **Did you speak to anyone at the rehab center or did anyone talk to you about brain injury?**
- **What has helped you to get used to any changes?**
- **Are you doing more at home than you did before (housework etc)?**
- **How are things at school?**
- **Social life, friends, activities any changes?**
- **Relationship with un-injured parent, what's that like compared to before injury?**
- **Relationship with injured parent, what's that like compared to before injury?**

Appendix I

Chapter Three:

Parent and child information sheets

South Birmingham NHS
Primary Care Trust

West Midlands Rehabilitation Centre
Out-patient Brain Injury Rehabilitation Service
(Moor Green)
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel: 0121 442 3400
Fax: 0121 442 3420

Research on Parental Brain Injury:

Information Sheet - Families

My name is Chris Morrell and I am a student at the Universities of Coventry and Warwick. I am currently researching the impact of parental traumatic brain injury on children. I am currently looking for families to participate in my research and would very much appreciate it if you could take the time to read this information sheet. This research project will be supervised by Dr Louise Lorenc, consultant clinical psychologist at Moor Green.

Background information

There has been a lot of research interest in the impact of traumatic brain injury on family members. Most of this research concentrates on the impact on the main caregiver, usually spouses or parents of the brain injured individual. Very little is known about the impact parental brain injury has on children. Some studies have explored the effect of parental brain injury on the child's behaviour, but such studies have not sought the views of the children themselves.

Why Do This Research?

This research study will aim to gain an insight into how the roles and responsibilities of children within the home may change as a result of brain injury to a parent. It is hoped that the information gained will help rehabilitation services develop. In particular it will identify specific needs of young family members that are often not addressed as part of the rehabilitation program.

What will do I need to do?

This study will involve interviewing young people between the age of 11-18 currently living at home with both parents. The interviews will take approximately 30 - 60 minutes and will be conducted within your own home or at Moor Green, whichever is more convenient for you. The interviews will be audio-taped for transcription at a later date. All identifiable information such as names and addresses will be removed to ensure confidentiality.

Do I have to take part?

You do NOT have to take part in this research and you do NOT have to give any reason for refusing. You can also withdraw from the study at any time, again without having to give any reason why. Refusing to take part in the research will NOT affect any of the services you are receiving or may receive in the future.

What will happen to the information gained?

The information gained from the interviews is entirely confidential. The transcripts will be coded to ensure that they are anonymous. Once the research is completed all tapes and transcripts will be destroyed.

The results of the study will hopefully be published in a number of journals that will serve to inform other professionals of the experience of parental brain injury.

What do I do if I get upset by the research?

Should you feel distressed in anyway by the research then you may contact the allocated psychologist or keyworker at Moor green who works with the injured parent. If you feel your child requires further support then you can refer them to psychological services via your G.P.

What do I do now?

Decide as a family if you would like to take part. If you and your child would like to take part then sign the consent form that came with this information sheet. The completed consent form should then be sent back to me.

What if I want to know more?

If you want more information or have any questions then my supervisors Louise Lorenc at Moor Green and Dr Eve Knight at Coventry University or myself will be happy to answer them, our details are below.

THANK YOU

Louise Lorenc
Moor Green
Moseley Hall Hospital
Moseley
Birmingham

0121 442 3400

Dr Eve Knight / Chris Morrell
Clinical Psychology Doctorate
George Eliot Building
Coventry University
Priory St
Coventry
CV1 5FB

02476 888328

South Birmingham NHS
Primary Care Trust

West Midlands Rehabilitation Centre
Out-patient Brain Injury Rehabilitation Service
(Moor Green)
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel: 0121 442 3400
Fax: 0121 442 3420

Research on Parental Brain Injury:

Information Sheet - children

My name is Chris Morrell and I am a student at Coventry and Warwick Universities. I am researching how people aged between 11-18 adapt to having a parent with brain injury. I am asking young people if they would like to take part in my study.

What will I have to do?
I would like you to answer some questions about family life since injury to your parent. This will take place at your home and will take between 30 – 60 minutes. The interview will be tape-recorded so that I can listen to what was said in more detail later.

Do I have to take part?
You do not have to take part in the research and you don't have to give any reason for refusing. You can also withdraw from the research at anytime, and again you don't have to give any reasons.

What will happen to the information I give in the interview?
The interview will be tape-recorded. I will then listen to the tape and type all that is said onto computer. Your name and personal details will be kept private. Once the research is completed all tapes will be destroyed.

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 others who work with people with brain injury.

What if the interview upsets me?
If you get upset by what has been talked about in the interview you will be given the choice of talking things through with your parents or doctor who can find someone qualified for you to talk to. If you want a completely confidential service

you will be given the number for Childline, a telephone support service for children

What do I do now?
Decide if you would like to take part. If you would like to take part then tell your parents and sign the consent form that came with this information sheet. The completed consent form should then be sent back to me.

What if I want to know more?
If you or your parents want more information or have any questions then my supervisors Louise Lorenc at Moor Green and Dr Eve Knight at Coventry University or myself will be happy to answer them, our details are below.

THANK YOU

Louise Lorenc
Moor Green
Moseley Hall Hospital
Moseley
Birmingham

0121 442 3400

Dr Eve Knight / Chris Morrell
Clinical Psychology Doctorate
George Eliot Building
Coventry University
Priory St
Coventry
CV1 5FB

02476 888328

Appendix J

Chapter Three:

Consent forms

South Birmingham **NHS**
Primary Care Trust

West Midlands Rehabilitation Centre
Out-patient Brain Injury Rehabilitation Service
(Moor Green)
Moseley Hall Hospital
Alcester Road
Moseley
Birmingham
B13 8JL

Tel: 0121 442 3400
Fax: 0121 442 3420

Consent Form

If you would like to take part in the research project then please read the following information before signing the consent form and tick the boxes:

- I have read the research information sheet. ☐
- I understand that I can withdraw from the research at anytime, and I do not have to give reasons for doing so. ☐
- I understand that not taking part in the study or withdrawing at anytime will NOT affect the services I receive. ☐
- I understand that all information provided will be made anonymous, and that I will not be identifiable from any final reports written. ☐
- I understand that findings from this research will be written up for publication in journals read by other professionals who work people with brain injury. ☐

I have read and understand the information regarding the research project and agree to my child taking part: (both parents to sign)

(1) Name of parent or guardian .... (please print)

Signature of parent or guardian..

(2) Name of parent or guardian .... (please print)

Signature of parent or guardian..

I have read and understand the information sheet regarding this research and agree to taking part (children to sign).

Name(s) of children .... (please print)
....

Signature(s) of children ....

Would you like your mum or dad to be with you during the interview – YES / NO (please circle)

....
....

Today's Date .... / .... / ....

I would like to receive a summary of the research findings YES / NO (circle)

Appendix K

Chapter Three:

Sample transcript

R so that's seven weeks that must have been quite tough

Falling behind in homework. Further impact on schooling.

C7 that's another thing like going back to my schoolwork, because we were in hospital until about 8 o'clock every night because....(Mum says-he didn't want to leave me)...no one did really, so I was having to do some of me homework at the hospital so I wouldn't get all of it done some of the times

Impact on schooling

R so quite a disruption, and what was it like when you got home, was the house all upside down and ...?

C7 yeah, dad was cooking and stuff so it was takeaways most nights

(laughter)

R but very odd not having your mum here and obviously it sounds like you just didn't want to be apart from her, be away...

Not wanting to be away from injured parent

C7 no, I just didn't want to be away, and I mean if go home for the weekend, I would go see my mum in the morning and when I got back I would go and see her in the night and then go back home

Hard to be away

R apart from the people at school did you speak to anyone else about what had happened?

Choose to keep his thoughts & feelings mainly in the family circle.

↓

Why talk to people (peers) when they don't really understand.

C7 erm, no not really. I suppose I didn't really know what to say really. I spoke to a couple of my close friends about it, but I didn't really speak to anyone else, apart from I suppose the people in my family, just like my auntie

Talking to others.

R what sort of things did they say, your close friends...?

C7 erm, well they were just concerned for me more than anything, asking me how I was and ......(inaudible)

R do you think they understood what had happened?

C7 I think, I don't think people really understood what a stroke was, I don't think they really knew that it was as serious as it was

R but you realised....

(cat enters room-discussion about pets)

200 R so you still see your friends quite a bit, how about activities and sort of things with your mum and dad, has that changed at all

Adapting to + accepting mothers level of impairment – Focus on physical disability.

C7 yeah, I suppose because like me mum…like when we went on holiday, some of the stuff like when we played pitch and 205 putt golf or miniature golf, me mum couldn't join in because she couldn't use her left arm so…that was a bit different and sometimes it was a bit upsetting for me mum I suppose because she couldn't join in

Accepting impairments.

R and was that upsetting for you that she couldn't join in?

C7 yeah it was a bit yeah, I felt a bit sorry for her really

R not very nice to think I can do this and mum can't

(discussion about holiday)

R when your mum first went into hospital and when she first came out, did anybody talk to you about what happened, like doctors or nurses…?

Initially @ acute stage, no contact c̄ profs. All info was passed on by his uninjured parent.

C7 no they didn't, I think they spoke to my dad a little but it was more like explaining to my dad, because my dad was there 213 nearly all day everyday so dad got, my dad always sort of relayed the information

Information handed down

R so dad relayed the information, do you think he held anything back?

C7 I don't know really. I think he told me most things, he was quite…but a couldn't really say, I don't think he held anything back

(mum interrupts)

R so what about when your mum started at (rehab ctr) seven weeks ago, has anybody spoken to you from there like (OT) or anybody?

Contact/ involvement in rehab services – no direct work offered to him regards his thoughts + feelings.

C7 no, I was here once when me mum had to practice cooking a meal in the kitchen and she made me something, I just had to be here for that didn't i…and me mum just made something and I just had to be here to eat it

Involvement in rehab.

R that's a tough job isn't it, I just gotta be here to eat it. So do 224 you know what the actual point of that was?

Understanding of rehabs limited, not explained to him.

135 C7 I suppose to see how practical my mum was around the house and to just try and help her do things

Limited understanding

R and were there any other things that erm, so you have seen her doing the cooking, and you had to eat it (laughter) but there are other things people might need help with like their memory or things like that…

Cognitive impairments leading to family conflict or disagreements

C7 141 yeah, I mean, sometimes she does forget things I suppose, and sometimes there can be like arguments about things, because my mum will tell me to do something and then when I've done it she will sort of tell me again and sort of end up like….there could be an argument…

Frustrated by deficits.

R that sounds quite tough, because that must be quite frustrating to be told that…

C7 it can be quite frustrating

R but you understand why she is doing that, because it's a memory problem…does your mum use a diary or anything like that?

C7 erm, I don't think so

R no one has spoken to you about using a diary

(mum interrupts)

R what do you know about the (rehab ctr) diary?

C7 erm, I thought it was just about when she had to go and do certain things and….physiotherapy…

Involvement in Mums rehab - what she has observed + understands from such observations ✓

R we have talked a bit about doing the cooking, which is occupational therapy, you mention physiotherapy, what sort of things happen in physiotherapy…?

C7 I think it's just to erm, it's like trying to help my mum with her arms and things like that and sometimes when she's in pain with her shoulder they help her with that, like with acupuncture and things like that…yeah I was there one day when me mum had to have acupuncture because that was in the summer holidays, because we had to go out…..

limited understanding

R so you have actually been along to physiotherapy, you have been along to that, you've seen a bit of OT work going on.
169 Are there any other things that your mum struggles with?

Assisting in rehabilitation programme.

C7 well I mean first of all there was her speech and sometimes we had to help her, because she had sheets to practice words and we would like read things out and stuff and mum would like read them to us...speech therapy...my sister done quite a lot of it, just like holding the sheet for me mum, and me mum would read for a bit and then tell her if she had done some words wrong

involvement in rehab.

R and what do you think all that achieves at the end of the day?

Unrealistic expectations of brain injury rehab

C7 I suppose to help her get back to a more normal life, the same as before the stroke happened

Expectations of rehab.

R and what do you think, your mum's been at (rehab ctr) for 7 weeks, erm, what do you *think* goes on there, what's your idea of what goes on there?

Basic understanding of out patient ctr, high expectations.

C7 I suppose (inaudible) are that they help her become more active, like she said she gets bored at home and things like that and like I said again to like help her get back to normal

R what sort of things go on there, is it the sort of stuff that you have seen...

C7 erm, yeah I know that she does a woodwork class where she is making something, things like that

R what does that sound like to hear your mums doing woodwork?

C7 it sounds a bit strange

R it's great in there isn't it (brief discussion about woodwork) so it's a place where your mum can go to meet people and get better. What do you think about that in terms of the future, where do you see your mum in a year or two years time?

Beliefs about the future in terms of recovery + prognosis - expectations.

C7 I don't know really, I do try to be more positive about things. I think she will be like a lot more back to normal, her speech will be a lot clearer and I think something that me dad said, like her stamina, she will be able to walk further and do things

Positive views.

R has anybody spoken to you about recovery from stroke, like how long it can take?

C7 no, no. I suppose I have heard different things, like it can take a long time

306 R what about for you then, you see things getting better for your mum, what about your views of the future, do you think anything will change for you because of this?

The future in terms of his own needs & wishes. Which appear to be rather dependent upon mums progress & wellbeing — will he still have to be a carer?

C7 I think erm, I don't know really, maybe I will have to do less things for my mum, because she will become more independent, that's all I can think off

R are there things, have you got like hopes and ambitions and things…

C7 yeah I'm interested in journalism, like writing for a sports paper

R so that's your goals (short discussion around college and university)

318 C7 (referring to university) it depends how mum is and if dad can cope with it, and my sisters if there at home or…

Future ambitions

R so you would think about all that before choosing where you would go, if you felt comfortable you could go off further if you wanted to…

C7 yeah, I mean I could live at home and just catch a bus to Birmingham University (mum interrupts)

R so in terms of the future you still have a good focus and feel that things are quite positive for your mum and things, how about things for your dad and sisters?

The future for the rest of the family. This has been affected by role reversals exp by family members

C7 328 erm, I think there will be less pressure on me dad, I suppose sometimes it can get a bit much having to take over the central role

changing roles.

R so is his role like your mums…?

C7 yeah, he used to be sort of more, I dunno, you (addressing mum) used to be more in control and …

R so mum was the boss

C7 but now dad has to do a lot more

R that must have been a massive lesson to learn to lose the main provider the one who holds the place together. Do you think he will stay doing more?

C7 yeah

Appendix L

Chapter Three:

Details of major themes, composite recurrent themes and number of times themes emerged in transcripts.

Recurrent themes identified from each interview transcript forming each Major Themes

Key to annotations:

C (+number)	Participants e.g. C1
Number	Page numbers
Bold print	Major Themes
Italics	Recurrent themes

(short term) INITIAL SHOCK

Emotional impact	C1, 28, 31 / C4, 312
Shock	C1, 47 / C2, 121 / C3, 202 / C5, 75 / C7, 130 / C8, 32, 268 /C9,156/C10,34 / C11,114
Realisation	C1, 79 / C6, 42 / C7, 385 / C8, 273 /C10,42
Initial fears	C1, 95 / C6, 38 / C6, 52 / C7, 154 / C8, 74/ C9,161
Turning to god	C3, 249

(long-term) IMPACT ON CHILD

Hopelessness/feeling lost	C1, 141, 341 / C2, 104 / C4, 54, 525/ C9,50,191,193 /C12,3,54
Bottling of feelings	C1, 125 / C2, 333 / C3, 21 / C4, 37 / C6, 219 / C7, 43 / C8,184
Need to be near	C1, 126, 178 / C2, 527 / C6, 16 / C7, 181 /C10,38 /C11,7
Reliability of parent	C2, 13 / C4, 460-466
Feeling forgotten	C4, 45, 65, 177, 280
Shattered dreams	C4, 327
Behaviour	C4, 42 / C6, 110 / C7, 107
Impact on schooling	C1, 35 / C7, 73, 171 / C8,163/ C9,109/ C11,54, 93

PERIOD OF ADAPTATION

Strength of relationships	C1, 63 / C2, 45, 192 / C3, 211 / C5, 34 / C7, 352/ C9,325 /C10,181/ C11,180,207
Changing roles	C3, 60, 228 / C4, 27, 28, 90 / C5, 9 / C7, 328/ C9,101,204 /C12,15
Responsibility	C2, 110 / C3, 65 / C5, 260 / C7, 3 / C8,14/ C9,94,371/ C10,9,25/ C11,216 /C12,25,42
Sacrifice	C1, 469 / C2, 233 / C4, 5, 18 / C5, 49, 177 / C6, 27/ C9,361 /C10,190
Support from family	C2, 230, 251 / C3, 28 / C4, 17, 501 / C7, 444 / C8,172/ C12,87
Peer support	C1, 165, 333 / C4, 516 / C5, 168 / C6, 100, 189, 196, 232 / C7, 188/ C9,126,209/ C10,109
Support from school	C10,62,68/ C11,62

ACCEPTANCE

Making allowances	C1, 6 / C3, 26 / C6, 9 /C9,248,256,341 /C10,3
Accepting impairments	C1, 376 / C3, 4, 7, 194 / C4, 211 / C6, 6 / C7, 11, 205 /C9,20/ C10,13,35 /C11,134,195
Take things day by day	C2, 212 / C2, 16/ C11,36

BELIEFS ABOUT RECOVERY

Positive view	C1, 396, 416 / C2, 455 / C5, 86 / C5, 246 / C7, 297, 465 / C12,173
Slow process	C2, 37, 67
Expectations	C2, 400 / C3,158,340 / C4,303 / C5, 251, 288,332 / C6, 179 / C7, 278/ C9,28 /C11,222

INFORMATION NEEDS AND PROVISION

Trying to forget/	C2, 53, 85 / C3, 16 / C7, 49
Don't want to know	C9,288,301
Shielded from information	C3, 91 / C3, 289
Information handed down	C3, 288, 324 / C5, 104 / C6, 60 / C7, 218 / C9,96
Input from professionals	C1, 155 / C2, 89 / C3, 126, 282 / C4, 290 / C6, 75/ C9,276 /C10,86/ C11,137/ C12,111

UNDERSTANDING OF INJURY AND REHABILITATION

Prior experience/knowledge	C1, 296 / C3, 205 / C7, 131
Rehab a home	C1, 390, 392, 408 / C2, 265, 306 / C4, 271, 275
Perception of rehab	C1, 264, 283 / C2, 261 / C4, 259 / C5, 190 / C7, 235 / C8, 307/ C10, 158,166 /C11,157 /C12,119
Understanding of injury	C4, 129 / C5, 115 / C6, 158 / C8,48/ C10,122,130/ C12,62
Frustrated by deficits	C4, 123, 132 / C7, 242/ C9,259

PERIOD OF REFLECTION

Life not perfect	C1, 195 / C4, 317
Reality of life	C1, 197 / C4, 337, 338, 339 / C6, 204, 206
Feeling guilty	C1, 353
Duty	C2, 188 / C5, 154
Regret	C4, 182
Time is a healer	C5, 350/ C11,167
Could be worse	C7, 410, 414 / C8,100

VIEW OF THE FUTURE

Giving something back	C1, 309
Future ambitions	C1, 299 / C7, 318
Change of heart	C2, 101
Concerns	C4, 99, 106, 285 / C6, 212 / C8, 336, 358
Make the most of life	C9,60 /C10, 142