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UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

**A study of family transition in the first year post-head injury: perspectives of the non-injured
members**

by

Charlotte Jane Whiffin

Thesis for the degree of Doctor of Philosophy

October 2012

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Doctor of Philosophy

A STUDY OF FAMILY TRANSITION IN THE FIRST YEAR POST-HEAD INJURY: PERSPECTIVES OF THE
NON-INJURED MEMBERS

by Charlotte Jane Whiffin

Background: A traumatic brain injury is a potentially devastating injury. The family responds to this injury by supporting the individual and their recovery but is perceived as being at risk from the challenge of meeting both new and existing demands. While the perspective of individual family members has been well documented there is growing interest in how the family as a whole makes sense of their experiences and how these experiences change over time.

Research Questions: What are the changes reported by non-injured family members during the first year of a family member's traumatic brain injury? And: within one family what are the effects of traumatic brain injury up to one year following injury?

Methods: A longitudinal narrative case-study design used in-depth qualitative interviews and a structured questionnaire. Nine non-injured family members from three families were recruited and data collection took place at one, three and twelve months post-injury. Analysis was completed on three levels: the individual, the family and between family cases.

Narrative Findings: Trauma, recovery, autobiographical, suffering and family narrative threads were identified. Narratives emphasised that the year post-head injury was a turbulent time where family members were active agents in the process of change.

Quantitative Findings: Data suggested that families recruited to this study had healthy levels of family functioning and these characteristics were sustained in the year post-injury.

Discussion: It is possible that although the structured measure suggested family functioning stayed relatively stable these families were embarking on a series of changes to enable this to occur. The significance of these less obvious changes needs to be acknowledged.

Conclusion: Working with families to validate their experience, resolve their trauma and prevent suffering may go some way to enabling family members to positively adjust to life in the wake of head injury.

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DECLARATION OF AUTHORSHIP

I, Charlotte Whiffin

declare that the thesis entitled

A study of family transition in the first year post-head injury: perspectives of the non-injured members

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- parts of this work have been published as:

Clark, C., Brown, J., Bailey, C. and Hutchinson, P. (2009) Supporting families in the context of adult traumatic brain injury, British Journal of Neuroscience Nursing, 5(5) pp 216 - 220

Signed:

Date:.....22nd October 2012.....

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Definitions and abbreviations

The definitions provided here enable a brief introduction to the key concepts and conditions in this study. However further discussion and explanations of these are provided in the chapters that follow.

Acquired Brain Injury: An injury to the brain that occurs after birth and can be caused through traumatic and non-traumatic means

Traumatic Brain Injury/Head Injury: A specific subset of ABI whereby the brain is injured through trauma often caused by motor vehicle accidents, assaults and falls. Within the text both terms, traumatic brain Injury and head Injury, are used interchangeably.

Family: 'the family is who they say they are' (Wright and Leahey 2005)

Family systems theory: views the family as containing a structure, rules of operating and established methods of communicating (Maitz and Sachs 1995)

Abbreviations

ABI: Acquired Brain Injury

TBI: Traumatic Brain Injury

GCS: Glasgow Coma Scale

PTA: Post-Traumatic Amnesia

FACES-IV: Family Adaptability Cohesion Evaluation Scale Version Four

1 Introduction to Thesis

1.1 Orientation to the research

The focus of this research originated from my clinical experience in the field of neurology and neurosurgery. As a registered adult nurse I frequently managed the care of patients who had sustained a head injury. Within an acute specialist ward I was often required to support families through a distressing period when their relative was displaying a range of unfamiliar behaviours. Some of these behaviours I knew would resolve and others I thought may be a permanent reminder of their injury. Of course it was impossible to know which was which and families would watch and wait for signs that their relative was still the person they knew before their injury. In the adult care setting I, and my adult nursing colleagues, found supporting the family challenging and we often felt we were unable to support them adequately. Support mechanisms usually came from within the family. However without the additional support from healthcare staff these support mechanisms sometimes failed and family relationships often appeared strained or tense. Other families grew stronger from the experience and the bonds between family members were deeply embedded within their ability to navigate through the experience. As a result of this clinical practice I was interested to explore the experiences of families in order that I may further assist healthcare providers to establish more effective support mechanisms for the non-injured family members.

1.2 Orientation to the researcher

I am a 34-year-old white female. In 2001 I graduated with a first class BA (Hons) degree in Adult Nursing. Having already developed a passion for neurological nursing as a student I gained employment in a dedicated neurosciences hospital. I then continued to work on acute neurosurgical wards during a year in Australia. In 2004 I became a nurse lecturer where I was able to pursue my research interests within a PhD programme.

From a personal standpoint I consider myself quite well-spoken and usually try to present myself in a smart and tidy manner. At this moment in time I feel very lucky that I can say I have never been seriously ill and neither have any other members of my existing family. However, in 2002 my father died of cancer and this event gave way to a number of complex events and circumstances that were difficult for the whole family to negotiate. As a result of this I often find myself connecting and empathising with other people's situations especially when I feel they are of a similar nature to my own.

1.3 Orientation to the thesis

1.3.1 Chapter One

Chapter One contains an orientation to the research, myself as the researcher and then the thesis itself. First the rationale and origins of the research are explained followed by an introduction to me as a researcher to help the reader understand my personal and professional context. The chapter then continues with a description of the structure and content of each chapter.

1.3.2 Chapter Two

Chapter Two presents 'the ripple effect' as a metaphor for understanding family in the context of TBI to help illustrate how an injury to one person has such far reaching consequences for the whole family. The metaphor is further justified through exploring the typical circumstances of TBI and populations considered at most risk. It is argued that damage to the brain causes a complex and diverse range of physical, cognitive, emotional and behavioural impairments that create conditions where all family members must make adjustments. Traumatic brain injury as a long-term condition is then explored through the continuing support needs of both injured and non-injured members that can be required for a life time. Finally consideration is given to useful definitions of family that consider both the family as membership and the family as a dynamic system.

1.3.3 Chapter Three

Chapter Three continues exploration of this ripple effect by conducting an in-depth evaluation of the empirical literature. A systematic search was employed to search the most relevant and contemporary studies. Two main areas of the evidence base are discussed: first how TBI affects individual family members and second how TBI affects the wider family system. Through these discussions an in-depth understanding is generated regarding the impact of TBI on primary carers, parents, spouses and children, in addition to the importance of family functioning, family needs and family contexts. Through building a picture of the current evidence base and its strengths and limitations, it was possible to see where future studies should concentrate their efforts. As a result, research questions and objectives are generated to respond to the gaps identified and provide the justification for this study.

1.3.4 Chapter Four

Chapter Four defends the choice of research design used to investigate the research questions. The chapter begins with a discussion of the merits of both quantitative and qualitative approaches and how investigations can be enhanced through the mixing of methods. An

orientation to epistemological and ontological assumptions is then presented through the choice of social constructivism and narrative theory. Next a qualitative case study methodology is explored for how it facilitated this investigation to conduct a family centred investigation.

Within the methods section of this chapter the sample, access, and recruitment of family members are explained alongside justification for inclusion and exclusion criteria. Data collection procedures are then presented and the choice of both narrative unstructured interviews and a structured questionnaire defended through the contribution both made to answering the research questions. The chapter then moves into a discussion of the ethical implications of this study and finishes by examining the analytical approaches undertaken to support presentation of the findings in Chapters Five and Six.

1.3.5 Chapter Five

Chapter Five contains the narrative findings from this study. Findings are presented as five narrative threads; specifically these are Trauma, Recovery, Auto-biographical, Suffering and Family. The chapter is organised so that the unique circumstances of each family case are introduced followed by an exploration of the data supporting the interpretation of each thread. Threads are interpreted through their relevance and context to each specific family. Illustrations are then used to portray the overall understanding that was reached for each narrative thread.

1.3.6 Chapter Six

Chapter Six contains the quantitative findings from FACES-IV. This chapter presents longitudinal datasets for each family member followed by a discussion of the relative health of the whole family system. Datasets from each of the families are then compared to facilitate a discussion of how family functioning changed, or not, as determined by the self-completed questionnaire, during the first year following TBI.

1.3.7 Chapter Seven

Chapter Seven contains the discussion and conclusions for this study. The five main findings are explored by drawing on supporting literature. Specifically the findings were: using narratives to understand the processes involved in the judgement of pre- and post-injury change; recognising and validating the stories of non-injured family members in their own right; working with narrative structures; identifying misaligned narratives and understanding the complexity of change in families post-TBI. Reflections are made on the possible limitations

of the study and implications for practice and research are presented before a final conclusion is made.

2 The Ripple Effect of Head Injury

2.1 The ripple effect

Traumatic brain injury (TBI) initiates a ripple effect within a family whereby the initial injury is only the beginning. As the ripples radiate through family life, TBI has the potential to devastate the lives of all family members (Gan et al. 2006). TBI affects the family in a number of complex and diverse ways and it has been argued that because of this, TBI can be as traumatic for the non-injured family members as it is for the person who sustained the injury (Gan et al. 2006; Jumisko et al. 2007).

Although the injured person is undoubtedly in a unique position with each embarking on a personal journey of recovery, they rarely undertake this alone. Spouses, parents, siblings and children are ever present in the journey and are usually an integral part of it. These other family members, who are often heavily relied upon for physical, emotional and social support (Curtiss et al. 2000; Gan et al. 2006) therefore embark on their own journeys, perhaps not from injury, but in response to a major life event that may ultimately change their family, and themselves forever (Ergh et al. 2002). It is subsequently argued therefore that TBI does not happen to an individual, a TBI happens to a family.

Traumatic brain injury has far-reaching consequences and a ripple effect is a useful way to conceptualise the impact this injury has within families. Although this metaphor will be used throughout this thesis it is worth remembering there are still limitations in the ability of this metaphor to truly capture how and why the whole family is so affected by TBI. The following chapter will therefore go on to paint a picture of TBI, exploring what is known about the risk factors for injury, the journey of recovery from injury and the expected consequences and outcome.

2.2 A picture of traumatic brain injury

The typical picture of TBI is a young man who has sustained his injury whilst engaging in some sort of high-risk activity (Powell 2004; Abelson-Mitchell 2008). Common high-risk activities include: driving without due care and attention, falling from a substantial height, or being the victim of assault. Frequently these activities are further complicated by the excessive consumption of alcohol. Often, TBI is sustained under preventable conditions or in complex circumstances where there is frequently someone to blame for the aftermath. This adds another layer of emotional complexity upon the already challenging nature of TBI.

Of course not every injury is sustained under such circumstances. Frequently head injuries are simply tragic accidents that can happen at any age and will affect men and women equally. However, there are groups considered at greater risk and certainly the association between head injury and gender is universally recognised. Abelson-Mitchell (2008) reviewed 20 research papers with head injury epidemiology data from the UK, Europe, the US and Australia. Within these data men were consistently reported as being between 2 – 3 times more likely to sustain a head injury than women. More specifically data for England reflect this trend and figures for 2010-2011 cite men as accounting for 68% of all admissions to English hospitals following an injury to the head (HESonline 2011).

Age is also a widely recognised factor in TBI and those who are aged between 16-24 years are considered to be at most risk (Sorenson & Kraus 1991). It is thought the high incidence rate at this age is attributable to younger people having less appreciation of the risk associated with the activities they engage in. Typically at this age young adults are commencing employment, choosing further education and leaving home (Fleminger & Ponsford 2005). Therefore TBI interrupts this development and the normal life cycle for both the injured person and their family.

Although not reported by all epidemiological studies, there does appear to be another incidence peak occurring for those over 75 years of age attributable mostly to the high rate of falls in older people (Abelson-Mitchell 2008). However, because life expectancy is only minimally reduced following TBI if the injury is sustained at a younger age the individual and their family will live with the consequences for many years. Therefore it is the high incidence of TBI in the young that is said to be of most concern because of the significant emotional and financial burden it creates for families and the services that will provide for their long-term needs (Gottesman et al. 2003; Engberg & Teasdale 2004; Tennant 2005).

2.3 The consequences of TBI

Traumatic brain injury is a condition that affects millions of people every year both in the UK and worldwide (Teasdale 1995). Thought to be the leading cause of disability in those under 40 years of age, TBI is a major public health concern (Fleminger & Ponsford 2005). For those with a life-threatening injury acute management is centred on saving the person's life and as medical and surgical interventions continue to improve many more people survive their injury than ever before. Improved survival rates after TBI can be attributed to increased knowledge regarding neuroscience, implementation of national guidelines and advances in medical technology (Hutchinson & Kirkpatrick 2002; Hickey 2003; National Institute for Health and

Clinical Excellence (NICE) 2007). However Hickey (2003) argues that the cost of this increase in survival is that for some, quality of life may be severely reduced by subsequent long-term disability.

Damage to the brain not only causes physical and motor deficits but may also result in an extensive range of psychosocial, emotional and behavioural impairments (Engberg & Teasdale 2004; Donnelly et al. 2005; Wood et al. 2005). Recovery from physical injury is usually the main focus in acute care and early rehabilitation; however, it is the long-term nature of many of the more subtle impairments that typically have the most effect on people's lives (Ergh et al. 2002; Wood et al. 2005; Cloute et al. 2008).

An extensive range of conditions and impairments are a 'frequent legacy' of brain injury (Wood et al. 2005, p845). As a result of these impairments those with TBI may require small adjustments to their daily routine or, conversely, the injured person may become completely dependent on others for every activity of daily living. Impairments range from the visible such as a muscle weakness or paralysis to the invisible such as short-term memory loss, poor planning and organisational skills, fatigue, reduced motivation, irritability and fluctuations in mood (see Table 2.1). Although these latter impairments are less obvious they are as debilitating in everyday life. In addition, unlike a muscle weakness or paralysis that may require a mobility aid such as a wheelchair, the neuropsychological and neurobehavioural impairments are often hidden from the outside world. However, the family is usually acutely aware of these impairments and these are often cited as most challenging for families to adjust to (Perlesz et al. 2000; Connolly & O'Dowd 2001; Harris et al. 2001; Ponsford et al. 2003; Wells et al. 2005; Blake 2008; Jackson et al. 2009).

Effects of head injury (adapted from Iggulden 2006) Any one or a combination of these problems following a head injury will affect personal, family, social educational or working life	
Perception Memory Concentration, Attention Information processing Awareness/Insight Relationships Personality Mood/emotions Executive skills (planning organising)	Movement Co-ordination/balance Stamina/tiredness Sensory perception Motivation Speaking Language Skills Inhibition, impulsivity Tolerance

Table 2.1 Effects of Head Injury

2.4 Personality change following TBI

Personality change following TBI is a well-established construct and identified as an antecedent of many of the challenges families face post-injury:

‘The concept of “personality change” following acquired brain injury (ABI) refers to an alteration or discontinuity in personhood post-injury.’ (Yeates et al. 2008, p567)

The seminal writings of Muriel Lezak (Lezak 1978; 1986; 1988) referred to the injured person as categorically altered and told the brain injury community to be prepared for a different person to emerge following TBI.

In clinical practice families are frequently prepared for ‘the worst’ and once the chances of survival are tipped in favour of life and recovery the next consideration is usually ‘what will we get back?’ In some circumstances the medical team have already pre-empted change and informed the family that due to the extent of brain damage sustained their relative will never be the same person following their physical recovery:

‘Brain injury, sudden and unpredictable tears violently at the whole of individual mind, body, spirit. Brain injury renders the parts of the whole disrupted and shattered, exposed and torn apart [...] and so it is, from this point on, the struggle and the search begin. For wholeness and meaning within our brokenness, for the integration of our parts into our whole, and for the integrations of our present with our future, our present with our past and our past and our present with our future’ (Tasker 2003, p337)

Neurological processes within particular regions of the brain are responsible for specific functions. Therefore it follows that neurological damage within these regions can be directly linked to traits that may become exaggerated, or diminished with the presence of neuronal damage (Yeates et al. 2008). The cerebral cortex (grey matter) forms the surface layer of the hemisphere and is responsible for higher intellectual functions such as thought, memory and intellect (Crossman & Neary 2005). Damage to the cerebral cortex caused through TBI can result in loss of sensory function and reduces the brain’s ability to interpret information. More specifically damage to the frontal and temporal lobes causes a range of memory and attention deficits, mood and behaviour disorders and these are considered particularly challenging (Fleminger & Ponsford 2005).

However, this biological view of personality has been challenged in more recent literature and Yeates et al. (2008) argue that personality change is not simply due to the biological changes that occur. Key papers have therefore emerged that consider the biopsychosocial construction of personality (Yeates et al. 2008), the role of identity and social processes (Cloute et al. 2008),

and how people construct a sense of self after brain injury (Gracey et al. 2008). Yeates et al. (2008) suggest that the psychological and psychosocial processes that are affected are more important in identifying personality change. However these processes are not as easily identified through neurological imaging and therefore the answer to 'what will we get back' is mostly unknown.

Personality change has previously been seen as a problem for the non-injured family members as the person with the injury was originally thought to have little insight into how much they had changed (Lezak 1986). However a series of qualitative studies challenged this position and revealed those with brain injuries to be suffering from a loss of self that was having a negative impact on their life (Nochi 1997; 1998; 2000). An important construct, identified by Nochi (1998) was the 'opaque self': a feeling of unfamiliarity with physical, cognitive and emotional capabilities. When a person feels they are unfamiliar with their own sense of self they will feel unfamiliar with their relationships with other people and thus the implicit relationships held within the family are questioned and appraised. More recently Yeates et al. (2007) interviewed three couples consisting of the injured person and their significant other, whereby the injured person had been purposively selected as someone who had specific awareness deficits. Yeates et al. (2007) identified that even these injured persons felt a sense of being different somehow and were able to reflect on their current sense of self in terms of their past self.

Therefore personality change post-TBI may be explicit as a direct result of damage caused by injury or more subtle as a result of shifts in psychological and psychosocial processes leaving the injured person feeling disconnected. For the brain injured population the discontinuity experienced between pre-injury and post-injury self has emerged as a key issue in recovery and rehabilitation (Gracey et al. 2008).

2.5 Injury and outcome

Injuries are classified as mild, moderate or severe and Table 2.2 has been constructed to demonstrate the differences in classification between each of these categories. Although there are several different ways of classifying the severity of initial injury the Glasgow Coma Scale (GCS) is by far the most commonly used indicator in the TBI literature (Tagliaferri et al. 2006). The GCS was developed by Teasdale and Jennett (1974) to standardise neurological observation and the assessment of impaired consciousness. Following the assessment of eye opening, verbal and motor response the score is calculated on a scale of 3-15. Fifteen is considered fully alert and orientated and three is interpreted as deep coma (Hickey 2003).

	Measure of Injury Severity				
	Glasgow Coma Scale	Glasgow Coma Scale Plus imaging	Loss of Consciousness	Injury / Intervention	Post Traumatic Amnesia (PTA)
Mild	15 – 13	15 – 13 with no brain abnormality	< 30 min	Admitted for less than 48hrs	< 1hr
Moderate	12 – 9	15 – 13 with brain abnormality or 12 – 9	>30min <6hrs	Admitted for more than 48hrs but do not require neurosurgical intervention	Up to 24hrs
Severe	8 – 3	8-3	>6hrs	Patients who require intensive care or neurosurgery	>24hrs

Table 2.2 Classifications of injury

It would be reasonable to assume that those with the more severe injuries have the most severe impairments thus causing the most distress for injured individuals and their families. However, research has not always supported this direct correlation (Ergh et al. 2002) nor does it predict to what degree the post-injury sequelae will affect their quality of life (Gan & Schuller 2002; Turner-Stokes et al. 2003). Even those with mild injuries report anxiety, irritability, poor memory, and or fatigue for an extended period of time, or permanently (Landau & Hissett 2008). The correlation between injury and outcome is therefore unclear (Turner-Stokes et al. 2003), so there is potential for all individuals, and their families, to be significantly affected by any severity of injury.

2.6 Traumatic brain Injury is a long-term condition

Medical stabilisation is usually achieved relatively quickly post-injury (Teasdale & Engberg 2005) and in the following six months both physical and cognitive recovery is at its most rapid. For those patients admitted to intensive care that are intubated and sedated the future is unknown until they awake from this state. Patients may then go on to make rapid progress and are quickly transferred to less acute environments and then onto rehabilitation when necessary. At this stage many milestones are passed quickly, patients open their eyes, start to communicate and broken bones heal. Families are understandably relieved by these events

and their expectations of a full recovery and return to 'normal' are often at their highest in these early stages.

Fleminger and Ponsford (2005) suggest that the most recovery occurs in the first two years with some improvement reported over the subsequent 5-10 years. Although deficits may improve over an extended period the pace of this improvement in physical and cognitive recovery slows dramatically (Lindsay et al. 2010). Therefore over time rehabilitation and support services become less intensive and often following hospital discharge contact with the health care team can be lost completely (Teasdale & Engberg 2005). As physical and cognitive recovery start to slow family members begin to adjust their perception of the future and their ability to return to their previous lives.

Although it would seem logical that over time families should adjust to life after TBI and therefore burden and stress should reduce, research has shown stress, caused by supporting a person with TBI, often increases over time (Ponsford et al. 2003). This increase in stress and burden has been attributed to decreased expectations of recovery, realisation of permanent change and the continuing strain of caregiving (Wood et al. 2005). Traumatic brain injury is therefore a long-term condition and thus support may be required for many years, or for an entire lifetime (Gottesman et al. 2003; Rotondi et al. 2007).

2.7 Rehabilitation and support services for TBI

Ideally a person who sustains a TBI should receive pre-hospital care, treatment at a specialised centre for neurosciences, acute in-patient care and access to long-term rehabilitation (Tagliaferri et al. 2006). Without these components patient outcome may be severely affected (Tagliaferri et al. 2006). Although the need for physical, psychological and cognitive rehabilitation after TBI is widely recognised national provision is extremely variable and this has major repercussions for the injured person's recovery. Rehabilitation is an essential element of recovery and must start early to maximise potential outcome. However, often specialist rehabilitation beds are unavailable and patients are left to occupy acute beds without the ability to access the next stage of care (Seeley et al. 2006). In addition to this, although the emphasis for rehabilitation is on the first six months, rehabilitation services may be required many years later (Gottesman et al. 2003). Therefore provision of sustained acute and community rehabilitation is important for both injured and non-injured family members.

The proposed research was conducted in the East Anglian region of the UK and therefore it is prudent to reflect on the provision of rehabilitation services within this area. In a letter to the

British Medical Journal, Hutchinson and Pickard (2006) identify a lack of physical, cognitive and vocational rehabilitation in East Anglia. The Eastern Region Head Injury Group illustrated this gap in service provision by classifying, coding and then mapping all the rehabilitation available for head injury patients in the region (Pickard et al. 2004). The result of this process was to reveal that availability and access to specialised rehabilitation services is fragmented and this is further exacerbated through a disorganised unstructured approach between acute and community providers. The lack of available services has major repercussions for the injured person's recovery and the impact this disjointed and protracted process has on the injured person and their family is said to be substantial.

2.8 The impact of TBI on the family

The importance of the family in the recovery process often means family members are relied upon, or expected, to provide much of the necessary care and support (Gan et al. 2006; Degeneffe & Olney 2008). Family members are therefore usually required to change their own lives in response to the impairment that may be evident following TBI. Inevitably the family can be left feeling vulnerable and may be at risk from the challenge of meeting new and existing demands (Degeneffe & Olney 2008).

In the initial phase of recovery the density of social networks increases as family and friends come together to help and support each other through the changes required (Douglas & Spellacy 2000). However, as changes persist and spontaneous resolution becomes more unlikely peer relationships fall away and the quality of the relationships within the family can become strained putting added pressure on all family members (Douglas & Spellacy 2000; Wood et al. 2005). Without the appropriate support families may find the demands of providing this care overwhelming. As a result relationships may irrevocably fracture and families may fragment as members distance themselves from each other rather than face the challenges alongside the injured person (Ergh et al. 2002).

Therefore, the impact that TBI has on the non-injured members of a family has been the subject of extensive investigation (Wood et al. 2005; Duff 2006). Research studies have traditionally focused on the high levels of psychological distress, such as anxiety, stress and burden, that have been identified in groups of non-injured family members (Livingston et al. 1985; Brooks et al. 1986; Brooks et al. 1987; Blake 2008; Schönberger et al. 2010). Although psychological distress is important following TBI much of this literature does not demonstrate the complexity of how and why the family is so affected (Anderson et al. 2002). Researchers in head injury have therefore been turning some attention to broader constructs such as family

functioning (Anderson et al. 2002; Gan et al. 2006; Hanks et al. 2007). The investigation of family functioning enables the context of family life to be examined and the relationship this may have to the family members' quality of life.

Families are recognized as fundamental to the injured person's functional and social recovery post-TBI and in addition contribute to their overall sense of well-being and life satisfaction (Turner-Stokes et al. 2003). Research continues to identify an association between families that are able to function well together and the increased ability to meet rehabilitation goals, moderate negative feelings towards caregiving and reduce anxiety, depression and sleep disturbances (Wells et al. 2005; Wongvatunyu & Porter 2005; Hanks et al. 2007; Jumisko et al. 2007; Yeates et al. 2007). However if family members share in success they may also share failure when rehabilitation goals are not met or expectations exceed reality. This perception of failure may then add to the already mounting pressure placed on what may already be a distressed family.

2.9 The relevance of the family to national policy

The importance of the family to those with complex and long-term conditions was emphasised in the National Service Framework for Long-Term Conditions (Department of Health (DH) 2005). Within the NSF Quality Recommendation 10 (QR10) outlines the government's strategy to support families and carers. Although QR10 initially identifies the need to support carers both in their role as a carer and also in their own right, it goes on to acknowledge that the whole family is affected by this injury. The authors then suggest that a 'whole-family approach' to managing TBI may be helpful (DH 2005, p55). In contrast to previous policy (DH 1999) and statutory acts of law (Carers Act 1995; 2004), which imply there is a carer and a cared for, the National Service Framework for Long-Term Conditions recognised that TBI, and other long-term conditions, affect more than just those identified as the primary carer.

The emphasis on families as well as carers can be seen in more recent publications including *High Quality Care for All: NHS Next Stage Review* (Darzi 2008), the National Carers' Strategy *Carers at the heart of 21st. century families and communities* (DH 2008), *Report of the Standing Commission on Carers* (DH 2009) and *Recognised, valued and supported: next steps for the Carers' Strategy* (DH 2010).

In Lord Darzi's review long-term conditions were identified as a priority and it was advocated that all those with a long-term condition should have a personalised care plan. These plans are dependent on partnership working between service users and the professionals who deliver

those services. The review went on to state that ‘personal care also considers the needs of the patient within the context of their support network, including carers, family and employers’ (Darzi 2008, p21). This statement identified the need to consider the family context of the person whose health care needs are of primary concern.

The national carers’ strategy put carers at the heart of families and was underpinned by a philosophy to recognise and value carers as ‘being fundamental to strong families and stable communities’ (DH 2008, p9). Through this and subsequent reports the relevance of caring within the family context, and wider support network was emphasised (DH 2008; 2009; 2010). Interestingly there seems an increasing responsibility on the carer to maintain the stability of the whole family and that may be why a ‘whole-family approach’ is once again recommended (DH 2010):

‘Personalisation can provide individuals, carers and families with more choice, more control and more flexibility in the way that care and support are provided. Personalisation and a whole-family approach are complementary – it is important to look at a family’s needs as a whole but also to make sure that individual carers’ and users’ views are sought and cultural expectations are clarified when considering how best to support a family. No assumptions should be made about a carer’s ability and willingness to care. A whole-family approach is particularly relevant where young carers and inter-generational carers are involved but service users and carers of all ages can benefit from an integrated and holistic approach to providing personalised care and support.’ (DH 2010, p19)

The focus of health and social care policy has therefore shifted from the focus on the primary carer to a more family-based approach. The individual family and social context needs to be considered to enable an agenda of personalised and person centred care. A whole family approach may be useful in practice but greater clarity regarding how it can be achieved is needed (Clark et al. 2009).

2.10 Working with families

One barrier to implementing a whole family approach may be the difficulty in defining who the family is. Defining the family is problematic and definitions are often restrictive. Families may find alignment with the traditional nuclear structure of two parents and their children, or more contemporary and extended arrangements. The quote below from Pratt and Fiese (2004) emphasises the complexity of family arrangements and the differences in the bonds formed by blood, marriage and friendship:

‘The relationships we have with kin are complex and variable, but they are also life-long and indeed enduring across generations; families are the places where these enduring bonds grow, develop, and are often tested. We may choose and then reject friends, our

associates, even our spouses, but the bonds of parents and children, or those of siblings, even if troubled, are not so voluntarily or easily discarded' (Pratt & Fiese 2004, p3)

When exploring the family literature for a useful definition there appeared two main areas of debate. The first considered the issue of defining family simply through its membership and the second considered defining family through its social interactions and responsibilities.

2.10.1 Family as membership

Since the 1960s the family has evolved almost beyond recognition and this change has been attributed to changing attitudes towards marriage, divorce, sexuality, cohabitation and childbearing (Featherstone 2004; Hunt 2009; Dallos & Draper 2010). These changes have led to a rise in one-parent families, same sex families, unmarried parents and families brought together after re-marriage. Roles within families have also developed, fewer men are expected to be the sole breadwinner and more domestic roles are now shared (Dallos & Draper 2010). The family as a concept has therefore changed enormously over the last 40-50 years and the family that consisted of two-parent families living in the same household being the norm has given way to a more contemporary and diverse picture of the family which is more inclusive of extended and non-traditional roles and relationships (Silva & Smart 1999).

A classical definition of the family is offered by Broderick (1993, p52) as 'people related by blood, marriage or adoption living under one roof'. However family membership is personal, diverse and often unique; therefore the nuclear view of the family is not always helpful. In the definition from Broderick (1993) the stipulation that family members must cohabit assumes those living outside of the family home are no longer able to affect, or be affected by, those who do live together. Therefore a more useful definition was that proposed by Shields et al. (2007) who developed the definition of family by Nixon (1988) to include significant others who do not usually cohabit with the family:

'The family is a basic social unit having at its nucleus two or more persons, irrespective of age, in which each of the following conditions are present:

- a) the members are related by blood, or marriage, or adoption, or by a contract which is either explicit or implied;
 - b) the members communicate with each other in terms of defined social roles such as mother, father, wife, husband, daughter, son, brother, sister, grandfather, uncle, aunt; and
 - c) they adopt or create and maintain common customs and traditions.'
- (Shields et al. 2007, p6)

This definition is more appropriate because it refers to the inclusion of persons who are related by an implied contract. Therefore those who are long-term partners but not legally married and those in non-traditional family roles such as guardians can be considered as integral parts of the family structure.

However, Wright and Leahey (2009) suggest that adopting a position of fixed family membership is limited because it imposes a conception of family that may not always be appropriate. By working with an individual's own perception of their family their perception of what relationships are significant can be honoured. The definition offered by Wright and Leahey (2009) was therefore that 'family is who they say they are' (p60). Adopting this definition in this study removed possible restricting definitions and enabled those who belonged to a family to identify their own membership.

2.10.2 Family as interactions and responsibility

Sociologists argue that the family should not be considered in simple terms of membership and roles such as parent, sibling, and child (Sclater 2000). Beyond membership are particular issues of importance that identify the defining characteristics of a person's family. The family as a relational entity emphasises that being a family is more about what is done than what simply is (Featherstone 2004). Family has therefore evolved to represent the meaning of connections that exist between people not simply blood or marital ties (Silva & Smart 1999). As such the significance of kinship, family function and changing roles should be explored to further understand how each individual family functions.

However given the unique structure, circumstances and life history of each family unit these interactions are increasingly complex to understand (Kao & Stuifbergen 2004). Therefore the literature frequently cites family systems theory as a means of understanding these dynamic processes:

'the family is defined not in terms of the individual members, but by the structural elements in the family system, which include positions, norms, roles, and the function and interaction of these elements' (Maitz 1991, p67)

The TBI literature has also advocated the use of family systems theory to enhance family orientated research (Gan & Schuller 2002; Verhaeghe et al. 2005; Gan et al. 2006).

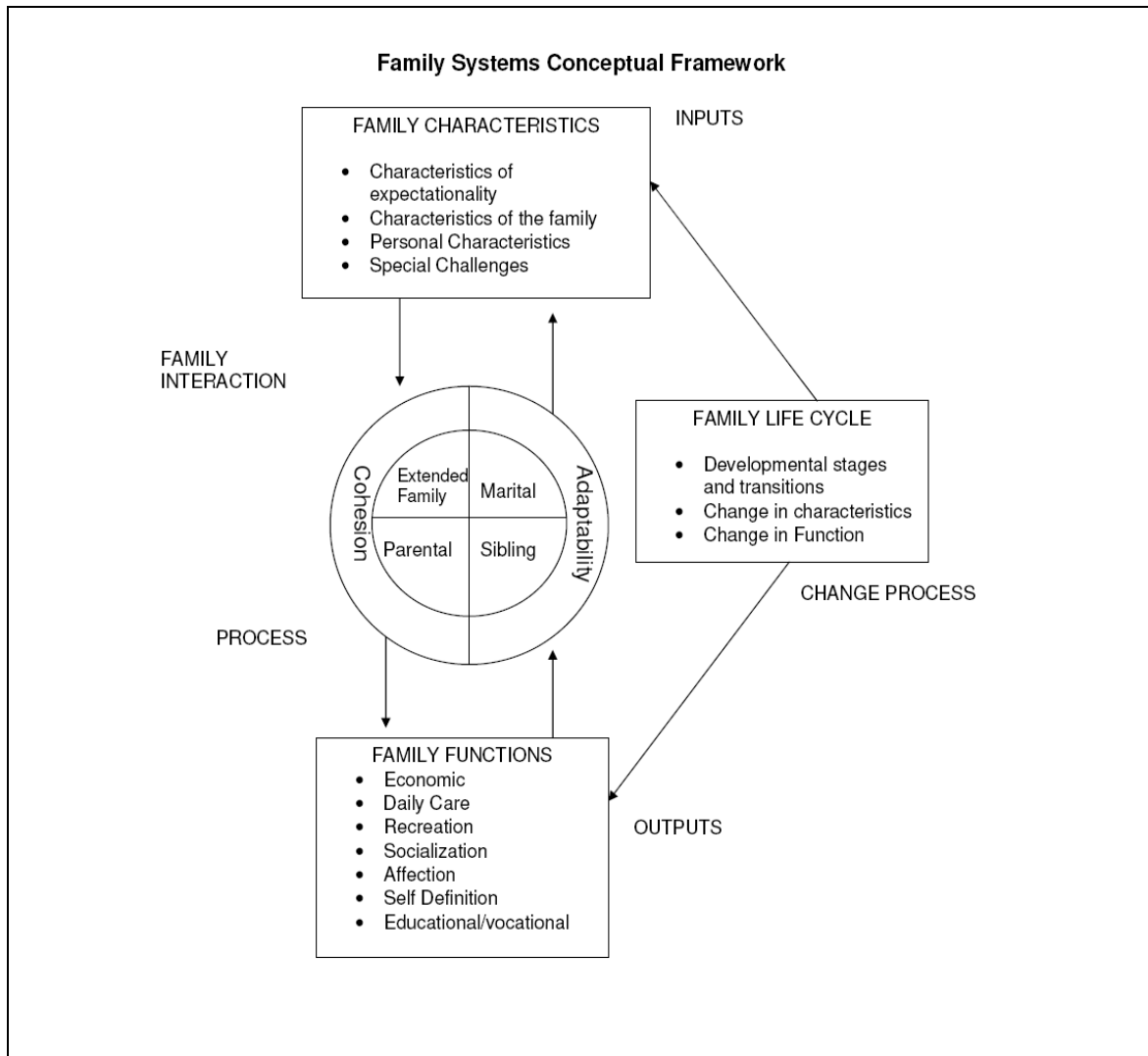


Figure 2.1 Family systems conceptual framework (Turnbull AP and Turnbull HR (1991) Understanding families from a systems perspective IN: Williams JM and Kay T (eds) *Head injury: a family matter*. Baltimore: Paul Brookes Publishing Company p39 Used by permission)

Family systems theory states that each part, or member, of a family is interrelated to the others who exist within the system (Walker & Akister 2004). Family members are therefore interdependent and mutually influence each other (Maitz & Sachs 1995). Family systems theory also illustrates how one part of the family cannot be understood in isolation from others. This understanding enables examination of how changes in one member cause changes to occur in other family members and how the system as a whole then responds to this change (Maitz & Sachs 1995; Walker & Akister 2004). The model of family systems adopted by Turnbull and Turnbull (1991) in the publication *Head Injury a Family Matter* places family members at the centre and starting from this point family characteristics, the family life cycle and family functions can be explored (Turnbull & Turnbull 1991, see Figure 2.1).

Leaf (1993) explains that there are four main components of family systems theory, and each is identifiable in Figure 2.1. Firstly, members are interrelated and interconnected in numerous

ways (seen in the centre of the model and includes the cohesion between members and the adaptability of these members to change). Secondly, the system is constantly developing and evolving and as such does not have a defined start or finish, but is shaped by key life events such as birth and marriage. Thirdly, when one member of the family changes their role and function all other components must change to accommodate this, however during such change there will often be a period of unrest and disruption. Finally the characteristics of the family give the system a unique identity that sets it apart from any other.

Therefore in this thesis the term 'family system' is frequently adopted and often used in place of simply referring to the family. The family as a system evokes a broader view of the family than mere membership and denotes a more complex and individual perspective that is continually evolving in function and purpose.

2.11 Chapter summary

The preceding discussion demonstrated that TBI has far reaching consequences for the whole family and not just the injured member. Following injury complex physical, cognitive, emotional and psychosocial impairments are common and these impairments have led to the perception that people often change following injury. In extreme cases family members see the injured person as fundamentally different. The family must therefore respond to these changes through adapting their role, structure and function in response to a family member with new needs. The family is a key part of working with patients following TBI and the National Service Framework for Long-Term Conditions advocated a whole family approach. This whole family can be defined through membership but it may be more useful to understand families through their individual context, interactions and relationships. The effects of injury extend far beyond the injured person reverberating outwards and into the lives of all the non-injured members. The family system must respond to all the changes and understanding these dynamic processes may help generate further insight into post-injury adjustment for all family members. Thus the metaphor of 'the ripple effect of TBI' is a useful way of conceptualising the movement that occurs in families as a result of this traumatic event.

3 An Examination of the Evidence Base

3.1 Introduction

If a ripple effect is a useful way to think about how head injury radiates through the family an in-depth literature review should further enhance an understanding of why this is the case. Chapter Three will consider the empirical evidence base for what it can illuminate about non-injured family members in the context of adult TBI. The aims of this literature review are to develop an in-depth understanding of the research literature that has investigated how the non-injured family members are affected by TBI and to identify areas of limited understanding in the evidence base to support the development of research questions. The process and product of systematic searching is detailed below to illustrate how relevant contemporary research was accessed and appraised to inform the debate. To facilitate understanding of the evidence base the literature review answers two primary questions. First, how does TBI affect individual family members? Second, how does TBI affect the wider family system?

3.2 Systematic search methods

A review of recent literature was undertaken to more fully understand how non-injured family members are affected by TBI. This topic area has been investigated from a range of professional and theoretical contexts and therefore both health and social care databases and psychological / sociological databases were accessed. Specifically the databases searched were: British Nursing Index (BNI), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Allied and Complementary Medicine Database (AMED), MEDLINE and PsychINFO. The main search terms aimed to bring together the terms 'Family' and 'Head Injury'. Related search terms were developed to further refine the search and were combined using the Boolean operators AND / OR. Due to the extensive number of hits obtained search terms were mapped to medical subject headings (MeSH), or equivalent, when appropriate to ensure relevancy of identified publications. Limits were applied to the search and included English language only and to source a breadth of contemporary material a publication restriction of ten years was set (Cronin et al. 2008). These limits were also pragmatic decisions and influenced by prior exploration of this extensive evidence base. Tight parameters helped to focus the search process and facilitated synthesis of literature to develop a critical discussion. However, it would be a mistake to completely ignore the contribution of older studies. Therefore where research is cited in this review which is beyond the date restriction it may be considered seminal work or important to the context of the debate. A complete Medline search can be found in Appendix 1.

To identify further research the reference lists of papers were reviewed. In addition a hand search of relevant journals was completed for the last five years. Specifically these journals were: *Brain Injury*, *Journal of Neurosciences Nursing*, *British Journal of Neurosciences Nursing* and *Head Trauma Rehabilitation*.

3.3 Search outcome

The search yielded a vast number of papers perhaps because of the broad search terms that were used. Although it would have been preferable to have achieved a more focused search with fewer citations it was important to review all possible studies for inclusion. Across the five databases over 2500 citations were reviewed for relevance. Therefore transparent decisions about inclusion/exclusion criteria had to be made so that the review was not biased toward the inclusion or exclusion of particular studies (see Table 3.1).

3.3.1 Inclusion criteria

The paper had to have a primary aim of investigating the effects of adult TBI on the non-injured members of a family. Family members included all kin and those identified as carers. Studies to investigate specific outcomes such as burden, stress and coping were included in addition to studies examining broader constructs such as quality of life and the lived experience. Research populations most commonly separate traumatic brain injury from non-traumatic brain injury. Those with non-traumatic injuries include people with strokes, tumours and infections. However, some studies will recruit participants with Acquired Brain Injury (ABI) that includes a mix of both subclasses. A decision was made to exclude studies that only examined non-traumatic injuries because of the differences in aetiology and patient demographics. However if the study recruited ABI participants that included those with TBI the study was included. No restrictions based on severity of injury, research design or country of origin, were made.

3.3.2 Exclusion criteria

Reviewing the citations it was immediately obvious that there were results that were not relevant to the aims of this review and were excluded. Papers included animal studies, in-vitro studies, brain stem death, organ donation and new innovations in the medical/surgical management of head injury. However other literature was not as straightforward and required careful consideration of the impact that removing these papers would have on the overall depth of understanding achieved in this review.

There was a great deal of literature that examined incidence, prognosis or outcome data. Two types of study dealt with these questions. The first examined these data in isolation, establishing the epidemiological perspective of head injury. The second examined the associations between these patient variables and family outcomes/family functioning. The former were excluded because they revealed little about the effects of TBI on the non-injured members. However the latter were included for what they could illuminate about the wider family implications of head injury.

There is a body of literature pertaining to the child with head injury. However paediatric head injury is different from adult. Although head injury remains a devastating and life-threatening injury, children often have better outcomes than adults, recovering quicker with fewer long-term deficits. In addition, children are treated in environments that advocate family-centred care and thus the experience of care may be different. Children live at home and are mostly dependent on their parents before injury, adults are usually not. For these reasons it was decided to exclude the literature that examined paediatric head injury.

The last decision about exclusion criteria was the most difficult and referred to family intervention studies. These studies may be useful in terms of further illuminating family functioning and family needs. However when reviewed as part of earlier work it was not felt that these papers offered further insight into how the non-injured family members were affected by TBI and were therefore excluded from the review.

Inclusion	Exclusion
Carer/ Non-injured family member All kinship All severities of injury Mixed ABI studies if recruited TBI also Burden, stress, coping, adaptation, life satisfaction, quality of life, needs All countries	Incidence, prognosis, Patient outcome, interventions, medical surgical management, Family intervention studies Paediatric / childhood studies Organ donation Validation studies

Table 3.1 Inclusion exclusion criteria

Following this process a total of 91 papers were selected. The search process is summarised in Figure 3.1.

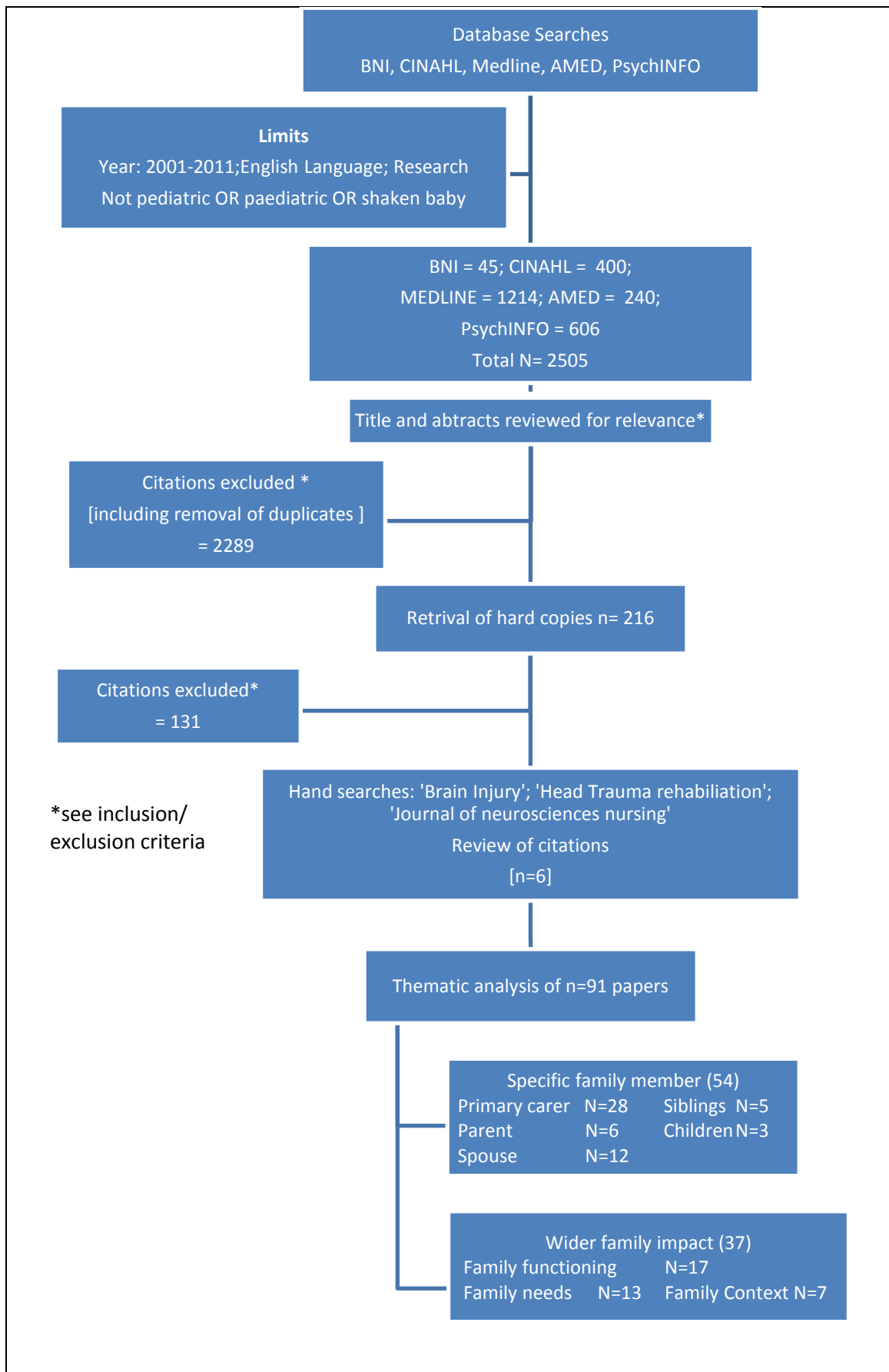


Figure 3.1 Systematic search process

3.4 Quality appraisal

If all the literature obtained in this review utilised a single methodology a standardised appraisal could be completed to assess the quality of each study. However when a more diverse evidence base is appraised this process is less clear and there is little consensus as to what standardised measures of quality should be used. Therefore a pragmatic approach was taken to the judgement of quality of the literature based on the three core issues of critical appraisal: 1) validity and rigour of methods employed, appropriate to the specific methodology; 2) what the study found and the strength of these findings; 3) applicability and relevance to the research question (Melnik 2003; Krainovich-Miller et al. 2009). If there were clear concerns about the quality of a study it was excluded prior to the synthesis process. For the remaining literature, quality and applicability were assessed and detailed comments added to a research matrix of selected studies. Although these comments have not been reproduced in this thesis relevant issues are discussed within the synthesis presented below.

3.5 Data extraction and synthesis

Each of the 91 papers identified in this review were read and logged into summary tables. This table required information pertaining to: purpose, design, data collection, sample, and key findings (this table can be found in Appendix 2, Tables 1-8). Through tabulating the papers trends and patterns within this large body of literature were identified. During this process it was evident that studies could be categorised into one of two main themes. Congruent with the observations of Schönberger et al. (2010), either the study aimed to investigate how TBI affected the specific individual family member (54 papers) or the study aimed to examine broader outcomes that were relevant to the family rather than a single member (37 papers). In addition to these 91 papers, a further 18 citations were added to a table entitled 'other selected literature' (Appendix 2, Table 9). These additional citations were studies included in the discussion of the evidence base that fell outside of the date restrictions imposed.

It is important to clarify that due to the number of publications identified in this review it was not possible to examine all the studies in-depth within this chapter. However, those papers that make the most significant contribution to the evidence base are explored in further detail where appropriate.

3.6 How does TBI affect individual family members?

To understand the ripple effect of head injury it was a logical decision to first examine the literature that had investigated the impact of TBI on individual family members. The literature

represents perspectives from all family members and included spouses, parents, children and siblings. However the predominant perspective was that of family members who consider themselves to be a primary carer to the injured person. Therefore this section of the literature review first considers the primary carer and how their life is affected post-head injury. The review continues with the specific perspective of parents and then spouses because these are the family members who most frequently provide the most amount of care post-injury. Section 3.6 finishes by examining the effect of head injury on other family members including siblings and children.

3.6.1 Primary carers

Carers have been singled out for special attention within the TBI literature under the premise that those within the family who assume the role of the primary caregiver are at most risk. A picture has been painted within the literature that depicts the carer as burdened by the care needs of the person with TBI. Subsequently it has been argued that these carers are at risk of negative psychological symptoms such as depression, anxiety and stress (Livingston et al. 1985; Brooks et al. 1986; Brooks et al. 1987; Kreutzer et al. 1994). In more recent literature reviews these outcomes continue to be identified as important considerations in the lives of carers post-TBI (Blake 2008; Schönberger et al. 2010).

The familiar demographics of head injury heavily influence the characteristics of those who support their care needs. As discussed in Chapter Two the common picture of TBI shows how young men are at most risk. These young men may not have developed significant relationships so that the responsibility for their care usually falls on parents (most commonly mothers). Where a person has entered into a pre-injury relationship the non-injured spouse usually becomes the primary carer. With more men than women sustaining injury this spousal carer is usually the wife (Sinnakaruppan & Williams 2001). The TBI literature reflects this trend with parental carers frequently outnumbering spousal carers in study populations. Demographics of these groups of carers are similar across ethnic groups. However, Hart et al. (2007) and Sander et al. (2007) identified that African-American and Hispanic groups were more likely to be caring for extended family members than groups of white carers.

Studies that investigate carer outcome most commonly recruit mixed samples of people caring for adults with TBI. Anderson et al. (2009) criticise this literature for treating carers as one homogenous group. Within this literature the carer is often poorly defined and studies range from carers who provide a large amount of affective or instrumental support each day to studies where the adult with TBI is living in a long-term care facility. With such poor distinction

between groups of carers the impact that TBI makes to their lives may be incorrectly estimated.

The significance of kinship in carer populations has been examined to identify if outcomes differ by family role. The most common comparison is that of parent to spouse. Early studies by Mauss-Clum and Ryan (1981) and Brooks et al. (1986) concluded that parents commonly cope with the TBI of a child with relatively more ease and less reported stress than a spouse. To test this hypothesis Perlesz et al. (2000) compared data from 19 wives to 37 mothers. Mood states assessed with the Profile of Mood States (McNair et al. 1971) showed wives had higher scores for anger than mothers ($p < 0.05$). Family satisfaction was measured with the Family Satisfaction Scale (Olson 1995) and scores were lower for wives than mothers ($p < 0.04$). Conclusions drawn from this study included that mothers may be more resigned to their situation because they do not have the option of divorce. On the other hand a spouse may have lost a supportive partnership leading to a greater sense of burden that may account for the higher levels of psychological distress (Perlesz et al. 2000).

More recently, Anderson et al. (2009) recruited 64 spouses and 58 parents and measured types of stressor with the Family Assessment Device (Epstein et al. 1983) and the Brief Symptom Inventory (Derogatis 1993) and found that both groups reported high levels of distress. However there were differences in the variables that caused this psychological distress. The presence of cognitive impairments in the injured person was more likely to increase psychological distress in groups of parents. For spouses, cognitive and behavioural impairments did not have a direct effect on distress. However these impairments did have an indirect effect on family functioning that in turn caused increased psychological distress. In addition social impairment increased distress only in spousal carers. Anderson et al. (2009) postulated that the direct association between cognitive impairment and psychological distress in parents may be because parents are more concerned about the injured person's future care needs. It was also suggested that in families with two parents the effect of behaviour on family functioning may be moderated by the presence of another non-injured adult. However, it may be less useful to consider carers' outcomes in terms of who is at greater risk and instead think about what makes that carer at risk and what facilitates their post-injury adjustment.

3.6.1.1 Psychological symptoms

The post-TBI carer literature has tended to focus on two main groups of outcomes. The first are levels of self-reported psychological symptoms and the second are outcomes related to life

satisfaction and social support. Historically the former have dominated the evidence base and such studies have investigated levels of self-reported depression and how these data compare to population norms. Results frequently reveal that carers in TBI populations report higher levels than would be expected in normative groups. Carers are often identified as either 'at risk for depression' or exhibiting symptoms of depression. Either way this makes carers a vulnerable population.

Perlesz et al. (2000), Harris et al. (2001), Riley (2007) and Rivera et al. (2007) each aimed to assess levels of depression within their samples. Harris et al. (2001) and Riley (2007) both used the Zung's Self-Rating Depression Scale (Zung 1965) in cross-sectional self-report postal surveys. Harris et al. (2001) identified that 49 out of 58 (84%) carers had scores indicative of higher rates of depression than the general population. Furthermore 23% of their sample had clinically significant levels of depression. Riley (2007) recruited 40 carers at least 12 months post-TBI and found the mean score for the whole sample was above population norms and that all but seven carers scored above the cut-off for mild depression. Rivera et al. (2007) used the Centre for Epidemiological Studies-Depression (CES-D) scale (Radloff 1977) and found 29 out of 60 caregivers (48.3%) had scores that met the criteria for being 'at risk' for depression. Perlesz et al. (2000) identified that, depending on the measure used (Beck Depression Inventory (Beck 1996), State Trait Anxiety Measure (Spielberger et al. 1983) and the Profile of Mood States (McNair et al. 1971), between 35% and 49% of primary carers displayed a level of psychological distress that would require clinical intervention.

However, the research literature frequently ignores the relevance of understanding pre-injury characteristics and context. There is a tendency to view head injury in a vacuum devoid of contextual information that may contribute to developing symptoms of depression, stress and anxiety. Therefore, Davis et al. (2009) specifically considered the relation of pre-existing characteristics to perceived burden and emotional distress. Unsurprisingly those who had a significant medical illness or had been treated for psychiatric illness reported higher levels of distress. The study illustrated the importance of pre-injury characteristics that are sometimes neglected in practice and research.

To understand further why it is that TBI carers report such high levels of negative symptoms studies have examined what impact patient outcome has on the carer. Most studies reviewed have found gender, age and educational level not to be significantly correlated with carer outcomes. However a variable that reliably predicts carer outcome is the presence of cognitive and neurobehavioural sequelae in the injured adult post-TBI (Perlesz et al. 2000;

Connolly & O'Dowd 2001; Harris et al. 2001; Ponsford et al. 2003; Wells et al. 2005; Blake 2008; Jackson et al. 2009). In a study by Connolly and O'Dowd (2001) the association between disability and stress following head injury was examined. In a sample of 70 caregivers at least one year post-injury behavioural disability had the strongest association with stress as measured by the Perceived Stress Scale (Cohen et al. 1983) ($p < 0.001$). Furthermore in a UK study Ponsford et al. (2003) recruited 143 carers at follow up clinics at two, three or five years post-injury and despite the longer time since injury cognitive, neurobehavioural and emotional changes were still the strongest predictors of carer anxiety ($p < 0.001$). These studies tell us that it is not the physical demands of caring but trying to live around changes in behaviour, cognition and personality that generate the greatest sense of burden.

3.6.1.2 Satisfaction with life and social support

Studies measuring the presence or absence of psychological symptoms have tended to be one-dimensional in that they only allow participants to report the negative outcomes of the caregiving experience. Although it is important to establish the presence of depression, stress and anxiety in these groups when studies include the opportunity for positive assessments, a high number have reported positive appraisals of their situation (Wells et al. 2005). In a study of long-term outcome Wells et al. (2005) recruited 72 pairs of adult TBI survivors and their carers (time since injury 1-40 years). Although stress and depression were common amongst this group of carers Wells et al. (2005) found that their population of carers endorsed more positive caregiving feelings than negative ($p < 0.001$). In addition Machamer et al. (2002) found 93% of 180 significant others felt happy to have had the opportunity to care for the person with brain injury. Therefore, although it is important to remember that carers are at risk from suffering from the burden of caring for a relative with head injury there are also positive appraisals of life post-injury that suggest caring can be a fulfilling and meaningful part of life.

A number of studies have considered quality of life and/or life satisfaction often through the use of specific outcome measures such as the WHO Quality of Life Scale developed by the WHOQOL-Group (1998) and used by Chronister and Chan (2006); Jackson et al. (2009) and Chronister et al. (2010). Alternatively studies have used the Satisfaction with Living Scale (Diener et al. 1985). Examples included: Ergh et al. (2003); Wells et al. (2005); Hart et al. (2007) and Livingston et al. (2010). These studies have tried to establish if life satisfaction scores are lower when caring for people with head injury when compared to other groups of carers, and what variables mediate or moderate their life satisfaction scores.

Jackson et al. (2009) examined quality of life in a mixed sample of people providing care to those with ABI (N=222) and compared self-reports with those looking after dementia patients (N=132). Jackson et al. (2009) reported that negative carer reactions were greater in the ABI group and quality of life assessments were both worse overall ($p=0.001$) and in all domains of the WHO Quality of Life Scale. Conclusions drawn included that those with ABI are at greater risk of lower quality of life post-injury than those caring for people with dementia. However these results may have been affected by the significant differences in age, gender and co-habitation between the two groups. The carers of persons with TBI were significantly younger and the proportion of male to female carers was less. In addition 23% of those in the dementia group were living in residential care. Therefore it is possible that quality of life for these relatives was higher because the person with dementia's long-term care needs were already being met.

The variable thought to most commonly moderate the effects of TBI caregiving is the use and availability of support from both within the family and within the carer's social network (Ergh et al. 2002; Ergh et al. 2003; Lefebvre et al. 2008a; Chronister et al. 2010). Ergh et al. (2002; 2003) completed structured interviews with 60 pairs of adults with TBI and their carer. Injuries were either moderate or severe and sustained four months to nine years previously. In this cross-sectional study levels of social support were grouped into low, moderate and high. Ergh et al. (2002) identified that social support moderated psychological distress and those in the low support group also had significantly poorer adjustment than did the moderate and high groups. The low social support group was also found to have significantly poorer life satisfaction than moderate or high groups ($p<0.01$) (Ergh et al. 2003). Findings were supported in a more recent study by Chronister et al. (2010) who also found those carers who accessed emotional support and tangible support were found to have the strongest associations with quality of life as measured by the WHO Quality of Life Scale ($p<0.001$).

Given that social support and social integration are clearly important following TBI Lefebvre et al. (2008a) examined determinants of long-term social integration and the impact on carers. In one of the few qualitative studies in this area data were collected using separate semi-structured interviews with 22 TBI patients and 21 caregivers (mean time since injury 12.8 years). Findings of a content analysis showed that of the persons with TBI only 45.5% were satisfied with their level of integration with the other 54.5% either ambivalent or dissatisfied. A key facilitator of their social integration was the input from the carer and the family. However this input took a great deal of resources and one third of carers reported that the needs of the injured person had impacted on their ability to continue their main occupation.

Devoting time to the injured person also decreased the carer's wider social circle with the presence of TBI sequelae creating significant barriers to social integration. Therefore although the injured person needs the carer to facilitate their social integration the time and effort this takes may substantially affect the carers own use of social networks.

Primary carers of adults with TBI are considered a vulnerable group that suffer from higher rates of depression than would be expected in general population norms. However it is not the physical demands of caring that pose the greatest threat to carer quality of life but the behavioural sequelae that frequently accompany TBI. Despite this, many carers report positive aspects of caring and the use of social support networks has been identified as moderating the negative effects of caregiving in this population.

3.6.2 Parents

It was argued earlier that of the parents who provide care it is usually the mother that takes on the carer role. This may account for why the literature to explore the parental perspective is dominated by the maternal view (Kao & Stuifbergen 2004; Wongvatunyu & Porter 2005; Wongvatunyu & Porter 2008a; 2008b; Fumiyo et al. 2009). The exception to this was a study by Minnes et al. (2010) who recruited a mixed sample but were unable to explore any specific differences because only 5 of the 47 parents recruited were men. Therefore although fathers have been included in mixed samples of caregivers there is little literature that considers their specific perspective alone.

Assumptions borne out of the carer literature were challenged within the parental studies. First was that parents, more specifically mothers, perceive the caring role as a more natural one for them to undertake and as such are at less risk (Perlesz et al. 2000). Kao and Stuifbergen (2004) used a descriptive phenomenological approach to describe the meaning of the relationship between 12 young adult TBI survivors and their mothers. Participants were asked about their experience during separate semi-structured interviews lasting between two and four hours. Findings suggested that mothers perceived their role as an integral element of their adult child's recovery and would often take on the role of supporting specific rehabilitation needs such as re-training and re-learning after injury. However, as a result mothers reported that they struggled with feeling over-protective towards their child. In addition, Kao and Stuifbergen (2004) suggested that mothers were more reluctant to express their feelings because they felt the continued need to be strong for the family. Their conclusion was that mothers suffer from the load of caregiving and may actually be at greater risk because they are not always able to express their needs. This important finding reminds

us that 'less risk' does not mean 'no risk' and that mothers may feel additional pressure related to the demands of the whole family not just in response to the injured person.

The second assumption challenged in the parental literature was that family members feel burdened by the need to support the person with head injury (Nabors et al. 2002).

Wongvatunyu and Porter (2008a) stated this view was not supported in their study because irrespective of caregiving duration no mother spoke of being burdened by their role. However if mothers did not feel burdened by their responsibilities this may be a moderating factor in developing negative psychological symptoms and as such support the first assumption that parents are at less risk.

The study by Wongvatunyu and Porter (2005, 2008a, 2008b) recruited seven adult children (aged 20-36) with mild-severe TBIs ranging between eight months and 20 years post-injury. Three interviews with each participant were conducted over two months to explore their lived experience. The findings suggested that mothers took a central role in developing the family post-injury. Mothers reported that they felt a need to re-invent family life and construct a new normalcy in order that the family may move forward following TBI (Wongvatunyu & Porter 2005). Instead of the family trying to return to a pre-injury way of life the mother tried to find a new equilibrium in the wake of the changes that TBI imposed on the family system.

These studies emphasise that non-injured parents, specifically the mother, have additional concerns that relate to the wider family system. Additional pressure is mounted on this core member who may see their role as an integral part of both the injured person's recovery and the survival of the family.

3.6.3 Spouses

A spousal relationship is commonly at the centre of a family. Where a family has been supported by two spouses and one sustains a head injury, the other must assume sole responsibility (Zeigler 1999). Often the relationship is put under strain as a result of meeting these new responsibilities in addition to negotiating the physical and/or cognitive deficits the injured person may have post-injury. Behaviours such as irritability, diminished self-control, fluctuations in mood and disinhibition (Iggulden 2006) serve to increase the pressure felt by the non-injured spouse. In addition Zeigler (1999) suggested that these behaviours may be worse when the spouses are together and less evident in the company of others.

Oddy and Herbert (2003) identified that because of this lack of insight from other people a great deal of tension can exist within families and especially between the spouse and the

injured person's parents. It is suggested that because parents usually live outside of the marital home they may have a distorted perception of the deficits or impairments of their adult child. Parents can then add more pressure on the spouse by not fully appreciating how challenging it is to live with their injured son or daughter.

In the long-term if the strain is unmanageable spouses may separate or divorce and the family breaks apart as a consequence. Therefore within the literature head injury is habitually referred to as a factor that threatens marital and family stability (Gosling & Oddy 1999). Early studies by Panting and Merry (1972), Tate et al. (1989), Mauss-Clum and Ryan (1981) and Oddy et al. (1985) established high rates of divorce and separation within the TBI population. Within their study populations divorce or separation rates were reported as ranging between 40 to 55%. In addition a study of late outcome in very severe head trauma, of nine patients who were married two and a half years post-injury seven had divorced by the 10-15 year follow-up (Thomsen 1984). However, it has been subsequently argued that these earlier studies suffered from small sample sizes and cross-sectional designs and may have overestimated the separation rates in this population (Arango-Lasprilla et al. 2008).

Therefore Kreutzer et al. (2007) and Arango-Lasprilla et al. (2008) both conducted cohort studies to examine the rates of separation and divorce following TBI. Kreutzer and colleagues followed 120 consecutive admissions for mild, moderate and severe TBI completing a follow up 2.5 – 8 years post-injury. In this sample 17% were divorced and 8% were separated. Similarly, Arango-Lasprilla et al. (2008) followed 977 TBI couples with mild to severe injuries during the first two years following injury and recorded a slightly lower combined rate of divorce and separation of 15%. These more recent studies have identified more modest and optimistic rates of marital stability post-TBI but are still limited by the lack of a control or comparative sample.

In an effort to understand the factors that contribute to marital stability several studies have explored characteristics of the spouses and their relationships. Of particular interest have been the age of the couple and the longevity of the marital relationship (Wood & Yurdakul 1997). Kreutzer et al. (2007) indicated that both age at injury and length of relationship were significantly related to relationship status (both variables $p < 0.001$). Similarly, Arango-Lasprilla et al. (2008) calculated the odds of being unstably married were 4.03 times greater for a patient in the 25% quartile (aged 36.2 years) when compared to the 75% quartile (aged 57.3 years). Interpretation of the findings indicates that older couples and those in longer relationships were less likely to divorce or separate following TBI. However the relationship

between age and marital status is not universally identified as a protective factor. For example in a smaller study of 48 partners of adults with severe TBI Wood et al. (2005) found the only predictive factor of marital instability was the presence of mood swings.

To further examine the influence of age on relationship durability Layman et al. (2005) used a qualitative design with a mixed group of eight TBI patients, seven partners and a non-injured control group for comparison. Content analysis was applied to semi-structured interviews that were either completed over the phone or face-to-face. Interviews ranged between 37-78 minutes in which 14 questions were asked. Arguably the time allocated per question may have led to some superficial responses. However, despite this, the study revealed that many of the relationship changes evident post-injury were attributed to ageing and age-related issues rather than as a direct result of the TBI. In addition, older individuals were more likely to demonstrate persistence in their relationships emphasising the increased connection between those who had been together longer. These findings suggest that the individual context of the relationship, for example, the maturity and life history of the couple may be important in predicting long-term family and relationship stability.

It has been argued that simply examining marital stability, though clearly important, is a limited perspective because marital stability does not consider marital quality or cohesion (Johnson et al. 2010; Godwin et al. 2011). Conclusions are especially difficult to draw when samples are not compared to normative groups and therefore the number of marriages that were likely to have failed without the presence of head injury is unknown. Therefore, researchers have turned their attention to broader constructs that may reveal more understanding of marital relationships post-TBI. Specifically Katz et al. (2005) considered coping mechanisms and burden, Eriksson et al. (2005) and Burrridge et al. (2007) examined relationship satisfaction, Blais and Boisvert (2007) and Hammond et al. (2011) examined marital quality and two papers investigated specific aspects of marital quality: communication (Bracy & Douglas 2005), and sexual relations and intimacy (Gill et al. 2011).

Eriksson et al. (2005) and Burrridge et al. (2007) both conducted investigations to examine relationship satisfaction in mixed samples of those sustaining ABI. Eriksson et al. (2005) recruited 55 couples where a partner had experienced an ABI one to five years prior (only 18% had a TBI). Using a questionnaire developed specifically for the study data pertaining to perceived impairments, limitations and life satisfaction were collected. Although aspects of several other validated measures were used to construct the questionnaire little testing of the instrument's validity and reliability was reported. Both partners were recruited to the study

and classified by Eriksson et al. (2005) as happy, discordant or not happy. In only 16 couples both ABI survivor and spouse were satisfied with life as a whole. Similarly, Burrridge et al. (2007) also found their ABI participants were less satisfied with life than healthy volunteers (partners $p=0.006$, patients $p=0.002$). However, while these studies by Eriksson et al. (2005) and Burrridge et al. (2007) show the most obvious correlation is that relationship satisfaction reduces following TBI little further insight into marital quality or different perspectives were offered in these studies.

Therefore Blais and Boisvert (2007) considered what characteristics of each partner favoured adjustment and marital satisfaction. A cross-sectional self-report survey was administered to 70 TBI couples and 70 controls (both spouses were recruited). The control group enabled Blais and Boisvert (2007) to consider results that appeared specific to the TBI population. Across both groups characteristics that predicted adjustment included positive attitude towards problems, infrequent use of avoidance, and perception of positive communication skills. However, findings showed that TBI couples had fewer of these characteristics than the control group. Blais and Boisvert (2007) concluded that these characteristics were important in psychological and marital adjustment and if TBI couples lack these they may be at greater risk of marital difficulties post-injury.

In contrast a few small in-depth qualitative studies have provided further insight into what may contribute to dissatisfaction in spousal relationships (Chwalisz & Stark-Wroblewski 1996; Gosling & Oddy 1999; Gill et al. 2011; Hammond et al. 2011). These studies illustrated the differences in relationships post-injury whereby equal partnership is lost and non-injured spouses can feel parental towards the injured person because they are required to care for them. Subsequently sex could feel ethically/morally wrong and following TBI relationships were often reported as no longer equal, sharing or providing companionship (Gosling & Oddy 1999).

Chwalisz and Stark-Wroblewski (1996) conducted a qualitative analysis of subjective loss post-head injury with 27 spouses and reported comments such as 'it is like being married to a man who looks like him and has some of his characteristics but is no longer him' (p32) and 'I am still confused, however, as to who is this man I live with, and where is the other one, I unconsciously wait for him to return' (p33). Losses were numerous and included occupational losses, intellectual losses and loss of affection. This study also highlighted the difference between those spouses who knew the injured person before the injury and those who had developed a relationship post-injury and reported that some carers felt thankful they did not

know their spouse prior to injury because before and after comparisons were not so easily made.

In a UK study, Gosling and Oddy (1999) used a mixed methodology approach to explore relationship satisfaction in 18 non-injured wives. These spouses reported their current marital relationship was significantly worse than before injury ($p < 0.001$). Although a small sample size the semi-structured interviews that were included in the study revealed that ten women responded affirmatively that their partner had 'felt like a stranger' since the injury. This study echoed the earlier observations that suggested a wife may feel married, but without a husband (Lezak 1978; Mauss-Clum & Ryan 1981).

More recently Gill et al. (2011) used a grounded theory approach to explore the experience of intimacy from the viewpoint of persons with TBI and their partners. In contrast to the study by Gosling and Oddy (1999) both partners were recruited. Eighteen couples were interviewed separately and findings revealed that although there was some overlap in the issues raised there was a noticeable difference in their perspectives of barriers to sexual relations and intimacy. Both participants talked about change post-injury; however wives expressed more views that sex felt wrong. In addition wives were more likely to feel parental towards their injured husband. However, more similar views were expressed between groups when talking about how relationships managed to remain strong over time. Reasons for relationships to be enhanced included unconditional commitment to each other and bonding through surviving the experience together. There were additional positive aspects identified in this study and some reported that their sexual relationship had improved. However, the more diverse views expressed in this study may be attributable to the fact that five couples began their relationship after the TBI was sustained and therefore may not be directly comparable to studies that compare pre- and post-injury change.

To further enhance understanding of the views of non-injured wives and husbands Hammond et al. (2011) examined how TBI affected marital relationships by conducting two gender specific focus groups with 10 spouses. To be eligible participants had to be married to a person with TBI sustained at least four years prior to recruitment. Importantly by separating wives from husbands a clear difference was identified between the two groups. Using a grounded theory approach to analysing the transcripts it was concluded that women stayed married through hope of the injured spouse returning to their pre-injury state, women spoke of needing time away as a coping mechanism and were less able to recall happy memories. In contrast men spoke of love in the present tense and used spending more time together as a

copied mechanism. Men were less blaming than women and in support of the findings of Gill et al. (2011) women used mother child comparisons more frequently. Hammond et al. (2011) concluded that these dynamics and the way change was perceived may have an influence on whether the family 'pulls together' or 'pulls apart' post-TBI.

Spouses have been singled out in the TBI literature and post-injury relationships given close consideration. Although recent studies have been more optimistic about divorce and separation rates in this population, TBI continues to be referred to as a threat to marital stability. However, marital stability does not adequately reflect the impact of TBI on couples and marital quality is increasingly recognised as a more informative outcome post-TBI.

3.6.4 Siblings

Although a clear priority has been given in the literature to parents and spouses several studies have been conducted to emphasise that the repercussions of head injury reverberate far beyond those people who might immediately assume the role of primary carer. Sibling bonds are important to individuals and families as these relationships are frequently the longest a person will ever have (Degeneffe & Lynch 2006). In addition the long-term nature of TBI means that siblings often take over caregiving responsibilities once parents can no longer manage or have passed away (Orsillo et al. 1993). Although the sibling literature is quite sparse a number of studies have identified this population also has high levels of psychological distress and depression (Orsillo et al. 1993; Degeneffe & Lynch 2006). In addition studies have shown how non-injured siblings perceive their own life to be significantly affected by head injury (Gill & Wells 2000; Degeneffe & Olney 2010).

Orsillo et al. (1993) measured the stress and coping skills of 13 non-injured siblings. This small study concluded that 83% of the sample reported significantly higher levels of psychological distress than a normative group. Although a small study findings were supported by the later work of Degeneffe and Lynch (2006) and Degeneffe and Burcham (2008) who found although siblings were more likely to provide affective rather than instrumental support following TBI siblings still reported higher rates of depression than would be expected of the general population despite few actually living with the sibling at the time of the study. Results showed nearly 39% of the 233 siblings recruited had a score indicative of clinically significant depression compared to a general sample that would usually have only 21% reach this level (Degeneffe & Lynch 2006). Data from 170 siblings showed an inverse relationship between the level of depression reported and the perceived availability of support ($p < 0.001$) (Degeneffe &

Lynch 2006). These data suggested an association between the support provided by friends and family, and a reduction in feelings of depression.

Qualitative studies provide further insight into why these siblings may have reported psychological distress and symptoms of depression (Gill & Wells 2000; Degeneffe & Olney 2008; Degeneffe & Lee 2010; Degeneffe & Olney 2010). Gill and Wells (2000) examined the experience of eight siblings aged 14 – 30 who lived with a brother or sister who sustained a TBI at least one year prior to the study. Siblings described their life as different since the injury but were unable to describe it in terms of being better or worse. Feeling different was brought about by changes in the injured sibling such as their physical appearance, physical ability and personal habits. However the changes in cognition, behaviour and interpersonal skills were reported as having most effect on the non-injured siblings' relationship with their brother or sister. In addition to the changes they perceived in their sibling they also spoke about how they perceived their own lives had changed with their own futures perceived differently than they had before. Degeneffe and Olney (2010) concluded that the impact of TBI on the life of the non-injured sibling was significant and presented data that illustrated how the whole family had been required to respond to the needs of the injured person often taking parental attention away from the non-injured sibling. Some families were depicted as breaking apart whereas others were portrayed as pulling together and higher meaning had been interpreted from the event whereby life had a greater sense of purpose post-injury. Degeneffe and Olney (2010) also stated that nearly all respondents had felt the event had changed them in some way, for better or worse, reinforcing the earlier findings of Gill and Wells (2000).

Despite many siblings not living with their injured sibling or being directly involved in the provision of care these studies suggest siblings can be profoundly affected. Siblings were concerned by changes in their personal relationship with the injured person, the altered function and structure of the family and on-going concerns about long-term responsibilities.

3.6.5 Children

Over 20 years ago it was noted that in comparison to research into children with parents who had psychiatric disorders there was limited literature regarding children of head injured parents (Urbach 1989). Unfortunately in subsequent years there remains a dearth of literature in this area. Yet despite this severe lack of empirical evidence it is well accepted that following parental TBI children can be profoundly affected (Uysal et al. 1998; Butera-Prinzi & Perlesz 2004; Harris & Stuart 2006; Kieffer-Kristensen et al. 2011).

An early investigation by Pessar et al. (1993) recruited parents instead of children to survey their perception of how the injury had affected their child. In this study by Pessar et al. (1993) 24 non-injured parents reported that children frequently displayed challenging behaviours such as increased 'acting out' and increased emotional and/or relationship difficulties following a parental TBI. However, these findings were not supported in a later study by Uysal et al. (1998). Sixteen family groups were recruited that included a mix of the parent with TBI, their spouse and their children. An additional sixteen family groups were recruited where there was no disability to act as a control. The findings showed no significant difference in behavioural problems between either group. Uysal et al. (1998) questioned if this conflicting finding could be explained by the longer time since injury in their study that ranged from 2-39 years whereby children may have had more opportunity to adjust. Despite not finding difference in the levels of behavioural problems Uysal et al. (1998) did identify significantly higher rates of self-reported depression in the children that had a parent with TBI.

In more recent literature, two papers used an exploratory design to investigate the experiences of children from their own perspective (Butera-Prinzi & Perlesz 2004; Harris & Stuart 2006). Each study recruited four children to complete one qualitative interview. Butera-Prinzi and Perlesz (2004) recruited children in Australia aged between seven and twelve years while Harris and Stuart (2006) recruited adolescents in South Africa between 17 and 19 years of age. Both studies identified the disruptive behaviours, previously identified by Pessar et al. (1993), such as inappropriate expression of anger towards their father. However they also explored the complexity of coexisting emotions such as anger and disappointment, embarrassment, love, resentment, sadness and ambivalence (Butera-Prinzi & Perlesz 2004). Children were found to be worried and anxious about the future of their family, they feared family disintegration and expressed concern for their mother's suffering. Loss and grief were also present with past images of their father held in high regard and juxtaposed how they perceived their father post-injury (Butera-Prinzi & Perlesz 2004).

Butera-Prinzi and Perlesz (2004) stated children had all taken some positive outcomes from the experience and all children said they felt differently about their future (Harris & Stuart 2006). Lezak (1988) also noted from her clinical work that children of parents with TBI had to adapt to less parental attention. Through the experience children reported developing a new found maturity that may have stemmed from a need to increase their responsibility within the families and the subsequent adoption of more traditional parental roles (Butera-Prinzi & Perlesz 2004; Harris & Stuart 2006).

In contrast to exploring the lived experience of children following TBI Kieffer-Kristensen et al. (2011) specifically sought to examine post-traumatic stress symptoms in 35 children aged seven – 14 (only 26% of the ABI sample had specifically sustained a TBI). Each child had a parent (mothers or fathers) with a moderate to severe ABI (mean time since injury 3.7 years). Kieffer-Kristensen et al. (2011) also recruited a comparative group of children who had parents with diabetes (N=20). The study used parents', children's and teachers' responses to assess post-traumatic stress symptoms and behavioural characteristics. Results showed that 46% of children with ABI parents met the clinical criterion for post-traumatic stress disorder compared to 10% in the diabetes group ($p < 0.01$). The findings of this study exemplify the vulnerability and support needs of this particular group. Yet, despite this in a survey of 263 multidisciplinary staff working in 54 ABI rehabilitation services across the UK there were very few services that were inclusive of children when supporting patients or families post-TBI (Webster & Daisley 2007).

3.6.6 Summary

The metaphor of a ripple effect to illustrate how TBI affects the non-injured family members was supported in the literature that examined specific outcomes for individual family members including the primary carer, parents, spouses, siblings and children. Quantitative studies have shown that those who care for adults with TBI are at risk of developing psychological symptoms of depression, stress and anxiety. Furthermore quality of life and satisfaction with life are often reduced in comparison to the general population or other groups of caregivers. However studies have also shown when the opportunity to provide positive appraisals of caregiving is provided caregivers will often report positive experiences, suggesting the experience is not always detrimental.

Although primary carers and spouses may be at an elevated risk of maladjustment all family members are at risk and thus the effect on other family members should not be dismissed. The smaller qualitative studies have provided further insight into the lives of these individual family members and have shown that perhaps restricting investigations to the presence or absence of psychological symptoms may be a limiting view. Such studies have shown that understanding the individual experiences of primary carers, parents, spouses, siblings and children, is an important feature of the evidence base that may help us to further understand why some families pull together and some pull apart. However, what is not immediately clear from this literature is how individual family members contribute to the wider family system or how the rest of the family system impacts on individual adjustment and coping post-TBI.

3.7 How does TBI affect the wider family system?

Research studies that have aimed to investigate beyond the specific family member have achieved this through different means. Participants in many of these studies are not recruited because they provide care to the injured person. Rather they aim to explore how TBI impacts upon the family and therefore participants are often identified as family members, relatives or significant others. These studies investigate the effect of TBI on family members by asking participants to complete family outcome measures such as the Family Assessment Device (FAD) (Epstein et al. 1983), Family Satisfaction Scale (FSS) (Olson 1995), Family Assessment Measure (FAM) and the Family Adaptability, Cohesion and Evaluation Scale (FACES) (Olson & Gorall 2003). Family members have also been recruited to examine family needs either through the Family Needs Questionnaire (FNQ) (Skinner et al. 1983) or using qualitative designs to explore needs in further depth. Finally there are studies that have aimed to consider the family context and the influence of this context on the way TBI is experienced within the family system, frequently through the use of qualitative designs. Each is discussed below.

3.7.1 Family functioning

Family functioning has emerged as a key variable post-TBI. This literature has taken a positivist approach to inquiry whereby family functioning is evaluated using validated outcome measures. These outcome measures serve to classify family functioning using descriptors such as positive, healthy, balanced or negative, unhealthy, unbalanced. Undesired characteristics of family functioning would include disruptive and chaotic ways of living together and these families would be grouped together as having negative, unhealthy or unbalanced features of family functioning.

Increasingly, unhealthy family functioning is found to correlate with increased strain and depression and reduced life satisfaction for both injured and non-injured family members (Anderson et al. 2002; Nabors et al. 2002; Carnes & Quinn 2005; Gan et al. 2006). There is also increasing recognition that healthy family functioning is related to better rehabilitation outcomes for the injured person (Sander et al. 2002; Sander et al. 2003; Sady et al. 2010). Therefore the studies that use measures of family functioning recognise the family as a key variable in recovery post-TBI for injured and non-injured members alike.

The Family Assessment Device (FAD) (Epstein et al. 1983) has emerged as the predominant outcome measure of family functioning within the TBI literature and was developed by Epstein et al. (1983) in line with the McMaster Model of Family Functioning. The FAD is often used as

a single summary measure of family functioning within a research study (Ponsford et al. 2003; Testa et al. 2006; Winstanley et al. 2006; Schönberger et al. 2010; Gregório et al. 2011; Vangel et al. 2011). The six scales included are: problem solving; roles; communication; affective responsiveness; affective involvement; and behaviour control. In addition a General Functioning Scale score is calculated that reflects overall family functioning and families are then described as having 'healthy' and 'unhealthy' levels of family functioning.

Sander et al. (2002) used the FAD (Epstein et al. 1983) to investigate the relationship of FAD scores to rehabilitation outcome. Those families classed as healthy were more likely to have patients show greater improvement following rehabilitation. In this study a cohort of 37 severe TBI patients and one family member completed the FAD questionnaire at admission and approximately one-month post-discharge. Within the analysis families were separated into healthy and unhealthy groups. In the healthy group over half of all patients reported improvement following rehabilitation. In contrast only 28% in the un-healthy group improved. In the healthy group only 11% reported a decline in rehabilitation outcomes in comparison to over one third who declined from the unhealthy group. These results suggest that those patients who go back to home environments with more available support and encouragement are more likely to maximise their recovery potential. Therefore this study illustrates the importance of a well-functioning family post-injury.

Studies of family functioning most commonly recruit individual family members to report on the wider family. However there are studies that allow a number of members from the same family to participate. In these studies a more general picture of family functioning can be obtained. An important example of this was conducted by Perlesz et al. (2000) who compared data from a sample drawn over a twelve month period. Relatives from 65 families were recruited and categorised as primary, secondary and tertiary carers based on the amount of care provided within the family. Seventy-two primary carers, 43 secondary carers and 22 tertiary carers completed a postal questionnaire that included the Family Satisfaction Scale (Olson 1995). Perlesz et al. (2000) hypothesised that as the responsibility for caregiving increased so would reports of distress and depression. Although this correlation was supported in the primary carer group, who were the most distressed group of relatives, the correlation was not supported for the secondary and tertiary groups of caregivers who both reported varying levels of depression, anxiety and satisfaction. However the definition of primary, secondary and tertiary carers was slightly ambiguous and although those providing most care were identified clearly as the primary carers there was not such a clear distinction between secondary and tertiary carers. In addition there was a significant difference between

the ages of primary carers and tertiary carers that may have accounted for why primary carers reported greater levels of distress. Despite the differences between levels of caring the study concluded depression and distress exists within family units that cannot always be directly attributable to the amount of care provided.

Additional studies to recruit more than one family member include those using cross-sectional designs by Gan and Schuller (2002), Carnes and Quinn (2005), Gan et al. (2006) and Gregório et al. (2011). The aim of these studies was to investigate family system outcome and they therefore sought the participation of a number of people from the same family unit. Gan and Schuller (2002) recruited 92 family members of 43 injured patients and Gan et al. (2006) recruited 148 family members of 66 injured patients. Carnes and Quinn (2005) examined family adaptation through the reports of 123 family members of 65 injured patients and Gregório et al. (2011) recruited 76 family members (61 caregivers and 15 others).

As previously identified in the primary carer literature, studies of family functioning rarely find there are significant differences between the reports of different family members. Therefore these studies suggest all family members can perceive equal amounts of family dysfunction post-injury (Gan & Schuller 2002; Carnes & Quinn 2005; Schönberger et al. 2010). However one of the few studies to identify differences between family members was by Gan et al. (2006). Using The Family Assessment Measure Gan et al. (2006) found mothers', spouses' and siblings' scores were indicative of worse family functioning than a normative sample whereas FAM scores from fathers and offspring were not. The FAM is derived from a Process Model of Family Functioning and was developed by Skinner et al. (1983). The FAM places an emphasis on the family system and interactions between members. A four point Likert scale is used to score seven dimensions 'task accomplishment, role performance, communication, affective expression, involvement, control, values and norms' (Skinner et al. 2000, p190). These dimensions are assessed on three levels: the whole family system, the relationship between responder and another family member and a self-rating scale. These findings by Gan et al. (2006) were explained by the possibility that fathers may be more capable of maintaining pre-injury responsibilities in the family whereas the non-injured mother or non-injured spouse adopts the carer role. In addition although off-spring were not significantly more distressed overall than a normative sample Gan et al. (2006) points out that 78% of this sample still had at least one subscale of the FAM that was elevated beyond normal limits. Notwithstanding the similarities and/or differences between the reports of different family members these studies all point towards the importance of attending to the whole family system post-injury and

support the hypothesis that the effects of brain injury go well beyond the injured person and their primary caregiver.

Cross sectional and longitudinal studies both suggest the presence of unhealthy family functioning in the sub-acute phase and over time. Testa et al. (2006), Winstanley et al. (2006), Ponsford and Schönberger (2010) and Schönberger et al. (2010) each conducted longitudinal follow-up studies. Testa et al. (2006) aimed to identify risk factors for poor family functioning by having family members complete outcome measures at discharge from rehabilitation (N=122) and again at one year (N=73). Descriptive analysis revealed approximately one third had unhealthy levels of family functioning on the FAD General Functioning Scale (Epstein et al. 1983) that remained relatively stable across time. Winstanley et al. (2006) had participants complete measures approximately one month post-trauma and again at a median time of 16 months. Family functioning measured by FAD-General Functioning Scale decreased slightly at follow-up but the difference did not reach statistical significance. In contrast to the literature that reported neurobehavioral sequelae to predict distress this study of 134 severe TBI patients and their relatives did not find a direct correlation between these variables. Instead the impact of neurobehavioral sequelae was found to be mediated by the level of community participation achieved and supports similar findings in the carer literature (Ergh et al. 2002; Ergh et al. 2003; Lefebvre et al. 2008a; Chronister et al. 2010). This suggests that the impact on families is greater if the person with TBI is restricted in social participation.

In the studies by Ponsford and Schönberger (2010) and Schönberger et al. (2010) longer term outcomes were assessed. Ponsford and Schönberger (2010) followed up 301 participants at 2 years and 266 at 5 years post-injury and Schönberger et al. (2010) followed up 66 relatives at both two and five years post-injury. Both studies confirmed the findings of Testa et al. (2006) and Winstanley et al. (2006) and concluded that there was also no significant difference in FAD scores over time with one third remaining unhealthy at 5 years.

To understand the determinants of family functioning post-injury consideration is being given to pre-injury family characteristics (Curtiss et al. 2000; Sander et al. 2003; Davis et al. 2009). Both Sander et al. (2003) and Sady et al. (2010) aimed to explore the effects of pre-injury family characteristics, as measured by the FAD (Epstein et al. 1983), to determine post-injury adjustment or community integration. By assessing family functioning so early post-injury it was anticipated that a more accurate representation of pre-injury characteristics would be obtained than could be achieved in retrospective reports. Sander et al. (2003) recruited 191 caregivers of people with TBI and measures were completed no longer than three months

post-injury. Findings indicated that 37% showed symptoms of emotional distress and 25-33% reported unhealthy family functioning on one or more of the FAD subscales for the month before injury. This study indicated that a number of families may already be experiencing unhealthy family function before injury (Sander et al. 2003). As such they may be less able to cope with new demands that TBI necessitates of the family system.

An alternative measure used to assess family outcomes is the Family Adaptability and Cohesion Evaluation Scale (FACES) (Kosciulek 1996; Kosciulek & Lustig 1999; Curtiss et al. 2000). Godwin et al. (2011) stated that the FACES instrument could be a useful way to evaluate the family system. The FACES tool is a closed answer questionnaire developed by Olson and Gorall (2003) and is used as a means of evaluating the relative health of the family system. The primary hypothesis suggests that families who have a healthy level of flexibility (adaptability) and a healthy level of togetherness (cohesion) are well equipped to cope with changes to the structure and function of the family unit. In support of this hypothesis Kosciulek (1996) concluded that in his study of 82 families, those who were classified as balanced were functioning more effectively than those classified as extreme. Extreme families were characterised by disengagement, separateness between family members and rigidity in both roles and in control. Such characteristics have been considered unhealthy and disruptive in TBI families (Curtiss et al. 2000). It was thought that differentiating between these family types could help to identify at risk populations (Kosciulek & Lustig 1999).

Another variable being considered in recent literature is the reaction of family members in the acute period post-TBI and have included the presence of emotional distress and symptoms of post-traumatic stress. Norup et al. (2010) investigated the emotional distress of 31 relatives of adults with severe ABI an average of 25 days post-injury. Even in the sub-acute period quality of life scores were lower and rates of depression and anxiety higher than Danish population norms. Acknowledging the trauma that non-injured family members face in the wake of TBI Pielmaier et al. (2011) specifically assessed post-traumatic stress symptoms (PSS) in 69 relatives of patients with severe TBI who ranged from 5-23 days post-injury. Post-traumatic stress symptoms were measured by the Impact of Event Scale-Revised (Weiss & Marmar 1997) where scores of 33 or higher indicate the presence of clinically relevant levels of PTS symptoms. Over half of the sample (52.2%) scored above this threshold. Although these studies did not examine family functioning per se they considered family members' immediate reactions to trauma, which arguably may impact on family functioning and the family's ability to adjust in the sub-acute period or more long-term.

Family functioning has been defined as a variable that has been evaluated using a number of validated outcome measures. These studies suggest family functioning is important to both injured and non-injured members as these variables show associations with family member outcomes such as psychological distress, strain and rehabilitation outcome. These studies serve to emphasise the impact this injury has on the whole family.

3.7.2 Family needs

The needs of families post-TBI have been considered in both quantitative and qualitative studies. Those using quantitative designs most frequently use cross-sectional self-report surveys that include the validated measure the Family Needs Questionnaire (FNQ) developed by Kreutzer and Marwitz (1989). Forty items are included in the FNQ and each respondent is asked to rate the importance of the identified need. Needs pertain to six areas: health information, emotional support, instrumental support, professional support, community support network and involvement with care. Each need is then rated as being met, partially met or not met.

The importance of family needs was considered by Moules and Chandler (1999) and Chronister et al. (2010) who examined the quality of life in carers of persons with TBI. Using the FNQ Moules and Chandler (1999) identified that in 22 carers those with more unmet needs reported lower quality of life and had a higher proportion of psychiatric symptoms as measured by the General Health Questionnaire (Goldberg & Williams 1988). Similarly Chronister et al. (2010) concluded family needs remained important over time and were found to correlate to the level of self-reported quality of life and appraisal of stress.

Studies that used the FNQ (Kreutzer & Marwitz 1989) to describe the expressed needs of family members include Kolakowsky-Hayner et al. (2001), Murray et al. (2006), Arango-Lasprilla et al. (2010) and Chronister et al. (2010). Despite differences in research designs studies always report that health information needs are the most important need of the FNQ in TBI populations (Stebbins & Leung 1998; Moules & Chandler 1999; Kolakowsky-Hayner et al. 2001; Murray et al. 2006; Arango-Lasprilla et al. 2010; Chronister et al. 2010). According to two literature reviews on family needs families of persons with head injury want clear and honest guidance about what head injury means, what to expect during the period of recovery and what the final outcome will be (Sinnakaruppan & Williams 2001; Friedemann-Sanchez et al. 2008). Perhaps the priority given to information needs is amplified in this population because there is so little that can be predicted with certainty following TBI.

Similarly needs to be most frequently ranked as least important in these studies are those from the emotional sub-scale (Moules & Chandler 1999; Murray et al. 2006; Arango-Lasprilla et al. 2010). Examples include 'help in remaining hopeful about the patient's future' and 'help getting over my doubts and fears about the future'. These studies suggest needs of an emotional nature are of less importance in comparison to others including information and involvement with care. In contrast to the need for information which is usually identified as a need that was met in TBI populations the needs most commonly identified as not met are usually from the emotional sub-scale (Moules & Chandler 1999; Murray et al. 2006; Arango-Lasprilla et al. 2010).

It has been suggested that investigations using measures like the FNQ tend to focus too closely on general overall needs without examining their complexity or the reasons for the diversity of these needs (Friedemann-Sanchez et al. 2008). A reasonable interpretation of the finding that emotional needs were of less importance would be that emotional support for families is not a significant need post-TBI. However qualitative studies and clinical practice experience would dispute this interpretation.

Qualitative studies of family needs post-TBI include Paterson et al. (2001), Leith et al. (2004), Lefebvre et al. (2005), Duff (2006) and Lefebvre et al. (2008b) each of which emphasised the importance of information to this particular population. Despite literature that suggests information needs are often reported as having been met Paterson et al. (2001) suggest a perception exists in practice whereby practitioners report giving information to families and yet families frequently state it was not. Paterson et al. (2001) aimed to investigate why it was that families did not always perceive that their information needs were being met. Semi-structured interviews were completed with eight people with TBI and a family caregiver who were interviewed together where possible. In addition focus groups were held with four groups of healthcare professionals to examine their perception of the process of information giving post-TBI. Paterson et al. (2001) reported that seven out of eight families could not remember having received any information. In contrast, all those professionals in the focus groups reported giving extensive information in preparation for discharge. The healthcare professionals attributed these conflicting perspectives to family members having difficulty in assimilating information due to high levels of anxiety.

Oddy and Herbert (2003) suggested that over time families develop their own interpretive strategies and find ways to filter information, and subconsciously select information they are willing to assimilate and filter out that which they may not be ready to accept. However,

family members in the study by Paterson et al. (2001) spoke of feeling intimidated, and overwhelmed, and that information-giving was poorly timed. The findings of Lefebvre et al. (2008b) support this conclusion with family caregivers indicating that their primary complaint, especially in acute care, was that information was lacking and that when information was provided the way it was conveyed was often inappropriate.

An important study by Verhaeghe et al (2007a; 2007b) recruited family members from the intensive care units of two Belgian hospitals to explore the complex relationship between information and hope that was displayed by family members of patients in traumatic comas. Using a grounded theory approach semi-structured interviews were conducted with 22 family members of 16 patients during their stay in ITU. In the interviews family members were asked to talk about issues such as: reactions to the news; contact with the hospital, the patient, the professionals; responsibilities; coping; support; positive and negative experiences. Findings emphasised the complexity of information needs in the acute phase by demonstrating how the perception of, and need to have, hope was always intertwined with the provision of, or access to, information about their injured relative (Verhaeghe et al. 2007a; 2007b). Over time it was understood that family members learnt to trust their own interpretation of the situation and could become distrustful of information provided by healthcare professionals if they were perceived as providing wrong or misleading information (Verhaeghe et al. 2007a).

The study by Verhaeghe et al. (2007a; 2007b) showed that family needs are not always objective and independent of each other. Family needs depend on contextual factors, the environment and the family itself.

3.7.3 Family context

As previously discussed in this literature review positive, balanced or healthy family functioning has been identified as a protective factor post-TBI moderating effects of caregiver strain, stress and burden. Family context, including individual relationships and social characteristics, can therefore promote well-being and adjustment (Johnson et al. 2010). However, studies using a family functioning outcome measure have not been able to consider in-depth how this family context underpins family functioning. A narrative literature review by Kneafsey and Gawthorpe (2004) argued that the nature of TBI demands that the whole family changes. As such relationships, lifestyles and quality of life may change both immediately and in the long-term, threatening the equilibrium of the family system (Verhaeghe et al. 2005). Therefore the multiple contexts of individual family systems need to be explored to understand this further.

A study by Duff (2002; 2006) aimed to include family units by incorporating in-depth interviews with multiple family members and observations of these family units within the intensive care setting. Although the research question focused on determining family needs and concerns the findings went beyond the identification of defined needs and explored how 25 family members from 11 families made sense of severe TBI in post-comatose unawareness or minimal responsiveness. Although the papers contained little theoretical debate to defend the rigour of approaches used the study illuminated an important process of family negotiation that may underpin later adjustment. Duff (2006) also identified that the non-injured members were as much a part of the critical illness journey as the patient themselves. During this acute period, families were negotiating between themselves to establish roles and responsibilities such as who would take over key elements of daily family life. Therefore those with close, strong and supportive families appeared to be more resilient and responded better to the demands placed upon them (Duff 2002; 2006). These findings support the quantitative literature that healthy family functioning is more suggestive of positive outcomes for injured and non-injured members.

Kean (2010) also recruited multiple family members (twelve adults and twelve children from nine families) and this was one of the few studies to conduct family group interviews where all non-injured members of the same family were interviewed together. Kean (2010) aimed to examine ambiguous loss following brain injury that resulted in permanent brain damage. Kean (2010) argued that the on-going nature of ambiguous loss left families unsure of all their futures adding further that the 'future had become an elusive concept' (p70). The paper therefore illustrated some of the interwoven features in the experiences of both injured and non-injured family members.

A key paper to consider family context as a component of sense making following brain injury was completed by Yeates et al. (2007). Qualitative interviews were completed to explore disability and change, meaning of change and managing different perspectives. Separate interviews of the three ABI survivors and their significant others lasted between 60 and 90 minutes. Case histories are presented in the paper showing two adults survived TBI two years prior to interview and the other survived intracranial haemorrhage ten years earlier. Each survivor was identified following an intensive programme of neuropsychological rehabilitation as having specific awareness deficits. As such they represent a specific group of ABI survivors with long-term neuropsychological concerns. Findings of this study included that family members used previous knowledge of the injured person as a resource to make sense of what was seen or experienced post-injury. This knowledge was contextually bound within the

family system and as such family context was a significant feature of the family member's ability to make sense of brain injury and the subsequent life changes that followed. This study illustrates the importance of the exploration of family contexts in order to understand more fully the family experience of TBI.

These interwoven aspects of family life following TBI were also revealed in a study by Jumisko et al. (2007). Eight close family members, each from different families (two mothers, one father, two partners, two siblings, and one daughter) were interviewed to illuminate the meaning of close relatives' experiences of living with a person with moderate or severe TBI (median time since injury 8 years). Although the focus of the study was clearly centred on family members not family units the findings of the phenomenological analysis revealed how the non-injured family member's relationships had been affected by their relative's injury. For example siblings who provided care after injury reported that their own children felt jealous of the time and attention given to the injured person and this caused friction within their family. Although family members reported their familiar world collapsed causing fear, uncertainty and anxiety, there were also elements of gratitude, pride and pleasure in the experience of post-injury family life. In addition relatives realised that family was important to them and through this experience new bonds were formed and existing relationships were strengthened. Therefore there was the opportunity to grow from the experience and take away positive meaning. Jumisko et al. (2007) illustrated how TBI affects aspects of life both internal and external to the injured person's family system and that family context was key to understanding life post-injury.

These qualitative studies have aided further understanding of the multiple contexts of individual family systems. They have suggested that families are part of the critical illness journey and their acute experience may well affect their ability to positively adjust post-TBI (Duff 2002; 2006; Kean 2010). Furthermore family member resilience may be underpinned by the structure and function of the family system. Jumisko et al. (2007) and Yeates et al. (2007) both proposed that family context can help to understand further how families adjust, cope and adapt post-TBI and that understanding this context may be useful in practice and research.

In 1999 Perlesz et al. conducted an in-depth critical review of the literature regarding the impact of TBI on the family. The conclusions made over ten years ago are still relevant today and included more emphasis on qualitative research to enhance understanding of the process and patterns of adaptation following TBI. In addition Perlesz et al. (1999) also specifically referred to the need for the in-depth analysis of single family units.

A more recent literature review to consider stress and coping in family members following brain injury also emphasised the need to explore the family unit:

‘Future research might be directed at the reaction patterns of the family unit instead of addressing each individual family member. It is also worth investigating the typical ambivalence among the family members of brain trauma patients, e.g. how hope and despair interrelate and what are the influencing factors in this regard. Research on the evolution of the reactions of family members at the onset of trauma and at a later phase also appears needed’ (Verhaeghe et al. 2005, p1009)

Since the comments by Perlesz et al. (1999) and Verhaeghe et al. (2005) steps have been made to achieve a more multi-dimensional view of the family experience of TBI. However the evidence base is still far from comprehensive and it has been argued that more should be done to understand the complex and changing nature of the relationships within families following TBI (Jumisko et al. 2007).

3.7.4 Summary

The literature that examines how the wider family system is affected by TBI has considered family functioning, family needs and the family context. Both quantitative and qualitative studies to date have made a convincing argument that the family system has an impact on both patient and family member outcomes. Quantitative studies that classify families as healthy/unhealthy or balanced/unbalanced demonstrate this association between family variables and the presence of stress, depression and overall life satisfaction. However the literature is dominated by a picture of general family functioning that cannot unpick the context of individual circumstances, family history, established roles and relationships and if these moderate the effect of head injury on the family system.

Studies are starting to consider many of these issues within the smaller qualitative designs but more is still needed to understand how family dynamics, structure and relationships contribute to the overall experience of adaptation to life post-TBI. Such studies may be able to uncover more about the multiple contexts of individual families and how the family system can create a positive environment so that all family members can adjust to the changes required.

3.8 Chapter summary

The literature reviewed from the last ten years emphasises that all members of a family can be profoundly affected by TBI. Although those who provide the greatest amount of physical or emotional support are often the focus of investigation, other family members have been identified as at risk of undesirable outcomes such as stress, depression, low life satisfaction and unhealthy family functioning. Family members that have attracted special attention in the

literature include parents, spouses, siblings and children and confirm the extent to which all family members can be affected. However researchers are now considering the family as a dynamic system and as such the focus is shifting from the individual to the family unit.

In summary, the evidence base continues to suffer from a dominance of cross-sectional studies (Kendall & Terry 2009; Schönberger et al. 2010). Therefore, longitudinal designs are needed to understand how families change over time and future research needs to explore the evolution of the family experience from onset of injury to a later stage (Verhaeghe et al. 2005). Such prospective studies need to explore multiple contexts as those with TBI move through acute, rehabilitation and community service provision (Cloute et al. 2008). In addition closer consideration should be given to the importance the acute period plays in how families come to understand and make sense of the traumatic events they experience (Yeates et al. 2007; Holm et al. 2009; Pielmaier et al. 2011). Through these methods the complexity of family contexts, family capacity, resilience, and the process of family adaptation could be further understood (Duff 2006).

3.9 Research questions and objectives

To respond to the gaps within the literature a longitudinal prospective study was designed to answer the following research questions and address the subsequent research objectives.

3.9.1 Research questions:

- What are the changes reported by non-injured family members during the first year of a family member's traumatic brain injury?
- Within one family what are the effects of traumatic brain injury up to one year following injury?

3.9.2 Objectives

- I. To explore the changes reported by non-injured family members affected by TBI at one month, three months and one year following injury.
- II. To identify how these changes impact on the functioning of the family as a whole.
- III. To use the findings to inform supportive practice for families affected by traumatic brain injury.

4 Constructing a Research Design

4.1 Introduction

Rigorous, scientific enquiries are based on a set of theoretical and philosophical perspectives about the nature of reality and knowledge, and these should be made explicit during the inception of the study (Creswell 2009). These assumptions are the basis for the construction of the research questions and guide the researcher through the selection of specific research methods (Bowling 2009). Therefore the aim of this third chapter is to present a coherent and cogent argument to defend the choice of methodology and methods that have been used to pursue the leading research questions.

First a debate will be presented to explore qualitative and quantitative approaches. The choice of paradigm and the related ontological and epistemological assumptions underpinning this investigation are then defended. Qualitative case study methodology will also be evaluated as to how this approach enabled examination of the family experience of TBI. Approaches to data collection will then be justified within the methods section alongside exploration of sampling, recruitment, ethics and data analysis.

4.2 Quantitative or qualitative: an old debate

Before entering a critical debate regarding the decisions made concerning this study's research design it is worth spending some time exploring the quantitative qualitative divide in research and hierarchical status afforded to each in evidence-based practice (EBP).

Quantitative research reduces inquiry to that which can be observed and measured (Ellis 2010; Topping 2010). Measurement of variables produces numerical values that can be compared across large data sets. The value of such an approach is the examination of relationships between variables, such as cause and effect, correlation and association (Newell & Burnard 2006; Polit & Beck 2008). The use of such knowledge is immediately obvious within healthcare and studying the effectiveness of interventions would not be possible without it. As such quantitative methods have been given higher status within EBP for its ability to answer research questions for large populations with a level of certainty that is essential in healthcare.

The core principle of quantitative research is to examine relationships that can be generalised beyond those who participated in the study (Polit & Beck 2008). Therefore quantitative studies examine patterns in the data that are true for most of the population. However *most* does not mean *all* and commonly the needs of smaller, marginalised, or extreme groups are

overlooked. Newell and Burnard (2006) refer to this as the *individual* versus the *general* experience. Furthermore, to establish cause and effect so much control must be exhibited over the study, to reduce bias and the effect of extraneous variables, that often the conditions the study was conducted in do not reflect real life. Therefore qualitative inquiry is an essential component of the evidence base that enables the study of things that are not so easily reduced to statistical measurement. Such things include human behaviour, social processes, meaning and sense making (Topping 2010).

When the inquiry seeks to understand the meanings people draw from their daily life a study must find an alternate way of examining their world. Therefore, qualitative research seeks to understand the world from the perspective of those who occupy these worlds (Litva & Jacoby 2002). The only way this can be achieved is to enter this world and try to understand how people make sense of, and give meaning to their experiences (Litva & Jacoby 2002; Denzin & Lincoln 2005). Such goals demand in-depth approaches and the collection of narrative materials (Polit & Beck 2008). Therefore qualitative research rejects the pursuit of quantified answers to research questions (Pope & Mays 1995).

From an evidence-based perspective qualitative inquiry is essential when a phenomenon is poorly understood (Newell & Burnard 2006). Such studies can illuminate the constructs of an experience that, over time, can lead to the identification of more defined variables. Once such variables have been identified quantitative inquiry can examine these on a larger scale and examine the relationships, correlations and associations that exist within larger data sets (Newell & Burnard 2006).

From an inquiry-based perspective quantitative and qualitative data types are most commonly kept separate to avoid the problematic epistemological and ontological debates of mixing research designs that are considered polar opposites. The difference in the underpinning principles of reality and truth has led to historical arguments that mixing methods is inappropriate (Simons & Lathlean 2010). Until recently the literature, both theoretical and empirical, supported and encouraged this division (Topping 2010). Now diversity of research methods is recognised as strengthening the evidence base, especially within nursing (Topping 2010):

‘Quality in research is about using the most appropriate approach for investigating research problems and about researchers adopting a systematic, rigorous and transparent approach for exploring, discovering, confirming and understanding.’
(Topping 2010, p129)

Therefore, decisions about qualitative or quantitative methods are less about which is more valid in healthcare but which is most congruent with, and which will most adequately answer, the research question. In pursuit of this goal more researchers are combining qualitative and quantitative approaches to add value to their study (Topping 2010). However, when doing so it has been argued that one approach should always be dominant in a study with the second acting as supplemental data (Morse 2010; Simons & Lathlean 2010). This study adopted this principle of mixed methods and was led principally by the qualitative paradigm with a secondary quantitative element. The theoretical drivers of this study were constructivist inquiry and narrative theory and are discussed in Section 4.3. The decision to include quantitative data is then defended in Section 4.7.2 and the interpretation of data sets explored in 4.9.6.

4.3 Social constructivism and narrative theory

Given the earlier discussions in Chapter Three it was clear very early on that an investigation into the family experience of head injury would require an approach that was flexible, open to change and would enable the family to be conceptualised as a dynamic, individualised and socially constructed system. The constructivist paradigm met these criteria, firmly placing the emphasis of investigation on subjectivity and the value of exploring the difference in people's experiences.

A constructivist paradigm views reality as relative to those experiencing it and the complexity of human existence ensures that experience is created, shaped and constructed through social interaction and individual interpretation (Denzin & Lincoln 2005). The detail and description of a socially constructed world is important to the way people understand the world they live in and shapes their everyday experience. The assumption therefore is that the experience of being in the world is never singular or objective. Within research this allows several different perspectives to be examined so that a deeper understanding can be reached about how individuals make sense of their experiences.

The constructivist paradigm advocates that meaning is shaped and constructed through both internal and external interactions and influences (Plano-Clark & Creswell 2008). The relationships people have and the interactions they make with each other are based on their ability to interpret and understand the meanings held within the situation experienced. The generation of knowledge has the potential to reveal new interpretations and to better understand events from an external view. The richness of this approach therefore is not so much in the 'what happened' but in the 'why was it perceived in that way'. Exploring these

differences and similarities can reveal new meanings to make a unique contribution to the evidence base (Pope & Mays 1995).

Constructivist research is complex and can be attached to a number of research designs or theoretical frameworks such as ethnography, grounded theory, discourse analysis and narrative inquiry (Gubrium & Holstein 2008). Exploring the priorities of the constructivist paradigm revealed its close relationship to many of these approaches but more specifically to narrative theory (Sparkes & Smith 2008). It was for this reason that narrative was explored more closely for how it could facilitate this inquiry.

Within narrative traditions the person is seen as an innate storyteller and through these stories they construct and portray the meaning held within their experiences (Lieblich et al. 1998):

‘Narratives, in significant measure, constitute human realities and our mode of being. They help guide action and are a socioculturally shared resource that gives substance, artfulness and texture to people’s lives. They form the warp and weft of who we are and what we might or might not do.’ (Sparkes & Smith 2008, p295-296)

The above quote demonstrates how narratives help people to make sense of the lives they live and emphasises the fact that humans are socially constructed beings (Bruner 1990).

In defining narrative fundamental characteristics pertaining to this design can be highlighted. The definition by Riessman and Quinney (2005) is useful here and states narratives are:

‘extended accounts of lives in context that develop over the course of single or multiple interviews. The discrete story [...] gives way to an evolving series of stories that are framed in and through interaction.’ (Riessman & Quinney 2005, p394)

Bingley et al. (2008) explain that as our normal routine of daily life is disrupted a story of the event is created. Furthermore it has been argued that there is a human desire to re-order the chaotic or inexplicable into something which is tangible, useable and meaningful. Bingley et al. (2008) add that ‘stories, therefore, gain a particular relevance at times of life transition or change, seemingly as a way of ‘sense-making’ or attempting to reshape and manage the shifting ground of our lives’ (p655). When such events happen in life the person affected is compelled to tell a story about it. Embedded within these stories are the materials that the person has used to make sense of their experience. The critical illness of a close family member can turn the experience into a told, re-told, and reaffirmed story of illness, recovery, meaning and new life (Frank 1995).

Narratives are therefore instruments for social negotiation, produced by people, and the way these narratives are crafted reveals something about the meaning attributed to them (Bruner

1990). In his text *Acts of Meaning* Jerome Bruner called for the field of psychology to return to more human concerns of meaning making and its importance to 'being in the world'. Bruner (1990) stated 'I have been at great pains to argue [...] that one of the most ubiquitous and powerful discourse forms in human communication is *narrative*' (p77). The process of meaning making through the act of narrative is explored in direct contrast to positivism, reductionism and the status afforded to cause and effect and predictive science.

Stories are always about something, for example, illness, disability, treatment, everyday life (Holloway & Freshwater 2007a). Frank (2000) argued that stories 'offer those who do not share their form of life a glimpse of what it means to live informed by such values, meanings, relationships and commitments' (p361). However, stories are told about objects, people, events, or in the case of this study, about the TBI of a family member. They are rarely told explicitly about the storyteller themselves and yet the storyteller is embedded within the story they tell and can be known further through the analysis of their story (Lieblich et al. 1998).

McAdams (1993) poignantly wrote the following:

'If you want to know me then you must know my story, for my story defines who I am. And if I want to know myself, to gain insight into the meaning of my own life, then I, too, must come to know my own story.' (McAdams 1993, p11)

McAdams (1993) therefore puts forward the proposition that stories are an integral part of our sense of self. However in the presence of illness what has been assumed about our lives and our perception of the future shifts or alters completely. As Holloway and Freshwater (2007b) stated 'individuals find themselves in a process of deconstructing and reconstructing [their] identity' (p706). This concept of a life, as it is known and understood, coming to an end and being replaced with a new and unfamiliar life, creates stories of suffering and has been explored within the chronic illness literature for some time (Charmaz 1983; 1999):

'Telling the story of suffering is a way of creating continuity and wholeness in the face of disruption - a life torn apart. It is a way of understanding what happened. It is a way of coming to terms with a changed life.' (Charmaz 1999, p373)

In Michael Bury's investigations with people diagnosed with rheumatoid arthritis, chronic illness was conceptualised as 'biographical disruption'. Biographical disruption was characterised as unfamiliarity with daily processes, and understanding of how to 'be in the world' is challenged through disability and disablement (Bury 1982). These deficits then change the expected and anticipated future of the person and their family disrupting their sense of self.

A critique to Bury's position was put forward by Williams (2000) who suggested the term disruption is a restricted view of illness that focuses on the assumption that life is 'shattered' by illness. Williams (2000) suggested it may be more appropriate for some to see illness as biographical *continuity* or indeed *reinforcement* of their sense of self. Williams' (2000) critique of Bury relies on a person's total separation from or connection to their past, present or future self through the presence of illness. What may be more useful however, is to consider illness as more of a *challenge* to identity and the known self (Ellis-Hill & Horn 2000). Through this challenge certain aspects of self are called into question, reinforced or enhanced, altered or played down, or indeed may be completely disrupted.

To explore further how identity is challenged following illness Ellis-Hill et al. (2008) presented the Life Thread Model as a different way to conceptualise life following stroke. Instead of relying on a theory of loss the Life Thread Model builds on the concept of disruption but extends it to a more balanced and positive view of life after stroke. Narrative theory underpins the model and it considers how the biographical self is a collection of stories that ultimately facilitate connection of the past, present and future.

Chronic illness is usually depicted as a debilitating condition whereby cure, course and recovery are all uncertain (Miczo 2003). Although Hydén (1997) argued the experience of acute illness is different to chronic illness parallels can be drawn between chronic illness and TBI because in both of these cases the course and extent of recovery are equally unknown. Although TBI is not a progressive or degenerative condition it is considered a long-term condition. However, in this case onset is immediate and often life-threatening. From that point life and perception of the future may be changed for injured and non-injured family members alike. The use of a narrative framework can therefore facilitate exploration of how non-injured family members make sense of TBI and move forward with their lives in the wake of this potentially devastating injury.

It follows then that narratives are ways in which humans put together their actions, events and experiences to make sense of them in an attempt to create an 'understandable composite' (Polkinghorne 1988, p13). A key element of narrative is therefore the temporality of experience and the sense of self that connects past experience with the present and the future. This shaping and ordering of past experiences reveals a central issue of biography and how the person narrating the experience uses this to know themselves and subsequently interpret the events they are faced with (Chase 2005).

The utilisation of social constructivism and narrative theory acted as an underpinning framework to shape ontological and epistemological assumptions of this study. These ideas were then used to inform decisions regarding methodology and methods and create an appropriate research design that would answer the research questions.

4.4 Qualitative case study methodology

The selection of qualitative case study methodology for this study stemmed from its principle aim which was to conduct a family-centred investigation. Rather than focusing on a collection of individuals it seemed a logical and pragmatic decision to use case study as a means of conceptualising each family as a unique case. Individual family members could then be asked to provide data which, together, would ultimately inform a greater understanding of the case, or in this study, the family.

The first challenge was to acknowledge that case study can be seen as a methodology, research design, the object of investigation as well as the final product of the research (Creswell 2007), and would often meet all these criteria within the same study. There is consequently much debate about the definition and use of case study in empirical research. The aim therefore is to steer a logical path through that debate to prioritise the needs of this investigation.

Within the literature it is largely understood that, executed with skill, case studies can provide a powerful story that illustrates the experience of the phenomenon under investigation (Grbich 1999). Furthermore case study research is described as an 'intensive, holistic description and analysis of a single unit or bounded system' (Merriam 1998, p12). The major benefit therefore is the depth that comes with studying a limited number of participants. This intimate knowledge captures a different perspective than can be achieved through other forms of qualitative research.

The aim of qualitative case study is to examine the particularity of the case for what it reveals about the phenomenon. Priority is first given to what can be learnt about a single case through in-depth understanding and examination of the meaning held within it (Merriam 1998). Single cases are therefore explored for their particular complexity and then to increase knowledge and understanding comparisons can be made to other similar cases. A thick description of its features is then required to identify what can be learnt through the specific case, or cases, to generate new knowledge and understanding about the issue of ultimate interest (Merriam 1998):

‘A case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly understood.’ (Yin 2009, p18)

Following the quote above Yin (2009) goes on to explain that because the phenomenon cannot always be separated from the context of the case, case study inquiry accepts there are many more real life variables than can be examined in one investigation and that multiple sources of evidence enable closer convergence on in-depth understanding and theory generation. It is through these multiple sources of data that depth is usually achieved facilitating an understanding that could not be achieved by using single methods alone (Gangness & Yurkovich 2006). Therefore what may be conceptualised as a qualitative case study does not have to be restricted to qualitative methods alone and may use a mix of both qualitative and quantitative evidence within the one inquiry (Yin 2009).

The understanding of case study put forward by Stake (2005) has been particularly influential in this study. Appleton (2002) critiqued the application of case study designs and also found the method by Stake (1995) to be most commensurate with constructivist inquiry:

‘Case study [...] fits well with the requirements of constructivist ontology that emphasises the holistic nature of realities and the importance of studying phenomena in their natural uncontrolled contexts.’ (Appleton 2002, p89)

Stake (2005) identifies three types of case study: intrinsic, instrumental and multiple/collective case study. The most important difference is that which exists between intrinsic and instrumental case studies. Intrinsic case studies are used when there is a need to understand a particular case and instrumental case studies are used when the focus is more on investigating a specific phenomenon. However, the current study used a collective case study approach. These are essentially instrumental cases (Stake 2005; Anaf et al. 2007) where the case is chosen to generate more understanding of a particular issue, but more than one case is selected for a broader and more general understanding. Therefore, a number of family cases were chosen for what they could illuminate about the experience of living through a family member’s TBI.

A possible limitation of using the case study approach is the selection of the case. What is learnt about the phenomenon is wholly dependent on the case identified and recruited to the study. In a clinical environment the selection of families was determined by availability and willingness to take part and therefore it was not possible to choose a particular case from a list of possibilities. Although the aim of the study was not primarily to generalise findings to similar situations it was important to reflect on the cases recruited to the study. Consideration

was given to how decisions made in the research process, such as inclusion and exclusion criteria, affected how the cases compared to other families affected by TBI and how this would affect the transferability of final findings.

4.5 Defining the case

In the current research it was useful to start by considering the position that case study is first a choice of what it is that is to be studied (Stake 2005). In defining the unit of analysis, or the case, Merriam (1998) refers to 'fencing in' that which will be investigated. Appleton (2002) also emphasises the importance of not just describing the case but also making it clear how the case has informed the research process and how the case will enable greater understanding of the phenomenon under investigation.

This process involved identifying what was internal to the system, bounded within the case, and what was external (Stake 2005). Helping in the process of case definition was family systems theory. As previously discussed in Chapter Two family systems theory enables a broader understanding of the family than simple membership and recognises the complexity of a dynamic system that evolves in both function and purpose over the life cycle.

Family systems theory is part of a wider group of approaches that considers integrated wholes consisting of two or more parts (Anaf et al. 2007). The use of system approaches within case study research appears a relatively new concept and there is a paucity of literature about the relationship between case study and systems theory approaches. However Anderson et al. (2005) argued that a systems approach could be useful in case studies to more fully understand the network of relationships and interactions that make the system an integrated whole. Therefore by utilising a systems approach it was thought that the definition and description of the case, or in this case the family itself, could be enhanced (Anaf et al. 2007).

There are however valid criticisms of the use of systems theory in qualitative research. The primary concern is that, to date, few qualitative studies have incorporated systems theory and therefore it is questionable how such a framework would contribute to an exploratory investigation. The potential risk discussed in the literature is that the exploratory and interpretive nature of qualitative inquiry could be stifled, rather than enhanced, by the systems approach and because of this systems theory has had more natural utility within quantitative designs (Sandelowski 2005).

However the qualitative approach does not need to be compromised and this can be achieved by ensuring that systems theory fits into the interpretivist stance and not the other way

around (Anaf et al. 2007). Family systems theory was therefore used to facilitate the inquiry not lead it. Primarily within the research methods explored later in this chapter, family systems theory was used to map out and describe the case recruited. However when it came to data analysis family systems theory was put to one side to facilitate interpretation that was not restricted to, or limited by, the domains depicted in Figure 2.1 (p17).

For the purpose of this investigation the case was defined as a family where a member had sustained a traumatic brain injury within the previous month. This family unit therefore provided the fundamental boundedness required for case study investigations (Stake 2005). However, specific decisions were made that fundamentally shaped the cases recruited to this research.

The first was the decision to define family using the definition by Wright and Leahey (2009, p60) that 'family is who they say they are'. This definition was chosen to underpin the proposed research because it meant recruitment did not have to be limited by a conceptual definition that may have led to the inappropriate exclusion of a relevant family member. The research was therefore designed to allow the family to self-select relevant members for participation. The second decision referred to the number of people a case could include. An in-depth case study requires the exploration of multiple sources of evidence. To examine a family case study this requirement was interpreted as the need to recruit a number of different family members from the same family unit. However, knowing how large some families could be, it was felt necessary to restrict the number of people who could take part. The maximum number of family members per case was set at four, with a target of three cases. This was felt to be preferable to recruiting a single case with a larger number of family members. By recruiting a small number of cases a range of similar and contrasting experiences could be explored.

The third decision related to imposing an age restriction on the family members recruited. It was decided that only those who were 18 years of age or over would be invited to participate. The exclusion of children is discussed further within Section 3.7 under ethics, but was decided after extensive consultation with internal supervisors, peer reviewers and the ethics committee.

The final element that affected recruitment to the study, and therefore the subsequent generation of understanding about each case, was the decision to focus on the non-injured family members. This decision was made during exploration of the literature and subsequent generation of the primary research questions. In addition it was thought that during the first

year the injured person would be recovering from their injuries and therefore it was more appropriate that the research questions related specifically to the non-injured members.

4.6 Method

A prospective design was chosen to investigate a trajectory of the non-injured family members' experience from point of injury and throughout the first year of expected recovery with data collection taking place at three intervals namely one, three and twelve months.

4.6.1 Sample

Qualitative case study methodology usually requires a purposive sampling technique that involves identifying who or what would be considered bounded within the case (Yin 2003). Participants should therefore be chosen that have direct access to the phenomenon investigated. To meet this criterion the participants were all family members of patients admitted to a regional centre for neurology and neurosurgery following TBI. Between August and December 2009 nine people from three families were recruited, giving a sample of three cases. Recruiting only three cases and a small number of participants has facilitated a very in-depth inquiry that would not be possible if additional cases, or larger cases, had been assembled.

The aim was to recruit family members who were relevant to the person sustaining the injury and therefore potential participants could not be identified in advance. Snowball sampling is a strategy that uses 'human networks' to identify participants for a study (Procter et al. 2010, p149) and is often used as a sampling strategy when the population are hidden, unknown or difficult to define (Polit & Beck 2008). Following a similar approach it was decided that a senior family member would be asked to identify other relevant family members who may wish to take part. The most identifiable senior family member was considered to be the documented next of kin. This process was quite complex and required several stages of access, recruitment and consent.

4.6.2 Access

Access to participants was negotiated over a sustained period of contact with a regional centre for neurology and neurosurgery. Early discussion with the medical team established that there was a population who could meet the requirements of this study and within this team the clinical nurse practitioner for neuro-trauma agreed to act as a gatekeeper by identifying potential participants. Their role involved briefing family members and distributing

recruitment packs. Therefore I was unable to meet with a family unless they expressed an initial interest in the study.

Identification and recruitment of participants was designed to follow three clear stages. First was the identification of the patient, second was the next of kin and third were the family members.

4.6.3 Identification of patient

Although the experiences between families would be very different the aim was to converge around a core event that was shared between each group. Therefore patients were identified who shared commonalities and exclusion criteria were set so that the focus was on how the TBI had shaped the family members' lives. A summary of these can be found in Table 4.1.

4.6.3.1 Inclusion criteria

A decision was made very early on in the design of this study that the focus would be on adult TBI. The care and recovery of paediatric TBI is different and investigations should focus attention on one specific group of patients. Therefore only those patients who were 18 years of age or over were identified.

Although any severity of injury can leave a person with a range of neurological deficits it was decided that the injury sustained should be classed as a moderate or severe TBI.

Although not always the case, it is more likely that these patients face a more sustained recovery and are in contact with health care professions for a more prolonged period.

Injury would be defined by a Glasgow Coma Scale (GCS) of 3-8 (severe injury) and 9-12 (moderate injury) (for an explanation of GCS see Chapter Two pages 9-10). To also increase the probability of sustained contact with health care services an additional criterion was set whereby the patient should be assessed as potentially requiring inpatient rehabilitation.

During conversations with members of the ethics committee it became clear that it would not be suitable to recruit people whilst admitted to the neuro critical care unit. During this period of care the patient's condition is usually too unstable and the family too vulnerable. Therefore patients had to be established on a main neurological ward within the hospital. As previously stated data collection was designed for one, three and twelve months following injury. Therefore another inclusion criterion was created. For the family member to be interviewed within a month of their relative's injury their relative had to be at a stage of recovery whereby they were well enough to be

transferred to the ward environment. Early conversations had suggested this would not be problematic as most patients, except the very severely injured, were on the ward within this period. However all families recruited were almost at the limit of this four week window and several patients were excluded because the injury necessitated a longer period of intensive care.

Inclusion Criteria	Exclusion Criteria
18 years of age or above	Prior head injury
Moderate – Severe TBI	Previous psychiatric history
Will potentially require inpatient rehabilitation	Dementia
Within one month of injury	Alcohol or substance abuse
Admitted to a ward	Living in a long-term care facility

Table 4.1 Inclusion and exclusion criteria for patients

4.6.3.2 Exclusion criteria

Exclusion criteria centred on excluding cases that were made even more complex by the presence of other challenging conditions. A family that was dealing with long-term drug or alcohol addiction may already be struggling to cope. The impact of TBI on such a family may then be difficult to investigate with the presence of other issues in their life. Therefore it was decided to exclude patients with a history of a psychiatric disorder, dementia, prior head injury, history of alcohol or substance abuse or who were already living in a long-term care facility. In reality many of the cases admitted were complicated by the presence of alcohol addiction, often accounting for the fall that caused their injury. Therefore, when recruitment to the study became difficult and recent admissions were reviewed, the presence of possible alcohol addiction impacted substantially on the number of family members eligible for the study.

In addition it was felt that it would be unethical to approach a patient's family if the patient had additional injuries or multiple pathology that put them in danger of further deterioration. This was left at the discretion of the clinical nurse practitioner so that appropriate approaches could be made.

4.6.4 Identification of the next of kin

The role of the next of kin was to identify family members who they considered to be the patient's family and who they thought may want to take part in the study. Once a patient had been identified that met the criteria above the clinical nurse practitioner would review the medical notes for the documented next of kin. With the exception of age, the criteria set for

the next of kin were minimal. The only criteria were that they had to be 18 years of age or above and have the ability to provide informed consent.

4.6.4.1 Recruitment of the next of kin

The clinical nurse practitioner was able to discuss the study informally with the next of kin during usual professional conversations and if the next of kin felt this was something they wanted to know more about they were given a recruitment pack. The return of the reply slip to me would then indicate that they wanted to meet to discuss the study. However in reality many expressed this wish through the clinical nurse practitioner who then called to invite me to speak with them. During this meeting the study was discussed and if the next of kin felt other family members would wish to take part they signed a consent form and took additional recruitment packs to give to their family members.

4.6.5 Identification of family members

Family members were therefore identified through the next of kin who was encouraged to give consideration to who the injured person would consider as their family. There were however four criteria that needed to be satisfied. The first was that the family member had to be 18 years-of-age or over and the second was that they were able to provide informed consent. The third criterion was set after seeking specialist advice from a neuropsychologist regarding the study design. Their advice was to ensure that all family members knew the diagnosis of their relative prior to taking part in the study. A family member would therefore not be approached if they did not understand the type of injury their relative had sustained.

The final inclusion criterion was set to address the likelihood that relatives do not always live near their family and it was thought that it may not be possible to recruit a relative who lived a considerable distance away. However it was not possible to state prior to the study commencing what this considerable distance would be. Therefore the criterion set referred to the relative as having to live within an accessible region of the UK and during recruitment possible challenges for data collection were explored.

4.6.5.1 Recruitment of family members

Once the next of kin had given the recruitment pack to the family members, individuals who wished to know more about the study were asked to return the reply slip in the pre-paid envelope to myself. Following receipt of the reply slip family members were contacted via telephone and the study was explained and any questions answered. During this conversation the possible places for interview were explored and decisions made about reasonable

distances to travel. In reality all three cases were from the Eastern region; however two family members from two cases lived outside of the region and visits were made to them in the city where they were currently residing. If family members indicated they were willing to participate in the study interviews were then scheduled at least 48 hours afterwards allowing them time to consider whether they wanted to continue or change their mind. At this meeting, before the interview was commenced, a consent form was signed to join the study.

Discussions with clinicians had predicted no problems in the recruitment of families to this study. However, the reality was somewhat different and recruitment stalled after the first two families were enrolled. During this time I increased my visibility at the hospital making more visits, reviewing admission lists with the clinical nurse practitioner and speaking with other members of the medical team to raise awareness of the study. During these conversations it was suggested that the exclusion criteria were amended. However, just as plans were being made to change these criteria the final family agreed to take part in the study.

In total six families were approached to take part and three of these agreed. Of the remaining three, one family did not meet the inclusion criteria and had been mistakenly identified by the clinical nurse practitioner. One next of kin, a mother, really wanted to take part but the rest of the family did not. The third family decided they did not wish to take part and did not wish to receive any further information.

4.6.6 Patient consent

A condition of ethical approval for this study was that the patient should be given the opportunity to provide informed consent that would allow their family members to take part. The challenge was that capacity fluctuates after TBI and where a person does not have capacity at commencement of the study they may well regain capacity midway through the research. Judgement of capacity is informed by the principles of the Mental Capacity Act (2005) and is made by assessing three main aspects. First is the ability of the patient to understand the information presented, second is the ability of the patient to retain this information and then use or weigh the information as part of the process of decision-making and third is their ability to communicate any decisions they have made. Therefore a process was devised that aligned with normal practice in the clinical area for judging capacity for consent to procedures and involved assessment by the senior members of the supervising medical team. The clinical nurse practitioner then informed me of the decision and the process set out below was followed.

No patient in this study had capacity at the start of the study; however, all three patients regained capacity before the twelve month interviews were completed. In these cases the clinical nurse practitioner liaised with the supervising medical team during routine reviews in the TBI outpatient clinic. When the patient was judged as having capacity they were given an information pack by the clinical nurse practitioner and the return of the reply slip to me indicated they wanted to know more about their family's involvement with the study. Following a meeting with me their consent was sought for the continued participation of their relatives. It was an on-going concern that if they did not provide their consent their family, along with their data, would be removed from the study. However, to protect against this occurrence family members were always encouraged to be open and honest about their participation. In all three cases I was able to have informal conversations with the injured person, usually before a research interview was scheduled with their family member. If there were any questions or concerns these could be addressed enabling those who were injured to be comfortable with the purpose of the research, the participation of their family member and my presence in their home.

4.7 Data collection

It was understood that case study methodology often used several sources of information to facilitate closer scrutiny of the case (Yin 2009). Data collection was therefore designed to take place at three intervals during the first year of injury. Having spoken with several healthcare professionals regarding the journey through health care services in this period it was decided to design data collection to mirror these key stages of recovery. Specifically these key stages were, hospital based, possibly following a period within the neuro critical care unit, early rehabilitation, this could be as an inpatient or as an outpatient in the early stages of discharge home, and the last stage was to reflect more long-term recovery when most patients would have been established within a community dwelling. Timing of data collection was therefore set for one, three and twelve months following injury.

Data collection methods were designed to facilitate a comprehensive understanding of the research question. Two specific data collection methods were employed to a) explore the changes reported by non-injured family members affected by TBI at one month, three months and one year following injury (research objective one) and b) identify how these changes impact on the functioning of the family as a whole (research objective two).

Interviews were chosen as the staple of qualitative research (Holloway & Wheeler 2002; Silverman 2006; Creswell 2007). It was felt that within an interview a participant could be

asked to explore their individual experience in depth. From their interview an understanding could then be reached regarding the changes they perceived they and their family had experienced as a result of their relative's TBI. Secondly a structured questionnaire was incorporated into data collection. The questionnaire was used to identify the characteristics of overall day-to-day family functioning, then to assess the change occurring to these characteristics in the year following TBI.

A qualitative case study can combine quantitative and qualitative data and remain within the naturalistic, or in this case constructivist, paradigm (Yin 2009). Beginning with the theoretical position of social constructivism and narrative theory, methods needed to be reflective of interaction-based social phenomena (Silverman 2009). It must be stressed therefore that these two data collection techniques were not brought together to converge on one central truth or reach a more certain conclusion. It was anticipated that the use of these two data collection techniques would together contribute to a greater understanding of the context of change and family functioning following TBI than could be achieved through one method alone. Both interview and questionnaire data collection techniques are discussed in more detail in Sections 4.7.1 and 4.7.2.

Through facilitating an understanding of families' responses to TBI recommendations for clinical practice could be made to achieve the third research objective: to use the findings to inform supportive practice for families affected by TBI.

4.7.1 Interviews

To address the research question in a way that complemented both social constructivism and narrative theory, unstructured narrative interviews were selected. The unstructured interview enabled the interview to be flexible and responsive to the information that the interviewee chose to share. Most commonly in an unstructured interview a broad opening question is asked to commence the interview and then questions are developed from the account shared by the interviewee. Without a structured or semi-structured interview guide in place the interviewee is more in control of the pace and direction of the interview (Holloway & Wheeler 2002). More specifically the narrative unstructured interview approach in research is thought to be particularly useful when investigating difficult, distressing or traumatic events (Hydén 1997). With the interviewee in more control the unstructured approach shifts power and control away from the researcher. Therefore the account that is shared is shaped by the interactions between the interviewer and interviewee. As such, the outcome of each interview was different (Silverman 2006).

Holloway and Wheeler (2002) suggest the freedom in an unstructured account can result in the most useful data but also the highest amount of 'dross'. The 'dross' Holloway and Wheeler (2002) refer to is data that are collected but frequently removed or ignored during data analysis because it is thought they have little to do with the research question. To address this issue a broad framework for the interview was developed that centred the family member on a specific event and the experiences related to it. A narrative style of interview allows this focus on specific events, or periods of time, and can help the interviewer and interviewee to explore how meaning is created from the account people create about these events (Silverman 2006).

To develop this interview framework an adapted three stage process advocated by Wengraf and Chamberlayne (2006) was utilised. The first stage involved inviting the family member to talk about their experience relating to the injury of one of their relatives. During their account family members were not interrupted, only nods or signs of encouragement were given. The second stage was to ask questions about subjects raised by the family member. Wengraf and Chamberlayne (2006) state that these questions should be asked in the same order they were spoken about, using the same language used by the participant. In doing so the chronology of the account is maintained and the participant feels more comfortable with the familiar language.

The third stage would usually be conducted in a separate interview. However, because this research was longitudinal this stage was combined into the same interview. Questions were developed for this stage that addressed issues previously identified in the literature as being significant to families and TBI. These included, relationships, key moments, needs, challenges and perceptions of the future (Kosciulek et al. 1993; Oddy 1995; Webb 1998; Gosling & Oddy 1999; DH 2005). However when these issues had already been explored in an earlier part of the interview these questions were not asked and the interview was brought to a close. An interview schedule can be found in Appendix Three.

4.7.1.1 Piloting of the interview

To ensure that the methods advocated for the interview were appropriate several pilot interviews were conducted with professional colleagues. As a result of these interviews potential problems that may stifle an interview with a family member recruited to the study could be explored. In addition it was always intended that if the first research interview was unsuccessful changes would be made to the interview schedule. In reality the interview guide, structure and content worked well and no significant changes needed to be made.

4.7.1.2 Completion of the research interview

Once a family member had agreed to take part in the study an appropriate environment for the interview to take place was agreed. For some this was in their homes or place of work, as this was most convenient for them, and for others the interview was conducted in the Wellcome Trust Clinical Research Facility (WTCRF). It was more usual for initial interviews to be conducted in the WTCRF while the injured person was still an in-patient. Once discharged all interviews were completed in a home or work environment. It is important to make those participating in an interview feel confident and comfortable so they are not in awe of the researcher or the environment (Holloway & Freshwater 2007a). When in their own homes or work place the family member controlled the environment which helped them to feel more in control and helps re-balance the power between the participant and the researcher.

However when using the facilities of the WTCRF the environment was very much a medical facility and the rooms used were obviously used for outpatient clinics with examination beds, and investigation trolleys. Therefore before each meeting the room was 'de-cluttered' to leave the minimum of furniture including two chairs of equal height. Even after these attempts the room and environment was still clearly a clinical area therefore it must be considered if this influenced the family members to tell a more medical account than they may have if a more neutral setting was used.

Interviews were commenced and a digital audio recorder was used to record the interview and a few field notes were made on the interview form. Field notes are records of observations made during or after data collection (Corbin & Strauss 2008; Gibson & Brown 2009). Those made during data collection were primarily for the purpose of posing follow-up questions as part of the interview itself. Those made after were to describe the events that had taken place, to reflect on those events and to identify any particularly pertinent issues (Corbin & Strauss 2008). It was expected that the interviews would take approximately 60-90 minutes; however in reality this ranged from 40 – 137 minutes.

Predominantly the unstructured interview style worked very well and once participants became comfortable with the lack of direction they were able to talk for extended periods without interruption. This un-interrupted account was especially powerful in the very acute stage after injury perhaps because this was the first time family members had spoken in-depth about the experience. However, later in the study there were two family members in particular who really struggled with the lack of structure in the interview and pushed for more direction. These few interviews were conducted using a style that was closer to a conversation

than an interview but this helped those participants to feel more comfortable and able to engage in the research.

4.7.2 Structured questionnaire

To identify and describe change in the family system post-head injury, and contribute further to addressing the research question 'What are the changes reported by non-injured family members during the first year of a family member's traumatic brain injury?' a structured questionnaire was used. Arguably family functioning is a construct known to the TBI literature and was explored in Chapter Three Section 3.7.1. Where a phenomenon is considered to be well understood research designs are frequently quantitative in nature and use outcome measures validated to collect data on that specific phenomenon. Therefore it seemed a logical decision to use a tool designed to measure the core characteristics of family system functioning and through this it would enable any changes in these values to be identified.

In clinical practice measures that are frequently used predominantly only considered change in terms of the injured person. Common measures such as the SF-36 (Ware & Sherbourne 1992) and Glasgow Outcome Score (Jennett & Bond 1975) are used to estimate disease burden and quality of life for the patient. What was required for this study was a tool that could examine the characteristics of the family and identify change for the non-injured individuals.

In the research literature popular outcome measures for the family included the Family Assessment Device (FAD) (Epstein et al. 1983) and the Family Adaptability and Cohesion Evaluation Scale (FACES) (Olson & Gorall 2003). These tools are considered to be some of the most used and psychometrically sound measures of family functioning (Kaslow et al. 2011). Kaslow et al. (2011) stated that 'self-report measures are easy and inexpensive to administer and score, useful in assessing family relations and processes and can measure change' (p304). Therefore, these tools were retrieved and reviewed for their ability to examine family functioning and identify change.

Following this process the outcome measure FACES was judged to be the most appropriate for this investigation. The FACES tool has been designed and validated using family systems theory and asked questions regarding family functioning that may not be explored within an interview. Permission to use the FACES instrument was provided by Life Innovations Inc. (see Appendix Four) and a copy of the questionnaire can be found in Appendix Five. FACES-IV is the most recent and considered to be the most comprehensive version. The tool utilises the Circumplex Model of family functioning (Olson et al. 2007) and the main hypothesis of this model states:

‘Balanced levels of cohesion and flexibility (low to high levels) are most conducive to healthy family functioning, while unbalanced levels of cohesion and flexibility (very low or very high) are associated with problematic family functioning.’ (Olson & Gorall 2006, p3)

Therefore the FACES tool evaluates the relative health of the family system by measuring the balance of these two constructs: cohesion and flexibility. The system is rated as healthy or unhealthy based on self-reports from the family members completing the survey. The underpinning principle is that if families are too separate or too close together, too flexible or too rigid, when faced with a substantial change or traumatic event the family may not be able to adapt. The model suggests that this inability to adapt to the change in roles, relationships, structure or purpose can put the system at risk of severe disruption and distress.

Although presented as one complete survey the full FACES-IV package actually consists of three separate scales that should be used all together (Olson & Gorall 2006). The first is the FACES-IV questionnaire, the second is a family communication scale and the third is a family satisfaction scale. The scales are all self-report ordinal measures, using a five item response Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), or 1 (very dissatisfied) to 5 (extremely satisfied) (Olson & Gorall 2006).

The FACES-IV tool is a 42-item scale that asks questions pertaining to six areas of the Circumplex Model that correspond to the two variables cohesion and flexibility. First the cohesion variable is associated with how the system balances separateness and togetherness. Systems that achieve this balance are thought to have a more functional life cycle (Olson & Gorall 2003). The three specific measures are the cohesion, enmeshed and disengaged scales of the questionnaire. Second flexibility is hypothesised to be a balance between stability and change. The ability of the system to adapt to change is thought to be a characteristic that distinguishes functional from dysfunctional families. The three specific measures are the flexibility, rigid and chaotic scales of the questionnaire.

Lastly the communication and satisfaction questionnaires are two ten item scales based on how the family member perceives communication strategies between family members and overall how satisfied they are at that time with how their family functions on a day-to-day basis. Olson (2010b) suggests that communication strategies aid families to alter or adapt their level of cohesion and flexibility. The complete package has a total of 62 items, takes approximately 15 minutes to complete and is validated for those twelve years of age or above (Olson & Gorall 2006).

4.7.2.1 Validity and reliability

Since the first publication of FACES in 1979 a version of this tool has been used in more than 1,200 articles and dissertations (Olson et al. 2007). This suggests that it has widespread utilisation and application across health and social care research. Content validity for the instrument was ensured through engagement with family therapists and previous development of earlier instruments FACES-II and III. Construct validity was demonstrated through an extensive confirmatory factor analysis (Olson et al. 2007). In addition FACES-IV was also compared to three other family assessment scales as a measure of concurrent validity. Specifically these were the Self-Report Family Inventory (Beavers et al. 1985), the Family Assessment Device (Epstein et al. 1983) and the Family Satisfaction Scale (Olson 1995). The results of this comparison demonstrated the FACES tool was of equal validity as the tools it was compared to.

Reliability of the instrument was demonstrated through an alpha reliability analysis. Internal consistency is the accepted measure that a tool can reliably measure the same trait consistently and can facilitate the identification of measurement error in quantitative instruments (Polit & Beck 2008). When calculations are completed higher co-efficient scores are more indicative of greater reliability. The specific results for FACES-IV were Enmeshed = .77, Disengaged = .87, Balanced Cohesion = .89, Chaotic = .86, Balanced Flexibility = .84, Rigid = .82. Overall therefore the internal consistency of each of the six scales revealed very good alpha reliability (Olson 2010b).

4.7.2.2 Completion of the questionnaire instrument

It was important to identify the correct time to request family members complete the FACES questionnaire. It was felt that if family members completed the questionnaire at the start of the meeting and just before the interview it may change the focus of their attention to be more in line with the questions the survey asked. Therefore it was decided that following completion of the first interview the family member would be asked if they would like a short interval. After this short break they were orientated to the questionnaire, its purpose and structure and they would be invited to complete it. Before subsequent meetings family members were asked if they would like the questionnaire sent to them in advance for completion before the interview. Almost all participating family members requested completion prior to the interview.

Use of the FACES-IV tool in this study presented some challenges. First during its completion there were some comments from participants about the language used in the questionnaire.

The tool was created in America and questions sometimes felt awkward. Secondly the way in which the questions were phrased also raised some discussion. Family members wanted to know how to interpret a question such as 'it is hard to know who the leader is in our family' and if their answer would be perceived as a positive or negative trait of family functioning. In addition it was also felt that for older families where children were outside of the family home questions like 'there are strict consequences for breaking the rules in our family' appeared less relevant or appropriate. Despite these concerns the family members completed the questionnaire with relative ease and very few omissions. Most completed the questionnaire in their own time and made little comment following the first administration.

4.7.3 Data collection summary

Unstructured narrative interviews and a structured questionnaire were chosen to explore the changes reported by non-injured family members and the subsequent effects on the family as a whole up to one year following a TBI. The interviews were chosen as a means of exploring in-depth the individual account and the structured questionnaire provided a specific measure of the changes associated with the way the family functioned throughout the first year of TBI.

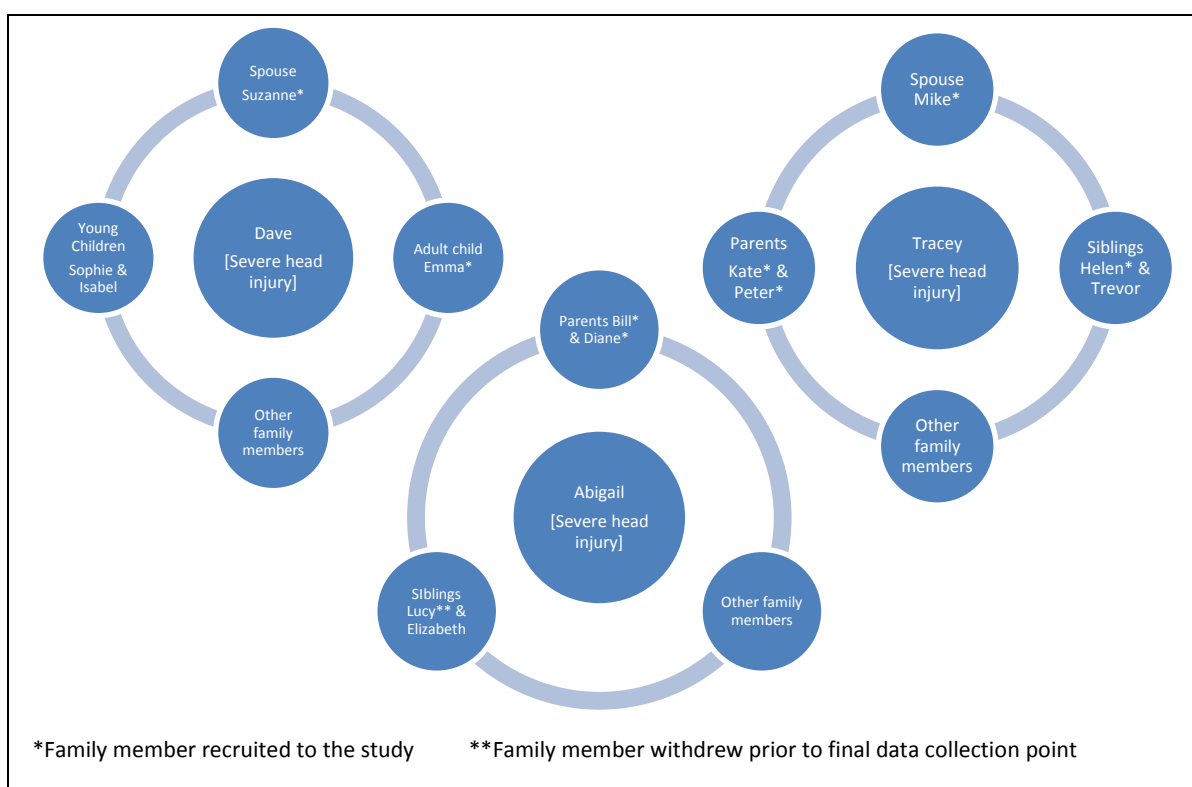


Figure 4.1 Family cases recruited to the study (all names are pseudonyms)

The families recruited to the study are illustrated in Figure 4.1 (all cases were anonymised and pseudonyms assigned to family members). The first case consisted of two family members, a

wife and a daughter. In the second case three family members were recruited, two parents and a sibling. However in this second case, one member was unable to complete the questionnaire at the three-month data collection point and another member withdrew before the final interview. In the final case four members participated, a spouse, two parents and a sibling. Therefore this study included a total of 26 narrative interviews and 25 completed questionnaires.

4.8 Ethics

4.8.1 Ethical approval

Ethical approval for this study was granted by the Cambridgeshire 2 Ethics Committee in October 2008 (REC Reference Number: 08/H0308/181). However before approval was granted the panel specifically requested a change to the research design that would ensure that the injured family member was given the opportunity to be informed of the research and provide their consent for family members to take part. This requirement and subsequent development of the research protocol was discussed under Patient Consent in Section 4.6.6.

There were also several other ethical issues that were particularly pertinent to this research. Specifically these were informed consent, inclusion of children, support for participants, support for myself as the researcher, confidentiality and anonymity.

4.8.2 Informed consent

The patient, next of kin and the participating family members were all given detailed written information in the form of a recruitment or information pack. Each pack contained a cover letter, information sheet, reply slip and an example of the consent form (see Appendices Six - Nine). If the reply slip was returned I would either meet with the family member face-to-face or discuss the study over the phone. All those taking part in the study had at least 48 hours between these initial discussions and the completion of a formal consent form. All participation was voluntary and participants were reminded that they could withdraw at any time.

4.8.3 Inclusion of children

Following extensive discussions with supervisors, professionals and members of the ethics committee it was decided not to include children in the current research, despite the knowledge that children are frequently missing from investigations and that a family-centred investigation may be limited without their inclusion. However there were a number of

challenges that were thought to increase the child's vulnerability and perhaps put them at greater risk of harm.

Firstly was my own limited academic and professional contact with children that meant I was potentially ill equipped to deal with data collection involving children especially regarding such a sensitive issue. Second was the timing of interviews that took place very soon after the accident. It may have been inappropriate to talk to the child at such an early stage. Thirdly was the development of more appropriate and child-centred data collection approaches that would support a child to take part but would need to differ greatly from the adult tools used. Arguably these challenges meant that it was considered in the child's best interest not to be asked to participate in this specific study.

4.8.4 Support for participants

It was acknowledged during the design of the study that interviewing participants following such a traumatic event would be challenging and a strategy should be in place to provide support where necessary. This strategy included putting the Headway helpline number in the information pack. Headway is a charitable organisation that provides support services for people affected by brain injury. Family members were reminded before and after the interview that they could contact Headway at any time to seek advice and support (permission for this was granted by Headway and is included in Appendix Ten). Before the interview commenced the family member was also reminded that if they felt uncomfortable or upset during the interview they could stop at any time.

All family members who participated have at one time found the re-telling of their experiences emotionally difficult. It was important during these moments to first give the family member time and not to interrupt them. After a silent moment many found their voice again and continued. Others were given the opportunity to suspend the interview while they recovered. One family member chose to continue but another found it too distressing and we terminated the interview. After the interview was suspended we continued to talk and this family member said at the time that she was simply not ready to tell her story. I invited her to contact me if she felt she wanted to complete the interview at a later stage; however it was not till the third interview was scheduled that we met again.

Before leaving an interview support mechanisms were explored such as who they were going home to and who they could contact to talk about how they were feeling. In addition a few days after the interview family members were followed up with a phone call to see how they

were. During this conversation the Headway organisation was again identified as a useful support mechanism for them to follow up when they felt it was appropriate.

It has been suggested that for those who are from the caring professions role conflict in research is a particularly contentious issue (Holloway & Wheeler 2002). The distinction between the needs of a researcher relationship versus a clinical relationship should be defined and the related limits and boundaries of the researcher role understood by both parties (Hennink et al. 2011). Although the researcher should still respond to emotional distress, therapy is not the goal of interviewing and confusion in role definition can shift the balance of power and change the dynamic of the researcher participant relationship (Holloway & Wheeler 2002).

However, Colbourne and Sque (2004) are less concerned by the notion of role conflict, instead preferring to emphasise that a nurse has many skills that can be useful in a research setting and these should not be dismissed. Therefore I was always mindful that my position was as a researcher but felt I was able to offer comfort and reassurance. In such situations I preferred to actively listen and only offered support when I felt it was appropriate. In addition I was careful to ensure this support was not advice; instead I signposted to support services and enquired about other support mechanisms. It is worth noting that none of those participating in this study were using any external support networks and although many spoke of the possibility of contacting Headway only one person said they had; however, this contact was for specific advice about her husband's driving licence. Although the research interview is not a form of therapy interviews can be, and were often described by participants, as therapeutic (Holloway & Wheeler 2002). Several participants said they were grateful of the opportunity to talk about their experience and were concerned that without the study there would not have been anyone to speak to.

4.8.5 Support for the researcher

Although I knew interviewing people during this period would be personally difficult and useful support mechanisms were put in place I did not realise just how much their lives would infiltrate my own. It was particularly hard dealing with the accounts during transcription and analysis as interviews were replayed and re-read to ensure an accurate representation had been achieved. Such immersion in the minutiae of their stories at such traumatic times was something I was not prepared for and was the hardest stage of the study. Etherington (2007) wrote about this situation when she asked someone to transcribe her research interviews about drug abuse. Etherington (2007) said that while listening so closely and repeatedly to

stories that contained traumatic images, objectivity and distance were hard to maintain. Furthermore the person transcribing also talked about feeling like an intruder or voyeur at times. I too grappled with these feelings at particular times in the research process. During the transcription process it felt wrong to examine their story as if it were an object of intrigue. Curiously I did not feel such strong emotions during the research interview, perhaps because it felt more 'of the moment', I could judge body language, intervene if necessary or offer some comfort if appropriate. Alternatively it may be that during the interview some of the details and powerful images were missed in the unfolding account that later during transcription became so moving.

Support mechanisms to deal with this included regular face-to-face supervision, ad hoc phone calls to supervisors regarding how to address specific issues and peer support at my place of employment. It was also important during this period to take time out, consider the whole story and why the family member was telling me their story in the way they were. Using a reflective diary to log these emotions and feelings helped to process and structure my thoughts. A counsellor is also employed by the Cancer, Palliative and End of Life Care research group in the Faculty of Health Sciences, University of Southampton, and access to the counsellor was agreed before the study commenced. Although interviews were quite challenging the need to access this more formal support did not arise.

In research where there is prolonged engagement with the participants and/or environment of interest it is common to build a close relationship with people over the course of the study (Butler-Kisber 2010). Therefore as the study came to a close there was a sense of uneasiness that I would no longer be in contact with these people and no longer have access to their unfolding journey. However, I have kept in touch by informing participants of the study's progression and they know that I will be in contact with them once the study is complete to ask if they would like a summary of the findings. Arguably it would not be appropriate to maintain any more contact than this and all those participating knew I would not be in regular contact after the completion of their final interview.

4.8.6 Anonymity and confidentiality

Due to the personal nature of qualitative case study anonymity and confidentiality present particular challenges. The first stage was to allocate each family member a code so that any personal information that was collected could be held separately from the interview and questionnaire data. The second stage was to provide each family member with a research pseudonym that would be used during transcription of the interviews. In addition other

places, names and immediately identifiable information were changed at the point of transcription. However, because this was such an in-depth study with several family members taking part there was an increased likelihood that even after these precautions were taken families would be able to identify themselves and the account may feel familiar to others external to the family, for example those involved in the injured person's care.

Although participants were made aware of this during the consent process the necessity for detailed and thick description means there remains a tension in the ability to make the data completely anonymous (Pope & Mays 2006). As such this process needs great care and consideration to the balance of risk and potential harm in the re-telling of their story (Butler-Kisber 2010). During the analysis more distance was achieved between the person and the data and over time it was easier to identify elements of the account that could be changed or removed without affecting the integrity of the analysis. It was important to achieve a sensitive re-telling that balanced what was said in the research setting and what needed to be re-told in the findings.

4.9 Data analysis

The data analysis process is described in the following paragraphs and worked examples of each stage are presented for clarity. Data analysis is separated into three sections for discussion. First is the analysis of the narrative interview data, second is analysis of questionnaire data and third is how the two data sets were brought together for final conclusions to be made.

4.9.1 Representing the case

Although it has been suggested by Yin (2009) that there is a lack of definition in the data analysis process he goes on to say that a general analytical strategy is required that identifies the priorities of analysis. One of the first aims of this analysis was the clear and detailed description of the case under investigation (Yin 2009).

A thorough exploration of the family case was achieved as the first stage in the analytical process. Diagrams were drawn to represent what was initially understood about the family system and reflections made in a research diary. Consideration was given to who could be considered as the core family members and what relationships they had with each other. Other members of the family were also identified through the interviews that were in more supporting roles such as cousins, aunts and uncles. Once a map of the family system had been drawn questions were then posed about the family that helped me to understand the

structure, form and function of each particular family. These questions were developed from the elements of family systems theory portrayed in Figure 2.1 (p17) and were reflected on in a research diary. Information from the interviews was then used to identify family characteristics, the family's life stage, day-to-day function and purpose, the nature and circumstances surrounding the injury itself and what seemed to be changing in the family as a direct result of the injury sustained. This process of representing the case was then included in the first part of the transcription page to support and inform analysis of the interview data (see Appendix Eleven).

4.9.2 Analysis of interview data

The process of analysis for the interview data is detailed below. The discussion outlines how raw data were turned into the final findings and moves through three main stages. First raw data were turned into a transcript, second the transcripts were organised, coded and reflected upon and finally an interpretive process was required to identify narrative threads that translated into the primary findings of this study. Throughout the analysis a number of interpretive decisions were made that influenced the final findings of the study and are discussed below.

4.9.2.1 Narrative analysis

Many researchers refer to the collection of qualitative data as the collection of 'narrative'. What they refer to is textually based material that during analysis is usually broken up into pieces and treated as separate from the surrounding discourse (Riessman 1993). However approaches to narrative inquiry are specific research strategies that consider how the re-telling of events and experiences can reveal more about the experiences than simply identifying a factual account (Bingley et al. 2008). In this narrative form the textual data collected are treated more holistically and attempts are made to maintain or reconstruct a whole story rather than break the experience into small pieces or fragment the story into thematic categories (Riessman & Quinney 2005).

Narratives are continuous stories with connections that are threaded and intertwined throughout (Holloway & Freshwater 2007a). The most important difference between narrative and other text-based data is 'sequence' and 'consequence' (Riessman & Quinney 2005). Sequence is the temporal ordering of events that have been selected for sharing, organised to fit together with the 'what came before' and the 'what should go after' and are thus connected in some way. This ordering provides a platform for plot and storylines to convey meaning that will help show others what the experience was like from the teller's

perspective (Floersch et al. 2010). Therefore the process of sense making of life before, life now and life after reveals temporality and plot that are the hallmarks of narrative inquiry.

There are a range of narrative approaches within the literature that Riessman and Quinney (2005) helpfully portray as a continuum. At one end is the consideration of entire life stories and at the other situated or discrete stories within an account become the unit of analysis. The method employed in this study is in the middle of this continuum. Riessman and Quinney (2005) exemplify this approach by stating:

‘Here, personal narrative encompasses long sections of talk – extended accounts of lives in context that develop over the course of single or multiple interviews. The discrete story that is the unit of analysis in Labov’s definition gives way to an evolving series of stories that are framed in and through interaction.’ (Riessman & Quinney 2005, p394)

Bleakley (2005) explains further that for those applying a structured analysis to a unit of data such as the approach by Labov and Waletzky (1967) will attend to the ‘what’ of a story. In contrast analysis that considers the social meaning of the storied account can be considered the ‘way’ of a story.

The application of analytical approaches to qualitative data is challenging because researchers are often required to interpret the approach or framework and apply it within the context of their own study. As strategies become less prescriptive the researcher has more freedom to custom make a procedure that will be appropriate for the aims of their study (Creswell 2007). Although there is freedom within the interpretation and application of data analysis techniques there are general principles and theoretical underpinnings that should be applied, and are essential to valid and rigorous data analysis (Miles & Huberman 1994; Holloway & Wheeler 2002). Therefore the understanding of narrative put forward by Mishler (1995), Lieblich et al. (1998) and Riessman (1993; 2008) have been particularly influential to the process of narrative analysis used in this study.

Lieblich et al. (1998) explained that narrative analytical processes have two main dimensions. In the first there is a choice between holistic or categorical approaches. In the second the researcher’s intention is to pay attention to either the content or form of a narrative. This study chose a holistic content approach. A holistic approach intends to preserve a narrative in its whole form as much as is possible and in examining content considers the ‘what happened and why’.

However consideration also needs to be given to the limitations of narrative approaches. The primary critique is the use of 'story' as research. In a guest editorial for *Qualitative Researcher* Thorne (2009) asks is a story enough to make a valid contribution to the evidence base. Thorne questions the ready acceptance of 'it's true because they say it is' in qualitative, and more specifically narrative approaches. However, stories told and interpreted are not usually accurate representations of what actually took place (Carter 2008). The emphasis in stories is the interpretation of meaning rather than discovering the 'truth'. Indeed, Bruner (1990) stated that the status of stories will always be somewhere between real and imaginary. However, Holloway and Freshwater (2007b) remind us that the motivation of the storyteller is rarely to tell lies and highlight the importance of exploring the intentions and motivation behind the account:

'When talking about their lives, people lie sometimes, forget a lot, become confused, and get things wrong. Yet they *are* revealing truths. These truths don't reveal the past 'as it actually was' ...(T)hey give us instead the truths of our experiences...Unlike the Truth of scientific ideal, the truths of personal narratives are neither open to proof nor self-evident.' (The Personal Narratives Group 1989 cited in Riessman 1993, p22)

This explanation suggests that narrative analysis examines the 'point' of the story and why it was told in that way. As such identifying cause and meaning is important. The focus therefore is to ensure methodological rigour to provide the backbone to a sound and scientific investigation. Narratives should not be text simply repackaged and presented as the product of research. Narratives need to be analysed thoroughly and inductively to look for the 'why' not just the 'what' and extract the meaning held within an experience shared (Riessman 1993).

4.9.2.2 Stage one: transcription

The first step in working with interview data is to turn the raw data into what Miles and Huberman (1994) refer to as an 'intelligible write-up' (p51). The writing up of audio files produces a transcript that is a record of what took place between the interviewer and interviewee. Transcription is a re-presentation of the raw data into a new form (Gibson & Brown 2009). There are therefore several issues which affect how this account is recorded.

It was always intended to create a transcript that recorded all of the participant's account. Not only because the richest data is thought to stem from the fullest transcription of audio material (Holloway & Wheeler 2002) but also because of the commitment of the narrative approach to explore the whole experience. It did not therefore seem appropriate to remove or ignore aspects of the interview data at such an early stage.

A Microsoft Word document was created to facilitate the transcription process. Firstly a front page was developed that would be used for each participant's transcript. Information was to be recorded that referred to the date, time and location of interview, the code and pseudonym assigned to the participant and their family, any biographical data that were useful such as the nature of the relative's injury and stage of recovery and also a simple family diagram to help orientate me to the structure of the family system. Secondly the pages were set up to incorporate a margin at both the left and right hand side for notes and indexing, and page numbers were inserted in the footer (Holloway & Wheeler 2002). It was decided that because predominantly only the participant was speaking in the interview that whenever I as the interviewer spoke, to perhaps ask a question, this would be denoted by 'CW' in the margin otherwise it would be assumed the text represented the interviewee.

Holloway and Wheeler (2002) suggest using a form of indexing so that lines of text can be traced back to their origins within the data set. During transcription this indexing followed the time line of the interview; however because the transcription software counted down rather than up the indexing started at the total time the interview took and ended at zero. For an example of the front page and transcription page layout see Appendix Eleven.

The final decision about what would actually be recorded within the transcripts was decided upon after several attempts at representing the raw data. A focused approach to transcription uses parsing to separate the lines of speech and will also often record intonations of speech by using specific symbols to note such things as inflections and pauses (Gibson & Brown 2009). However after attempting this approach the transcript produced became fragmented and the representation created felt more detached from what actually took place. To address this problem Riessman (1993) suggested that a rough analysis can be used first followed by more detailed analysis later. Therefore a more unstructured approach was applied that would still provide a detailed overview of the entire data set but without separation into clauses. Pauses, sighs and emotional responses were then written in the transcript where appropriate to ensure the original emphasis was not lost.

Transcription should also enable the researcher to apply structure and order to the data so that they can orientate themselves within the data and find their way around (Holloway & Wheeler 2002). However by choosing not to use clauses some of this structure was lost and the transcript was in danger of becoming pages of unbroken text. Therefore it was decided that the text would be separated into paragraphs consisting of sentences that were immediately related to each other. A paragraph would end as the participant made a natural

pause in the account or when they changed the content of what they were talking about. This process helped to keep relevant issues within the original context to which they were discussed. A new indexing system could also then be applied that numbered each paragraph sequentially from one upwards and the format used for transcribing was updated (see Figure 4.2).

1:13:10	54.	But the first day I just couldn't be, I mean I just couldn't talk about my husband I just...it was just too much. I mean I did after a while but not on the first day, I was devastated.	<i>I was devastated</i>
1:13:00	55.	Because Dave is like the pillar of the house...I mean when I met him, I mean we've got a twenty year difference gap [laughs]... but er, when I met him he was ... he'd lost his wife... erm, his first wife died [...] so he went through hell.	<i>He's the pillar of the house</i>
1:12:39	56.	But when I met him he had already set up his business, and you know he had his bank and everything, you know, I mean he was just er...he was living on his own so I kind of, when I met him I kind of tagged along and er, I let him do all the financial, all the finances and everything... so when the accident happened I had to deal with his business... I had to deal with his customers I had to deal with the bank and the building society and you know...I'd never done that before because, because he'd...he's always done it and I didn't see	<i>I tagged along</i> <i>I had to deal with...</i> <i>He's so disorganised</i> <i>He's always done it</i>

Figure 4.2 Extract from transcription and coding process

For novice researchers transcribing the interviews personally is recommended (Holloway & Wheeler 2002) and by transcribing the interviews in this way they are able to become immersed in the data. All audio files were therefore transcribed personally using transcription software. This software allowed playback at variable speed, fast forward, rewind, and management of digital audio files. Becoming immersed in the data was also helped by constantly returning to the audio data to check the accuracy and appropriateness of what had been written as a representation of the account (Gibson & Brown 2009). This process also acted as a means of becoming more familiar with the data and helped to maintain a focus on the individual's whole experience.

4.9.2.3 Stage two: coding

Once a transcript had been created the next stage was to work through the transcript to identify aspects of the account that were relevant to the research question. Floersch et al. (2010) argue that those engaging in narrative techniques rarely discuss coding strategies. However, all analysis must start somewhere and although Floersch et al. (2010) state that narrative analysis focuses on temporality and sequence, linguistics and the use of language, rather than apply a coding process, for the purpose of this study this felt too ambiguous.

Therefore it was felt that a coding technique could still be used so long as the account was not fragmented and relevant contextual material was not lost.

Codes were therefore assigned to the transcript to identify where within the transcript an issue of importance was located. This process of coding is considered to be the beginning of analysis where the researcher really starts to work with the data and moves beyond the raw account:

‘Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to ‘chunks’ of varying size-words phrases sentences, or whole paragraphs, connected or unconnected to a specific setting. They can take the form of a straightforward category label or a more complex one (e.g. metaphor).’ (Miles & Huberman 1994, p56)

However, during the coding process it was difficult to identify what should and should not be allocated a code. To code everything can create too much information to get lost in and to code too little would risk a superficial analysis. Both approaches can lose sight of the account as a single whole (Holloway & Wheeler 2002).

Therefore Miles and Huberman (1994) recommend that before commencing the coding process it is useful to return to the research question and ask questions of the data that relate directly to it. Therefore from the primary research questions ‘what are the changes reported by non-injured family members during the first year of a family member’s traumatic brain injury?’ and ‘within one family what are the effects of traumatic brain injury up to one year following injury?’ the following questions were developed: ‘What happened and what is happening now?’, ‘Who is this person and who is this family?’, ‘What is shifting, changing being redefined? And ‘What does the future hold?’. Asking these questions during analysis acted as a means of foregrounding certain issues without engaging prematurely in an interpretation of the text.

Although the data became more manageable and organised following coding, this process is associated with breaking the whole into pieces and risked losing the original context of the surrounding discourse. To keep the whole as intact as possible but still make the data manageable to facilitate analysis it was important not to move away from the original data too early in the analysis process. Codes were used as a means of labelling an aspect of the transcript that could be returned to again after the coding process to explore the surrounding discourse and origins of that code. Codes were either single words or phrases that had been used by the participants. These simple codes were used to ensure assumptions and interpretations were not imposed too early (Holloway & Wheeler 2002).

However some selection and prioritisation of the data is always necessary during this process therefore most paragraphs, but not all, were assigned one code or several. However re-playing of the audio and re-reading of the transcripts helped to ensure important aspects of the account were not missed and increased understanding of the whole account (Riessman 2008). Codes were then written in the margin of the transcript clearly linked to the piece of text to which it was assigned (Miles & Huberman 1994). An example of the simple codes assigned to an extract of transcript can be seen in Figure 4.2 (p83).

Coding is, or should be, more than just paraphrasing what was said. Coding should facilitate the researcher to move from description to a more conceptual level (Corbin & Strauss 2008). Therefore beyond the stage of assigning simple codes came the search for meaning held within the codes. Memos about the codes assigned were therefore recorded in a research diary. Memos are ideas and thoughts about the data, reasons for patterns and recording of assumptions (Corbin & Strauss 2008). This research diary was maintained to enhance the trustworthiness of the final findings by recording an audit trail of the origins of any interpretations made (Holloway & Wheeler 2002; Creswell 2007) (see Figure 4.3).

Memo: He's the pillar of the house
Describing her husband as the pillar of the house Suzanne is explaining how
important Dave is to the day-to-day functioning of the family. If this pillar
was removed, as it now has been, would the family fall apart? It would seem
that Suzanne felt prior to the accident that would indeed be the case. Later in
the transcript Suzanne speaks about 'I just tagged along'. Does this suggest
that she does not see her role as valuable to the survival of the family as Dave's?
Is the absence of Dave, during admission to hospital, more distressing because
Dave is so central, so core, so indispensable?

Figure 4.3 Extract from research diary

At this stage codes were very descriptive and reflected the motivation of the research question. However it was then necessary to align the analysis more closely with narrative theory. Temporality and sequencing are the key technical differences that set narrative analyses apart from other forms such as thematic and grounded theory approaches (Floersch et al. 2010). In addition, the exploration of context is said to deepen the interpretation and portrayal of the experience (Cortazzi 2001; Riessman 2003). Therefore the process of analysis had to be developed so that sequence and consequence could be clearly identified (Riessman 2008). To address these key elements of narrative, codes were organised into a table using columns entitled sequence, context and consequence (see Table 4.2).

The column entitled 'sequence' was used to organise codes designating chronology and temporality within the account. These codes would orientate the reader to the time and place being described. The 'contextual issues' column was used to bring together any social and personal aspects that were spoken of and finally the 'consequence' column was either the description of what actually happened next or a perception of what the family member thought might happen in the future. By assigning each code from the transcript to a specific column the chronology of the original account could be respected. Once all codes had been assigned the table was reviewed and codes were then interpreted, condensed and reduced into more meaningful statements.

Sequence	Contextual issues	Consequence
Orientation to the day of the accident		
Injury	Knew it was bad	He could have died I was really worried about the brain
First sight	I thought I was strong enough I shouldn't have taken the children	Children scared to return need to protect them from further harm
Critical care unit	Unfamiliar medical world Search for information	In the end you knew more than they did
Deterioration	Sedation, intubation Pneumothorax chest drain Allergic reaction was careless	He could die Realisation It's a miracle
Sharing stories	Other family members gave support So many people are worse off Everyone was so kind	Who will be next? Wanting to help others
Waking up	Told he won't be the same What will be lost	Looking for signs "it almost looks like him" Discontinuity

Table 4.2 Organisation of interpretive codes (extract from analysis)

This process was to 'restory' the narrative into a format that enabled chronology, context and a causal link between ideas (Creswell 2007, p56). The concept of restorying the account was derived from the work of Mishler (1995) who presented a typology of three narrative analysis processes: reference and temporal order; textual coherence; structure and narrative functions. This study fell into the category of reference and temporal order where there is an 'order of the told', the assumed sequence of the account in real time and the 'order of the telling', the narrativised account that is created to tell a story about the events that happened. Mishler (1995) stated that 'adopting this realist perspective, researchers tend to privilege the 'real' sequence of events, giving it an objectivity independent of language' (p92). The specific approach applied in this study was 'reconstructing the told from the telling' and is often used where large amounts of data are collected:

'researchers reassemble selected episodes from interviews and other sources into a chronologically ordered series: they reconstruct an order of the told from the telling(s). This becomes the 'narrative' for further analysis.' (Mishler 1995, p95)

Mishler (1995) used this approach to assemble work trajectories into a real chronological order for further analysis. Following this example the principle aim of the analysis was to pull the data together into a whole that could be understood from a macro perspective. The order applied followed the chronological timeline from point of injury and through the milestones of recovery. Once the whole could be seen and worked with the minutiae could be analysed and important elements of the narrative identified for the relevance they had to the whole account. Each of the sequence codes was then explored alongside any relevant contextual issues and their related consequences. These explorations were recorded in a research diary and connected to extracts of data where appropriate. These narrative elements represented the significant events held within the account and the meaning attached to them. This process is depicted in Figure 4.4.

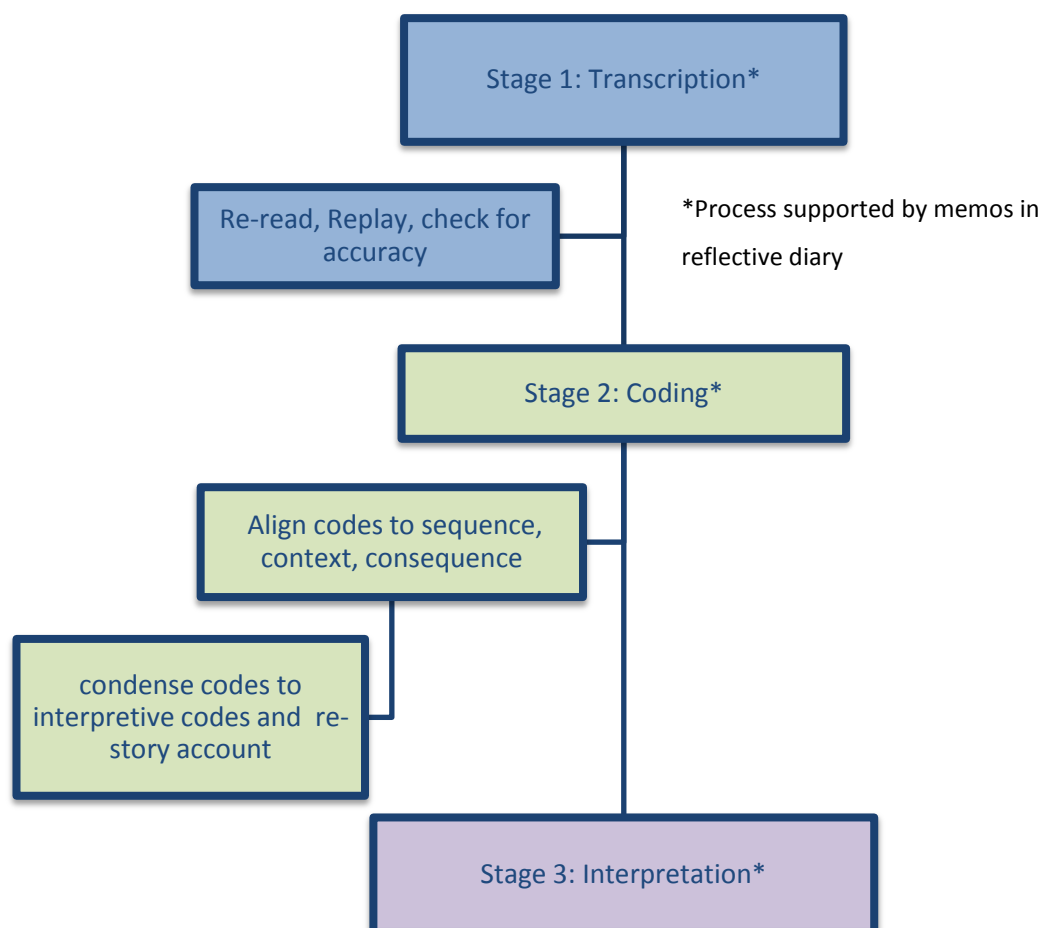


Figure 4.4 Flow chart of data analysis process

4.9.2.4 Stage three: interpretation

The next stage was to move beyond codes and restorying the account into a stage of more in-depth interpretation. The aim of this interpretive process was heavily influenced by the Life

Thread Model described by Ellis-Hill et al. (2008). Conceptualising the whole account as comprising a number of narrative threads enabled a more holistic analytic approach. Therefore the aim of the analytic process was to create narrative threads that when combined represented the whole story as told by the participants. Narrative threads were first interpreted on an individual level and then how these contributed to overall family narrative threads was considered. When a narrative thread was identified it was considered in terms of temporality and plot. Therefore narrative threads emphasised the beginning, middle and end of the narrative and each contained a core message that conveyed the 'point' of the story.

This interpretive process required a number of analytical layers. First was consideration of each individual family member's account at each data collection point. These were titled 'individual narrative threads'. Data from all three data collection points were then compared together to create 'longitudinal narrative threads' for each family member. Finally the narrative threads from individuals of the same family were compared to create 'family narrative threads'.

4.9.2.5 Individual narrative threads

The first level of interpretation considered each of the participant's accounts on an individual basis. The codes assigned to the table depicted in Table 4.2 (p86) were reviewed alongside the extracts of interview data that underpinned them. Working backwards and forwards between the transcript and subsequent interpretations a number of narrative threads were identified that reflected the individual's experience, the effect that the family member's head injury had had on them, and their perception of how the experience had affected others.

In qualitative inquiry researchers are encouraged to become immersed in their data and Morse and Field (1996) suggest that qualitative data cannot be analysed sufficiently without doing so. However this immersion has led to researchers feeling as though they are 'drowning in data' (Morse & Field 1996) and the clear pathway through the data to interpretation is fraught with complexity. Therefore strategies should be employed to maintain structure and order in the process of analysis and enable control over what can be an unwieldy amount of data (Holloway & Wheeler 2002).

Unlike analysis strategies where data can be managed and organised by breaking it apart into small units of text, narrative approaches maintain a commitment to keep data together, as far as is reasonably possible. However keeping lots of data together further adds to the challenge of managing large amounts of information and interpretations. Therefore the aim of analysis

was to be as systematic and organised as possible, thereby creating an audit trail through the research that would clearly identify how raw data had informed final interpretations.

Following the advice of Miles and Huberman (1994) a matrix was created for each individual analysis (see Figure 4.5, text is for illustration purposes only, an example matrix can be found in Appendix 12). Each matrix enabled raw data, interpretive codes and reflections to be recorded in one place. Once a narrative thread had been identified the interview transcript was reviewed and all quotes that related to the specific thread were added to the table. In doing so reflections could be made about any data that were not reflected in a narrative thread. This process reduced the likelihood of missing or ignoring relevant aspects of the participant's account. Working with the data in this way also enabled the narrative threads to be challenged and further developed alongside the re-reading of the original account in a similar way to a negative case analysis (Hennink et al. 2011). Earlier reflections that had been made in a research diary were then added to the matrix alongside new reflections that were helping to develop an understanding and interpretation of each individual narrative thread.

Narrative Thread		Injury + One Month
Is my husband the same or different?	Codes	Quotes
	Knew it was bad; search for information; told he won't be the same; what will be lost; 'he's not my husband'; it almost looks like him; discontinuity; things will change; the way he put his hands	and I thought awww [nervous laughter...] it doesn't look too good I mean it looked really serious and everyone was sitting down and he said "right...your husband had a major fall we think that, he fell probably from six or seven metres high so it's a very high height to be falling from and basically he's got, severe internal injuries, severe bleeds, severe head injuries, he got a fractured skull and he's got swelling to his brain and he's got a fractured leg... 22:14 I mean at the time the fractured leg wasn't an issue because I was really worried about the brain... 23:12
	Memos	...and I didn't know where I was standing and whether it was their job to do so. I didn't know. We don't...no-one tells us anything. You have to... I don't know what we were meant to be doing...you know if, I was meant to interrupt the doctors, or if I could ask the nurse or if I mean, we were trying to read the notes but we got told off one day so...[laughs]... well I just wanted information, without being too...you know... 28:15 After his ten days of being sedated they tried to, to wake him up, and the last time it worked so we were pleased with this and erm...so he was still in intensive care and he woke up and er... he managed to say his name where he was, if he knew where he was...he said yes. You know, are you in any pain? He said no. What's your name? Dave... He couldn't remember where he lived at this stage but then it all came back, so that was quite encouraging. What I wasn't prepared for was the er...although I was told...when one of the surgeons er, spoke to me and he said, you know, when he's gonna wake up his face might just be distorted. And...you know, he might, he might look aggressive and violent but I thought well may be but...[telephone rings]...and er...when he woke up he was actually quite vocal and frontal and he said "right... er, right... er" well he couldn't remember where he was...and then he kept saying "oh right get me my clothes...take my clothes in the cupboard here and right we're going home, we're going home". And I said well Dave you can't just go home you know you're in hospital you had a nasty...I had to explain everything all the time so he'd say "oh alright, alright then lets go" [laughs]. So that was quite funny, I mean I did right a few things down that he said because they were so funny. Though it wasn't funny, but those things he said were funny in the intensive care... 29:32 But I think he got a bit too agitated and he really wanted to go home at some stage he actually physically wanted to walk off. So we had to... I think they had to calm him down with some pills or something. Not sedation but something similar and er...and he calmed down slightly. But each time he would see me he would get really agitated. And I mean he would remember my name but he was very vocal and er, you know "get me out of here". You know...as if he was in a prison or something you felt really yeah he felt like he was restrained you know. Like somebody was holding him or something...prisoner or something like that. That was quite hard I wasn't prepared for that. Though they had warned me but not...not that well I thought, I thought I was not

Figure 4.5 Individual narrative thread matrix (for illustration purposes only, an example matrix can be found in Appendix 12)

Individual narrative threads were then explored in a written account documenting the individual family member's experience. This analysis was completed for each individual at each time point.

4.9.2.6 Longitudinal narrative threads

The second level of analysis involved moving from the individual account at a specific point in time to an account that represented the longitudinal experience. This analysis aimed to compare the data from the individual time points and identify narrative threads that would

represent the changing experience over time. To achieve this aim the narrative threads from each time point were laid alongside each other with their corresponding interpretive codes (see Table 4.3).

Time since injury		
One Month	Three months	Twelve Months
Individual narrative threads		
<i>'Is my husband the same or different?'</i>	<i>'He's done so well'</i>	<i>'To the outside world he's the same'</i>
<i>Codes:</i> Knew it was bad; search for information; told he won't be the same...	<i>Codes:</i> Compromise and routine, so happy, maybe it wasn't that bad...	<i>Codes:</i> So much improved, skills are there, looks the same, no worries, amazing, hasn't realised what's possible...
<i>Personal growth and achievement</i>	<i>We're back to normal but some things have changed</i>	<i>A shell you're used to</i>
<i>Codes:</i> Unfamiliar medical world; I thought I was strong enough; not prepared...	<i>Codes:</i> How the children are being affected, she feels guilty, nothing you can do with ifs...	<i>Codes:</i> Shouts at the children, he's not realised, fear, never used to be like that, critical, emotional...

Table 4.3 Example of threads over time

Once again connections between the data could be seen and new longitudinal narrative threads could be identified. Once the longitudinal threads had been identified these were also placed in a matrix and could be challenged and reshaped alongside the quotes used to illustrate the thread, the codes aligned to, and the reflections made about, each of the threads (see Figure 4.6).

Narrative thread	One Month	Three months	Twelve Months
Recovery, change and loss	<p>Exemplars</p> <p>When he first woke up, you know, I mean I could see that... even when he was asleep, the way he was putting his hands... and I thought... oh... yes, you know, that's him... I was really worried that he would not be him at all... that was one of my worst fears, that you know if he's not like his old good self, will I still love him, and will he still love us? Will he remember what we've been through...^{30:1-12}</p> <p>It was really, really worrying, I mean I'm not so worried now, though I, I mean I am still quite worried because when you read all the paper work and you think, you know things will change. He will maybe not return to his good self... And I realise that when I was in intensive care one of the nurse, a male nurse, said bluntly to me... he said 'you know he will never go back to normal, he'll never be himself'... and I thought wwwwhhh(laugh)... it came as a shock because I didn't realise that. I thought well he's speaking, you know he's looking alright. He's gonna be alright... [said very softly] but probably not...^{32:1-9}</p> <p>so... may be, well, he will not be back to normal, but he will be, I mean if he's like... 80, we'll give you 80% I'd be like... that would be nice! But again we don't know so... just</p>	<p>Exemplars</p> <p>We don't know, we still don't know whether he fell on the concrete or whether his face hit the er... the building... because there was a building in the way... or if it's just the ladder that just banged on his head... we don't know... 'cause the er... the thing is he didn't have many, he didn't have much, many scratches or bruises or grazes on his face so... if he had landed on concrete I would suspect that there would be more bruises, oh I don't know... so maybe it wasn't as bad... as it was... I don't know... but luckily... luckily, you know, and, and he says that... you know 'I'm lucky to... not to be... you know... more... sort of... damaged in a way, you know, I'm lucky not to suffer too much... so</p> <p>And he hasn't... when they say... you know, you're husband's probably gonna be different... you know with his frontal injuries and everything... er... I don't think his personality's changed that much... he's probably more... not self-centred but he likes talking about himself... and if somebody comes and sees me for example... he would just come limping and say 'ohhh, I'm not too well or you know... do you want to hear what happened to me?' ... and I mean I do understand but he doesn't see the other, he wouldn't...</p>	<p>Exemplars</p> <p>that's when we sort of find that... under stress doesn't cope as... as well as before... because he's sort of, sort of a calm person and... he would just deal with it you know really well... I think now he just gets really vocal and... Sometimes you know if you walk into his office and you say something her just... BURST... or he snaps or he slams or he... breaks or... that's something that you know... he never used to do before...^{25:1-6}</p> <p>So we know it's not his fault... and you know put it down to... er... the accident but that's, that's the thing that... that's the sort of concern for us really... that's the only little thing that's left over from the accident...^{26:1-3}</p> <p>He's just been out and he comes back and... he tells you that... he's met all these stupid people... and everyone's stupid and... everyone's so stupid on the road and... you think... it's very sort of... well it's not typical of how he was before... he wouldn't say that so... so little bits, not much, and it's not all the time but... all these little things... that when you live with him all the time... you realise that... it's... they're a bit different... from how he used to be...^{28:1-6}</p> <p>...and again it's because he looks so well and... you know...</p>
	<p>Memos</p> <p>Change is predicted early, exposed to information about change and told by nurse he will be changed. What does a 50% mean? What is truly too different to cope with? Making sense of predicted change by bargaining, establishing continuity and using discontinuity when needed to explain behaviours during PTA</p>	<p>Memos</p> <p>Some slight changes are considered but not causing a problem, the most frustrating characteristic is made sense of in terms of his normal/pre-injury personality. Making sense of change by rationalising normal characteristics, age related. Rationalising is also emphasised through we're so lucky, he's so lucky and could the injury have been all that bad? New emotional side made sense of by realisation he nearly died.</p>	<p>Memos</p> <p>Definite change identified at T3. Recovery is separated into physical-ne worries, and emotional/social/behavioural. Exacerbated by hiding from clients, friend/family. 11 leaves Stephanie isolated. Still underpinned by a small aspect of his character. Certainly less than the 50% bargained for at T1 still balanced by what could have been the outcome - coma, disability.</p>
	<p>Codes</p> <p>Knew it was bad, told he won't be the same, what will be lost, 'he's not my husband', it almost looks like him, discontinuity, things will change, the way he put his hands, search for information</p>	<p>Codes</p> <p>maybe it wasn't that bad, we still don't know, he's really, really well, loss of smell, planning skills intact, worries about seizure tablets, headaches, walking, so many questions, we didn't know, need to put the pieces together, told more about injury, shown images, back to his happy self, nothing has changed, emotions, 'me, me, me', back to work, customers, ladders, anger, will it change, he has to slow down, I keep my eyes out, some worries but I'm sure he will be alright,</p>	<p>Codes</p> <p>So much improved, skills are there, looks the same, no worries, amazing, hasn't realised what's possible, working really hard, people think he's the same, don't want to disappoint, he feels the same, does Emma realise, kept from customers, hiding problems, we know different, questionnaire, he's not realised, fear, never used to be like that critical, emotional, self-centred, something is different, annoying, near accident, He was right, the girls want daddy back, Scared</p>

Figure 4.6 Longitudinal narrative matrix (for illustration purposes only, an example matrix can be found in Appendix 12)

4.9.2.7 Family narrative threads

The final level of analysis involved bringing together the longitudinal narrative threads from each family member. Comparing these narrative threads enabled an exploration of the wider family context and subsequently an understanding of how TBI had affected the family could be developed. As the analytical process unfolded narratives that were common to each family became more visible. Specifically these were: Trauma Narratives, Recovery Narratives, Autobiographical Narratives, Narratives of Suffering and Family Narratives (see Figure 4.7). Although these narratives were shared across the three families the meaning within, and importance of, these narratives was different. Once these threads were identified the matrices that had been used to support the analysis and create a very clear audit trail started to feel restrictive, unwieldy and perhaps unnecessary. In the later stages of analysis the five narrative threads enabled more freedom and creativity in the interpretive process so that final narrative threads were less restrained and descriptive.

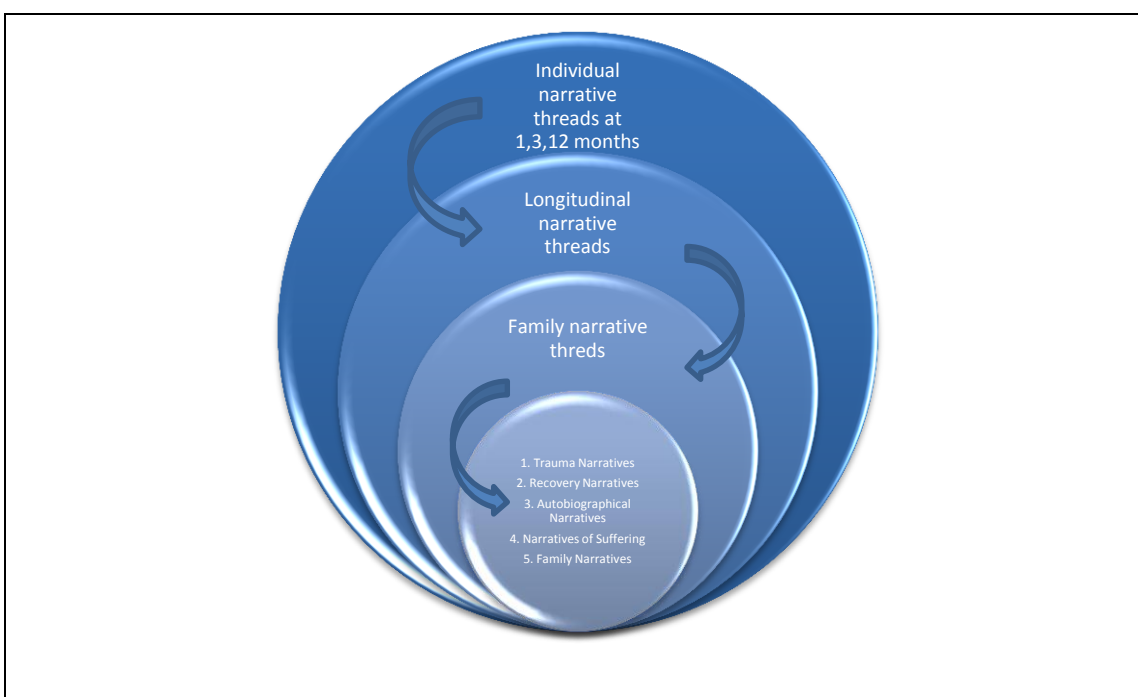


Figure 4.7 Interpretive process to identify narrative threads

Final narrative threads explore the temporality of the experience, the connection between past, present and future and how this changed over time. By the end of the year many of these narrative threads were unfinished and in reality would have continued well beyond the scope of this study. For others there were narrative threads that by the end of one year were being tied off as a complete story, something to store in the past and move beyond. The tension created by both types is discussed in Chapter Five. Presentation of Chapter Five also

includes the core meaning of each narrative thread that summarises the narrative and demonstrates how the narrative was interpreted. Where possible, drawings have also been included to help illustrate these central meanings further. However it is acknowledged that in narrative inquiry there will be other possible interpretations of this text.

Findings of this analytical process are presented in Chapter Five for each family with extracts of supporting data where appropriate. The size of data extracts selected was influenced by the amount of contextual material that was deemed to be relevant to the interpretation. For most it was important to show how the issues were situated in the surrounding discourse. Where original data have been used numbers depict the paragraph number and line number from the original transcript for example '...so we went back in the house... we sat there for half an hour... we couldn't stop any longer...' ^{7:1-2} would be paragraph seven in the interview transcript and lines one to two of that paragraph.

4.9.2.8 Summary of analysis for interview data

The first stage of data analysis was to prepare the data through accurate and appropriate transcription. These documents were re-read and audio files re-played to ensure the transcripts represented the account appropriately. The second stage was to organise the transcript and assign simple codes to aspects of the account that related to the research question. These codes were then organised by assigning them to a table and organised into sequence, context and consequence to summarise the whole account. Codes were then reviewed, condensed and interpretations made to produce a re-storied account. The final stage was to move from the interpretive codes to narrative threads. A Level One interpretation identified narrative threads for the individual family member at a specific point in time, Level Two involved identifying longitudinal narrative threads and Level Three was to bring the longitudinal narratives for each family member together to identify the family narrative threads over time.

4.9.3 Rigour

In qualitative case study research the researcher is intimately involved in both the process and the product of the study (Horsburgh 2003). Therefore rigour refers to the integrity and competence of the researcher and their research product. However, a more appropriate term in qualitative research is trustworthiness: by achieving this, rigour can be accomplished. Trustworthiness is a central tenet within qualitative research and refers to 'methodological soundness' (Holloway & Wheeler 2002). There are four main elements of trustworthiness and these are dependability, credibility, transferability and confirmability. Dependability is the

consistency and accuracy of the research methods applied. The specific process by which the findings were identified should therefore be transparent and auditable. Credibility refers to how compatible the findings are to the experiences of the participants. Transferability is the ability of the findings to be transferred from one context to another and confirmability is to ensure the data can be traced back to its original source. Those external to the research should therefore be able to follow the path from the findings to the original data to confirm the findings are rooted in the participant's accounts. Of these four issues credibility is considered the most important and reflexivity is fundamental to them all (Holloway & Wheeler 2002).

Validation by participants is considered to be an important stage of qualitative inquiry (Morse & Field 1996) and involves the return of research findings to those taking part to seek their views on interpretations made (Creswell 2007). In doing so researchers can avoid misinterpretation or misrepresentation of the data and increase the credibility of their final results (Holloway & Wheeler 2002). However narrative theory claims that the creation of narrative is an inherently collaborative process between the participant and the researcher. The researcher transforms and interprets textual materials to meet the aims of the research. Although it is essential that the analysis of narrative text results in the voice of the participants being heard above all else (Miczo 2003) final narratives are considered a co-constructed experience between researcher and participant (Mishler 1995):

‘It is clear that we do not *find* stories; we *make* stories. We retell our respondents' accounts through our analytical redescription. We too are storytellers and through our concepts and methods-our research strategies, data samples, transcription procedures, specifications of narrative units and structures, and interpretive perspective-we construct the story and its meaning. In this sense *the* story is always co-authored.’ (Mishler 1995, p177 original emphasis)

Bleakley (2005) and Leiblich et al (1998) remind us that stories do not have one interpretation and Riessman (1993) stated ‘in the final analysis, the work is ours. We have to take responsibility for its truths’ (Riessman 1993, p67). As such respondent validation is not necessarily a hallmark for quality in these studies.

Holloway and Wheeler (2002) identified several other challenges with regard to member checking one of which was that perceptions change over time. Respondent validation assumes interpretations are fixed and agreement between the researcher and researched will strengthen the study (Barbour & Barbour 2003). However this study sought to analyse narratives structures and interpret evolving meanings. As such it would not be logical to ask a participant to comment on structures they may have little or no understanding of. Riessman

(1993) reminds us that stories are not static and that the meaning of an experience changes over time. Therefore it would not seem to be appropriate to ask a participant to validate an interpretation that, for them, may well have already moved on to mean something different. For these reasons respondent validation was not employed for the study and credibility was established in other ways.

Credibility was first increased by the longitudinal research design. Prolonged engagement in research can establish a more trusting relationship between researcher and participant. In addition issues identified in earlier interviews could be either clarified in subsequent meetings or explored in more depth. Therefore prolonged engagement and longitudinal designs can also aid validation of emerging interpretations (Polit & Beck 2010).

Peer review was also employed to overcome researcher bias and increase credibility (Roberts & Priest 2006). Peer review has consisted of conversations with academic supervisors regarding data analysis and interpretation. All findings have been discussed and critiqued within supervision with experienced qualitative researchers. Feedback has also been given on alternative interpretations of data and has identified where the audit trail leading to findings discussed in Chapter Five has not been clear.

In addition an approach similar to negative case analysis was used. A negative case analysis is where the researcher actively seeks data that does not support the interpretations made (Creswell 2007). In this study during the completion of the matrices described within Stage Three of the data analysis process (Section 4.9.2.4) the narrative thread was refined and revised in light of the data extracted from the original transcription.

Finally a detailed and systematic process of analysis and careful reporting added to the credibility of this study. A thick description of the experiences was achieved through discussion and the use of verbatim quotes as evidence to underpin the interpretations made. Accurate transcription, verbatim extracts and thick description all increase the trustworthiness of the final research product (Roberts & Priest 2006; Creswell 2007). Additional steps taken to increase the trustworthiness of the study included maintenance of a research diary and establishing an audit trail from the data to the findings. This audit trail is primarily reflected in the recording of memos in a research diary that has been maintained throughout data collection, analysis and interpretation. This research diary facilitated the recording of reflections about the research process, meetings with family members, thoughts, feelings, assumptions and interpretations. Researchers should also reflect on how their role influences

the data (Silverman 2006). Therefore reflections were also made about personal and professional values and perceived relationships and interactions with participants.

4.9.4 Reflexivity

The story a participant chooses to share is always influenced by the relationship between them and the researcher (Bruner 1990; Carter 2008). Therefore it is timely to reflect on the influence I may have had on the story family members chose to re-tell. Reflecting back I would suggest that my relationships with family members developed in a positive way through sustained contact over time. As such they appeared more relaxed in subsequent meetings and perhaps therefore told me a narrative that more closely reflected their own personal motivations. However the presence of a digital recording device always disturbed the interview space and often what was captured in informal conversation was not repeated for the tape. This suggested that while the family member was perhaps comfortable with me they were never as comfortable with the research itself.

The account family members chose to tell was also possibly influenced by knowledge of my professional status as a registered nurse. Colbourne and Sque (2004) have debated hiding professional membership from research participants because of the effect it can have on a qualitative interview. However, it was also subsequently argued that actively hiding these qualities can lead to distrust in the purpose and motivation of the researcher and the study. Therefore during field work I took a pragmatic approach to disclosure with participants. Natural conversation with family members during recruitment would sometimes lead to an inquiry about my reasons for the research and personal background. Therefore if asked I told them I was a nurse and had worked in the hospital environment with head injury patients. These conversations were to put the family member at ease and some seemed more comfortable knowing I had an insight into their experiences. To reduce the potential influence this disclosure had on the story I would remind family members that they could talk about anything that they felt was important to them and I was always careful not to ask leading questions. In fact, I usually asked very few questions unless there was a specific need to.

In addition to the story being told by the teller, the researcher also has their own personal prisms and perspectives that will ultimately influence the narrative that is shaped through the research process and how the account is analysed and re-storied. Arthur Frank wrote about this as the 'standpoint of the storyteller' (Frank 2000). Maintaining the reflexive diary discussed in Section 4.9.3 also encouraged me to reflect on my own thoughts and feelings, naïve assumptions and past experiences. In doing so it helped me to understand the influence

I personally had on the interpretation of the data. Although this reflexivity cannot completely remove my influence within the analyses it encouraged me to look for alternative explanations and be open to different possibilities.

4.9.5 Analysis of questionnaire data

Analysis of the questionnaire data was a great deal less challenging than the qualitative data. In comparison to purpose building a set of procedures that would facilitate an in-depth analysis and interpretation of the data, FACES-IV came with instructions and a pre-programmed Microsoft Excel spread sheet. The Excel spread sheet provided by Life Innovation Inc. completed all the calculations necessary for the analytical process. In addition to the numerical values representing adaptability and cohesion within the family system Olson (2010a) stated that in a descriptive study both the FACES-IV profile and the Circumplex Model diagram could be used to further analyse a small number of participants. Although guidance is also given for the use of inferential statistics it was more appropriate for a study of this size to conduct a descriptive analysis only.

The analysis of the FACES-IV data was completed in a systematic way and commenced by loading the Excel spread sheet with the raw scores from the questionnaires. Each question required a Likert scale response, therefore raw scores ranged from 1-5. Where there was missing data the question was coded as 3 representing the middle of the Likert scale. However, in reality very few questions were left unanswered in the questionnaires returned. Once the questionnaire data had been entered into the Excel spread sheet the analysis process progressed in three stages. First plot profiles, family types and communication/satisfaction scores were calculated. Second cohesion and flexibility dimension scores were calculated and all scores from members of the same family plotted onto the Circumplex Model. Third a Total Circumplex Ratio score was calculated for each family member to assess the level of perceived relative health of the family system.

4.9.5.1 Plot profiles, family type and communication/satisfaction scores

Forty-two questions on the FACES tool correspond to one of six domains. There are two balanced domains: cohesion, flexibility, and four unbalanced domains: disengaged, enmeshed, rigid and chaotic. Raw scores for each domain are compared to normative data to produce a percentile score that can be plotted onto a FACES-IV profile chart. Within the two balanced domains higher scores are indicative of healthy family functioning and in the unbalanced domains higher scores are considered more problematic. The association between balanced and unbalanced scores is important because they illustrate the level of functional versus

dysfunctional behaviour that is thought to be present in the family system. The subsequent patterns created by the balanced and unbalanced domains were explored by Olson and Gorall (2006) during a cluster analysis. This analysis revealed six family types. Specifically these were: balanced, rigidly cohesive, midrange, flexibly unbalanced, chaotically disengaged and unbalanced (see Figure 4.8). A summary of each family type provided by Olson and Gorall (2006) can be found in Appendix 13.

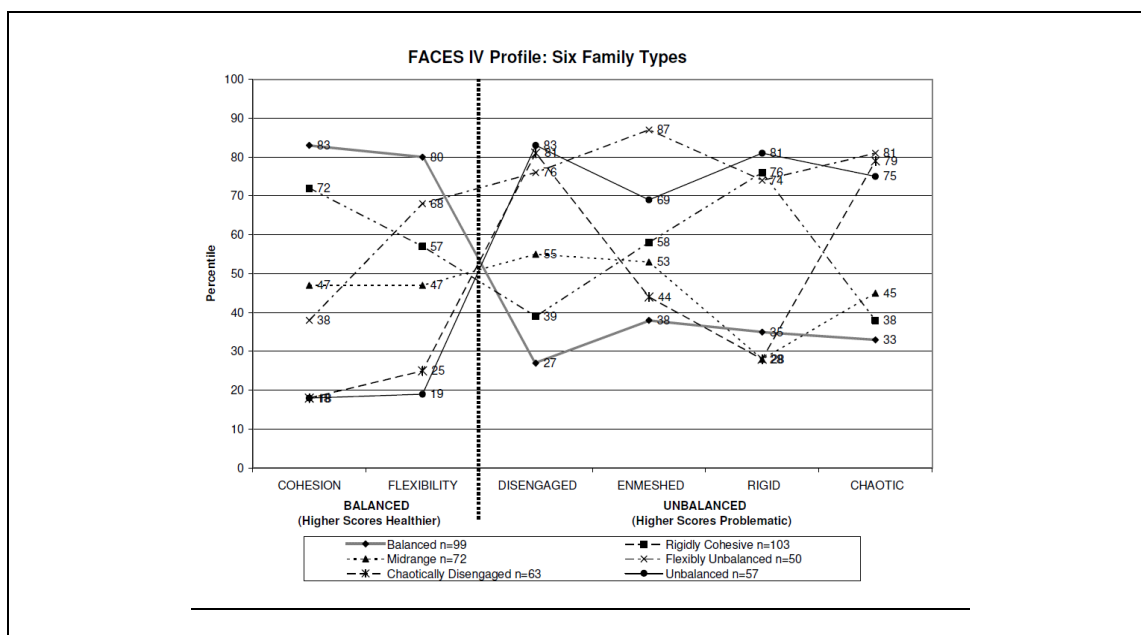


Figure 4.8 FACES-IV profile taken from Olson and Gorall (2006, p7)

Calculating family communication and satisfaction scores was reasonably straight forward. Ten questions were aligned to family communication and a further ten aligned to satisfaction. Therefore, raw scores ranged from 10-50 for each. These raw scores are again compared to normative data to produce a percentile score which is in turn allocated to a level ranging from very low to very high. Individual plot profiles and family types were then described alongside the scores attained for communication and family satisfaction.

4.9.5.2 Cohesion and flexibility dimensions scores

Data for the family was then brought together by calculating dimension scores for cohesion and flexibility. Results of these calculations were then plotted onto the Circumplex Model (see Appendix 14). Using the illustration provided by Olson and Gorall (2006) results for each family member were plotted onto the same graph to facilitate comparison. Plotting all family members' scores onto one graph allowed a visual representation of movement/change within the whole family and if data were similar or different between members of the same family.

4.9.5.3 Circumplex Total Ratio scores

The final stage of the descriptive analysis was to calculate the Circumplex Total Ratio score. This score acts as a single summary measure of the overall balance within the family system and represents the balanced versus unbalanced characteristics. Raw scores for the two balanced (Cohesion and Flexibility) and four unbalanced (Rigid, Enmeshed, Chaotic and Rigid) scales are turned into an overall Cohesion Ratio and an overall Flexibility Ratio. From these ratios the 'Circumplex Total Ratio' can be derived (Olson et al. 2007). The Circumplex Total Ratio score ranges from 0 to 10, with 1 indicating an equal amount of balance vs. unbalance in the system. The higher the ratio score over 1, the more balanced or healthy the system is considered to be, with most scores ranging from 0 to 2. Conversely scores below one show a lack of balance within the family system and these families are perceived as having unhealthy family characteristics that put them at risk of poor adjustment and separation. These ratio scores summarise how the family changed over time and supported the visual interpretation of the Circumplex Model.

Using the FACES-IV tool enabled the measurement of specific characteristics of family functioning post-head injury. Evaluations at different time points could then be compared directly to each other in order to identify if change in these characteristics had occurred within the first year of injury. Therefore it was anticipated that the questionnaire would provide a useful indicator of how the family as a system was adapting to life following TBI.

4.9.6 Combining data

The rationale for using a qualitative case study stemmed from the principle aim of the study to conduct a family centred investigation. Through the recruitment of several members of the same family the aim was to reveal more in-depth understanding of the family experience of TBI. Two data collection methods were utilised to examine different aspects of how TBI affected the non-injured family members and the subsequent affect TBI had on family functioning as a whole. According to Simons and Lathlean (2010) it is the integration of methods that brings the 'added value' to a mixed methods investigation. However they also suggest it can be appropriate to analyse the data separately with techniques that are commensurate with the corresponding approach (Simons & Lathlean 2010). Such research designs will wait till the interpretation stage of the study to attempt integration (Simons & Lathlean 2010).

Therefore, in line with the approach advocated by Simons and Lathlean (2010) this study kept the analysis of the two types of data separate. The presentation of findings in this thesis

maintains this distinction by presenting the data in two separate chapters. Chapter Five presents the qualitative findings through discussion of the five narrative threads and how these threads were represented in each family. Chapter Six then proceeds to evaluate family adaptability and cohesion through the findings of the FACES-IV instrument. Data for each family are presented separately and change or stability in the relative health of the family system is discussed.

Keeping the data separate in this way prevented any attempt to try to validate one set of data with another. It was never the intention of the study to use different data types in this way and Silverman (2009) warns it would be a mistake to do so. However, the interpretation of both data sets is considered a key stage when mixing methods and includes the 'purposeful search for convergence, divergence and discrepancy between the findings of the different methods' (Simons & Lathlean 2010, p339). Therefore there must be a stage of analysis that considers the case as a whole and by bringing all the data together understanding of the overall case, and the phenomenon of interest, can be enhanced (Gangeness & Yurkovich 2006).

Therefore although the analyses were completely separate Chapter Seven contains discussion of both data sets. By exploring and describing the findings of all the data a thick description of the three families in the context of TBI could be achieved (Creswell 2007). This type of case description is thought to be the hallmark of good qualitative case studies (Stake 2005).

4.10 Chapter summary

The current chapter has justified the use of a social constructivist paradigm and narrative theory to support an investigation into the family experience of TBI. A qualitative case study methodology was then selected because of its ability to concentrate analysis on one family unit. The case was described as a self-defining family unit and family systems theory was presented as a means of achieving a more in-depth description of the family case taking part.

Two data collection techniques were advocated to achieve a comprehensive understanding of the research questions. Narrative in-depth interviews and a structured questionnaire were therefore employed to explore the changes reported by non-injured family members affected by TBI and to identify how these changes impact on the functioning of the family as a whole. The data analysis process for both the narrative interviews and structured questionnaires was described and evaluated and the outcome of this process is presented in Chapters Five and Six.

5 Narrative Findings

5.1 Introduction

Chapter Five presents the narrative findings of this study. Although within case study research it may be more usual to present the findings of each case separately it was felt the qualitative data would be better served by presenting the findings of the between case analysis.

Therefore to maintain the integrity of the case but also enable discussion of how the threads are similar and/or different between the cases this chapter has been structured so that the context and relevance of each thread is explained first. The thread is then explored through its relevance to each family case. For example, trauma narratives for the Barker family are discussed first, followed by trauma narratives for the Hughes family and finally trauma narratives for the Wilson family. Within these narrative threads different core meanings were interpreted for each family; these are stated at the beginning and then the narrative thread is explored within this context. Each narrative thread is then concluded through a discussion of how the families share or have divergent narratives.

5.2 Introduction to the family cases

5.2.1 Case 1: The Barker Family

Injured family member: Dave aged 58 married to Suzanne and has three children (one from a previous relationship).

Participating family members: Suzanne (spouse) aged 36 and Emma (adult daughter) aged 27.

Family dynamics: Suzanne is Dave's second wife and lives together with their two children Sophie aged 14 and Isabel aged 11. Emma lives outside the family home in a city approximately one hour away.

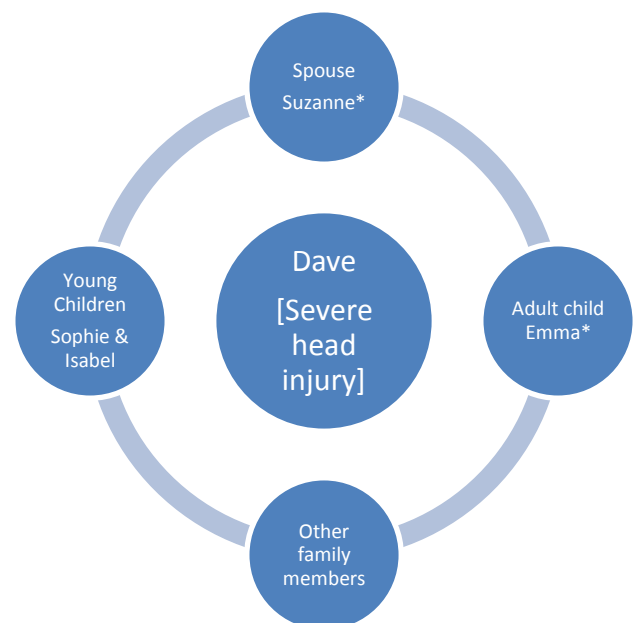


Figure 5.1 The Barker Family
*family member recruited to the study

Injury: Dave fell six/seven metres and it was unknown how long it was until he was found.

Dave sustained a severe head injury, fractured base of skull, cerebral oedema and a fractured leg. Although conscious on arrival he was confused and agitated. Admitted to the neuro-critical care unit where he was intubated and sedated for approximately ten days.

Subsequently transferred to a specialist ward and assessed for rehabilitation but no beds were available. Dave then self-discharged at one month post-injury.

5.2.2 Case 2: The Hughes Family

Injured family member: Abigail aged 19.

Participating family members: Diane (mother) aged 54, Bill (father) aged 55 and Lucy (older sibling) aged 22.

Family dynamics: All the children are reaching the age of independence and moving outside the family home. Abigail had been living away but has recently returned home and Lucy lives in a city approximately two hours away.

Injury: Abigail was involved in a road traffic accident as a pedestrian and sustained a severe head injury with a skull fracture and a fractured leg. Transferred to a specialist hospital for neuro-surgery (craniotomy), admitted to the neuro-critical care unit intubated and sedated, required intracranial pressure monitoring. Abigail was admitted to a specialist ward, then discharged home just over one month post-injury.

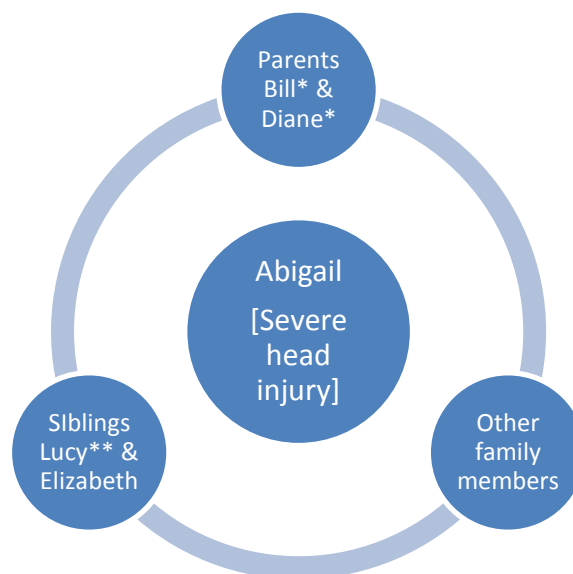


Figure 5.2 The Hughes Family
*family member recruited to the study
**Lucy withdrew from the study before the final interview.

5.2.3 Case 3: The Wilson Family

Injured family member: Tracey aged 27 married to Mike.

Participating family members: Mike (spouse) aged 29, Kate (mother) aged 54, Peter (father) aged 54, Helen (older sibling) aged 27.

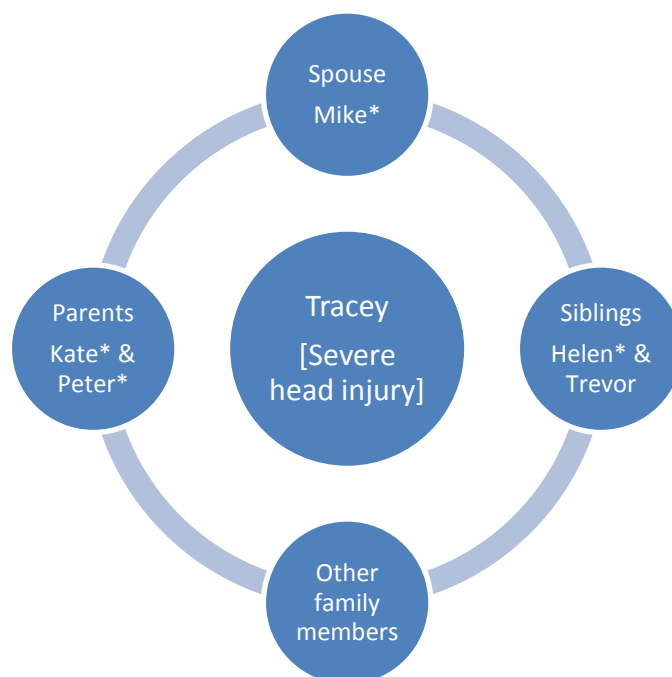


Figure 5.3 The Wilson Family
*family member recruited to the study

Family dynamics: Kate and Peter Moore are Tracey's parents who have two further children. Helen is the eldest and lives with her parents. Mike and Tracey live close to Peter and Kate, and Tracey visits regularly.

Injury: Tracey was in a road traffic accident as the driver (no other car was involved) and sustained a severe head injury, diffuse axonal injury, intracranial hemorrhage and cerebral oedema. Tracey was transferred to a specialist hospital and admitted to the neuro-critical care unit to be intubated and sedated, also required intracranial pressure monitoring. Tracey was admitted to the specialist ward one month after injury followed by a period of in-patient rehabilitation. Tracey was discharged home approximately three months post-injury.

5.3 Narrative findings

During the analysis I was struck by a series of related narrative devices that illustrated the meaning attached to the stories of head injury told by family members. Riessman (2008) stated that 'a good narrative analysis prompts the reader to think beyond the surface of a text, and there is a move towards a broader commentary' (p13). As such the findings of the narrative analysis moved beyond simply what was said and looked for how narratives were used to portray the storyteller's biographical sense of self, others and the family system. The analysis yielded five, interrelated, narrative threads. Specifically these were: trauma narratives, recovery narratives, autobiographical narratives, narratives of suffering and family narratives (the theoretical origin of each thread is explored further later in this chapter).

The first narrative thread presented in this chapter is trauma, an emotional reaction to deeply disturbing events that ruptured normal everyday lives. Second is the recovery narrative that attended to the perception that people change following brain injury and are no longer the person they were before (Lezak 1978). Interpretation of these narrative threads was heavily influenced by the theory of biographical disruption whereby illness can cause people to re-think their biography and self-concept (Bury 1982). However, in this context Bury's theory of biographical disruption was used to explore how the non-injured members made sense of the injured person's biographical identity and post-injury change. Third is the autobiographical narrative that illustrated how the non-injured member was pulled into a story of meaning and new life (Frank 1995). These stories represented how and why they had changed through the events and experiences they had been forced to encounter through their relative's injury. As such these stories represented a form of biographical revision in response to a major life event. The fourth narrative thread is narratives of suffering and represents a more subtle endurance of pain and distress over time, often from an accumulation of subjective loss.

Finally family narratives captured the evolution of the family system, how the system was perceived before injury and how it came to be after.

Underpinning many of these narratives was a sense of coherence (the relationship of the narrative to a valued goal) and direction (either towards or away from this goal) (Robinson 1990). Such narratives have been labelled progressive, regressive and stable (Gergen & Gergen 1983):

‘A progressive narrative moves towards the personally valued goal(s), and a regressive narrative moves away from such valued goal(s), and a stable narrative evaluatively sustains the same position in relation to the valued goals throughout the narrative sequence.’ (Robinson 1990, p1176)

Where the narrative thread represented progressive, regressive or stable direction it facilitated the interpretation of relevance and meaning. However, it is worthy of note that not all narrative threads had such clearly identifiable features.

5.3.1 Trauma narratives

While listening to the accounts of family members, during the interview and later during transcription, I was struck by the representation of deeply traumatic events. Such stories were not easy to hear. Family members themselves often found recalling, and then recounting, such stories hard and often their speech would become broken with emotion. The depiction of traumatic events was especially acute within the first interviews that were held just one month after injury.

However, before moving further into the exploration of trauma it would be timely to reflect momentarily on the definition of trauma underpinning my interpretations:

‘By definition, trauma overwhelms our usual abilities to cope and adjust, calling into question the most basic assumptions that organise our experience of ourselves, relationships, the world and the human condition itself. The crisis of trauma is pervasive, altering emotional, cognitive and behavioural experience, and the subjective experience of trauma not infrequently includes a crisis of meaning at a deep level of experience.’ (Landsman 2002, p13)

Therefore the reason trauma made such an impact on the analysis was for its ability to create a catalyst for crisis and distress. Embedded within the accounts of such crisis was raw emotion and desperate attempts by family members to make sense of the events that were unfolding before them. Family members represented trauma by talking specifically about the traumatic events that they had witnessed as a result of their relative’s head injury.

Traumatic events are defined in the *Diagnostic and Statistical Manual of Mental Disorders* through the following statement:

‘The person has been exposed to a traumatic event in which both of the following were present: (1) The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others. (2) The person’s response involved intense fear, helplessness, or horror.’ (American Psychiatric Association 2000, p467)

All families recruited to this study were faced with a relative’s injury that could have instantly ended their relative’s life. Some family members also went to the scene of the accident, and were witness to the full severity of injuries sustained. In addition there was a prolonged period where that relative’s life was still threatened on a daily basis and there was continued uncertainty as to the extent of long-term brain damage. Without exception all family members experienced some level of fear, helplessness, and/or horror. As such these particular storied events warranted special attention and were recognised as trauma narratives in this study.

However, these stories were very raw and many lacked the features of a full narrative with coherency of past, present and future helping the storyteller to make sense of what they had been through. These broken narratives find some alignment with the chaos narratives identified by Frank (1995). Stories are considered chaotic in nature because of the absence of narrative order that lacks the pursuit of purpose. Frank (1995) wrote that ‘the story traces the edges of a wound that can only be told around. Words suggest its rawness...’(p97). As such these are not considered ‘proper’ stories. Chaos narratives feel immediate and ‘of the moment’ because they represent experiences that continue to be lived through. Storytellers are thought to lack the metaphorical distance to facilitate self-reflection and the process of sense-making.

Although Frank (1995) argues that chaos narratives are ‘anti-narratives’ because of their lack of temporality, some of the trauma narratives identified in this study did have chronological features. The storied account often took the sequential and objective events of injury as its structure, onto which the narrative of trauma was hung. Despite these chronological features the trauma narratives would often lack movement between the past, present and future because knowledge of the final outcome was unknown or too painful to predict.

5.3.1.1 Barker: ‘Dealing with trauma: own and others’

The trauma narrative for the Barker family was interpreted as ‘dealing with trauma: own and others’ because of the need for both Suzanne and Emma to not only attend to their own

narratives of trauma but also to those of others including the children Isabel and Sophie. This thread consists of fragmented narratives that included being exposed to Dave's injuries and making sense of the severity of the situation. Underpinning these events were the mechanisms used by Suzanne and Emma to try and resolve the trauma they had been exposed to. Whereas the catalysts for trauma were largely shared between family members the ability to step in and out of this narrative thread made the resolution of trauma different.

The narrative thread begins with an orientation to the day of the accident. Suzanne received a call from a number she did not recognise and let the answerphone take a message. The message said her husband had fallen from a considerable height but he was conscious and was being taken to the hospital, it was unknown how long it was before he was found. Emma's narrative began while at work and a message was posted on Facebook by Sophie that said her dad had been in an accident. As phone calls were made and information relayed the situation began to sound more serious and questions abound for both family members about the extent to which Dave had been hurt. The children accompanied Suzanne to the hospital where they waited for Dave to arrive by air ambulance. While Suzanne was on her own with the children, she spoke of fear and dread. Although she had no previous experience of hospital Suzanne knew to be concerned when taken to a small room to be told about her husband's condition. The significance of an injury to the brain was immediately understood (see Box 1).

Suzanne [T1] "So...we didn't see Dave at once we had to wait about an hour and a half before seeing him...and er... I think it's the surgeon I can't remember his name we saw so many different people he said right you know I'm gonna talk to you about your husband, er, can I shut the door please"^{21:1-5}

"and I though awww [..nervous laughter...] it doesn't look too good I mean it looked really serious and everyone was sitting down and he said right...your husband had a...had a major fall we think that, you know, he fell probably from six or seven metres high so it's quite a very high...it's a very high height to be falling from and er he's got basically he's got, severe internal injuries, severe bleeds, severe head injuries, he's got a fractured skull and he's got swelling to his brain and he's got a fractured...erm...fractured leg"^{22:1-8}

"... I mean at the time the fractured leg wasn't an issue because I was really worried about the brain..."^{23:1-2}

Box 1

Suzanne was then allowed to see Dave and in the rush to be with him did not consider how the children might react. Dave's injuries were depicted through the description of his swollen eyes, his bruising and the dried blood that was all over his face and hands. Suzanne spoke of predicting her own coping mechanisms but then realised her children were not as prepared.

Suzanne's sense of trauma was exacerbated through her guilt at not protecting her children from such horror (see Box 2).

Suzanne [T1] "But then I thought well...I watch casualty every Saturday, it's gonna be alright! [laughs]...and er, yeah, I should have, I should have said... may be, or may be, they did suggest, you know, for the children but, I don't know...I just walked in there and I looked at him...and then Isabel, when Isabel saw him she was just like that [covers face with hands] "arhhhh" she screamed and rushed out and then...I said oh, and I ran after her, I went after her and said, it's alright, so you can stay in the waiting room and er, I'll deal with it... but it was quite upsetting because there were people screaming everywhere... they brought this lady with a broken leg and you could see her and..."*ohh no!*" [laughs]... it's not a nice place for the children but you know that's just what happens so..."^{158:1-11}

Box 2

Emma and Suzanne's narratives finally converge as Emma arrived at the hospital. Suzanne brought Emma into her narrative by explaining what she knew. Emma then depicts her own first sight of her father but was reassured by his confusion rather than further concerned by it (see Box 3).

Emma [T1] "Erm, and we all went through to see him... they'd already been in, I went through to see him... and he looked a bit of a mess... [pause]... erm, he had, black eyes and his eyes were stuck out, like I guess the most striking thing is like, he was like a goldfish, kind of really like stuck out, with these big black eyes. But he was awake and he was alert...and he was just screaming and swearing and...not himself in the slightest... just being very rude to everyone and telling everyone to... 'F off'... erm and trying to get up and go home...so... I guess that's quite a positive thing because... you know at least he was kind of, fighting! [laughs]... I think I would have been more scared if he was hungover..."^{13:1-9}

Box 3

The trauma narrative then progresses to accounts of the critical care unit where Dave was intubated and sedated for approximately ten days. The neuro-critical care unit is portrayed as a strange and unfamiliar environment that is not easily understood. However, trauma is relieved with the support of other people in the relative's room who shared their own experience and provide comfort and empathy. While in the critical care unit there was a convergence of shared narratives between families that helped Suzanne deal with the trauma she was exposed to. In contrast to this way of resolving trauma Emma did not feel at ease in critical care and did not find the sharing of narratives comforting. Emma spoke about seeing other people in despair and suggested the trauma of others compounded her own.

Trauma continues by trying to make sense of this medical world and engaging in comparisons between Dave's condition and the condition of others. Even though Suzanne initially tries to protect herself, by playing down the severity of her husband's injuries, transference of other people's situations to her own could not be avoided. Therefore when someone died Suzanne

super-imposed this event on her own situation and was left to wonder who would be next. Despite these comparisons it was only really when Dave developed pneumonia and his condition deteriorated that both Emma and Suzanne's narratives included the possibility that he could actually die. This turning point in the narrative made Emma reassess the possible outcomes and physical recovery was prioritised above all else.

Emma offered some further insight into the impact that her father's injury had on the children and in a particularly poignant account Emma spoke about Sophie's feelings of guilt that she had hidden from her family but had shared in critical care's relatives' book (see Box 4).

Emma [T1] "she comes across as slightly unemotional... and she's written in the relative's book... 'dear Daddy... I'm sorry I didn't go with you the day of your accident... sorry I didn't go with you, if I was there I could have called for help', because he was on his own for three hours we think after the accident ... 'I would have been able to tell you that the telegraph pole was rotten'... because he'd put a ladder up a telegraph pole and we think it might have been rotten or something... and, I don't know exactly what happened but it... it collapsed... he was injured, on his own for three hours, and then he was found... and my sister was feeling terribly guilty because firstly she hadn't gone to work with him, so she thinks that she could have got help sooner... but also because... they'd gone to the Science Museum, I think within the year before the accident, and there were three poles... and they had to knock on them and decide which one was rotten, or hollow, or something... and er, my Dad and my step mum had got it wrong, and she had got it right... so... you know... poor thing's thinking 'well if I was there I could have told you that the telegraph pole was rotten... and I could have called for help'... she was feeling really guilty and that was horrible to read that..." 60:2-21

Box 4

The trauma narrative has little temporal movement until mechanisms were identified to deal with it. Emma's narrative shows progressive features sooner than Suzanne's through the ability to step out of the trauma narrative and return to her life outside of the hospital. Emma frequently represented the importance of stepping away for both herself and Suzanne. The benefit in doing so was portrayed as protection against the negative effects of staying exposed to trauma (see Box 5). The valued goal that Emma moves towards therefore is self-preservation that will enable her to continue her provision of support to her family.

Emma [T1] "... you see some of the families that stayed there the whole time at hospital, you just, you see them every time when you go down there... and you know some of them just look like they'd have nervous breakdowns... because they didn't live near the hospital and they'd move, live in the halls of residence... and they were just exhausted and tired... and I just thought, you've got to give yourself a break at some point... and go out and just... get on with life outside of this hospital, because there's gonna be nothing left for you if you don't..." 59:1-8

Box 5

Suzanne's trauma narrative began to develop progressive features through her determination that she and her family would have to cope in order to move beyond the destructive effects of

trauma. Suzanne spoke several times within all her interviews about her resolve to cope but offered little insight into how that was achieved other than moving from one day to the next. In later interviews Suzanne compared their own situation to others suggesting other people went through worse. In doing so Suzanne found other situations more difficult to make sense of than her own and devalued the relevance of her own trauma narrative as a result.

Summary of the trauma narrative for the Barker family

Family members were exposed to traumatic events including Dave's initial injury and transposing other people's situations onto their own. Although narratives of trauma were closely aligned between Emma and Suzanne mechanisms to cope with trauma were different. Emma's ability to step out of the trauma narrative created a protective effect and she strongly encouraged Suzanne to do the same. Within the narratives there was reciprocity between Suzanne and Emma in addition to their mutual concern for the children. Overall trauma was dealt with through the resolve to cope and for Suzanne the understanding that other people were in worse situations than their own.

5.3.1.2 Hughes: 'Acute and painful'

The trauma narrative for the Hughes family was depicted as 'acute and painful'. This narrative was represented in this way because of the communicative power of these particular accounts. Broken narratives depict the significant events and lasting images that caused distress including the injury, the critical care unit and the anguish of predicting the future. Diane and Bill's trauma narratives seemed most powerful because they were more able to give voice to their trauma. In contrast Lucy actively tried to protect herself from trauma by not retelling her story in such a detailed account.

Within the first interview Bill and Diane gave parallel accounts of the traumatic events they had been exposed to that began with a phone call to tell them Abigail had been hit by a car not far from where they lived. While Bill took the call Diane said she knew something was wrong and prepared for the worst. Both then drove to the scene of the accident to be with their daughter. The scene was hard for them to make sense of: scores of children, ambulances and police illustrated the chaos. Diane described her immediate adrenaline that lifted her out of the car and to her daughter's side who was by then in the ambulance. Bill was left to make sense of the scene in front of him and the sight of his daughter's shoe in the middle of the road seemed to emphasise the reality of the events that had taken place (see Box 6).

<p>Bill [T1] "So... I don't know what you think, just didn't really, you don't imagine I suppose, not having seen her on the road... saw where her shoes were, or one of em in particular erm... your</p>

just sort of like, numb, I think that's the easiest way... just it's like something's opened up in your head, you've stuck the pieces in it, you don't know what to make of it because you don't know what's happened apart from what you can see... the ambulance, you see lots of police, you see lots of stuff lying around.... and you've got people telling you 'it was awful, you know, this car come through, we heard revving, he did this he did that bonk!' But you don't sort of associate, it's, it's disjointed... a bit like probably Abigail when she finally woke up and everything's sort of wrong and not coming together properly... it's that kind of, sort of like a numb feeling"^{113:1-11}

Box 6

Trauma continued to the emergency department whereby Bill struggled to describe seeing his daughter for the first time. Bill explained that his daughter was unconscious and Diane was sat by her side stroking her hair. Bill thought perhaps he was exaggerating, but Diane's hand looked lost in the gaping hole that was in Abigail's head.

Later that evening Bill and Diane returned home to rest before making the journey to the specialist hospital that Abigail had been taken to for surgery. Diane then talked about the vivid image of her daughter in the emergency department. These traumatic images prevented Diane from thinking of her daughter in any other way. Diane illustrated her desperate need to replace this image by searching for photographs. Only then could she remember what Abigail looked like (see Box 7). In the example below the mention of Abigail's glitter eye shadow underneath the medical tape seems to accentuate her daughter's age and vulnerability.

Diane [T1] "Er, but yeah...Bill was crying... he was sobbing... and I think, I didn't, I just ... in-between times I tried to sleep... but... I think we only had about fifteen, ten minutes were we probably closed our eyes... 'cause I couldn't stop seeing her...and I just, we'd seen her at the hospital and she'd looked awful then with the neck brace on and...oh...she just looked dreadful and I had to just keep looking at pictures, when I got up I had to sort of find some, well she'd got some photos by her bed and I sort of like got these photos and I had to look at them and say yeah that's what she looks like... because... she didn't look like that at all...and you just thought...ohhh...they'd taped her eyes down with er...and she'd got all her glitter eye shadow on, and the doctor's like 'yes I couldn't remove it!'...[laughs]...oh dear..."^{54:1-12}

Box 7

In contrast to the traumatic events experienced by Bill and Diane, Lucy's trauma narrative begins while she is away from her family and was unable to join them until the following morning. Lucy described meeting her parents for the first time when the gravity of the situation was realised.

Trauma continued into the critical care unit where, in a bid to understand Abigail's condition active comparisons are made to the other patients in this environment. Description of a particular Wednesday revealed the effects of witnessing the removal of life support from

several patients in the unit (see Box 8). This and similar comparisons compounded their distress and feelings of vulnerability as Abigail's life seemed very fragile.

Bill [T1] "and we'd already had the anguish of some of the other people that were in the unit where erm... it would seem that some of them had just been recently turned off... erm, who weren't gonna make it anymore or weren't surviving... erm, someone had died fairly naturally anyway... certainly one or two people that they had flicked the switches because there was nothing there when they tried to make them wake up, effectively"^{62:1-10}

"You know, and you have all those horrible... sort of thoughts, that you're gonna be there forever... then you start hearing they've turned someone off today, bloody hell how long they been here? 'only a week' and oh shit! If she don't wake up in a week, we're gonna get turned off are we?! [slight laugh]... so you have all those sorts of thoughts going through your head... I mean it's just strange"^{142:1-4}

Lucy [T1] "...We just used to go in... sit with her... all day... and just hope that, you know... we'd watch everyone else and have these sort of...I mean there was... it was a Wednesday and it was awful because... we saw three sets of relatives... have their patient, like their relative's machine's turned off... and mum and I were just like... oorgh... you saw all these people so upset... and it was so hard... and that, that was definitely in that period... that we were in such limbo... it felt like we were just... waiting to know which way we were gonna go... whether we were gonna be like that or... whether she was gonna get woke up and..."^{111:1-8}

Box 8

Within Diane and Lucy's accounts the temporality of the trauma narrative was suspended as much as it could be. For Lucy the need to be in the moment was so that she did not have to look too far forward and thus protected her from the need to consider less desirable outcomes. Diane, however, spoke of her own need to be immersed in the trauma and although the experience was painful, Diane said it was almost a pain that she wanted to feel. In doing so Diane was also able to immerse herself into Abigail's narrative. Sharing narratives in this way helped Diane to feel closer to Abigail despite the additional pain that it caused. Diane's trauma also extended into her dreams which she interpreted as representing her deep desire to turn the clocks back and make everything as it was.

Additional traumatic events included the initial attempt to wake Abigail from sedation. It was known that in doing so they would find out the extent of Abigail's brain damage. This impending event was understood through the knowledge that other families had reached this stage but as sedation had been turned off there was no indication of life. Subsequently the life support for these patients had been removed. Trauma is therefore exacerbated because this is a milestone that must be passed to progress onto recovery but it is feared because of the dire ramifications that may be revealed in doing so. As sedation was lightened Bill witnessed Abigail thrashing around the bed and talked about the need for three of the family and two nurses to restrain her. Bill explained his distress at seeing Abigail so frightened and vulnerable.

Three months later such images remained vivid and Bill said his mind was in constant turmoil. Bill reflected on his lack of sleep and said although he did not have nightmares, when he woke up the image of Abigail lying in the road was never far away. Therefore although the intensity of trauma was at its greatest one month after injury the effects were long lasting as little had been done to make sense of, resolve, or find purpose in these events. One year on Bill reflected back on their situation and said the family was wrenched out of their normal life and pulled suddenly into trauma without the time to adjust.

Aspects of the trauma narrative discussed so far have centred on the reality of traumatic events that were witnessed following Abigail's injury. These events were very much of the moment and lacked the temporal features that enabled reflections on the past and connection with the future. However there were also features of trauma within a hypothetical narrative whereby Bill and Diane, primarily, looked to the future and predicted what would be lost as a result of injury. These predictions were of a lesser future and caused distress and dismay. These trauma narratives therefore had a regressive temporality that moved Abigail away from her anticipated future. In the early stages Bill and Diane expected a poor outcome, considered vegetative states and predicted the possibility of Abigail being totally different from the person she was (see Box 9).

Diane [T1] "...I can imagine Abigail might be, you know, might be a problem...there's going to be difficulties ahead and I just worry for her...I want, I want to see her...doing like say... Lucy's doing, or...er...interviews for work... she's got a good boyfriend she's thinking of eventually travelling again...and she's hoping to settle down and have a family...and I think well is that what Abigail is going to have? She might not...and I was thinking, 'well lots of people don't get married...lots of people don't have children...and Abigail wasn't particularly maternal but she might actually want to have a family, she might not actually get that...I can imagine it putting people off...even if there's no real residual damage...even if it's only left her a bit moody...you know, people could find out and think 'ooo, ooo, a head injury?' they don't want to know about that... 'cause they're frightened of what else might of gone on..."^{86:1-14}

Bill [T1] "...so again I suppose... that, you know, at the time when they're telling you things are bleak, your brain is just, again, you're in this sort of...fuzzy area where, you don't know what the outcome is... you're sort of hearing what someone's saying to you, you don't want to hear what they're telling you, it's your own...flesh and blood, it's your own kid... you should not even be there in the first place... so why is it happening, why has someone decided that, that's gonna happen at that point... you know, it's your kid that's been run down, got a smashed head, probably not gonna do anything ever again...and you're just having all the negative thoughts you can think of..."^{145:1-9}

Box 9

The image of their daughter as such a bubbly outgoing person was juxtaposed with the image of someone with severe brain damage and further compounded feelings of loss.

Summary of trauma narrative for the Hughes family

Trauma narratives represented the distress and anguish felt by the non-injured family members. Family members were exposed to trauma, through events that were both real and imagined. Narratives of real traumatic events had few temporal features with some family members purposely removing the future from their story to protect themselves from harm. However, while dealing with the unknown, hypothetical narratives caused trauma as consideration of the future and the past were brought into the present and represented what could be lost.

5.3.1.3 Wilson: 'The worst case scenario'

The trauma narrative for the Wilson family was interpreted as 'the worst case scenario'. This interpretation was used because one particular event dominates the narrative thread. It was the understanding that Tracey may be in a vegetative state that provided the most coherent narrative of trauma and was characterised through despair, disbelief and grief. This particular narrative was regressive in nature as family members tried to comprehend a shattered future. However there were other more fragmented narratives such as being exposed to trauma within environments like the emergency department and the critical care unit that came first.

The narrative of trauma begins with an orientation to the day of the accident and included a series of everyday events. The accidental misplacing of house keys led Tracey to venture out to retrieve a spare set. However when Tracey failed to reach her destination or return home Mike called his father and both went out to search for her. In the distance they saw blue lights and as they approached Tracey was being put into the back of an ambulance. Mike described a surreal journey following behind the ambulance to the hospital and on arrival Mike tried to avoid seeing what state she was in. Left in a room to contemplate events he understood at that time they were trying to save her life. Lack of control and Tracey's vulnerability further accentuated his trauma (see Box 10).

Mike [T1] "I was sitting in that little room probably for about twenty minutes... half an hour because the other room was busy... before, and before any, any of my family members got there... and that was quite... harrowing... if you like... it was quite difficult to sit there and... and just, because I, obviously knew how bad it was because they'd explained it was bad... erm, and just to sit there thinking everything they were doing to her... knowing she'd got no control over anything they were doing to her..."^{98:1-7}

Box 10

Kate, Peter and Helen joined Mike at the hospital but little was spoken about this particular event. However, Helen did comment that, despite a large black eye, Tracey's injuries did not

appear all that severe. It was not until Tracey was transferred to a regional hospital and settled into the critical care unit that Kate and Peter's trauma narrative became more prevalent. Kate said she was simply devastated and although Peter had seen something similar before emphasised how different it was when it happened to their child (see Box 11). Protecting himself from the effects of this trauma Peter talked about his gradual hardening to the critical care environment over time.

Kate [T1] "And then um... and we drove over here... that was about half past four in the morning... difficult to remember seems such a long while ago... and then um... I think we sat in, we sat, we seemed to sit in the waiting room for ages... before somebody came and saw us... and... I can't even remember what time we went and saw her... and got to see her the first time... it was devastating... [...]... [long pause]... [deep breath]...[19 second pause]" ^{9:1-6}

Peter [T1] "Obviously we spent the entire... first night in the... in the waiting room... erm... and... eventually you get the chance to... to go in and see her... and then obviously at that point... sedated her and... and obviously got like umpteen monitors and... ventilators down her neck... and pipes and things... there's pipes and bags hanging everywhere like... initially it's obviously quite... it's quite traumatic to see it all... especially when it's one of your own children... er... it's not the first time I've seen someone on... on life support kit but erm... it's still quite traumatic to er ... to er actually see it on one of your own children..." ^{15:1-8}

Box 11

However, Helen described herself as distanced from the unfolding trauma through her ability to step out of the narrative that was shared by Mike, Kate and Peter. As such Helen was protected from its full effects and felt an increased capacity to cope. However despite this distance Helen was fully aware of the gravity of the situation and commented on the other ways in which the environment caused her distress (see Box 12).

Helen [T1] "But through the intensive care... with the other families... and you watch other people disappear because their families... the person their looking after's... not made it... that's quite upsetting to watch... other families fall apart... and one of the things that really upset me... you can hear them telling the families in the next room... you can't actually hear them say it... but you can kind of hear through the wall the responses... that was just awful..." ^{11:1-6}

"Like I say... all the days seem a bit like the same, when you're there... and when things obviously start going up when they shouldn't you find yourself panicking... and thinking 'oh god'... but then when I've spoke to my dad in the morning... erm... and stuff's happened through the night... like it's obviously been 'but she's ok now'... at the end of it I'm not the one sitting there... going through it when the machine's been going up and up and up... and not been able to get it down..." ^{68:1-6}

Box 12

Once in the critical care unit comparison to other people's situations seemed unavoidable and it was Peter who said every family there had a similar horror story. Mike talked about being exposed to the reality that people did not always survive their injury or illness. Comparing

their situation to others in the unit then became a stark reminder of the possible outcome. Although for some it was good to know other families were going through similar events, in such an acute environment comparisons to other patients rarely brought comfort.

As previously stated the strongest trauma narrative came from an understanding that Tracey's condition may be classified as a vegetative state. The close alignment of Mike, Kate and Peter's narratives illustrated shared events, interpretations and implications of this traumatic event.

The family were given a detailed account of a recent MRI, shown the scan and areas of damage, and then given a scale of prognosis that spanned the realm of possibilities from complete recovery to no recovery. Although the family felt they were given information because they asked the questions when speaking about the worst case scenario Tracey's current condition was referred to as a persistent vegetative state (see Box 13). These words were then the catalyst for despair and fear that all their efforts had been in vain and Tracey had been condemned to live an assisted life. It was Peter who referred to this predicted life as something worse than hell and Mike said it felt like the end of the road.

Peter [T1] "And just that one word... vegetative state... and you thought... oh hell... and we looked at each other... and your heart sank without a doubt... you know... you think... have we done her any justice like... have we got her life saved to be a vegetable... and you think god... what have we done... you know have we... has technology condemned her to... something worse than hell for the future... have we... have we done the wrong thing... you know has the world done the wrong thing in saving her... and you think... you just don't know at that point...well obviously... we're absolutely gutted at this point obviously..."^{120:1-8}

Mike [T1] "well you can imagine... to, to know that... she's gone through all the effort of actually... all the doctors and nurses have saved her life and Tracey's fought so hard to have her life saved... and she's got to the point where... they had saved her life... to think that... her life might end up... living in some home somewhere, because ... and with no idea of her surroundings and basically... a vegetable, er a persistent vegetative state... it's, it's... she may as well of... as hard as it is to say... she may as well of not made it out the car... ... 'cause she wouldn't want that... and, and... by the time six months gets here... if she is like that it's too late to turn any machines off, or to do the best thing for her because she's already way past that stage... and that's, that was really hard... the fact that... I mean if they could have said yes, she's gonna make a good recovery... then it's easy... if they could, if they're gonna say... no there's no way, she's got no chance of having any life at all... and you could do the best thing for her... I mean she wouldn't want to live like that, she's such an active person, such an outgoing person... and that er... it wouldn't have been easy but it would have been a lot easier than seeing her live in some... institution... for the rest of her life and not... being able to... eat, or being... fed through a bloody tube... just the thought of that is just, well... heart-breaking..."^{49:2-18}

Box 13

In conflict to the medical explanation Mike, Kate and Peter's accounts showed they tried to make sense of the prognosis together. Each revealed a misalignment between the medical assessment and their own. As they travelled back to tell the rest of the family a call was received to say the information given to them was wrong and that Tracey's condition could not be called a persistent vegetative state. Despite these conversations Mike, Kate and Peter continued on their journey to tell the rest of the family and in a subsequent meeting, held to correct the information received, family members still came away with a similar interpretation of Tracey's condition. Peter said it was an undetermined timeframe with an undetermined outcome. As the news spread outside of the family Peter described the messages of sympathy and condolences that came flooding in. At that moment Mike said it was like giving up and grieving for the person they knew.

In response to news that Tracey may not recover a narrative of hope was built and increased in importance. Each family member shared this narrative of hope for the future and consequently it pulled the family inward. Consideration was given to why the medical assessment was so bleak and Kate reflected on the damage that false hope can do in such situations. Despite this it was Mike who suggested when there was nothing else, hope was all they had. Therefore this narrative of hope helped to counteract the effects of trauma and prevented the narrative from developing, and sustaining, more regressive and damaging features.

Summary of trauma narrative for the Wilson family

Family members were exposed to trauma through the events they witnessed following Tracey's head injury. The most powerful trauma narrative came from the despair and disbelief arising from the understanding that Tracey was in a vegetative state. Following their immediate devastation narratives of hope accumulate and become an important mechanism to counteract the damaging effect this traumatic event had on the family.

5.3.1.4 Trauma narratives conclusion

Many of the trauma narratives that were identified for these families lacked the temporal features of a full narrative. These fragments of narrative, or broken narratives, illustrate the origins of dismay, fear and horror that families were exposed to. Riessman (2008) suggests that stories emerge from ruptures in our normal everyday lives. These trauma narratives serve to represent these ruptures and bring to mind the devastation that is left in their wake. What they lack in structure, self-reflection and purpose they more than make up for in narrative devices. Such devices included their communicative power, through emotional, raw and

detailed illustration and the purposeful characterisation of the actors in the story including family members and healthcare staff.

Where trauma narratives conform more fully to the interconnection between past, present and future these temporal features reveal the threat of developing damaging regressive narratives that move towards a future that means loss. Where little can be predicted with any certainty both real and hypothetical narratives wrap around each other and create their own form of trauma. Mechanisms to prevent the narrative from maintaining regressive features included actively removing consideration of the future from the present, self-determination to cope, self-preservation by stepping out of the trauma narrative and sustaining a narrative of hope. Figure 5.4 represents how trauma ruptures normal life through injury, continuing illness, critical care and comparison to other people's situations.

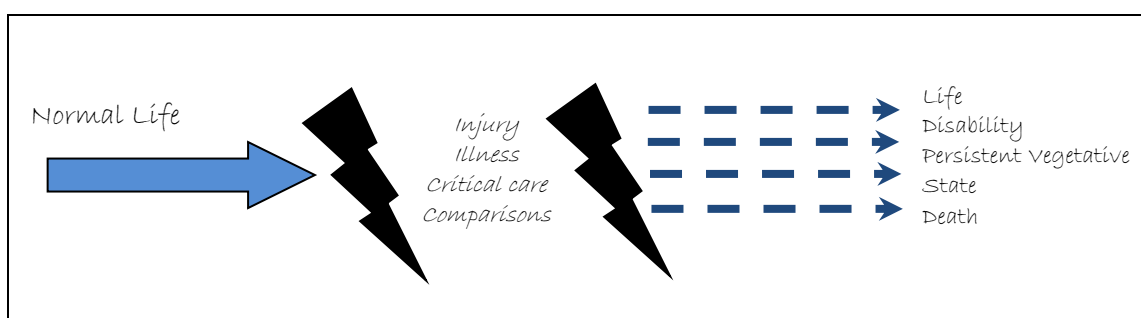


Figure 5.4 Trauma narratives rupture normal life

5.3.2 Recovery narratives

Recovery narratives were identified in all family members' accounts. These recovery narratives traced the chronological features of the injured person's progression from injury to the attainment of physical health. As such these were largely progressive in nature as the injured person moved towards the valued goal of return to their pre-injury state. However threatening this discourse of recovery was the perception of change. Within the TBI literature the concept of an injured person being different is well established (Lezak 1978; 1986; 1988). These recovery narratives grapple with the understanding that people who sustain head injuries often change and in these narratives of good physical recovery, change was often ambiguous, invisible, unknown, and hard to quantify or measure.

These recovery narratives were interpreted through the lens of biographical disruption (Bury 1982). Bury (1982) identified biographical disruption in the lives of persons with chronic illness suggesting the presence of illness disrupted their sense of self, disconnecting them from their past and anticipated future. Lawton (2003) explained that it was largely the work of Michael Bury that changed our understanding of the lay experience and helped us to see patients as

more than just a possessor of illness. Lawton (2003) wrote in *Sociology of Health & Illness* that 'despite the overwhelming interest in Bury's (1982) concept of 'biographical disruption' in the Journal's history, there has been no obvious attempt to extrapolate his ideas to the caregiver experience' (Lawton 2003, p37). Therefore, this study uses these concepts as a means to understand how non-injured family members came to their own understanding of if, and how, the injured person had changed. Alternatively the opportunity for recovery narratives to reveal biographical reconstruction (Williams 1984) continuity and reinforcement (Williams 2000) was also explored.

5.3.2.1 Barker: 'Perceptions of change and loss'

The recovery narrative for the Barker family was interpreted as 'Perceptions of change and loss' because although Suzanne and Emma shared narratives of physical recovery the narratives exploring change were different. During the year following head injury physical recovery was attained quite early but within these accounts there was an evaluative process of how much Dave had, or had not changed. The narrative threads between Suzanne and Emma gradually diverged as each evaluated change post-injury differently. Once physical health had returned, Emma's narrative remained stable over time and her perception of her father post-injury was connected to her perception of him pre-injury. However Suzanne's narrative regressed over time as her perception of Dave post-injury became disconnected from her memory of him pre-injury and hope of him returning to his pre-injury state diminished. The understanding that these recovery narratives were not aligned between the two family members distanced Emma from Suzanne and increased Suzanne's sense of isolation.

During their first interviews both family members' recovery narratives centred on return to physical health and objective markers were identified such as the return to mobility and an overall increase in independence. This recovery was contextualised within the understanding that given possible outcomes such as disability and coma they were all lucky Dave was not more damaged as a result of the injuries he sustained. Three months after injury Dave was perceived as having made a full recovery and Suzanne referred to both luck and gratitude that he had made so much progress in such a short space of time. However, by the second interview the rapid pace of recovery led Suzanne to question the validity of her trauma narrative and she wondered if it had all really been as severe as they were led to believe.

The indication that Dave may not be the same person he was before injury was first suggested by healthcare professionals while in the neuro-critical care unit. From this moment Dave's biographical continuity, as perceived by Emma and Suzanne, was under threat. Both family

members tried to make sense of this threat by attending to key features of Dave's biography while his outcome remained unknown. Suzanne and Emma explored what aspects of his character could be lost, and what could not be, to retain their perception that Dave was the same person post-injury. The perception of possible discontinuity forced family members to examine their own future and the future of the family without the person they knew (see Box 1).

Emma [T1] "he was saying...that, he should make a full recovery, and I thought but what's a full recovery mean? 'You know, everything kind of works again'... I was like but...so...and then he was like 'oh but his personality might be affected'...and I was like 'well...that's quite a big deal!' [laughs]...you know, 'here's your dad by the way he's not actually your Dad 'cause he's completely different to the person he was before'... and I thought well that's quite a blasé thing to say..."^{25:17-23}

Box 1

Therefore it was important to search for ways to establish if Dave, as the husband and father that was known before, had survived. As sedation was lifted and familiar mannerisms were identified these events reinforced Dave's biographical continuity within the acute phase of illness and relieved negative images of the future (see Box 2).

Emma [T1] "[Be]cause even when he was being an arsehole... when he initially woke up... just the way he used certain words, or phrases... erm, like he'd say 'yes, yes, boss, yes fraulein'... and he'd say that to everyone and it was like yes well that's the kind of thing he says, and that was such a relief, so despite him ...[laughs]... being quite horrible with it all, like little things like that...I guess even if you didn't think about it so much, it kind of made you feel like... probably wasn't going to be too... severe...yeah..."^{109:1-7}

Suzanne [T1] "When he first woke up, you know, I mean I could see that... even when he was asleep, the way he was putting his hands... and I thought... oh... yes, you know, that's him... I was really worried that he would not be him at all... that was one of my worst fears, that you know if he's not like his old good self, will I still love him, and will he still love us? Will he remember what we've been through?..."^{91:7-12}

Box 2

Yet, despite these early reassurances that maintained Dave's biographical continuity it was Suzanne who retained some questions over the manifestation of problems in the future. Although there were some elements of biographical revision noted in the acute period, such as characteristics that would be enhanced or subdued, these changes were not perceived as concerning. When told that Dave may have problems with planning and executive skills, these were contextualised within his pre-injury character. Problems with planning were considered a pre-injury trait and therefore continuation of this trait reinforced his identity rather than revised it.

Although Suzanne and Emma's narratives had been similar during the first month, once Dave was discharged home their narratives started to diverge. As normal life resumed Dave's behaviour and character post-injury were once again compared to their understanding of him before injury. Suzanne's narrative became gradually more regressive over time and biographical disruption became a key element of her recovery narrative by the one-year's interview. The examples in Box 3 illustrate the evolution of Suzanne's perception that her husband may be different. One year after injury Suzanne illustrated her perception of Dave's biographical disruption by describing him as 'a shell that you're used to but something on the inside was different'.

Suzanne [T1] "It was really, really worrying, I mean I'm not so worried now, though I, I mean I am still quite worried because when you read all the paper work and you think, you know things will change... he will maybe not return to his good self... and I realise that when I was in intensive care one of the nurse, a male nurse, said bluntly to me...he said '*you know he will never go back to normal, he'll never be himself*'...and I thought wwwhhh(laughs)...it came as a shock because I didn't realise that... I thought well he's speaking, you know he's looking alright... he's gonna be alright...[*said very softly*] but probably not..."^{92:1-9}

Suzanne [T2] "And he hasn't... when they say... you know, you're husband's probably gonna be different... you know with his frontal injuries and everything... er... I don't think his personality's changed that much... he's probably more... not self-centred but he likes talking about himself... and if somebody comes and sees me for example... he would just come limping and say 'ohhh, I'm not too well or you know... do you want to hear what happened to me?' ... and I mean I do understand but he doesn't see the other, he wouldn't... make a proper conversation... he... still rather focuses ... on... 'oh what happened to me, me, me'... but... it's hard for him to... er... ask questions... for example, or to be aware, you know of how people would feel..."^{11:1-10}

Suzanne [T3] "I remember I think in the first probably meeting I said, somebody said to me 'oh... your husband's never gonna be'... no... 'your husband's never gonna be the same' or something like that, was it similar or... and at the time I was quite shocked... but... he was right[!]... you know I mean... and it's a nurse but... he was right, but not to say it so plainly but to say right you know... it was your life before and now it's ... that's just what it's gonna be like..."^{374:2-8}

Box 3

Characteristics that Suzanne identified as changed included being quite self-centred, critical of other people, wanting to talk about himself, not able to hold a proper conversation and struggling to show interest in others. Suzanne also spoke of angry outbursts, frustration and agitation that she did not associate with her husband's usual personality. However many of these features were also made sense of through pre-injury characteristics and some served as biographical reinforcement rather than revision (see Box 4).

Suzanne [T2] "But otherwise... yeah we don't, I mean I can't just, you know, take him to the pictures or... we haven't attempted to go to a restaurant... he went with Emma while I was

away... but er... well Emma said he kept talking about him, him, him, I said well you know it's normal, that's just him, it's meant to be, I mean even before the accident... he was really me, me, me! [laughs]... now it's me, me, me and even more me! ... but, you know, that's probably what you should expect... I suppose so... I mean I can't blame him for it, you know and, and he, and he's saying things in great detail... and you know he can remember everything...^{42:12-23}

Suzanne [T3] "that's when we sort of find that... under stress he doesn't cope as... as well as before... because he's sort of, sort of a calm person and... he would just deal with it you know really well... I think now he just gets really vocal and... sometimes you know if you walk into his office and you say something he just... *BURST*... or he snaps or he slams or he... breaks or... that's something that you know... he never used to do before...^{25:1-6}

"So we know it's not his fault... and you know put it down to... er... the accident but that's, that's the thing that... that's the sort of concern for us really... that's the only little thing that's left over from the accident...^{26:1-3}

Box 4

Although the changes were not often perceived as problems for her and the family, she did not like this side of her husband's personality. In addition there were more subtle changes that were not always attributed directly to brain damage itself. Suzanne spoke of her concern for Dave's emotional state, how upset he got at certain situations and how he would not normally be so upset before the accident. The emotional changes were attributed to Dave coming to terms with his accident and thinking the same thing could happen to others (see Box 5).

Suzanne [T3] "you know... it's... for example... er... not... not to work's clients but for example a couple of days ago... was it a couple of days ago yesterday... he came back and he said 'oh... I nearly had an accident... erm... going down... because some, some prat just over took me and er... and you know he was going too fast so then I *chased* him'... and I thought 'oh no'... you know you're gonna get involved in, you know you could get into trouble so he stopped the car and he banged on the window and he said 'oh sorry have you noticed what you've done... and you know this is dangerous'... and I said Dave don't do that...^{153:1-9}

"because he's a big guy and people might just be scared so... this poor chap was in his car apparently and he'd locked his door so... [laughs]... really scared... because Dave's quite scary he's... if you don't know him... he can be sort of... you know a scary sort of guy... and some people are always scared of him so... I said please don't do that... you know don't think that... you're gonna save the world you know... so whether it's... because he's realised he nearly died I don't know he just wants to change things or... but to me it's not sort of normal behaviour... [laughs]... and especially not when you're driving... you know...^{155:3-11}

Box 5

In stark contrast Emma did not talk about these behaviours as being different to the person she knew, in fact they served as biographical reinforcement because these were familiar to her in her childhood. Accounting for these different narratives in the present was attributable to not sharing narratives in the past. Emma suggested it was only when her father met Suzanne that his personality softened. Emma was therefore very explicit that these characteristics

were not indicative of change in his personality suggesting if anything they had merely shifted back to how he used to be (see Box 6).

Emma [T2] “And... when I grew up I kind of confronted some of those issues... with him when I kind of hit my teenage years... erm... the fact that he could be like quite angry and volatile... not very caring... like never the sort to... to give you a hug or pick you up or... he can be... [pause]... he can be erm... very sympathetic... but... yeah he’s not... he’s not the most caring man... or... he’s a man’s man... he’s an alpha male... you know, he doesn’t do... softly, softly and cuddles and stuff! [laughs]... and stuff like that... he’s just angry and fiery and has a temper in him... and my step-mum doesn’t see any of that in him... which I find hilarious...”^{97:1-9}

Box 6

For those external to the family home the recovery narrative was perceived as sustained and progressive. Recovery was a valued goal that attracted praise from family, friends, customers and healthcare staff. However, the process of biographical disruption destabilised the recovery discourse and suggested recovery had not been achieved. Suzanne portrayed herself and her children as the only ones who could see Dave was different and attributed their unique insight to the fact that they lived with him and to spend real time with him was the only way to see what they saw. As this particular narrative thread is not shared with anyone else Suzanne feels an increased sense of isolation that builds over time. This isolated narrative is exacerbated by actively ignoring change and hiding the problem from others so they would not realise Dave was not fully recovered (see Box 7). Suzanne explained that she did not want to disappoint people by correcting her husband’s story of injury and subsequent survival.

Suzanne [T3] “Well I don’t think they do... and I don’t think his sister does either... I don’t think they realise how poorly he was... how, how he nearly died... and you know I had to keep this... from his customers, I couldn’t say... oh well... you know I don’t know if he’s going to make it really... [laughs]... and you know everyone would have left us and I say the business would have just collapsed... so... it was sort of you know... I had to hide it... a bit er...”^{148:1-6}

Emma [T3] “Erm... so I think that was quite horrible for Suzanne and... then these... sort of... changes in temper and mood... and... short fuses that she’s told me about I don’t think that’s very pleasant for her to deal with... but yeah... I imagine that would have been the worse bit when everyone just thinks it’s all back to normal... myself included... and you’re there... dealing with it... erm... in a longer term thing... because if his mood swings are that much different... I mean that’s going to be very obvious... when you’re married to somebody... and it’s going to be a real change... and if no one else witness it or... no one else kind of sees it... you... that must be pretty tough... you spend a lot of time wondering if... I don’t know... I don’t know but that must be really tough... I imagine... [slight laugh]...”^{65:1-11}

Box 7

Summary of recovery narrative for the Barker family

In the acute phase of injury Suzanne and Emma shared closely aligned narratives of recovery as Dave resumed physical health. However narratives became divergent over time as

biographical disruption threatened the stability of Suzanne's recovery narrative. Without a shared narrative Suzanne became isolated in her view of Dave's recovery post-injury. This narrative of incomplete recovery and biographical disruption juxtaposed the story of survival and return to health that was held by others. The same behaviours that underpinned Suzanne's evaluation that her husband was different were used by Emma as biographical reinforcement and were connected to a pre-injury view of her father that preceded his relationship with Suzanne. Therefore recovery narratives were misaligned and caused Suzanne to feel isolated in her experience.

5.3.2.2 Hughes: 'Accepting loss and dealing with difference'

The recovery narrative for the Hughes family was interpreted as '*Accepting loss and dealing with difference*'. Recovery narratives that were shared between Diane, Bill and Lucy depict Abigail's return to physical health that progressed beyond that predicted and there was hope for the future. Once again these recovery narratives showed how family members evaluated if, and how much, Abigail had changed following her injury. Although Bill and Diane's narratives shared common concerns, predictions for the future and reflections on the past, Lucy maintained a very strong narrative that could not be opened up to any negative predictions. Narratives revealed the importance of past hopes and ambitions, which were an integral part of family members' biography for Abigail, and these were threatened in the wake of injury. Narratives illustrated how family members came to terms with, and made sense of the loss of an anticipated future and by the end of the first year narratives of recovery showed how compromises had been made to enable biographical continuity and connect Abigail's future to her past.

Narratives of recovery were largely progressive in nature towards the attainment of full physical health. Recovery narratives began by a shared feeling of fragile hope. However, while still in the neuro-critical care unit Bill illustrated how his narrative put him at odds with other family members. Keen to understand what he could about his daughter's injury he tried to prepare his family for a different outcome to that which they were hoping for. Predicted futures were therefore misaligned and caused some tension within the account. However as sedation was lifted and the recovery narrative was established narratives emphasised the speed of recovery and their related disbelief (see Box 8).

<p>Bill [T1] "Everything that we'd heard, and read at that point, 'cause I read this Headway book thing, which er... I don't know if that's a good idea or not... but erm, the family kept moaning at me 'cause I'd read it from cover to cover... and er... their all being positive and I'm saying... 'it ain't gonna be, ain't gonna be like that', 'they'll have this problem, there's gonna be that</p>
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problem, they don't do this and they won't do that'... course, there she does, she does exactly what... the book says won't happen, they won't just lie there 'Hi Mum, I'm here now'....so that was the first real plus point...and we stayed with her for about half an hour to an hour maybe before we all... went back, really, really happy that you know, she was... effectively, back with us at that point, which was really good"^{68:1-10}

Diane [T1] "I think you just think 'oh, you're going to be left with somebody who's totally zombieified'... and she's such a bubbly outgoing person, you can't imagine having her home sitting there not being able to do anything... .. you imagine things are going to be totally... different to how she was...so...that was all we just thought she was going to be like...a vegetable may be or a bit more than a vegetable and take a lot longer to come round... but like she would do in time... you don't imagine that she's going to sit up and go 'YEAH'!... [laughs]... basically..."^{109:4-12}

Box 8

As the recovery narrative progressed immediate fear for the future began to diminish and Lucy exemplified this narrative by saying in situations where so little could be expected every aspect of recovery that was achieved was more reassuring of the final outcome. Despite this recovery concerns for the future continued and included the future possibilities of self-fulfilment in life, family, work and relationships. Diane and Bill also continued to be concerned about the possibility that Abigail may be weakened in some way. Diane spoke of haemorrhages and early dementia and Bill spoke of cancers, growths and tumours at the site of injury.

Over time as physical health was regained the narrative became stuck in the present and could not progress any further until Abigail had received an operation to replace the piece of skull that was removed. Diane illustrated how entwined all their narratives were by saying none of them could move on until she had undergone this surgery (see Box 9). Once the operation had taken place the recovery narrative was more complete and life was able to move forward again for them all.

Diane [T2] "...I didn't have a good day yesterday... [slight laugh/upset]... [pause]... everyone said 'ohh you're you should be so lucky, how good she is' and I know that's true... [starting to cry]... [long pause]... but I just know, I just think it shouldn't have happened... [slight laugh/tearful]...mmm... and I just want, I just want it ... I want her operation... I want her to get better and just like... get on with everything... [cries]... .. [long pause]..."^{43:1-6}

Box 9

Embedded within this recovery narrative was the perceived threat to biographical continuity. While the future was completely unknown Diane and Bill actively tried to predict the impact that head injury would have on Abigail. These predictions caused narratives of trauma as images of the future caused great fear and distress. However, Lucy did not share this narrative and tried to maintain her perspective of the present by not altering her perception of the future. However this means of coping put her at odds with other family members and she

found it difficult when they talked about their own concerns, from which she tried to distance herself. Lucy used positive representations of Abigail's character to help moderate negative feelings about the future. As such this process of biographical attendance helped sustain her progressive narrative of recovery (see Box 10).

Lucy [T1] "And my dad... I was just, he was just... [laughs]... he'd sit there and like... he's so blunt... 'oh I just don't want her to be a vegetable' [laughs] and I was like... 'dad... you can't, firstly say that and secondly she, she won't'... and I had this... eternal feeling that she wouldn't like... and I don't think I ever didn't believe that... I just, my sister's such a... like she's so flipping... feisty and such a... stubborn mule like... I couldn't ever see that leaving her and that she letting it... she'd just be like 'no, I'm not gonna give into you lot'..."^{98:1-7}

"...It seemed to be when you went and sat with Abigail... you'd all talk about it... and... dad said the same thing about knowing the doors were there but not going through them...but when he said to me once about the whole...vegetative state... I understood that he had thought about it more... and said he was worried about her dancing... and I think he had... sort of... he's really... even now very worried about what will happen... in the future and her eventual outcome..."^{124:1-7}

Box 10

The recovery narratives illustrate that biographical discontinuity was something that was first expected or predicted, then challenged as real or perceived and later realised and confirmed. Once woken from sedation immediate fears of biographical disruption were allayed and through recognition of familiar personality traits Abigail's biography was reaffirmed. Although quite confused early on Bill spoke of reassurances that Abigail was still the person she was and described her sense of humour as little bits of 'her' coming back.

Within the acute setting difference and change were masked by rapid recovery and an unfamiliar environment. So then it was within the phase of return home and resuming normal life that differences were more easily identified. Despite these differences the Hughes family appeared to be engaged in a process of biographical revision rather than disruption whereby current behaviours were contextualised within pre-injury characteristics and normalised as exaggerations of previous states. However, the possibility of these problems remaining in Abigail's future undermines the recovery discourse by suggesting recovery remained incomplete. Therefore although family members moderated the significance of these differences they did seem to trouble family members (see Box 11).

Lucy [T2] "but it sort of comes back sometimes... and she sort of funny, just funny things that she says... we were, one morning I slept in her room because erm... like my room's being, it's not my room any more... and erm... I stayed on the floor in her room when I came down one weekend... and erm... my mum wanted me to cook Sunday lunch so she... came in, in the morning... 'cause she works night shifts... and she was gonna go to sleep... and erm I was gonna get up and cook lunch then my mum would get up and help me out... when she's, when she's

had her like nap... and erm she came in in the morning and said to me 'Lucy you need do lunch for about two' ... and I said yeah, yes, yes, yes, in my half asleep... and then erm, I got up and Abigail comes down stairs and goes 'What's this... you're cooking lunch for just you and Mum' ... and I was like... no Abigail no... well... she goes... 'well I'm gonna go out for lunch' and she says, she was saying it in a like jokey kind of way... sort of a ha-ha but, but like she was quite sort of adamant...she was like 'well I'm gonna go out for lunch with my friends because you're having lunch, you're cooking roast for just you and Mum' ... and I was like why do you think that... no Abigail, not at all, I'm cooking it for everyone' ... 'because Mum said lunch for two' ... [laughs]... I was like not for two of us ... for two o'clock! ... and she went 'oh yeah!, oh yeah!... [laughs]...^{13:1-18}

Diane [T2] "But I took her... where did we go... [name of place] and she was smelling perfumes... and she's going... she has a little stick... the girl, the girl sprays it... and Abby goes... 'no... can't ...' [laughs]... she ran across the local store she goes, she came running, well basically... sped from one side of the shop to the other with this... 'smell it... is it nice' ... I'm like 'yeah it's ok... I'll come back with you'...[laughs]... because... she loves perfumes she can't smell them anymore... she can make out that there's a, that there's something there... but whether that's like she picks up certain, I don't know, perfume has notes doesn't it... so it must be a per, a note... certain notes that she can pick up... very sweet perfume she seems to be able to kind of get the gist of... but ... she does basically her perfumes now are all on memory... what she can remember... I think that's very sad... that that'll affect her life... I hope it returns... that... that the... the sense... or other senses like, like I suppose her taste could be taking over... I suppose somehow with her smell... I mean because when she's eating... I'll say something 'is it nice' ... 'yeah ok' nothing really tastes that good anymore... sad...^{30:1-14}

Box 11

The narratives of more subtle biographical revision were shared between members of the Hughes family. Bill illustrated this revision by saying his daughter had lost years and instead of the independent young woman of 21, Abigail was now more like a 17-year-old girl who constantly sought approval. However at the one-year interview it was Diane who made a more explicit reference that Abigail was different. Diane sought confirmation of this change through other family members. Diane said she asked Lucy if she thought her sister was different now to which Lucy apparently said yes. However it would appear the narratives of biographical revision that were shared between the non-injured members was not perceived to be shared by Abigail herself. The example in Box 12 clearly demonstrated the difference, change and vulnerability that exemplified Diane's recovery narrative. Not sharing these narratives divided the injured and non-injured members of the family.

Diane [T3] "I said, I've said to Abigail before you know... do you think this is what you were like before or... or is this something, 'oh yes[!]' she says, it was probably what I was like beforehand' ... er... [pause]... she was worried she was going to wash away on holiday [said very quietly]... she'd got a li-lo... and I said to her she could sunbathe in the water... and er... the bay... the beach we'd gone to was really calm... and you had to walk a long way out... [laughs]... she thought she might wash away... so she stayed nearby which was nice... but... I suppose"^{81:1-7}

Box 12

Where narratives were not shared with others it created an isolating effect. In addition to Abigail's absence from this narrative, concern was also expressed that difference was not always visible to others external to the family. Bill expressed continuing unease that within rehabilitation nobody seemed to take account of Abigail's pre-injury biography that was so important to them. Rehabilitation professionals were perceived as only seeing Abigail as the person she was in the present and it troubled him that they could not see the problems that the family could.

A central part of Abigail's pre-injury biography was her identity as a dancer. The family's narratives were all entwined with artefacts of this identity and it was even used to make sense of the accident and injury. Diane suggested that had the accident been caught on CCTV Abigail was probably doing a summersault and would have been seen pointing her toes. The lack of additional injury was attributed to her core abdominal muscles holding her in place. In addition Abigail's rapid pace of recovery was made sense of through an understanding that dancers use more of their brain and thus Abigail's brain was more able to repair itself.

Therefore, as a result of injury the biggest threat to biographical continuity was not Abigail the person but Abigail the dancer (see Box 13). Diane and Bill's recovery narrative was full of the impact the injury would have on Abigail's lifelong ambition and whether she would ever have the opportunity to fulfil her dream. Diane made comparisons to Abigail's friends who were already living the life that they had anticipated for their daughter and during the first interview wondered if Abigail's future was to be merely delayed or would be completely different.

Diane [T1] "And you just worry about what the future's gonna hold... whether she'll ever be able to, happily and confidently, you know, leave home... and be independent... I know she probably will because she's so stubborn... but I, you know, I just... worry for her, like you do being a mother obviously! [laughs]... I'm sure she won't want to live where we live for the rest of her days! [laughs]... you know..."^{88:1-6}

"But she might have to change... what she was planning to do... might have to be... bit of a change... but what she's always wanted, what she was doing is what she's always wanted to do since she was about three... *always*... you know, every year she's always done pantomime, she's always done the summers... the summer season... she's always been involved in theatres...it will come hard for her to be told that, say 'that isn't going to be her option any more'... she may have to re-think... ... so I don't know...[pause] ... it's difficult..."^{90:1-8}

Box 13

Three months after injury the narrative of a lost future built and Diane spoke of her sorrow at watching her daughter turn down the offer of an audition. Diane described Abigail's future as shelved suggesting Abigail's future was waiting for her to catch up to it. Diane hoped the experience would reinforce Abigail's known characteristics of strength and determination;

however it was Bill who said he thought the biggest change was Abigail's lack of these characteristics. Bill suggested it was as if Abigail did not remember just how important dancing was to her before the injury and she was now more likely to accept what she could not do rather than try to push past it. Again these narratives demonstrate misalignment. The non-injured members remember the importance of Abigail's past biography that was also an important part of their own. Before injury Abigail the dancer was almost a biographical certainty that is acutely disrupted post-injury.

At one year the family were more actively engaged in biographical reconstruction and revision, whereby Abigail was realising opportunities to reconnect her future to her past dancing ambitions. Although there was some revision of Abigail's future career with its subsequent delay by a few years the compromise was more acceptable. However despite these revisions Diane emphasised the narrative of a lost future by saying the future did not feel like it would turn out how they had planned.

Summary of recovery narrative for the Hughes family

Narratives of recovery for the Hughes family depicted the transition from injury to the attainment of physical health. However, adjustment was delayed as the progression of the recovery narrative could not continue as Abigail waited to have her operation. Lucy's recovery narrative tried to maintain a positive image and predictions whereas Bill and Diane were concerned early on about the impact of head injury on Abigail's future. Over time narratives converge as Lucy recognises some of Abigail's limitations and changes post-injury to the point where all non-injured members recognise difference at one year. However these narratives of change were not recognised by others including Abigail herself and healthcare professionals, adding to a sense of isolation that only those within the family understand. Throughout the recovery narrative the biggest threat to biographical disruption was to Abigail the dancer. Her immediate future was lost at the point of injury but over time efforts were made to reconnect the past and the present. However despite these efforts life post-injury was not considered of equal value to what had been predicted and comparisons made to an anticipated future only served to emphasise how much had been lost.

5.3.2.3 Wilson: 'A sustained and continuous medical miracle'

The recovery narrative for the Wilson family was interpreted as 'a sustained and continuous medical miracle'. This narrative thread was shared by all family members and represented a progressive narrative that although slow in the first interviews, gained momentum over time. A year on recovery was considered complete: Tracey was back to work full-time, driving and

independent once again. Integral to the narrative thread was the perception that Tracey had been given very poor odds of survival and this sustained the miracle feature of the narrative. Narratives represented a biographical coherence from very early on in recovery whereby Tracey post-injury was established as the same person she was pre-injury and this evaluation did not waver for any family member.

The recovery narrative began with predictions and expectations of the outcome, as discussed in the trauma narrative, and as such moderated family members' responses to Tracey's on-going improvement. Trying to make sense of their situation comparisons were made to other patients who, it was understood, usually regressed in their recovery journey. Therefore within this fragile recovery family members protected themselves from such disappointment by not wishing to hope improvements could be sustained. However, there was a turning point in the narrative as Tracey responded to a verbal request. Drawing on their knowledge of nursing assessment the significance of this event underpinned their understanding that recovery had been established (see Box 14). However despite this event the recovery narrative retained a protective feature that predicted the full extent of damage was yet to be revealed.

Kate [T1] "Well the first was her moving her eyebrows... she, she didn't move her eyes... erm... that was... I think that was when... she did start to move her hand in NCC... then they moved her round the corner... I think that's when she was moving all them... and Helen, her sister... made her laugh... which was... I mean we hadn't got any reaction like that at all from her... but Helen... obviously we think Helen... perhaps... clicked something... and... she obviously, there wasn't noise coz she's got the trachy in... but her shoulders were moving... and... and she's smiling... so... you could see she was laughing... something that Helen said to her... and coz... over a silly thing like that and you think... and you, you're so excited..."^{51:1-9}

Peter [T1] "Anyway er... we said oh we'll leave you with Mike... for er... for a little while... you because it's... obviously it looks like you're getting ready for a little sleep... and we'll pop back in a little while like... so I give her a little kiss... [...]... give her a little kiss on the forehead... and er... got to the end of the bed and said... right see you a little bit later darling... give dad a wave... she just lifted her arm up... and just done this ... [slowly waves]... [pause]... and you've gone... that was a... that was actually a response... did I... did she really do that... or did we see that... and... we... Mike witnessed it as well and we thought that was a physical... response to verbal request... now coz normally the nurses say to her... grip my hands... we'd say to her... come on hold my hand..."^{143:1-10}

Box 14

The recovery narrative was progressive in nature and although began slowly nothing destabilised its progression. However because the expected narrative of a poor outcome was so influential to their experience a miracle narrative builds in its importance and attracted praise and astonishment from family, friends and healthcare professionals alike.

Within family members' accounts the miracle narrative was reinforced. Everyday functions like using a knife and fork could not be taken for granted and all had to be re-learned. Some tasks the family took an active role in helping Tracey remember and others, to their astonishment, seemed to come back quite naturally. Although Tracey's emotional response was distressing at times Mike explained that they tried to interpret this response in a medical way that involved a functioning and connected brain (see Box 15). This interpretation represented hope and the potential for a positive outcome and three months after injury Kate was assured that the head injury would not be problematic moving forward.

Mike [T2] "For her to beg me to take her home was... .. in a weird way... brilliant, it really was... [uhh]... she wants us to take her home, she wants to be at home... she's, you know she's getting somewhere and for her to be able to tell us that... is all those things where... [cough, cough] ... for her to be able to... for her brain to be able to tell us she wants us to take her home... and we were looking at it like that as well... for her brain to tell her to pick up a pen and write her name, for her brain to ... you know, it was... so that was just another thing, you know... for her emotions to tell her she's upset and she didn't want to be there any more, that was... that was...*brilliant* because that was another part of her that was... *working*"^{151:1-9}

Kate [T2] "Well she's still got trouble with her foot... that's it... I think it's only going to be her foot I think her head's... I don't think... I don't think she's going to have a problem with her head... because... I don't think she is... I mean, I mean we was playing scrabble and she's not, no prob[lem]... although I had beat her which isn't usual... [laughs]...so... and then, she seems... as I say she seems alright with her head injury... I think it's just... although... it's because she can't move her big toe... I mean... so it could only just be that but I mean... or she might even make a full recovery... this time next year... but...so I don't think it was anything with her head... she seems... she seems ok... but you just don't know do you...she doesn't tell you everything does she, I'm her mum she's doesn't tell her mum everything do you... er..."^{88:1-10}

Box 15

The miracle narrative was also accentuated by characterising Tracey as the most expensive critical care patient and the approximated cost of her care emphasised the severity of injury and how far she had to go to achieve recovery. Mike said he questioned the doctors about how often they saw recovery in the way they were witnessing with Tracey and was told they never did. However the misalignment between the expected and actual narrative began to invalidate the veracity of their trauma narratives. At three months Mike spoke about his perception that people may have felt they had exaggerated the situation and that in some ways the recovery had made the experience feel like a sham.

Mike [T2] "And she had... she had numerous specialists... and... nurses, from the NCCU... come up to see her... because they were hearing the stories... and, and she was told, you know... we've come to see how you're getting on because we're hearing all about you... and that... for her that was an encouragement... but for us it was clear... that this wasn't... everyday life in there... you know, this sort of, what was happening was... er... well it was out of this world for us but... for her... [cough]..."^{120:1-6}

Kate [T2] "And course she's... she's just come on leaps and bounds... she's come home and she's come on leaps and bounds... she, she... it's a miracle on two legs really... I mean everybody... all the doctors she speaks to they're all amazed how well she's doing... and... and when you think where we were and where she is now I mean, she's talking about going back to work now... I mean... it just doesn't seem possible... we've been so lucky... I mean we, we do consider ourselves lucky to have her here the way she is..."^{21:1-6}

Mike [T3] "every single person on that unit... woke up that morning thinking that life was going on as normal... and everybody that ends up on there... that either are lucky enough to make it off, or don't make it off... it is literally the click of a finger... most of it... it's a car accident, it's a... an accident of some sort or... you know... the brain and the head is a very... it's completely different to anything else erm... so that, you know... constantly... it, it wouldn't of mattered if it was Tracey laying in that bed or the Queen next to her... in that sort of situation... you know... everybody is the same, doesn't matter how much money you've got in that situation you can't buy it... you can't buy your recovery... you know..."^{247:1-9}

Helen [T3] "I remember when she came out, when she first came out she'd erm... she'd obviously still signed off work... and she'd come into town with my mum sometimes... and they'd pop in to see me here and I'd run around the office with her going 'look, look at her'... [laughs]... like she was some like show and tell..."^{23:1-6}

Box 16

Even a year after injury the accomplishment of recovery was spoken about with a great sense of pride. Success was shared by all family members and was not a narrative owned by Tracey alone. These deeply entangled narratives led family members to try to make sense of why Tracey had made such a recovery. The early accounts centred on interpreting the odds of survival and consideration of aspects that were surely in Tracey's favour. Over time these elements developed into firm explanations for Tracey's survival and subsequent recovery. An understanding was reached later in the accounts of Mike, Peter and Kate that recovery required each and every link in the experience and that without any piece, no matter how small, it would not have been possible for Tracey to have recovered in the way she did. Recovery depicted like this emphasised the fragility of the experience and Mike explained that in such grave situations it was always the little things that counted.

Despite an understanding that Tracey, as the person they knew, could be lost (see Box 17) family members attended to key features of Tracey's biography while in the critical care unit using known character traits to help them create positive representations of the future. Character traits included stubbornness and determination and later in the narrative helped family members make sense of why Tracey had never given in to her injuries.

Mike [T3] "Because... .. er... the likelihood of getting her back was remote to say the least... or getting the... the, the doctor's words were basically... you know she's not going to be... there's a chance she could come home and live some sort of assisted life but she's not going to be the same Tracey that you knew... you know, and that was said in virtually no uncertain terms... she

will not be the same person... and... yeah... „104:1-5

Box 17

Biographical continuity was then established within the recovery narrative as soon as more than just basic brain function was assured. Narratives indicated that any concerns about Tracey's personality were soon dismissed through recognition of behaviour, language and facial expressions that were positively associated with the person they knew before the injury. However, before biographical continuity could be established the narrative was stuck in the moment, living through the narrative day-to-day and a coherent sense of the future was impossible or too hard to predict.

Once biographical continuity was assured the narrative could move forward again and all their futures could be predicted with more certainty. The recognition of character traits acted to reassure family members that recovery was possible, the Tracey as the person they knew had not been lost, and life could still be meaningful post-injury. The ability to hear Tracey's voice was also significant and through familiar language there was additional reassurance of recovery and reinforcement of biography (see Box 18).

Helen [T1] "... I came the day after and I said did you hear about [name] and [his girlfriend] and her face it was like... [deep intake of breath]... gossip face like she does... [laughs]... you know when you tell your best friend something and you go... [deep intake of breath]... I've got some gossip... that, she did that face at me... and she made me laugh... she was like 'oh my god I know!' ... [laughs]... „109:1-7

Kate [T2] "She, she was getting to sound more like herself... erm... she, I mean... from the start of it she was very placid, which wasn't Tracey at all... but then she was getting, she was still quite placid... but she's getting more and more... agitated and... a bit more short tempered... she's not that short tempered but I mean... and then erm... „61:1-4
"and I think she's going to be back ninety nine point nine per cent we're going to get her all back... so... I mean... and, and to recover so quickly... because I mean... well we didn't think it would be this quick... „69:1-4

Peter [T2] "No... because once she woke up and started talking... erm... she... she was... almost instantly back to... to her normal, normal self although she was obviously sort of... you know only just capable of talking and... just... you know... her manner and the way she's you know... talking and speak, speaking to people... it hasn't changed... it's just... it was wonderful to know... it was... it was our Tracey that was back and not... a half, a half something of a Tracey that was back... „169:1-6

Box 18

Biographical continuity was only threatened by the presence of a more placid nature that was most prevalent in the acute phase of recovery. Helen explained that the family had played down the significance of this change in character but later explained that her determination

and temper were core parts of her identity and if absent in the long-term would have caused some discontinuity in who she knew her sister to be.

However within the narrative there was evidence of some biographical revision at the end of the first year after injury as more subtle sequelae were identified that included memory loss and fatigue. Yet these sequelae did not define or direct their accounts and were seen as challenges that could be overcome with slight adaptations. Once again the entwined nature of the narratives was emphasised by Mike who talked about these adaptations within the context of all their lives. Therefore they all had to make revisions to way they lived with each other to help Tracey manage these changes in her own life.

Summary of recovery narrative for the Wilson family

The Wilson family all shared closely aligned narratives of recovery. Narratives were progressive in nature that illustrated how Tracey improved beyond that which had been predicted. The prognosis had been so poor that a miracle narrative built in its importance so that the trauma narrative was not completely invalidated. Threats to biographical continuity were quickly dismissed as the person they knew as Tracey became anchored in the present with this assessment remaining fixed over time. However there was some element of biographical revision as sequelae post-injury became apparent. Nevertheless, these sequelae did not insult any particular aspect of Tracey's biography and as such were considered an acceptable legacy that all family members found new ways of living with.

5.3.2.4 Recovery narratives conclusion

The recovery narratives for all families were largely progressive in nature as the injured person moved from injury to the attainment of full physical health. The only exception to this was in the Hughes family whereby the recovery narrative could not progress until an operation had been completed. However, later on such good recovery threatens the validity of the trauma narratives and their interpretation of the severity of their situations.

Embedded within these narratives of good recovery was also consideration of biographical continuity. Narratives of biographical change have the power to undermine the recovery narrative by suggesting recovery is incomplete. These narratives suggest that while there is evidence of biographical disruption there are also more complex processes of biographical attendance, revision, reconstruction and reinforcement. For some these revisions accumulate over time to a direct statement that the injured person is different but these references were still entwined with normality and pre-injury context.

All families identified biographical continuity of the injured person in the acute period. In doing so a more stable and positive perception of all their futures could be realised providing continuity for injured and non-injured members. Although artefacts of the injured person's character anchor biography in the present, often narratives changed over time especially following their return home. Notably, for the Hughes family there was a sense of pre-injury biographical certainty that reflected Abigail the dancer. As this future became dislocated from the present it created a great deal of subjective loss as all their futures were different to that which had been predicted. In contrast the sequelae that were evident in the Wilson family did not threaten their perception of the injured person or any of their futures and therefore subjective loss was not an active part of their narrative.

Shared narratives in these families were important because they acted as confirmation of events experienced and ways in which these were interpreted. When narratives were divergent they increased a sense of isolation for either an individual family member, as in the Barker family or the entire family may feel isolated from society because those external cannot see the problems they can.

Figure 5.5 represents the movement of biographical continuity that perceives the injured person to be reconnected to their biographical self in the acute period but may be re-evaluated over time.

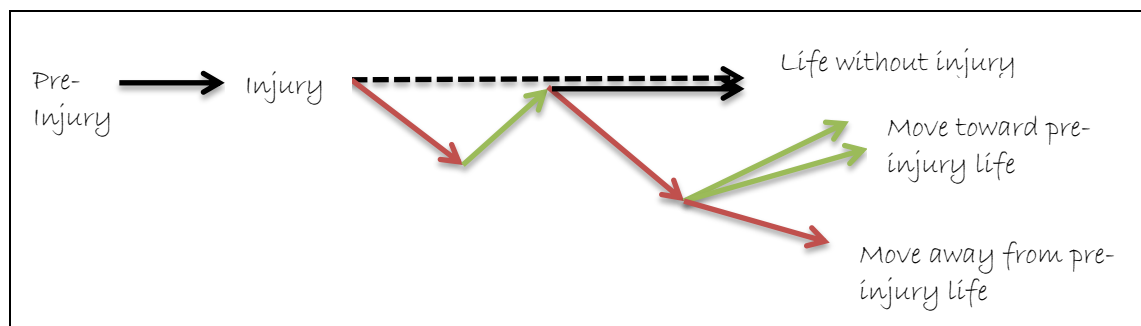


Figure 5.5 Biographical continuity in narratives of recovery

5.3.3 Autobiographical narratives

As was suggested in Chapter Three the critical illness of a close family member can turn the experience into a told, re-told, and reaffirmed story of illness, recovery, meaning and new life (Frank 1995). Therefore, when a relative sustains a head injury the family experience illness from a non-patient perspective. Through the re-telling of their story family members crafted their own autobiographical narratives. These narrative threads illustrated how the non-injured

members made sense of their experience and how the experience influenced their own biographical sense of self.

Pulled from their normal lives into the medical world family members embarked on a journey to make sense of what they were exposed to creating narratives to lend some coherence and logic to their situation. Normal life was suspended as they became submerged into a new narrative that called for a renegotiation of roles and responsibilities. Such a critical life event challenges people's sense of the person they know themselves to be. Life before injury provides context to the narratives as it predicts internal resilience and coping mechanisms. However, coming through the experience of illness many family members rethink their known self, illustrating some form of biographical revision.

For some family members these autobiographical narratives developed evaluative features that Bury (2001) labelled 'moral narratives'. The moral qualities of these narratives are relevant where 'people are more able to identify more clearly their own personal values and sense of self-hood' (p277). As such the theory of post-traumatic growth by Tedeschi and Calhoun (1996) is useful in consideration of the broad benefits that sometimes underpin the process of meaning making and pursuit of purpose. Tedeschi and Calhoun (1996) identify three categories including 'changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life' (p456) that can bring about a sense of benefit and purpose to traumatic events and illness.

Importantly, although the injured person is part of the overall narrative, it is after all their injury, they do not have an active presence in the narrative because of sedation, coma or confusion. This is relevant because these narratives of biographical revision and personal growth for the non-injured members are achieved in their absence. The consequence of this is a difference in narrative alignment between injured and non-injured members. The tension this may, or may not, have caused is discussed further within the context of each family.

5.3.3.1 Barker: 'Survival, growth and independence'

The autobiographical narratives for the Barker family were interpreted as 'Survival, growth and independence'. This narrative was represented in this way because of the response of both Suzanne and Emma to Dave's injury. Characterised as a central figure in Suzanne's narrative pre-injury, his absence had an immediate effect. New demands were placed on both family members to ensure the wellbeing and security of the family. Revision of previous roles and responsibilities pulled Emma into a shared narrative with Suzanne that suggested shared

function and purpose, common goals, shared success and being strong together. However, biographical revision and personal growth were strongest in Suzanne's narrative who cast her pre-injury self as someone she expected would not have been able to cope with the demands placed on her.

The narrative thread begins as Suzanne and Emma move into the medical world and their immediate attempts to make sense of this unfamiliar environment. Both members try to interpret medical jargon, the number of staff involved in Dave's care and the lack of consistent information (see Box 1). Emma also expressed frustration because the frequent use of different staff meant no one learnt their family's narrative and she had to continually tell people that Suzanne was the wife and she was the daughter.

Emma [T1] "it was tiring to spend time with him... it was a lot more draining... being around him... erm, but it was quite nice and it felt like there was things we could start to do then... we could give him water to drink, although every new nurse that came along, you kind of had to say 'I've been giving him water for eight hours!' and it's like ... 'oh I'll just go and check with the doctor'... doctor would go and check with the nurse that's on shift, oh I don't know how it worked out but it was really frustrating!" ^{42:1-7}

Suzanne [T3] "Well I mean I wasn't prepared for... for this sort of... you know when he was in intensive care all the shifts and everything... and... just this sort of aspect, I mean I suppose... you know you could just read all the information leaflets and everything if you wanted something in that waiting room but... you know you wouldn't see the same doctor and... for us, for me... it was very difficult to approach any, anyone who knew... I mean you could speak to the nurse and then erm... the nurse would say well, you know, I can only tell you that bit 'cause I've been here since eight o'clock this morning but really need to see the doctor and... he's gonna come at this, well we don't really know he's gonna come at some stage... [laughs]... today so... I wasn't prepared for that, maybe somebody could just talk to me..." ^{360:1-11}

Box 1

Suzanne's frustration at the medical world was substantial and remained a key element of her narrative over time. Suzanne's need to build a picture of her husband's condition and not knowing who to approach led her to try reading his medical notes, for which she was 'told off' by the staff. This event reinforced the delineation of medical and lay worlds that despite being brought into, there were rules that kept her as an outsider. However, as the transmission of information between staff was delayed or incomplete Suzanne said she felt she knew more than they did about her husband's condition. Suzanne was therefore immersing herself within the medical environment, learning what she could and becoming entwined in her husband's narrative of illness. In contrast Emma's feeling of unease in the critical care unit led to her preference to step out of this medical world as much as she could. Although feeling guilty for this method of self-preservation Emma contributed to the family's survival in different ways (see Box 2).

Emma [T1] "... And then...the next day... I'm pretty sure he had his operation the next day because I remember taking my sisters into town, while Suzanne went down to the hospital, I, there was a reason I didn't go... erm, but... by that time Dad was under sedation the whole time so it's, it felt like there is very little you could do when you were at the hospital... and I guess I felt more useful looking after my sisters and, kind of freeing up some time for Suzanne erm, rather than, kind of, like we all kind of stand there..."^{18:1-7}

Box 2

Although a difficult environment to be in, the critical care unit represented a place of safety and support that was gradually understood with time. The necessity for Dave's transfer to a general ward therefore changed the narrative direction by rupturing their familiarity and understanding of the medical world. The example in Box 3 would suggest that the ward also represented depersonalisation of care and a lack of human contact (see Box 3).

Emma [T1] "you know, asking people to kind of do the most basic... things...and with the nurses always changing is it's like 'David, David'... it's like call him Dave, and he'll do what you want, you know, just... no real kind of human contact, they're just worried about, you know, hitting targets... well that's what it felt like...we all felt quite angry about it..."^{52:1-5}

Box 3

Through the need to protect the future of the family both Emma and Suzanne's narratives showed features of biographical revision. Dave was characterised as the 'pillar of the house' where there was a clear division of responsibilities (see Box 4). Therefore Dave's absence during illness threatened the future security of the family.

Suzanne [T1] "But when I met him he had already set up his business, and you know he had his bank and everything, you know, I mean he was just er...he was living on his own so I kind of, when I met him I kind of tagged along and er, I let him do all the financial, all the finances and everything. So when the accident happened I had to deal with his business. I had to deal with his customers I had to deal with the bank and the building society and you know...I'd never done that before because, because he'd...he's always done it and I didn't see really the need... I had the house to...and the children to look after and everything so...I was kind of quite happy to let him do it. Which I shouldn't have done because now... it's not that easy but it helped me as well to er...to try to er...sort of feel that...that was sort of easy, looking back I should have probably erm...yeah I should have er...kind of tried to you know to, to do things with him rather than let him do everything 'cause it was quite hard to find out...I mean I couldn't remember which insurance he had for this or that. I had to look in his file because he is so disorganised, it wasn't easy [laughs]..."^{56:1-17}

Box 4

During the early phase, while Dave was in hospital, both Suzanne and Emma described their reassignment of roles in keeping the family, the business and themselves going. Despite it being a very stressful period there was a shared sense of success that both Suzanne and Emma navigated the experience together. Although Suzanne feared her past dependence on her husband and said she was not a strong person, biographical revision showed how her

confidence had increased significantly. Once Dave had returned home Suzanne described the need for her family to all find their place again.

However, the gains made from the necessity to take control and make decisions that would ultimately affect the security of the family were not perceived as being fully appreciated by Dave. Following her father's recovery Emma expressed disappointment that he lacked any gratitude for what she and Suzanne had accomplished in his absence. These accounts represented misaligned narratives between injured and non-injured members whereby biographical revision, personal growth and achievement went unrecognised.

As time progressed the intensity of the autobiographical narrative diminished, representing how the impact and influence of the experience decreased. Suzanne described her memories as less vivid and expressed her desire to move beyond the narrative of head injury. However, Suzanne was keen to emphasise that moving on did not mean forget, because she would never be able to forget what happened to them all. In contrast, Emma felt that she had already placed her father's injury firmly in the past and a year after injury struggled to remember many of the details of her experience. Both their narratives represent progression of the narrative towards placing head injury in the past. However this conflicted with Dave's desire to more fully understand and re-tell his story. This misalignment caused further conflict between those who wanted to remember and those who wished to forget (see Box 5).

Suzanne [T2] "with people coming home, because he was at home... he would just get really, really tired and he would have to say his story again and again and... I mean it was all very well for the first few weeks but... after a while when you heard it... when you've heard it, when you've heard it you know, so many times! [laughs] oh no! not again! But I think for him it was a healing process... you know, it was, it was... I suppose that's what you do when something bad happens to you, you just want to talk about it... and er, I think that has helped him a great deal er..." 8:1-11

Box 5

Summary of autobiographical narrative for the Barker family

Family members crafted their personal narratives through representation of the events and experiences they faced during Dave's illness and subsequent recovery. Both family members illustrated their sense of biographical revision as the need arose to compensate for the absence of Dave within their family. However, once back within the family this revision goes unnoticed or unappreciated. The consequence of which is misalignment in the narratives of injured and non-injured members that causes some conflict. Additional tension is caused as Suzanne and Emma adopted a desire to move beyond the experience before it was felt that Dave was ready to do the same.

5.3.3.2 Hughes: 'I feel different'

The autobiographical narrative for the Hughes family was interpreted as 'I feel different' because of the cumulative effects of Abigail's injury during the past year. As such this narrative thread must be considered within the context of other narratives including trauma, recovery and suffering. The consequence of living through the first year of head injury was some sense of biographical revision for the non-injured members. All family members used their emotional resources to try to make sense of their experiences but were left feeling different about themselves and the world around them. However, it was felt that Abigail did not have the same insights as the non-injured members and would not appreciate the revising features of their experiences and this caused misalignment between the injured and non-injured family members.

The narrative thread begins with Lucy's almost immediate intention to respond to the situation in a more supportive way than perhaps she would have normally. Through acknowledging her father's distress she makes a conscious decision to be strong and adopt a position to help her family (see Box 6).

Lucy [T1] "and then my parents came out and they looked like, completely different people... like... from the week before... I couldn't, I couldn't believe how different they looked, my dad looked like he was a hundred not fifty, you know? And he just looked so... upset... and I've never seen my dad cry... and this is the time, like, the night before, he'd been upset and that was hard, that was probably like, made it the most real because... my dad doesn't cry... well not like, he would never show it in front of us... and in, in private, I'm sure like when his, when like my granddad died... I'm sure he was upset but we never saw it as children and then that time was like, [deep breath] right OK ... and Liz came out and Elizabeth's absolutely hysterical and I thought... oorgh..."^{34:1-10}

Box 6

The thread continues with the need of the non-injured members to put their lives on hold and immerse themselves in Abigail's injury. Lucy illustrated this interwoven narrative between injured and non-injured family members by stating none of them were able to get through the experience until Abigail did. Diane's narrative contained the strongest thread of life on hold as she described a desperate need to be with Abigail in the critical care unit and did not want to concern herself with anything else. By entwining her narrative with her daughter's she could feel closer to Abigail but struggled to convey this need to others. Diane's narrative emphasised how entangled she was with her daughter's recovery by explaining why she had not been home since the accident (See Box 7).

Diane [T1] "And I think my husband's found it, I think he's found it probably hardest out of all of us, in some ways... I just couldn't imagine coming home and not bringing her

home with me...that was my... worst nightmare, I just couldn't imagine walking in the house and not having her anymore" ^{145:1-4}

"Initially I was like, I could have been glued to the bed and stayed there, but we used to go home to [name of friend]'s house. When you're at someone's house, as much as they're lovely... I mean they're, they're friends that we know and it's almost like 'ooo we gonna have a party'. I'm like 'no! I'm here for a different reason and I don't want to socialise' and I didn't want to talk to people... and Bill was having a beer... and I was like 'hang on minute, I want to go up to the hospital' 'oh what?' and it's like 'yeah! I do want to go and see my daughter'..." ^{163:1-8}

Box 7

However, Bill had tried to step out of the medical narrative where he could, sometimes because he needed to return home and deal with issues external to his daughter's recovery and at other times because he needed time out. Bill illustrated the importance of allowing others to have an insight into his world and drew strength from exchanges of text messages of support and good wishes. Bill expressed concern for his wife who had barely stepped out of this narrative and had not accessed support in the same way as he had.

The critical care unit was an unfamiliar world that needed to be made sense of in order to feel more at ease. Stories between relatives were gradually shared and helped them to understand what was going on. In contrast Lucy said the ability of them to feel comfortable in this environment confirmed the severity of Abigail's condition. Abigail's subsequent transfer to a general ward disturbed this familiarity, causing fear and concern. Abigail's later increased agitation and confusion was accompanied by a decrease in the family's ability to comfort her, leaving family members feeling disempowered and unable to help. In contrast to the immersion that was allowed, and encouraged, in the critical care unit transfer to a main ward meant greater restrictions in visiting hours and access to their daughter which was hard to adjust to (see Box 8).

Bill [T1] "and then you have the deflation of upstairs!...[laughs]... for the first few days...then you hear she was crying all night, we'd ring up in the early days...leave at, whatever time we'd get thrown out, about eight o'clock...so you'd then ring up at eleven half eleven or twelve... 'everything alright with Abigail?' 'yeah, yeah, she's quiet, or she's sleeping, or she's trying to sleep or whatever, yeah nothing to worry about'... and we said we'd come up and stay with her if she was a problem... and erm... we then quickly found out over the next couple days from the other people on the ward that her night time was not fine and she was awake...screaming, crying out for pain killers..." ^{154:1-11}

Lucy [T1] "Like... she was still... she was still quite noisy, like she was quite... upset and she was sort of screaming about her head... and saying her head hurt... and it was really like... I, I just remember feeling like this is too quick... they've taken her off that, real care and attention you get in the NCCU... to absolute, to what felt like, I mean it might, to me it felt like

nothing but obviously it wasn't nothing... but it just felt like a really big jump..."^{51:1-6}

Box 8

Following the severity of Abigail's injury and threat to life the non-injured members shared a narrative that Abigail did not. Misalignment of these narratives meant that the non-injured members did not feel Abigail could appreciate what they had been through and why they felt more protective of her. Through the understanding that Abigail may not survive her injuries a narrative of vulnerability builds in each family member's account. As such they perceived Abigail as fragile and in need of increased protection. Concern for Abigail's wellbeing was illustrated in an account by Lucy of the family coming home for the first time and her tripping over. Lucy used this event to show how removed Abigail was from their experiences (see Box 9).

Lucy [T2] "And... we had the very first thing that happened... was... and I think all of that pent up, kind of, tenseness the first thing that happened was... we parked the car, we got in from [name of city]... we parked the car... we went in the drive... walked in... we'd all like, me and my mum and my dad were bringing the stuff in... Abigail was moving round, it's a bit narrow round our like sofa a bit... she moved round and nearly, and like fell... nearly, like lost her balance and fell onto the sofa but my Mum saw it and my mum literally went Ohhhh and then my mum started to cry and my sister was just like... laughing sort of like why, what... and she just didn't Abigail could not fathom, at all... what had... the... the...sort of... why my mum was so, sort of... like her reaction... and Abigail was just sort of like 'what mum... it's not like anything happened... I'm alright I just slipped' and my mum's going...No, you don't... and it's... it was that, her initial comprehension, she, she, I don't think, I don't even know now if she completely comprehends... but that really... I think that really showed her a little bit how much it had affected us because my mum just literally just went ooohhh [imitates crying]..."^{31:1-15}

Box 9

Similarly during a documentary on head injury Diane said Abigail could not identify herself with any part of the programme or the people in it. These accounts represented the different narrative effect of the experience by emphasising the misalignment in the narratives of the injured and non-injured family members. As Abigail returned gradually to independence, socialising with friends and taking up part time work Diane spoke about the need to let go and stop being so protective (see Box 10).

Diane [T2] "well we're hoping to, we're going to a wedding at the end of the month... and Abby's going to stay at her sister's in [name of place]... her older sister that lives in [name of place]... and she's like [deep breath]... Abby's going to have a weekend... [laughs]... and we're all like arhhh! [laughs]... and all her friends are in college, well they all left, most of them have left college now, they're all gonna come and see her... see her in [name of place] so she's looking forward to that... so... that's going to be a bit of a wrench... to let her loose, to let her go... and have to trust her and her sister to be, you know... that she'll be safe... that has to have to look after her... But that kind of... side of its coming... more and more... where I have to say... 'yeah ...fine ok'... yeah you can go out... [laugh]... I think oh for god sake!"^{24:1-10}

Box 10

As a result of these incidents each family member experienced some form of biographical revision that left them feeling something had changed. Lucy had increased in maturity and responsibility both in her own sense of self and in the eyes of her parents. Lucy illustrated this in an account of her mother asking for her help and contribution in a way she had not been asked to before. In addition Lucy also spoke of her changed perception of the world around her. Lucy described the luxury of living in ignorance now she had woken up to the reality that bad things did actually happen and was more acutely aware of the dangers around her.

Three months after injury Bill tried to explain his sense of biographical revision but was unable to identify what it was that was different other than something inside him had changed. Some examples were given that explained these differences and suggested Bill found it hard to stay calm and lacked patience with systems, bureaucracy and red tape. Feeling better a year on, Bill was more able to identify personal growth within his narrative and illustrated these positive gains through his more sympathetic nature and being more open with his feelings within the family (see Box 11).

Bill [T3] "...and that's probably the biggest, the biggest change I think from an emotional... erm... and... showing your feelings... at things and empathising with people's situation... er... the perspective or the understanding I have of other people's plights may be now is quite different from what I might have had a year ago erm... always been a bit... I wouldn't say callous, a little bit hard, a little bit... lacking in understanding... but I think when you go through... the sort of... trauma that we've been through you have a totally different perspective on everyone's... incidence of... whatever's going on so... that's probably the biggest change that we've all gone through... erm..."^{36:7-15}

Box 11

Although Bill felt more adjusted with the passage of time it was Diane who talked about events taking their toll and a year after injury could identify she was different. Diane described how her past bubbly and confident nature had been replaced by a more timid and nervous disposition.

Summary of autobiographical narrative for the Hughes family

Family members created autobiographical narratives within which it could be seen how Abigail's injury had, over time, revised and reshaped their biographical sense of self. Lucy had taken the opportunity to mature but the experience had removed some of the innocence from the world. Although both Bill and Diane described less objective features of change, both felt different from the demands of negotiating an unfamiliar medical world and coming to terms with the fragility of life. As a result all family members felt an increased sense of vulnerability towards Abigail that she did not understand, nor did she seem to associate her experience

with others in a similar position. These narratives serve to exemplify narrative misalignment within the family and the division this can create between injured and non-injured members.

5.3.3.3 Wilson: 'A community of survivors'

Autobiographical narratives for the Wilson family were interpreted within the context of 'a community of survivors'. This metaphor was chosen because of how their narratives represented the importance of sharing in the same experience. People who share the narrative of head injury form a community and this community was of upmost importance in the family's accounts. As such the biographical revision that takes place, without the injured person, is membership within this community. The relevance of their experience and importance of this community is not considered to be fully understood by Tracey because she was not a part of it. Although there is some attempt to realign the narratives of injured and non-injured members it was thought that Tracey would never understand what they went through and as such she remained an outsider to the narratives they shared.

The unfamiliar medical world became demystified over time and became home, a place of comfort, strength and support. Family members became deeply embedded within the experience and made themselves an active part of the narrative. The critical care unit and the hospital were portrayed as an internal world where nothing else external mattered.

Understanding of this unfamiliar world was an important part of personal narratives and particularly Mike and Peter tried to learn as much as they possibly could. Within the acute narratives the relevance of intracranial pressure (ICP) dominated the accounts. The hierarchical importance of the ICP figure was represented in the statement by Peter that never had two digits meant so much and represented the fragility of life. A year on the narrative effect of concentrating on the ICP was evident through Mike reflecting on the vast knowledge of head injury that he had accrued stating he still thought about the effect of physical exertion on his own ICP reading.

However conflict between medical and lay narratives was apparent as the provision of information conflicted at times with their desire to learn. Mike illustrated this conflict by saying he wondered if families were left to assume early recovery was possible so they were protected from the full gravity of the situation. Their desire to learn enabled a greater sense of being in control and at times they felt they could influence Tracey's treatment and play a role in her recovery (see Box 12).

<p>Mike [T1] "But... the pressure's on her head, even, even the slightest, smallest of tweaks... in terms of moving her body... just made such a difference, and all these tiny little things they're</p>

doing there around her, adjusting... CO two level or... or a little tweak of oxygen or a drug or... even cooling her down by half a degree ... just made such a difference... and... with, a couple, some of the nights the nurses were just frantic all night trying, adjusting things and changing things... just to control this one little white figure on the screen that measured the pressure on her head... and they just... the dedication of those nurses and doctors... is just... phuu... astounding to be honest... [deep breath]... [finding it difficult to speak]... "28:1-9

Mike [T3] "We tried to understand every single process, every single machine what every figure meant... probably because it kept us sane more than anything, but we could also... because we were sitting there twenty four hours a day... the nurses were only there eight hours a day and we knew... we knew Tracey better, and her figures... I know they knew what they all meant... but we knew them better than anybody because we were there all the time... erm... "174:1-6

Box 12

However, sometimes the effect of entwining themselves in Tracey's recovery left Kate, Peter and Mike feeling disempowered and frustrated. Examples given included the story of a faulty cooling blanket. Peter went to great lengths to explain how it worked and how, if not repaired, the existing fault could negatively affect a future patient's outcome. Another example was the gradual reduction of an opioid infusion that Tracey was particularly susceptible to (see Box 13). These examples represented just how immersed these family members became during Tracey's stay in critical care.

Kate [T1] "...They did um... one of the nurses was trying er... well she took her off it once, and she had a reaction to it... she was gonna put her back on... she was only on two mls it's not a lot apparently... or... I think she was on five, ten and five the beginning of the day and... the nurse brought her right down to two... and then once shift changed over... they just thought they'd turn it off, just like that... well we did, we didn't complain we just made it known that we thought this was wrong... but it, it didn't matter what we say they do what they think's best... what they thinks best for Tracey... they took her off it and... she got put back on again... but only one, instead of two it was only on one... so it was some good coming out of it... "13:1-9

Box 13

Enabling their full immersion in Tracey's narrative of injury and survival was facilitated by their open access to the critical care unit through twenty-four hour visiting, the use of a relative's room and the ability to stay overnight. Although a frightening place initially the unfamiliar became familiar over time and during the acute period represented a place of safety and security that became home (see Box 14).

Peter [T2] "But er...as I said the whole... the whole world just seems to just, you know and not have any significance at this point other than what's happening in this one room... and... say it's... and then you're really thankful again by that the next night... there's a room that... you know that you're allowed to use again... the way things go you find that the key has to be handed in late, mid-morning and, or late morning... and you don't find it you have to ask the next day and you must remember to ask because if you don't ask... then there won't be one... and... erm...obviously there's a limited amount of space and obviously it's always going

to be allocated obviously on a priority needs basis and... [...] ... that was without a doubt, the fact that you was able to, to stay on sight was also a... real bonus...^{50:1-6}

Mike [T3] “because I lived in the hospital for... well I lived there for the first six weeks I didn’t leave the place and then after that... we were there... ninety per cent of the time... well I was there every day and... twelve hours a day when she was on [name of ward]...and, and on the rehab unit we were there as much as we were allowed to be there and, and the place was home... for three and a half months four months... erm... and because the outcome was so good it’s easy to go, for me it’s easy to go back and it’s... like I say it hold some... some good memories in the fact that the outcome and, and it’s, it’s a story with a good ending”^{77:1-9}

Box 14

Following immersion into critical care their familiarity and comfort was disrupted after the transition of care to the main ward. Their narratives showed anxiety and fear as family members were aware of patients who had regressed. The ward was interpreted as an environment with fewer registered nurses, fewer staff and less care with more rules and greater restrictions. For those family members who had become accustomed to the freedom and open access in the critical care unit the restricted visiting was heavily criticised (see Box 15). After spending so much time in an environment where they could do nothing Mike was keen to play an active role in assisting and supporting his wife. However the visiting hours left him disempowered and frustrated.

Kate [T2] “...But erm... Christmas, we wanted to go in... when we saw you actually... we had to come in, oh no it was flowers I think... we had to get them flowers... for Mike for Christmas... he’d ordered some flowers from the shop in the hospital... and we had to be there for twelve... so... visiting wasn’t until... two... on that ward... so we went and asked... if we could go in there early, we went up there... and... the nurse wouldn’t let us... and you thought... we’re here... why... and well she wouldn’t let us...and Tracey was getting upset as well in the mornings so... erm... I think it was after Christmas... we had a word with the charge you know the nurse in charge... and he told us you can go in early... you can come in at eleven because she was getting so upset... it’s boredom I think... but erm... so he let us in at eleven...”^{12:1-10}

Box 15

Further frustration came from the delay in transfer to the rehabilitation ward. However, to complain felt like betraying the good work that had been achieved in Tracey’s recovery. Later, although pleased to make the transition from hospital to home Mike called this the biggest leap of all. Moving from the safety of critical care to living back at home was very difficult to adjust to and led to a sense of being abandoned by the people and services they had grown to know so well.

The ability to navigate the experience of critical care was underpinned through their membership in a community of survivors. People were brought together through the most tragic of circumstances, where there was very little separation between life and death. This

community of survivors was born from within the relatives' room and was of immeasurable importance within the narratives of Mike, Kate and Peter. Mike suggested people brought together in such circumstances became a family and the relatives' room was regarded as a place of strength, comfort and hope. Compassion was first shown to them by others and then later they were able to show compassion in return. Through time spent in the unit they accrued knowledge that enabled insight into the medical environment, language, equipment and expected stages in care (see Box 16).

Kate [T1] "I mean the family room in there, I mean that's a godsend really because I mean, you're talking to people in there... I mean there's a [nationality] couple there who were a week ahead of us... and... when the nurses and doctors tells us something... well, they said well that's alright you know... this is what will happen and then that's what will happen... so it come, it sort of helped you to think well they've been through it so they must know... it's not just the doctors telling us... just to... shut us up or something... so... but... and then of course... you do the same for them... and we could pop back down there now... because there's people in there we still know... and... trying to help them... just find out how they're getting on... erm... [pause]..."^{29:1-9}

Mike [T1] "And even... the other way where... there was a vicar brought in... erm... and his wife was on her own... er, because her son lived in [name of county]... and he actually flew over but in the meantime while he was, while she was waiting for him to come over... she was on her own... virtually on her own... and explaining it all to her... and the fact that he, he had to go and have some major surgery... and even just the little things like when they, when the nurses say that they're gonna... give the patient a turn... so they don't get the bed sores and stuff... and can you give us ten minutes but you go back in ten minutes and the curtains are still closed... it's normally nothing to worry about because their ten minutes means half an hour, three quarters of an hour... but if you're not told that... you start to worry well... why are the curtains still shut... is something gone wrong or... is, is something happened or... and just to know that the likelihood is that they're just taking a bit of extra time... is just... so comforting to know that... that... the likelihood is that something hadn't gone wrong and they're just a bit blasé with how they, how much time they say... and that's, that's only the sort of information you'd pick up... from somebody else that's in that room and..."^{116:1-15}

Peter [T3] "But it is erm... we obviously made, made quite a few friends... while we was in there... I still visit... erm some of them that we met... in fact we er... went to visit er... Mr and Mrs [name]... erm... at the weekend... because their daughter's spent... six months... but a day in the critical care unit... and... obviously we, we feel that erm... well I don't know whether we don't go along because we, we give em support but you are effectively giving them support we feel by popping along and visiting and... and we're genuinely interested in how she's getting on..."^{7:1-7}

Box 16

Shared narratives of highs, lows, joy and despair brought strangers together. Friendships forged in the acute period were considered sincere and were sustained in the year after injury. This community and support network helped to validate feelings that those external to the

community could not understand or, as Kate thought, may grow weary of. Mike retained his perspective that on the outside people could sympathise but they could never understand.

The experience belonged to Mike, Kate, Peter and Helen and their world could not be known by others unless those others were there to experience it. When Tracey was ready to re-join the family, once recovery was established and maintained, she was an outsider to the experiences shared by others and had no real connection to the community that was of such importance to them. However, the non-injured members tried to re-orientate Tracey to her own narrative by gradually telling her exactly what happened (see Box 17). Despite these efforts Mike illustrated the significance of their narrative misalignment by saying it was almost like they had lived a life without her and as such Tracey would always be a step removed.

Mike [T3] "Since found out, you learn, we learnt a lot... erm... and even though she was awake she was probably still in some sort of a coma... and coming out of it... erm... and that's quite strange because... the experiences that... we had together with her awake... she can't remember... you know and it's really, really odd, it's almost as if there was another, another life running alongside... that, that she had no part of... erm... and ultimately she lost... two or three months of her life... but she was there... and we've all got very vivid memories of it and it's... it's quite surreal actually... erm... [cough]"^{46:1-7}

Box 17

Narratives of the injured and non-injured members were also misaligned as a consequence of Tracey's perceived vulnerability. Mike said this was because he knew where she had been and how close she had come to dying. However it was felt Tracey could not appreciate just how severe her injuries really were. Mike then had to make the transition away from advocate and protector to let Tracey be in command of her own life again.

At the end of a year there was a sense that the chapter had ended and life should move on where a new narrative could be created together. Mike added at the end of the account that although Tracey would like to forget it all, he never would because it has shaped both his future and himself as a person representing the personal growth and benefit that he had personally taken out of the experience. So much had been gained including new friends, valuing life and a change in attitude to work that Mike said, as long as the outcome was the same, he would go through it all again (see Box 18).

Helen [T3] "And I think we've just tried to get back to normal I think because Tracey doesn't really want to dwell on it... she doesn't want to keep going back... to thinking... 'oh I nearly died and'... just trying to be... think of like, trying to do a lot more fun things together and..."^{28:1-3}

Mike [T3] "Erm... but that's a question I always ask myself... whether I'd go through it again... and, and we... we've, you know... the outcome's been so good and we've made such good... friends... or me I, in particular have made a few really close friends... that... will... keep, you know, we'll

probably only contact each other once every two months... but we'll keep in contact for the rest of our life...you know there was... several people out of that... out of that relative's room... that... I wouldn't ever want to lose as friends and I'd never of met unless it happened... erm... and... some of them weren't so lucky and their... partners or... sons or daughters didn't... make it... but we keep in contact... and it's almost like a... it's almost like a secret club if you like... it's you know... if you don't know the secret knock you can't come in... and, and there's not many people in the world that have been through... what... the people that in that room go through... erm"^{209:1-12}

Box 18

Summary of autobiographical narrative for the Wilson family

Personal narratives from the Wilson family represented how Tracey moved out of a shared experience to recover from injury and the non-injured members immerse themselves in a medical world from a non-patient perspective. Narrative alignment between the injured and non-injured family members was different as it was perceived that, despite reconstructing Tracey's narrative of injury and survival, she would never truly understand their experience and its narrative effect on them as individuals.

5.3.3.4 Autobiographical narratives conclusion

Autobiographical narratives were interpreted for the family cases through the narrative effect on their biographical sense of self. The experience of illness from a non-patient perspective demands revision of certain taken for granted attributes of character. The consequences of which was a form of biographical revision as the experience of head injury leaves an imprint on the lives of the non-injured members.

However the narrative effect often goes unnoticed or unappreciated by the injured person because they did not have an active presence in constructing the original narrative. Non-injured family members therefore feel the effects of narrative misalignment that at worst causes conflict and further exacerbates a division between them. At best the non-injured members engage in narrative reconstruction helping the injured person to build, and take ownership of their narrative of injury, illness and survival. However, this is often with the caveat that they would never truly understand what the other family members went through. In addition there may be further tension caused as family members reach a stage at which they wish to move beyond the narrative of head injury and place it in the past. The time at which they reach this stage may be different causing tension between those who wish to remember and those who wish to forget. Figure 5.6 represents the movement out of a shared narrative and the subsequent misalignment between injured and non-injured members.

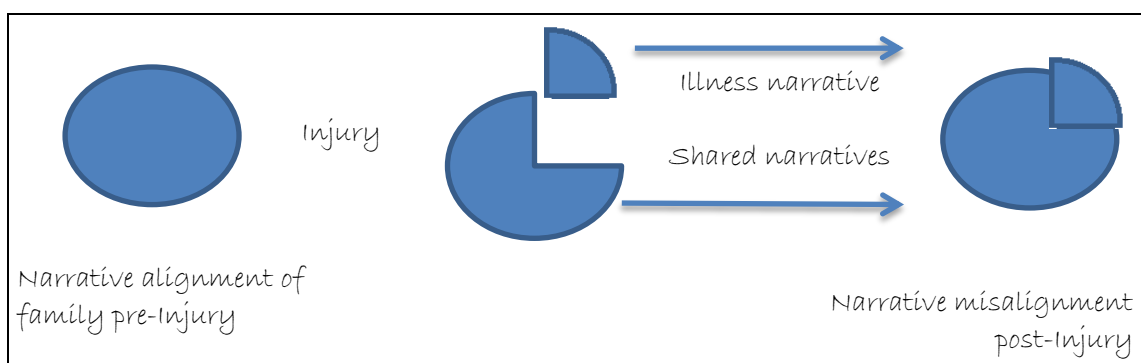


Figure 5.6 Narrative alignment in autobiographical narratives

5.3.4 Narratives of Suffering

As previously discussed in Section 4.4 trauma narratives represented an immediate communication of stories that seemed to exist within what Frank (1995) referred to as the 'incessant present' (p99) as many lacked the temporal shifts of past, present and future. Trauma was predominantly situated within the first interviews held one month after injury and illustrated how daily life was ruptured by traumatic events. However as the sharp edges of trauma dulled over the course of time there remained a presence of pain and distress manifesting in some family member's accounts.

In contrast to the trauma narratives, this pain and distress were less immediate, more gradual and the effects endured. These accounts were interpreted as a narrative of suffering and represent a more long-term accumulation of subjective loss and change. Charmaz (1999) identified that in people with chronic illness stories of suffering represented 'loss of control, loss of certainty and loss of an anticipated future' (p366) adding later that suffering is a consequence of an attack on the taken for granted future. Although not suffering from illness themselves, non-injured family members displayed many of these features within their narratives and as such these warranted closer consideration.

Within this study, suffering narratives continued some of the features of the chaos narrative (Frank 1995) that dislocates the future from the present. However the interpretation also resonated with the fracturing and enduring story lines that Brown and Addington-Hall (2008) identified in the stories of patients with MND. For example:

'The enduring storyline tells us about quiet suffering [...]. Enduring was a way to live through an unwelcome and difficult situation' (p204).

'The fracturing narrative tells of loss, breakdown of self, fear of the future, denial of reality and living in a surreal notion of time' (p205)

Although trauma narratives were identified in all family members' accounts, narratives of suffering were reserved for the few. The resultant effect of not sharing these narratives was further isolation and separation.

5.3.4.1 **Barker:** 'A family scarred'

The narrative thread of suffering was interpreted for the Barker family as 'a family scarred'. This metaphor was used by Suzanne in her final interview to explain how the family had been affected by her husband's injury. Temporal shifts caused suffering as Suzanne compared the past to the present and anticipated her future. The representation of the past as a place of happiness and togetherness only served to devalue the present state of the family. At three and twelve months post-injury Suzanne's account accumulated unsustainable compromise, stress and strain in the family home, feelings of hope were met with disappointment that ultimately led to reduced expectations. Physical recovery was established but narrative recovery was not as Suzanne was not able to find healthy means of communicating her emotions and validating her feelings. As Suzanne tried to resolve her narrative imbalance this used up a great deal of her emotional resources. Positive images of the future were gradually let go as the balance between hope and disappointment favoured the latter. Although Emma was sympathetic to Suzanne's situation she did not share the narrative in the same way, leaving Suzanne to endure alone and consider her own contribution to the suffering of the family.

Following Dave's discharge from hospital Suzanne created a progressive narrative that encompassed the whole family. There was the expression of joy at recovery and attaining their shared goal of bringing Dave back home. However, settling back into everyday life took adjustment for all the family and over time Suzanne's strength turned to strain as the compromises deemed necessary to aid Dave's recovery became unsustainable. Movement of the family towards a more stable narrative, that sustained the normality of childhood and life in general, was not easily achieved. One year on this stability had still not been reached and the narrative direction contained more regressive features as the family were dealing with the consequences of their changed life. Although Suzanne struggled with the transition back into everyday life she did not think she was the sort of person to ask for help and struggled to see how her needs could be a priority (See Box 1).

Suzanne [T3] "There hasn't been one time where somebody just... came up to me and said right do you want to discuss this with me..."^{366:1-2}

"May be I should have... asked... may be I... but you know you don't want to waste people's

time... [laughs]... you know poor man's [speaking about the consultant] got so many things already... can't just have a private meeting with all these patients, you know... relative's so er... may be somebody to talk to..."^{369:1-4}

"Somebody who would just have sort of erm... not a newcomer but somebody who would have followed it probably... would have been... helpful..."^{370:1-2}

Box 1

Narrative imbalance was exemplified by hope for the future and disappointment with the reality. There were several examples within the first year where Suzanne looked to a specific time in the future when she perceived the situation would get better. However when these markers were reached she was not prepared for life not to be improved (see Box 2). By the end of the first year Suzanne's regressive narrative became more established as she became more resolved to accept the present as it was and let go of the future she felt they might have had. Suffering could therefore be interpreted through the loss of an anticipated future and enduring as a way to live through the unwelcome change to her family's life.

Suzanne [T2] "a few days after I came back here he had a few... and I think it's probably because the children were there as well and were making a lot of noise and I remember the first few, few days when he, when he got back from hospital when he kept telling us, you know not to slam the doors and... he was fed up with the cat meowing and... pick your feet up when you walk up stairs and all these sorts of things, which we knew because we were prepared about but... just when we came back from [name of country] I assumed... well we were to assume that you know that would probably... go away, but it wasn't so... we had a few er... sort of... [laughs]... not very nice days! Laughs]..."^{12:10-18}

"...hopefully...everything's gonna go back to a ... normal sort of more normal... [deep breath]... situation... we hope ... yeah so we just want to... get on! [laughs]... yeah hopefully get on, we're thinking after Christmas... yeah make a new start next year...[laughs]...yeah I think it's gonna be a good..."^{131:4-8}

Suzanne [T3] "I think just around Easter time when he was being... really sort of er... difficult, you know I had a break down at work... you know I was crying... and that's never happened before... it's like 'oh Suzanne are you alright, do want to take time off' ... oh dear... you know I can't make it, I can't make it today I don't know it's just... it's just, you know... just one day I just couldn't do it... I though oh dear what's gonna happen..."^{333:1-7}

Box 2

While exploring her perception of the strain and stress in the family home Suzanne looked inwards and wondered if some of it was her own doing. Therefore suffering was also present in Suzanne's narrative through the 'breakdown of self' and accumulated loss of certainty for the future. Three months after injury Suzanne was already able to give voice to her own fears and negativity and a year on identified a vicious circle of stress between her and Dave (see Box 3). Suzanne compared her own behaviour to Dave's and as a consequence normalised his mood swings because her own seemed quite bad. However Suzanne found it hard to express

herself and described her feelings of guilt for sometimes adding to his pain. The consequence of this was to leave Suzanne frustrated and further isolated from her husband.

Suzanne [T2] "So... because if I say something, you know like oh I'm [inaudible] [laughs]... oh I'm fed up listening to you moaning every five minutes, every thirty minutes I got a health report! [laughs]... oh my taste is, oh my, my... 'cause he had an infection and then he took some antibiotics... and he, then he had this really foul taste in his mouth... so... every day is was just like... oh... I've got this really horrible taste in my mouth and every thirty minutes... it was like ... 'oh... I'm fed up with this taste in my mouth... GO AWAY taste...' it's like I'm fed up with you moaning, and then the girls would say... oh but Mummy it's normal... Daddy's not well yet you know... they were just trying to cheer me up and I thought 'oh yeah thank you' [laughs]... it should be the other way around!"^{126:1-10}

Suzanne [T3] "And I think that's had, that's had a bad effect on me... because then I swear too and then the children... hear us swear and then they swear too... [laughs].. you know it's never ending... a vicious circle so... so that's something we... trying to... er... to solve... so I'm trying to er... not to... use too many... words... but it's not easy because... if one person is stressed then... obviously everyone's going to be stressed and..."^{44:1-6}

Box 3

Unlike the narratives of trauma that were precipitated by specific events, Suzanne's suffering narrative was far less tangible or attributable to specific factors. Suzanne could not easily identify what it was that was wrong that made her feel the way she did. Suzanne recalled telling her husband that he could not expect her to be one hundred per cent happy and that it was not his fault it was just the whole situation. Suzanne attributed some of this negative feeling to wanting everything to be perfect but having to resign herself to the notion it never would be.

At the end of the year the narrative of suffering continued but Suzanne seemed more resigned to its presence in her life. Although stating she felt better and much happier she also said that before the accident she had a life but now described her life as an existence (see Box 4). Suzanne suggested she was unable to be extremely optimistic about her life and said she stopped dreaming a long time ago.

Suzanne [T3] "Because he said, I mean he said yeah I think, you know... what did he say... oh yeah... I've recovered better than you have... he said to me and I said 'oh ok' [laughs]..."^{278:1-3}

"...But yeah it was just... physical exhaustion and mental exhaustion as well... and I had a... difficult time... but no... much better now... I mean having said that a couple of weeks ago when I stopped, you know, work it feels like... you know the first few days... you feel sort of... even more tired... when you break up the sort of rhythm, you know you just get up later and... feel even more tired but no, no, no much better...back to... back to my former self... [laughs]... So much better...Yeah a lot happier, lot happier and better... mmm"^{294:1-7}

"It has changed... the whole family... well I feel I had my life before and after I've got an

existence... I exist... [laughs]... well I can't say that the children er... but there was my life before... and now I'm just sort of... surviving... but I'm not... I don't feel I can be happy hundred per cent as I was before... „344:1-4

Box 4

The imbalance between pre- and post-injury lives was illustrated through this narrative. The narrative imbalance caused tension and suffering radiates through. As life in the present, and predicted future, deteriorate, life in the past is idealised and only served to exemplify what had been lost. Therefore the temporality of the narrative became stuck in the present, unable to move back, unwilling to look to the future. Suzanne summarised the effect of Dave's injury on the family and said they had been left scarred and they could never hope it could be like it was (see Box 5).

Suzanne [T3] "But as a family... [exhale]... yeah we feel... what's the word... harmed I suppose, it's scarred... mmm... that's something that... you know... we'll remember always... it's changed, changed everyone... especially Isabel probably... you know it just, you know she... cries... and I don't know... she only little, poor thing... it's not fair... [cough]... yeah very scarred... [slight laugh]... „345:1-6

Box 5

When Suzanne did look forward it was with trepidation saying she did not want the conflict at home to escalate and did not want the children to be any more unhappy than they already were. The vulnerability of her children also caused Suzanne pain and concern for their lost futures. Although the children were perceived as resilient and more hopeful for the future than perhaps she was, there were examples as the year progressed that were more indicative of the consequences of their experience.

Suzanne [T2] "I think children actually yeah...they just do.... they've got ways... some ways to deal better... [slight laugh]... than we have... I don't know why... they probably think he's gonna improve and they knew that you know, that he, he nearly died and Isabel had to do a sort of er... chart... er... a few weeks ago... about, you know... most important... sort of er... not days in your life, but like steps you know throughout the years... you know from the day you were born... till the er... so she had like a time line and she's put a few years and, you know, and the she put you know... er... 3rd of July the day daddy nearly died... and then we put a bit of the article... and she glued it down, because she's you know, that was quite important for her... „127:1-10

Suzanne [T3] "Isabel's had a few nightmares... and she's said, you know, she wants daddy back... like he was but... we've talked about this and you know, it's not going to happen so... have to er, to deal with it and erm... „29:1-3

"...So Sophie as well she's had a few... at erm at school she's had a few problems with er... a few friends... one of them's very suicidal... [deep breath]... so she sort of tried to erm... look after her in a way... but the thing is that... that friend sort of had a big influence on her as well and [...] she said it was nothing and... but er... I suppose you know... [...] sort of very... unhappy

with, you know, with how things have been going..."^{30:1-9}

Box 6

Suzanne was concerned that the children would have bad memories from this period of their lives and the examples given in Box 6 made her realise how susceptible they were.

Summary of the Narratives of Suffering for the Barker family

Suzanne put forward a metaphor for her family post-head injury as a family scarred. Scarring denotes damage and an unwelcome alteration of a pre-injury state. The suffering narrative illustrated the tension caused by narrative imbalance as the present is disconnected from the past. Positive representations of the future were hard to create therefore the willingness to look to the future was reduced. The suffering narrative exemplifies how a regressive narrative quickly replaced earlier features of progression as the family welcomed Dave's recovery and return home. At the end of a year the narrative is more stable but only because the hope of moving back to how life was had diminished.

5.3.4.2 Hughes: 'Unresolved and unrelieved'

Within the Hughes family the narrative thread of suffering was interpreted as 'unresolved and unrelieved' because of the sustained level of disappointment, dissolution, anger and blame. For Diane and Bill the trauma and suffering narratives were directly linked as the failure to resolve trauma resulted in an enduring sense of suffering over time. Emotional resources were used to try to make sense of the situation but this took its toll within a complex circle of grief, blame, loss, and pain. Suffering was expressed through two vehicles. The first was isolation and abandonment. The second was the intolerable waste of their daughter's future by a person who they characterised as 'without remorse' for his part in the traffic collision and the need to go to court and hear the case for the defence. There was no pursuit of purpose therefore little positive meaning could be taken from the events of the past year.

Suffering caused through isolation and abandonment was first expressed within the narratives of being discharged home and feeling left to cope alone. Although retaining praise and admiration for the acute care received, treatment post-hospital was described as abysmal and characterised by the need to keep chasing the services they needed. Bill and Diane expressed such disappointment with their local GP that it dominated their three-month interview and discoloured their view of the world. Failure to make sense of a perceived lack of interest and support exacerbated their isolation. Re-telling the account of the GP not listening to, or validating, their concerns reveals the considerable damage this did to them (see Box 7).

Bill [T2] “When Abigail came out of hospital... you know, if I was a GP I cannot believe... I would of allowed... a patient... to come back from that injury... with the letter that said everything that had been done... and all the bits... erm and not even... even phone up and ask... ‘everything alright... do you want to see me... do you want to know anything... is there anything I can do... anything we should do, any support?...’ not a bloody dickie bird... that’s, I think that is crap... really... but erm... [deep breath]... it’s just me...”^{95:1-7}

Diane [T2] “you know the worst thing, I just think when I look back... the doctors don’t actually come and see you at home any more... ... mmm... [cries]... [pause]... even if, you know, when she was sick... err,[cries]... they just don’t come and see you... you ring them up... they don’t answer your phone or say they’ll get him to ring you later and he doesn’t ring back... then you get told ‘OH WELL, terrible accident’... [sniffs]... er... ‘thank God she’s doing well’... and er... just be grateful... grateful that she’s improving... and I just can’t get over how awful they are... [sniffs]... I mean years ago... you got in from hospital... you handed your letter in... and the doctor came to see you at home and he knew what she was like from a bit from discharge... and they saw you at home...”^{43:1-18}

“but he never saw her once... I can’t get over how dreadful, dreadful... I just think God... I can’t get over how the NHS is so awful... to people when they’re at home... even all over with my mum... I just can’t get over it... I’ve been nursing since I was seventeen ... [crying]... and I know I trained in the days when you had matron... and it was, you had district nurses... you had doctors that saw you... when you went sick... if you had child who was ill they came and saw you... [finding it difficult to speak]... I just don’t... I’ve had to fight all the time... and it’s nothing majorly wrong with her... that she’s got over the accident... there’s no thanks to them... I don’t think so really... and to think my GP is the head of the... the practice... and he’s telling me every single complaint that she had, and it was on the list of allergies... was a viral infection... I could not get over it... I just... I just could not get over it, even when I said she’s covered in a red rash... he couldn’t, he couldn’t even accept that it could be an allergy to her medication...”^{44:1-19}

Box 7

Diane and Bill talked about the continuous need to fight to get help and support. Diane used the words ‘all we needed’, reflecting an understanding that the help she was asking for should not have been an unrealistic expectation. When talking about this experience Diane was very upset and this led to the interview being terminated (the management of which was discussed in Chapter 4, Section 4.8.4). To emphasise their distress at this lack of support Diane characterised the lack of help from the GP as the worst part of the experience. Bill said that after all they had been through he expected some empathy at the very least as a human being and could not make sense of the ‘so what’ attitude.

In addition Bill’s narrative showed how he had tried to grapple with the paradox that although Abigail did not appear to need help, no one had tried to establish this was the case. Bill could not understand how the services could possibly know Abigail had recovered in the way she had. It seemed to concern Bill that although they had managed to survive their experiences other families may not be so lucky (see Box 8). A year on Bill illustrated the family’s isolation by suggesting that the health service fixed Abigail while the family fixed itself.

Bill [T3] "I just think... I still, I still think... you know in the support of the follow up of the incident... the national health... big term... within that process there should be... more erm... or there should at least be some kind of er... communication... to us as the family... to ask that question... because I'm sure... some families it would absolutely destroy them... pull them apart... something awful... no I think if Abigail had been... paralysed or... some other... real... lasting... defect if you like from the er... the injury... I think then... to the point where we are now the recovery, or whatever you want to call it, of the, the family unit or the recovery of how we all feel or... what we all feel about anything and everything would be quite different... you know... if she was walking around with only one leg and... one arm gone or half her arm gone or... you know couldn't hardly breathe without a respirator or something... because her lungs were crushed... I think then... the actual feeling of... of issues for us as individuals would be different, but the fact... that she's recovered so well from the injuries she sustained... erm... I think has made it easier... probably for us to get over... the problem... er... because effectively... the problem isn't there at the moment..."^{132:1-15}

"... you know, there must be something... there must be something available if you want it, but you shouldn't have to go seeking it... you should be offered it in those situations because you're dealt with as an emergency... you've been pulled into a... trauma... situation which if someone's, someone's got progressively sicker... through erm, whatever ailment... we may have... be it say, brain tumour or cancer or whatever... it often isn't... you're fine one day and you're... in the trauma the next... you you've built into a, you've gradually gone into this problem... so you've developed... anxiety or whatever... to that point... whereas when you're just going along in your way... suddenly you're wrenched out of this... normal life... into a new situation... that's a hell of a change, it really is... and erm..."^{136:1-10}

Box 8

Three months after injury suffering was further exacerbated through the additional worry and concern for Diane's mother who was no longer able to care for herself. Support from social services was needed but again these services were described as very unhelpful and it all took its toll. Their experiences were portrayed as frustrating and unfruitful in terms of receiving any meaningful support or assistance. Bill and Diane compared their own moral sense of right and wrong as a stark contrast to the help and support received. The effect of these responses was to devalue their narratives of injury, trauma, loss and pain. Without reciprocity and recognition by wider society their autobiographical narratives were invalidated as lacking in substantial meaning. The consequence of having their narrative invalidated, as opposed to resolved or healed, was suffering and was worsened through further isolation.

The second feature of suffering in this narrative thread came from the longevity of anger and blame and a chronic sense of a lost future. The cause for their trauma, suffering and loss is placed with the driver of the car that hit Abigail. The narrative gets stuck as they try, with little success, to make sense of why and how such an accident occurred. Not only could they not make sense of the accident but they could not make sense of the driver, who they felt had no remorse for his actions (see Box 9). Three months after injury Diane's distress was palpable as she broke down when talking about people who said they were lucky. This perception of good

fortune conflicted with Diane's narrative understanding of an injury that should never have happened in the first place.

Diane [T3] "I suppose in some ways you think that she's... at least she's like in one piece, she's well, she's more or less independent in her own way... but I mean it just needn't have happened... .. the worst thing that, if that had been a bit of road where you couldn't see... you know you would have felt sorry for him, but because the road is so... it's just... open... and well lit... and it was summer and you could see... he... just couldn't have avoid, I mean there's just no way, he could have avoided them so easily, just because the lights are on... green and they say go it doesn't mean to say you actually have to do fifty... well he said he was doing fifty five miles an hour... and... I just can't get over how someone can be so stupid..."^{176:1-9}

Box 9

Bill and Diane's suffering was exacerbated over time because of the necessity for the case to go to court. In court they were faced with all the details of the accident and the person responsible. Further distress was caused through the understanding that the person responsible had done something similar before. In addition they were told by the police to be extra vigilant because the defendant lived nearby. This caused a sense of unease around their home and daily life that could not be escaped. The inability to step out of this narrative further increased their suffering because they were constantly living with its negative effects. Although the court case and the defence council's dialogue was described as being as harrowing as the event itself, it marked a turning point in Bill's narrative. The sequence of events that were put forward, and the subsequent guilty verdict, meant Bill could find some peace.

However the anticipation of a holiday lifted their emotional burden and it was important for Diane and Bill to be away for the anniversary of the accident. In the future it was anticipated that they would always be away at that time of year. However, as much as they wanted this narrative to be tied off, dealt with and firmly in the past so that life could move on, both said they could feel the old symptoms returning when they talked about the accident. Diane reflected on the understanding that the mother held the family together but the need to do this seemed to distress her further (see Box 10). Furthermore Diane worried about Bill's health illustrating the physical toll that the year had taken.

Diane [T3] "you know it's just... between my, you know my mother... over the years... she's had like... all the family problems and... I think the mother carries all the burden don't they, I think in old families, I think even now... [tearful]... the mother holds it together for the family... somehow if the mother falls apart... I mean if Mum's in a bad mood... everybody's like... 'oh Mum's in a bad mood'... so I think that, that reflects as well if I don't hold it together... or... keep... like normality going then... whose going to do it... it, you feel as if there's got to be kind of like a lynch pin or something that's there... and I think... I said to Bill I wanted to stop work at you know... I think this confidence thing I've started to like, I don't want to do it any more..."

and he's like 'no you've got to keep going...' [slight laugh]... I'm like 'no... [slight laugh]... I don't want to, I want to be at home' ...^{133:1-22}

Box 10

Summary of the narratives of suffering for the Hughes family

The Hughes family represented their suffering through their inability to make sense of their isolation and abandonment, the way the accident happened and the man responsible. Loss of control was featured in the narrative through their struggle to get the help and support they needed both for Abigail and for Diane's mother. Loss of certainty was present during their wait for the judicial process and anticipating the possible outcomes. Their failure to make sense of, or find purpose in, their suffering led to a breakdown of the world they knew before injury. Their resilience to endure and live through this difficult time was found from within the family. Despite the desire to step out and move beyond this narrative, pain and distress resurface easily. This suggests that many of the issues that seemed buried actually went unresolved over time.

5.3.4.3 Wilson: 'Living in the shadows'

The suffering narrative for the Wilson family was depicted as 'Living in the shadows'. This metaphor was chosen to represent how the narrative was not created through the more obvious losses associated with suffering. In fact, in the Wilson family very little was ever spoken about that could be interpreted directly as 'loss'. Their ability to navigate their earlier trauma was underpinned by Tracey's return to full health. Although head injury attacked a taken-for-granted future, Tracey and the whole family maintained their biographical continuity as the present and future were reconnected to the past. As such, trauma was spoken of as if largely dealt with, tied off and in the past. Therefore the development of trauma into suffering over time was not a well identified part of these narratives.

Despite this, there was pain within the narrative that was sustained over time. This pain was embedded within the hypothetical narratives of what could have been, as opposed to what actually was. The temporality in this narrative thread showed how the present and anticipated future could only be understood within the context of a different outcome, an outcome that would have changed all their futures forever. Mike especially was still affected by these hypothetical scenarios and these narratives became ingrained in him as a person.

Interpretation of the narratives of suffering revealed how hard the experience had been on the Wilson family. Kate in particular found it difficult to give voice to her experience and simply referred to this as being 'hard' for them all. Kate's narratives were peppered with this

reference and the simplicity of this word hid the demands of the past year. Kate's narrative also showed a gentle defiance in the face of these challenges that meant they just had to be dealt with (see Box 11).

Kate [T3] "it was hard... it was very hard... to go, to go, I don't think I, oh, you say you can't go through it again but you would if you had to wouldn't you but... but it was very, very hard... I mean... I know I was writing emails to the sister-in-law who's in [name of country] where my mum was I mean... he must, I mean I was sitting there crying on the... but...but... [pause]..."^{64:1-5}

Box 11

Similarly Peter said little about the emotional difficulty of the past year but in his final interview he looked back and suggested he was at greater peace than he had been. The suggestion therefore was that quiet suffering was more in what was not said, than what was.

Mechanisms that stopped a narrative of suffering developing in the Wilson family were primarily attributed to Tracey's outcome. However, in addition to this there was a shared perception of support from and to each other that was maintained over time. The large size of the two families (Mike's and Tracey's) together was perceived as of benefit to the overall experience. Shared narratives were interwoven through the immediate and extended family and Kate said it was the whole family, not just the core members that had joined together and helped to come through the events of the last year. As a result of sharing these narratives there was a collective feeling of good fortune that pulled the family inwards and concern was expressed for others who were not so lucky. However, in terms of support Mike's narrative was less aligned than other family members' narratives. Mike compared his experience to that of Kate, Peter and Helen and reflected on the availability of their significant others to support them, when his was critically ill. These divergent narratives emphasised his isolation during the acute period (see Box 12).

Mike [T1] "Because... I can't fully understand what Kate and Peter are going through... because it's their daughter... and... likewise there's no way that they can understand what I'm going through because it's... it's my partner it's... and it's... I don't know if it's, it's not ... easy is the wrong word, it's not easier for them... but sometimes it feels like it's harder for me because... in any other circumstances... Tracey would be there to help me through this sort of thing and... I'm not on my own but... when I go to bed at night I am on my own sort of thing... and she would be the one to... if it had been her sister or something or my sister she'd be the one that would be there for me... and I don't have that... [fighting tears]... [deep breath]... which is obviously quite hard..."^{180:1-10}

Box 12

Mike's narrative of suffering continued with his internalisation of the prediction that Tracey was in a vegetative state (discussed within the trauma narratives Section 5.3.2) and the

possible actions they could have been asked to take. Mike said just the words persistent vegetative state would haunt him forever emphasising the powerful nature, and longevity, of this particular narrative. Staying in touch with other families met while in the critical care unit meant staying close to the narratives of other head injured people. These narratives acted as reminders that not all escaped unscathed and further served to emphasise how close they all were to a very different future (see Box 13).

Peter [T2] "I don't know where we would have been if it had, if it wasn't this state now... or when... had she still been... looking at the ceiling... still with a trachy in... down in [rehabilitation hospital]... which it could have easily of been... yeah... how we would of felt then I don't know... you know how we'd of, we'd of... we'd of obviously had to cope... but... no it doesn't bear thinking about...[pause]... You know it's er... that would have been er... would have been a disaster that wouldn't it, without a doubt... I mean there are obviously are people down there... that have obviously been there for... weeks... months... don't know about years, possibly, I'm sure there are some that have been there for... for a long while I bet..."^{231:1-9}

Mike [T3] "and every time, every now and again... he comes down to see Tracey... for business erm... and she asks, she's curious, she asks him how she is and... he tells us the stories you know she's... she's in... she's thirty four years old she wearing nappies, she's got three kids but she doesn't really know they're there... and that really... really brings it home... for her... because... you know she could so have easily been like that... it was so easily have been like that... you know, her husband has now stopped working to take care of her and it's... it's the life we could have had... very easily... or worse... you know and that... for that to be so close to her... is... is a check on reality all the time for her... because she sees the chap probably every month... erm... but... and she's not quite so lucky as Tracey... but exactly the same situation they were both in that critical care unit both with severe head injuries... why does Tracey... recover like she has... and the other girl not... and that, that really... she finds that quite hard to deal with..."^{52:3-15}

Box 13

With the passage of time, despite the narrative of recovery sustaining progression to full health, this hypothetical narrative increased in importance and strength. The hypothetical was further bolstered by the narratives of luck and a chance series of events that closed the metaphorical distance between the real and imagined (see Box 14). This hypothetical narrative disturbed Mike and the 'what could have been' was almost as much a part of the present as what actually 'was'. In contrast Kate referred to this acute period as the dark side and somewhere she never wanted to return. This perhaps accounted for her unwillingness to give further voice to her narrative and return to events she wished to keep in the past.

Mike [T2] "if they'd of done those MRI scans... if that first week... ... what would, what would the outcome have been? ..." ^{133:7-8}

"would they have said, you know, there's one in twenty thousand or whatever chance that she will make a recovery... but you know, realistically speaking... we should be turning the machines off... because I think that's what they would have told us... erm, you know what... it

doesn't bear thinking about... Thank God ... she was so bad... they couldn't do the MRI scan... and she managed to get through the worst of it because by the time they had done the MRI scan... she was... [cough, cough] she was probably about five per cent away from being completely off... the life support... she was only on a little bit of ventilation and that was it... if they'd of turned the ventilator off she'd of breathed for herself anyway... [slight laugh]... and that... scares the hell out of me... if they had of done that MRI scan when they wanted to, when they would normally have done an MRI scan and they'd of found what they found... I'm convinced, I mean I don't know for definite but I'm convinced they would of advised us to turn the machines off... and that is just... ^{134:1-13}

Kate [T2] "Now we're this side looking back... it was the dark side really wasn't it... you just don't want to go back there do you... I mean it's just... [pause]... I mean we did wonder... whether we done the right thing... you know if she'd done the right thing in surviving... if she'd going to be brain damaged for the rest of her life... I mean you don't want that do you, you wouldn't want it yourself... and you know she wouldn't... so then you think well have I done the right thing... it was obviously too late then because I mean... if, if she did survive with serious head injuries, serious brain damage... I mean it was too late to turn the machine off... she'd come through that part... but...[pause]... but erm... [5 sec pause]... no... [5 sec pause]... but I wouldn't want to go back there anyway... [pause]..." ^{95:1-9}

Box 14

Summary of the narratives of suffering for the Wilson family

Narratives of suffering were identified as 'living in the shadows' and explored how the real and perceived wrapped around each other within the accounts. At the start there was little separation between the hypothetical and the real because so much was unknown. However as recovery was established the hypothetical scenarios remain within the accounts, especially for Mike, and caused suffering, not through what was actually lost but what could have been. Although navigating the experience was very hard the sharing and alignment of narratives seemed to negate many of the damaging effects of suffering over time.

5.3.4.4 Suffering narratives conclusion

Narratives of suffering were interpreted within the family cases through loss of control, loss of certainty, loss of an anticipated future and the ability to make sense of trauma. Although not present in all family members' accounts it was important to understand how the accumulation of subjective loss, pain and distress led to endured suffering over time. A feature of much of the suffering was 'living through' and as such the narrative became stuck in the present, or sometimes in the past. Suffering frequently included the hallmarks of a regressive narrative as family members moved away from a positive representation of the future and reduced their capacity to look forward preferring to locate themselves, and their narrative, in the difficult present. There was also a sense that suffering was exacerbated by there being no apparent purpose to their experience, so that positive meaning could be taken from the events of the past year. Therefore, like trauma these narratives contain features of the chaos narrative

(Frank 1995) but also represent elements of fracturing and enduring (Brown & Addington-Hall 2008) including a breakdown of self, fear, denial and living through the undesired effects of head injury.

In contrast to the storylines described by Frank (1995) and Brown and Addington-Hall (2008), the findings of this study also emphasise the long-term effects of hypothetical narratives that represent the 'what could have been'. Illustrating how the real and perceived wrap around each other as hypothetical narratives are afforded as much status and attention as the real.

Figure 5.7 represents the relationship of the hypothetical and expected narratives to the narratives of what actually took place.

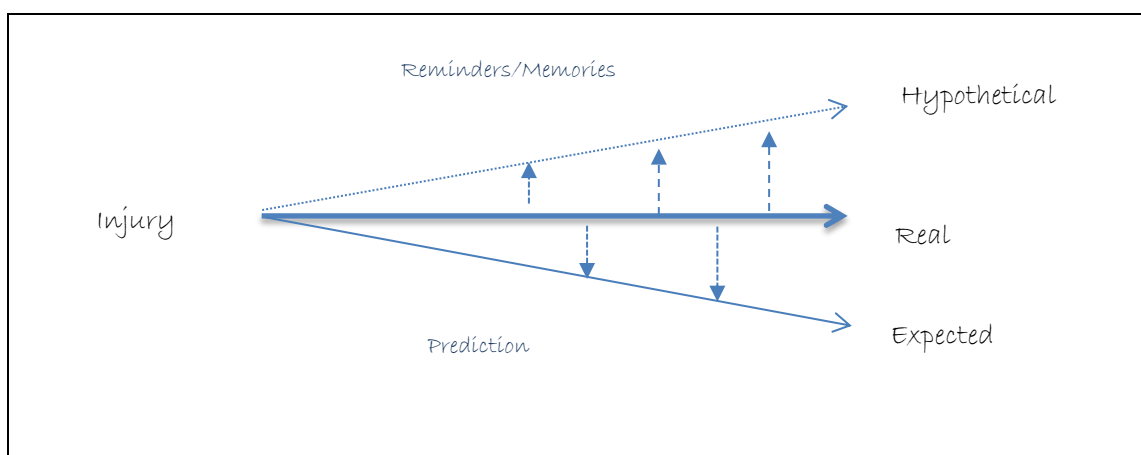


Figure 5.7 Narratives of suffering

5.3.5 Family Narratives

Family narratives combine many of the threads previously discussed and for that reason they were chosen as the last thread to explore in detail. Already discussed has been the impact of shared experiences of trauma, insight and evaluation of change during recovery, the narrative alignment of both injured and non-injured family members and the isolating effect of suffering over time. Family narratives reflect the subsequent effects of all these shared and non-shared narratives and the consequences on the shape and function of the family system.

As discussed in Chapter Three family systems theory exemplifies how family members are interrelated and that changes that occur to one person necessitate changes in others (Maitz & Sachs 1995; Walker & Akister 2004). As a result the family represents a dynamic system that shifts its shape and function in response to life events. As already discussed, the autobiographical narratives showed how the removal of one family member demands the renegotiation of roles and responsibilities. Autobiographical narratives therefore demonstrate personal growth and biographical revision in the face of their experience of illness from a non-

patient perspective. Subsequently the alignment of family members alters post-injury because the non-injured members inhabit a narrative that the injured person can only superficially understand. Furthermore, the recovery narratives demonstrated how, despite physical recovery, the injured person's biography may be revised or disrupted leaving the future of the whole family seeming different. Lastly the damaging effects of both trauma and suffering can leave family members with unresolved pain and distress. These narratives represent the ebb and flow of the family system that draws in during crisis and moves out again once crisis has resolved. The shape of the family may remain the same, may be worse or may be better in the wake of head injury.

Family narratives explore this evolution of the family system as family members all spoke about how the head injury of their relative had affected the family as a whole. As such family members aligned their narratives to represent their family in the past, how they functioned day to day and how 'close' they perceived themselves to be. Family members then reflected on the features of the experiences that drew them inwards in the face of crisis. The lasting effects of this experience were then represented in the narratives by predicting the shape and function of the family in the future. This coherent temporality of past, present and future defined these stories as family narratives for closer consideration.

5.3.5.1 Barker: 'Separation and connection'

Family narratives for the Barker family were interpreted as 'separation and connection'. This way of representing their narrative thread was chosen because of the way the family was described both before and after injury. Before injury it was Emma that was considered separate from the rest of the family. After injury Emma was portrayed as being closer to Suzanne and the children and Dave had become separate. This new division in the family meant the shape and day-to-day function of the family system were revised in the year post-head injury.

The narrative thread begins with an orientation to the family pre-injury. The Barker family was characterised through the 'normality' of everyday life. Suzanne, Dave and the children represented the nuclear family and Emma lived separately to this. Although content with her circumstances Emma did recognise a missed opportunity to know her sisters better than she did. Similarly Suzanne felt they had not taken the chance to spend more time together and recognised Emma's independent life. Both Emma and Suzanne acknowledged that they had a difficult relationship in the past that may have contributed to Emma's separation from the core of the family.

However, head injury provided this family with an opportunity to draw inward and forge new relationships between the non-injured members. Through sharing narratives of illness both Emma and Suzanne's narrative demonstrated the bonding that had occurred between the non-injured members. Although Emma suggested it was easy to make early promises and that as life got back to normal promises were often forgotten, there was an established bond between the non-injured members that remained. Relationships were more established, less fragile, more trusting and honest. Therefore this family narrative was most intense in the early stages, and although it relaxes as life reconnects, these bonds were sustained over time.

Suzanne's narrative thread revealed a moral evaluation of their circumstances during the acute period when she referred to the understanding that through hard times good things happened and reflected on how valuable it was for the children to spend time with Emma. Emma also reflected on the opportunity to get to know her sisters and said these moments were the highlights of her day (see Box 1).

Emma [T1] "...just little things like putting my sisters to bed...all brushing our teeth together and teaching them about make up, and telling them how to take off their make up!! [laughs]... you know things that I can be quite good at ... [laughs]... they were kind of like the highlights of my day but they were... ten times better than going out for another drink after work, and getting drunk and rolling in at some ridiculous time in the morning. Does that make sense? It was like... the good things that I had during that time period... were amazing...compared to what I'd call a good day in my normal day-to-day life before he had his accident... so...I was actually, kind of in a way having quite a nice time! [laughs]..." 19:1-10

Box 1

Therefore both Suzanne and Emma made sense of the experience through the opportunity to positively influence the shape of the family in the future. Resolutions were made in the acute period not only for themselves but also how they hoped the experience would affect Dave. Resolutions that were hoped for predominantly focused around the need for Dave to slow down and reduce his hours at work. Dave was characterised as a workaholic and although head injury could not have been predicted, illness was biographically anticipated. As such it was hoped this event would lead to Dave to make positive changes in his lifestyle and physical health (see Box 2).

Emma [T1] "...I've written him a letter...and saved it on his laptop 'to read when you're better'...which is just to say that...he needs to take more care of himself, and I think it's unfair that, you know, he's got a young family, and... his health is a bit of a mess anyway...he doesn't look after himself...and so...I kind of wrote him a letter to say, you know, you've got to, be a bit more responsible for the fact that you've made a decision to have a young family it's very unfair on them not to ensure that you can be around for as long as possible to see as...much of them growing up as, as possible..." 138:1-8

Suzanne [T1] "...I mean he's 58 now, you know, he's not as young as he used to be so...he'll have to slow down and take a few holidays! [laughs]...which is...I think it's gonna be good in a way...because he's always said...I can't leave, you know, I can't leave my business for a week...you know, something bad's gonna happen...and he's left it for over a month now and nothing bad has happened. Touch wood! [taps the table]...nothing yet...but, er...we managed, erm you know, we know that we can...he's got a good friend, the one who's helped us so...he could probably, you know, look after it for a week, you know..."^{187: 2-11}

Box 2

Therefore in the acute period it was predicted that the family narrative would be progressive in nature toward a valued goal where the whole family were closer and life was improved. However, the potential for positive biographical revision from Dave's perspective was not realised. This lack of revision, personal growth and re-evaluation of priorities led to further division in the narratives of injured and non-injured members. One year after the event few resolutions had been achieved and Suzanne had stopped looking forward to an improved quality of life.

As the hope of a progressive narrative diminished the narrative developed regressive features and Suzanne described fractured relationships within the family nucleus. Reflection on pre-injury relationships between Dave and the children emphasised what had been lost. However Suzanne did not think that Dave was aware that his relationship with the children had changed (see Box 3). Suzanne thought the children sometimes feared their father and encouraged them to spend time outside of the family home.

Suzanne [T3] "So but again it's always sort of stress related... or... when he's really... I don't know... focused on something and he wants it done... and if you can't help him then you're useless or the children are useless... or... stupid or... and that's very hard to... you know... sort of take really because he never used to be like that and I think for that reason the children are not as close as they were before..."^{45:1-6}

"Sophie and him used to be sort of an item... and they used to go out together and... you know 'oh Sophie come with me...' to get the chips for example... and out they go... and now it's... no one wants to go with him anymore because they're... not that they fear, but... they think well it's not going to be pleasant is it... he might just snap at me a gain or... so they want to avoid this... as much as they can... I mean they do sometimes... go with him but not as often... as before and I mean they do have hugs again... you know he's still and everything... but it's not sort of... not as often as before... I think it's very sad... you know... it's not the sort of things that's...very pleasant so..."^{188:1-10}

Box 3

Fractured relationships also represented Suzanne's relationship with her husband and her family narrative was entwined with the recovery narrative and her sense of Dave's biographical continuity. Suzanne said her relationship was different and a year after injury, although she still loved him, Dave was no longer the man she married (see Box 4). Suzanne

spoke of divorce at each interview. At the first it was mentioned in passing as if it was something at the back of her mind that she did not want to acknowledge, at the second although life was difficult that was not a reason to separate, and by the third there was more articulation of the possibility as if it had been given much more thought.

Suzanne [T3] *how do you think this whole event... has affected your relationship with Dave...*[CW]

"Changed... er... er... how would it change it?... I don't want to be... [laughs]... well yeah because I don't feel that... you know... he's the... well I don't think he's the man that I married... to... I mean he's there but... with that sort of... sometimes you know on a bad day I feel so cross... and you know I've thought on several occasions I've thought well... it would have been better for everyone if he didn't make it... on the really, really bad day that's what I think... on a good day no I wouldn't think that but... you know take it to the extreme... you know, I've said, you know things would have been so easier you know... so much stress free... I mean of course... you know it hurts and I can't say about the children but... yeah that's how it's affected ^{330:1-10}

" ... I mean you know I love him dearly and he does... also... but er... this... I don't know something that's gone wrong probably somewhere... [slight laugh]... we're not as close... ^{331:1-3}

" ... but I don't want to get... divorced [laughs]... and then she says 'oh please mummy don't get divorced' I said no I don't want...divorce but... you know you can't... when you hold on... you know it just er... sometimes it's not... you just want to break free... [laughs]... sometimes you want to break free and... you know you don't want to hurt anyone, I wouldn't do that to him but sometimes you feel [exhale]... I've had enough... but what would I do... [laughs]... and you know would it be the best solution or... [exhale]... probably not... ^{337:1-7}

Box 4

In contrast however, as a result of not sharing the illness narrative with her father, Emma perceived very little narrative effect on their relationship. Therefore Emma reflected a stable narrative whereby injury had neither made her relationship with her father better nor worse. Rapid recovery further served to hide the trauma of her father nearly dying and facilitated a return to their normal relationship. Emma explained that because they had not shared the same experience it was unlikely that her relationship would improve substantially over time (see Box 5).

Emma [T1] "...but yeah I was saying to the guys at work! [laughs]... like oh erm...I was just joking saying actually it's brought me and Suzanne and the girls really close together... but if anything my Dad's been a bit left out on that 'cause... [laughs] ... he was just asleep for a few weeks and wakes up! [laughs] ... kind of... where we've all being kind of... grouped together, I guess, he wasn't actually really a part of that. That's a bit odd really isn't it? You'd think that he'd wake up and you'd feel really close to him or something, well no...he was just under sedation and then being a weirdo and then...even when he was getting better, even now he's sleeping so much he's only awake... for er, you know, a matter of hours here and there, well now more so... yeah! [laughs] it feels like we had a crisis and he wasn't around and we dealt

with it... but he's not kind of benefited from all the bonding that gone on!... laughs]... [laughs] ... but I think he'll be really happy to see...certainly to see that...how much closer I am...to er, the girls and to Suzanne..."^{68:1-14}

Emma [T2] "I guess... I think I said it before... but... I think it's brought us a lot closer... me and Suzanne and the children... but... my relationship towards my Dad... I don't think it's changed... I don't think it's worsened... but I don't think it's any better than it was before... all of this..."^{33:1-4}

Box 5

The consequence of these family narratives was a family reshaped by head injury. The whole family is pulled inwards in the immediate aftermath, then over time the non-injured members are more aligned through sharing narratives and the injured person is more separate. By the end of the year Suzanne said that when the injured person makes such a recovery it would be easy to assume a family could go back to their life before but that was simply not the case.

Summary of the family narratives for the Barker family

Family narratives for the Barkers depicted a family where the non-injured members had become closer but Dave had become increasingly separate. The initial anticipation of an improved family future was not realised and as the family moved back into day-to-day life opportunities for positive meaning to come from trauma were lost. Following head injury the biographical continuity of the family was threatened and at the end of one year Suzanne did not perceive the post-injury family to be of equal value to how she remembered it was pre-injury.

5.3.5.2 Hughes: 'A new shape, a new function'

The Hughes family narrative was understood as 'a new shape, a new function' because of a shared understanding that the family, and their future, had changed. The family were represented as a close family with three children reaching the age of independence and leaving home. The family were then pulled inwards following trauma and later life was gradually allowed to return to normal. The Hughes family was different post-injury and this change made it necessary for family life to find a new rhythm.

The family narrative begins by contemplating the common assumption that trauma brings families closer. This assumption was the catalyst for exploration of how Abigail's injury had affected the family. These narratives illustrated temporal movement through reflecting on the past and predicting the future. Such movement within the narrative helps to make sense of the current situation and provides some meaning and purpose to the events experienced. As a

result of trauma, recovery and biographical revision for injured and non-injured family members, this family system was changed.

The pre-injury family was described as a close family with girls who were growing up and had started to live their own lives. Abigail's injury pulls these siblings back into the nuclear family and narratives between family members become entangled as they put their lives on hold and immerse themselves in Abigail's illness (see Box 6).

Diane [T1] "Er.... Er... I think... I think, what's come out of it, well I suppose you say 'ooo yes we got closer', but I think it's become more...obvious in some way, it, it can't be helped I mean obviously that Abigail has become more important, if you know what I mean..."^{141:1-4}

"Although there are other important things going on, my two younger, my two other girls... erm... I think, because we are quite a close family anyway, and I mean whatever anybody's doing the girls always keep in contact... and although it's always been Abigail's, always been quite a major part of the family because she's middle child syndrome... they always have to be, known about. So you always know you've got her..."^{142:1-6}

Bill [T2] "he said oh it's really strange... I forget who, whose some... sort of like Finnegan's law it's a law on something... and he said... when things happen in life... that are really traumatic... and you know whether it's a car accident... or someone dies... or something really ... heart wrenching... in your family circle... your natural instinct is to er... come back from all this expanse that we live in... and come right back to a family unit... all close together, nothing is important around you... work... everyone outside your family unit... doesn't exist for... a period of time... and you slowly re-open up again..."^{156:4-12}

"and that's exactly, exactly what it was... you come right back in... and it's like... you know, this protection thing you put round you're little family... and then you slowly let it out... again as things get better... I suppose, it's may be just that I don't know... bit of the old cave man instinct coming back or something..."^{158:1-7}

Box 6

The need for the Hughes family to find a new rhythm within their day-to-day life began with Diane's admission that she was initially very nervous to have Abigail home. Abigail was portrayed as quite a strong willed character that could be difficult to live with, especially when being restricted in her activities. Diane was worried that she may not even get on with her daughter if she was to be living at home for the long-term future.

Lucy represented the narrative effect of head injury by explaining how she felt more connected to other family members, putting life into perspective. Resolutions made after injury included the re-evaluation of personal values and the commitment to spend more time together. These resolutions reflected a moral component to the narrative that illustrates how Lucy tried to make sense of the events by taking something positive from them. Three months after injury Lucy had taken the opportunity to reaffirm her relationship with Abigail.

However the most powerful narrative effect was when talking about how Lucy's relationship with her father had changed. The experience had given Lucy the opportunity to revise her understanding of her father and her relationship with him (see Box 7).

Lucy [T2] "[through tears]... [sniff]... it just showed me another side to him... which I really needed to see... because... I just thought... it wasn't like I knew that he didn't care about us, and he didn't love us... and all that kind of thing... he was just always just so stand off-ish... a bit... and I felt like I was always in trouble... always getting shouted at... [crying]... and it just showed that he really cared about us... and he did shout at us for a reason! [laughs]..."^{113:1-6}
 "Erm... I've always been a lot closer to my mum... but now I feel like I can build a relationship with my dad as my dad and not just like my... my father... and that is something that is really, really positive and I don't know if... I don't think to him that's necessary, that he's necessarily aware of it... but to me that's just blown it open completely...strange...There's definitely things like... I definitely can be quite shirty... and quite... sort of, icy a bit like... oh my God you're so embarrassing... but then I'd never say that now... [cries]... mmm ... that's it..."^{114:1-7}

Box 7

A year after injury the family was considered to be back to functioning in a way similar to the way they were functioning before injury. The only difference identified was that Abigail now lived at home. However, Diane's narrative indicated further revision of the family's biography. Diane explained how the family dynamics had changed with Abigail's greater reliance on her younger sister Elizabeth. In addition a year after injury Diane indicated that Abigail's change in mood and temper had led the sisters to be less close than they were.

The changes to her family caused Diane great distress and a year after injury she used the metaphor of ripples radiating through her family to illustrate the narrative effect of their lost future (see Box 8). It may be that because Diane did not appear to share this narrative of change with other family members it served to isolate her from them.

Diane [T3] "...I know I can write... reams and reams... about how I feel because... the police were wanting Abby to write erm... a statement about how she felt... about the accident and... and Abby... couldn't put it into words really... she's like 'well I don't know how I feel... I don't remember it'... and I said 'well I can write it[!]' it's like schuch, schuch, schuch... [mimicking writing]... essay done here you go... [laughs]... and she's like 'oh'... I said yeah because... it's completely changed... everything... how it was... your future... everything how we were looking forward to... life... on... you know... as life was going to be a completely different world to what it is now... and we just had to kind of like... all of a sudden go... it's like a bump [slaps hands]... stop... and then it's like... this pond of ripples it's like... just coming out and we're having to... to just get used to the idea... there's nobody else that can deal with it except us"^{165:1-12}

Box 8

Diane felt the ramifications of the injury just went on and on and attributed the decline of her mother's mental state on Abigail's injury suggesting it was a turning point whereby she just

seemed to totally fall apart. Despite her frailty Diane said her mother always remembered to ask if they got the man responsible for the accident.

In addition, as the family pulled inward and prioritised Abigail, the needs of other family members went unmet. A year after injury Diane was very distressed at the ramifications for Elizabeth's future and her A-level results. The possibility of another lost or delayed future was almost too much to bear. However, Elizabeth did achieve the grade for her university of choice and there was a great sense of relief that another narrative was not dislocated from its anticipated future.

Summary of the family narratives for the Hughes family

In the year post-head injury the family narrative showed how the Hughes family had evolved. This narrative showed progressive features in the immediate post-injury accounts that illustrated the positive effects of head injury on the alignment of the family system. As the family moved back into normal life the narrative moved toward a more stable state. However Diane's narrative showed more regressive features as the pre-injury family was characterised as preferable to their current state.

5.3.5.3 Wilson: 'Close before, closer after'

Family narratives for the Wilson family were interpreted as 'close before, closer after' because of the sustained narrative effect whereby family members retained their positive evaluation of the family system pre- and post-injury. Family narratives were constructed to show how the Wilson and Moore families functioned well together. Pre-injury family members spent time with each other and played an active part in each other's lives. Family narratives were facilitated by living in close proximity and the ability to see each other on a fairly regular basis. Comparison to other families resulted in positive reinforcement of their family narrative (see Box 9). The family narrative was further illustrated through reference to being laid back and welcoming of new members.

Helen [T1] "...like my cousin and they don't speak... and they're quite segregated as a family and I think... well... we've always said and sometimes me and my sister might be sat down and arrange to do things... as a big family we're always the ones trying to arrange a big family thing it always seems to be us at the centre of it... so I think... in that kind of sense... we are fairly close as a family anyway... it has really kind of cemented it..."^{77:2-7}

Mike [T1] "...I wouldn't say it has changed significantly... as I say we probably are a bit closer but... [pause]... we're a close family anyway and if there's ever anything that needs doing... we always do stuff for each other as a family unit anyway..."^{181:1-4}

Box 9

The family narrative depicted a family that moved inwards during the acute period and autobiographical narratives illustrated the narrative alignment that emphasised a shared experience. However, the ability to feel closer to each other was also represented in the family narratives through the expression of mutual respect and understanding for each other and each other's unique narrative. The account by Mike and Peter about the necessity for Tracey's next of kin to sign consent forms on her behalf emphasised the importance of good communication and collaborative decision-making.

Peter [T1] "...and I think erm... a situation like this... like I say we erm... er... I don't know it... you know we are just open and frank with each other...we...we sort of like discussed...everything as a... although the ultimate... decision... which is a strange thing... is that... the consent forms needed signing by Mike... on the patient's behalf... course he's her next of kin...husband... now that's a... that's a bit of a strange... erm... experience... I am now, no longer... even though she is your child... you know although you have a say... it's... as to whether which they go ahead or which they don't... that is quite a strange... but as it happened in this particular case... and the group as it is... it wasn't the case anyway... because... we openly discussed.... between us... and came up with a... joint... agreed decision... even though he signed the forms..."^{164:1-10}

Mike [T2] "...I think it must have been very hard for Tracey's parents knowing that ultimately whatever they decided or whatever their views were... it's my signature on the bit of paper and for that and their... you know, she's their daughter... and that... I can't imagine what that felt like for them... but... for me to know... that ultimately I was in control of the situation... was... probably a lot easier for me, you know, whatever decisions were made, alright we made them as a group, but ultimately it's my signature on that bit of paper... and ultimately it was my decision..."^{90:1-7}

Box 10

Mutual understanding was also expressed between spouses Kate and Peter who acknowledged the effect of what each other had been through. Helen also spoke about a mutual understanding between herself and Tracey that they understood how each other felt but did not need to explicitly talk about it.

Important to the family narrative was the opportunity to share resolutions for the future if (or when) Tracey recovered. Over time many of these resolutions were realised and involved the family coming together and valuing time spent with each other. The moral evaluation of their narrative demonstrated positive revision of the family through enhanced relationships and a commitment to continue to do more together. Another resolution was to raise funds for the hospital. Doing so was a way of saying thank you but also represented a closing of the chapter and facilitated moving on.

It was important to family members that the narrative effect was not forgotten. Mike wanted to remind himself of what he could have lost so that he could retain his new personal values

and work life balance. Helen also wanted to remember how it felt to nearly lose her sister (see Box 11).

Helen [T1] "...I mean we do row a bit... occasionally... but only like sisters do, like she borrows my clothes and I'm like ergh! ... [laughs]... but I said to her before I wanted to try... and remember... and do something that would make me remember how it is now... 'cause, I mean in two years from now when I get in a strop about something, or we have a row about something... and I can think back and think well... I might not be having this row... or something like that... [pause]..."^{130:1-6}

Peter [T3] "...So I don't think it's actually... erm...impacted on our relationship... it's erm... er... I think we always had each other to lean on and er... we've supported each other... so we're... I don't think we had any... on our particular, our own relationship I don't think it's had any affect at all really... I mean we both consider we're lucky we both you know... we obviously, we must have leaned on each other... at the time which I'm sure we did... but erm... er... I don't know what to say, I think... whether you're any more tolerant now than you were for anything I mean you have your... you have to be fairly tolerant of each other because we do our own things and the children do their own things but we get together as well so... you know it's er... I think we've generally got a fairly good stable relationship anyway... famous last words... [laughs]..."^{79:1-10}

Box 11

Helen's narrative emphasised the importance of her bond with her sister by referring to Tracey as her first best friend. Over time Helen reaffirms this part of her biography by reconstructing her relationship with her sister. Speaking about the relationship between Helen and Tracey, Kate suggested that over time she expected the enhanced relationship to return to the norm of usual sibling arguments. However Kate said that did not appear to be the case and felt they were both taking opportunities to do things that they would not have done before (see Box 12).

Helen [T2] "...And it's nice that she responded to me... she did... er... I felt like she seemed to go for me... I don't know perhaps it was like the childhood bond or something that we had... but I did feel that like when I, she did seem to lean... for me and want to hold my hand and want me to be near her...that obviously made me feel quite... good inside that she's obviously seeking me out from a group of people there... to come to her... so obviously I'm second to her husband but... [laughs]... erm..."^{10:1-6}

Kate [T2] "...But then they have always been close... but they, I think when they lived together for a fair while they, they get on each other's nerves... but I mean... that's, I should say touch wood shouldn't I... I mean, you wouldn't think it would last would you but... you don't know do you, I mean I suppose when you nearly... when you nearly lose your sister I suppose... it is... well it's hard when you nearly lose your daughter isn't it... I mean you don't expect it... you don't expect to lose your children do you... but... erm... [pause]..."^{55:1-6}

Kate [T3] "...I mean Helen and Tracey... I mean when Tracey came out of hospital Helen and Tracey loved each other I mean they're sisters [laughs]... they used to argue, I wouldn't say argue like cat and dog but I mean... but even now... they still... Helen... and they still Helen still bites her tongue I mean... erm... Helen bought a new bike... so she's got her old bike,

well Tracey said that erm... Helen said that she could have it at her house so we took it down there without asking Helen... and... well when we told Helen 'well I didn't say she could have it but it doesn't matter'... well before she was 'rah, rah, rah'... so it's obviously made us all think... that... that really it could be any one of us really couldn't it...^{74:1-9}

Box 12

When Peter was asked in the final interview if he thought the family had changed during this experience he did not identify change within the family and instead he chose to talk about a shared experience that accentuated the family narrative. A year on Kate suggested there was a general sense of increased appreciation of others and other members spoke about an increased tolerance of each other and a decrease in willingness to argue.

Summary of the family narratives for the Wilson family

In the wake of head injury the Wilson family was reshaped. Family narratives were relatively stable as the family was depicted as close before and closer after. Although Kate and Peter struggled to identify the family as changed their narratives portrayed an increased sharing of lives and a commitment to realising all their resolutions. Helen and Mike took the opportunity to enhance their relationship with Tracey and as a result family members felt closer to each other. The family system accommodates this revision in family life and the family pulls inwards.

5.3.5.4 Family narratives conclusion

Family narratives all depicted families that moved inwards following head injury. Once ready to move out again all families were reshaped. Temporality of the family threads represented the family in the past, its structure, goals and values. The image of the family in the present, and predicted in the future, is compared to the past and evaluations made as to the positive and or negative revisions that had been made.

Head injury brings the taken for granted relationships between family members back into focus. Opportunities were realised for relationships to be forged in all families, but equally some relationships deteriorated. There was a sense that to feel closer was underpinned by a mutual respect, empathy, and understanding. The ability to communicate and openly discuss issues was another valued characteristic in several family narratives. These enhanced relationships were often interpreted by family members as the primary way that positive meaning could be taken from the experience.

The family systems literature supports the theory that a change in one person reverberates into the rest of the family system and demands that the family system responds (Maitz &

Sachs 1995). Although the TBI literature considers how the family responds to the change in the injured person, there is less consideration given to how the non-injured members are changing themselves and how the family system accommodates all these changes. Figure 5.8 represents the reshaping of each family that saw the non-injured family members move away from the injured member in the Barker family and all moved closer in the Wilson family. However the diagram of the Hughes family shows the ebb and flow a family reoriented in the wake of head injury.

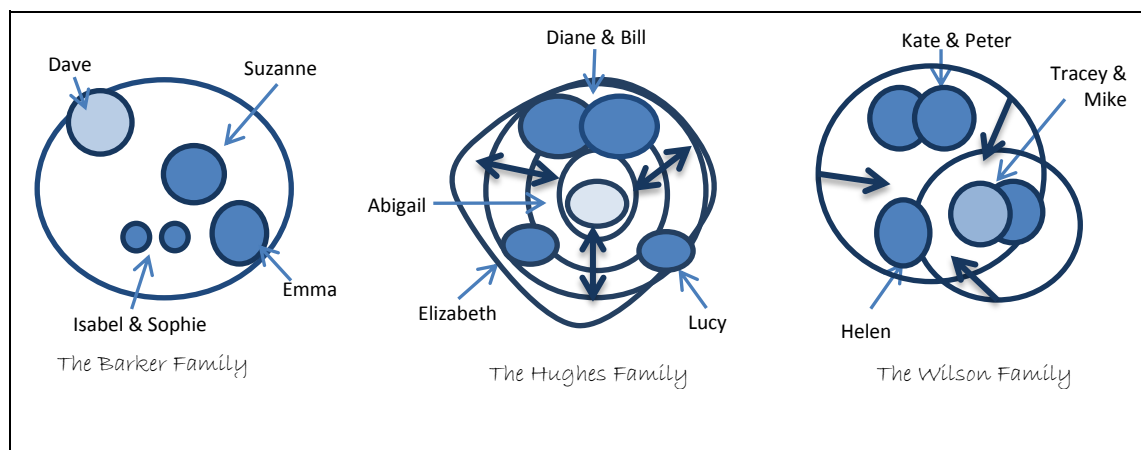


Figure 5.8 Narrative effect on families

5.4 Chapter summary

This chapter presented for discussion five narrative threads. Specifically these were: trauma, recovery, autobiographical, suffering and family.

It was argued that all family members created trauma narratives through which they illustrated events, both real and perceived that ruptured their normal life. Narratives were often fragmented because they were too raw to make sense of or denote a higher purpose. All family members told stories of recovery that illustrate how the injured family member had moved from illness to the attainment of full physical health. However these narratives also represented family members' perceptions of biographical revision, reinforcement and disruption that could undermine the recovery discourse. Autobiographical narratives showed how non-injured family members experience illness from a non-patient perspective and this major life event revises their own biographical sense of self. However this revision, and in some cases post-traumatic growth, were considered not to be fully understood by the injured family member and as such represent narrative misalignment that brings the non-injured members closer together but can exclude the injured member from their family. Narratives of suffering depicted the long-term effects of head injury on the non-injured members.

Subjective loss, unresolved trauma, pain and distress, sustaining hypothetical narratives, all contributed to the long-term causes and symptoms of suffering that were endured over time. Finally family narratives characterised the narrative effect of head injury on the shape and function of the whole family system. Taken together these narrative threads represent how the non-injured family members made sense of their experiences. These narratives emphasised that the year post-head injury was a turbulent time where family members were active agents and participants in the process of change.

6 Quantitative Findings

6.1 Introduction

Chapter Six presents the quantitative findings from FACES-IV. The rationale for including an outcome measure in this study was set out in Chapter Four Section 4.7.2 and stemmed from the principle that family functioning as a concept has been well explored in the literature. As such, it was felt to be appropriate to include a descriptive assessment of family functioning which would give an alternative understanding of how family functioning changed for these families in the year post-TBI.

In contrast to Chapter Five this chapter will present datasets for each family separately only drawing the findings together at the end. To achieve an in-depth analysis the longitudinal data for each family member are presented first followed by a discussion of the results for the whole family system. Datasets from each of the families are then compared to facilitate a discussion of how FACES-IV suggests that families have changed, or not, during the first year following TBI.

6.2 FACES-IV findings

The FACES-IV data evaluate family functioning by assessing self-reported levels of adaptability and cohesion within the family system. Olson and Gorall (2006) define cohesion 'as the emotional bonding that family members have toward one another' (p3) and flexibility is defined 'as the quality and expression of leadership and organization, role relationship, and relationship rules and negotiations' (p3). In addition data are collected that assess overall family satisfaction and family communication. Findings from each family member are described individually through plot profiles and family types, cohesion and flexibility dimension scores and a final Circumplex Total Ratio score (each is discussed further below).

6.2.1 Plot profiles and family types

Each family member is considered individually through representing their data at one, three and twelve months post-head injury on a FACES-IV plot profile. As explained in Chapter Four (Section 4.9.5) the FACES-IV questionnaire asks questions pertaining to either balanced or unbalanced characteristics of family functioning. Raw scores for each domain are compared to normative data to produce a percentile score that can be plotted onto a FACES-IV profile chart. Within the two balanced domains for cohesion and flexibility higher scores are indicative of healthy family functioning and in the unbalanced domains (disengaged, enmeshed, rigid and chaotic) higher scores are considered more problematic. Percentile scores for the balanced

domains are ranked on a scale from very connected, connected and somewhat connected or very flexible, flexible and somewhat flexible. Percentile scores for the unbalanced domains are all ranked on a scale of very high, high, moderate, low and very low.

Each family is then compared to the six family types identified by Olson and Gorall (2006) (see Figure 4.8 p97). The characteristics of each family type have been described by Olson and Gorall (2006) and the data in this study indicated family types were either *balanced* or *rigidly cohesive* (see Box 6.1, a full list of family types is located in Appendix 13). However, classification of family type is based on a 'best fit' principle and allocating plot profiles to family types proved to be the most challenging part of the analytical process for the questionnaire data. Although most plot profiles fitted clusters very well one family member did not seem to follow the common patterns making 'best fit' a more subjective judgement. In this case the author of the questionnaire was contacted with examples of the data to confirm my interpretation. These were in fact confirmed as correct; however I cannot imagine conducting this process with a larger data set with confidence.

Cluster 1, *Balanced*, is characterized by the highest scores on the balanced subscales of Cohesion and Flexibility, and the lowest scores on all of the unbalanced scales except rigidity, where the scores are near the lowest. This combination of high balanced and low unbalanced scores indicates a family type with high levels of healthy functioning and low levels of problematic functioning. These families are hypothesized to be able to best handle the stressors of daily living and the relational strains of changes in the family over time. This family type is the least likely to be seen in therapy.

Cluster 2, *Rigidly Cohesive*, is characterized by high closeness and rigid scores, moderate change and enmeshed scores, and low disengaged and chaos scores. This family type has as its hallmark high degrees of emotional closeness and high degrees of rigidity. This family type would be hypothesized to function well at times given their high degree of closeness. However, they may have difficulty making the changes required by situational or developmental changes due to their high rigidity.

Box 6.1 Characteristics of two family types by Olson and Gorall (2006, p8)

Family communication and family satisfaction scores were then calculated and percentile scores ranked from very high to very low. Interpretation of these rankings is provided in Tables 6.1-6.2.

Very High	Family members feel very positive about the quality and quantity of their family communication.
High	Family members feel good about their family communication and have few concerns.
Moderate	Family members feel generally good about their family communication, but have some concerns.
Low	Family members have several concerns about the quality of their family communication.
Very Low	Family members have many concerns about the quality of their family communication.

Table 6.1 Interpretation of family communication

Very High	Family members are very satisfied and really enjoy most aspects of their family.
High	Family members are satisfied with most aspects of their family.
Moderate	Family members are somewhat satisfied and enjoy some aspects of their family.
Low	Family members are somewhat dissatisfied and have some concerns about their family.
Very Low	Family members are very dissatisfied and are concerned about their family.

Table 6.2 Interpretation of family satisfaction

6.2.2 Cohesion and flexibility dimensions scores

Data from individual family members were brought together by calculating cohesion and flexibility dimension scores and the resulting figures plotted onto the Circumplex Model (see Appendix 14). The illustrations provided a graphical representation of the data and how cohesion and flexibility scores were balanced within a family system. These graphical illustrations proved very useful as a means of capturing the whole family's data in one illustration. Movement, indicative of change, was easy to identify and comparisons between datasets from different family members could be made to further facilitate a descriptive analysis of the family system.

6.2.3 Circumplex Total Ratio scores

Cohesion and flexibility ratio scores were then calculated, through which a final Circumplex Total Ratio could be determined. Ratio scores provide a summary measure of the relative health of family system functioning. Circumplex Total Ratios were calculated by the average score for balanced domains divided by the average score for unbalanced domains. Therefore the higher the ratio score over one, the more balanced or healthy the system is said to be (Olson & Gorall 2006). Comparison of these scores at each data collection point enabled a measure of how much change there had been in the year post-injury.

6.3 Barker family functioning

Descriptive data are presented below for Suzanne and Emma Barker. In the year post-injury plot profiles and family communication and satisfaction scores differed between family members. Interpretation of the data from Suzanne Barker suggested healthy characteristics of family functioning declined over time. This decline was accompanied by decreases in family communication and family satisfaction scores. In contrast Emma's data remained relatively stable over time with some increase in healthy characteristics of family functioning at three months that was not sustained at the one-year data collection point.

6.3.1 Plot profiles and family communication/satisfaction scores

Percentile scores for the Barker family can be viewed in tables 6.3 and 6.5. Family communication and satisfaction scores are displayed in Tables 6.4 and 6.6. Plot profiles are then illustrated in figures 6.1-6.2. The interpretation of these longitudinal data is discussed below.

6.3.1.1 Suzanne Barker

One month: Scores for the balanced domains of cohesion and flexibility were high. Scores for the unbalanced domains were classified as very low. This pattern between data in the balanced and unbalanced domains of the FACES-IV instrument is aligned to a *balanced* family type and suggests there was a healthy level of family functioning. However, there was one peak in the rigid domain (*moderate*); higher levels of rigidity suggest the family is less able to adapt to change (Olson & Gorall 2006). The percentile score for family communication was considered *very high* and family satisfaction *high*.

Three months: The dataset follows a similar pattern; however the flexibility dimension has reduced from *very flexible* to *flexible* and the rigid domain has increased from *moderate* to *high*. A decrease in a balanced domain and increase in an unbalanced domain suggest some reduction in family functioning. Despite this the plot profile is still classified as *balanced*. Percentile scores for family communication and satisfaction decreased to *moderate* and *low* respectively.

Twelve months: Although the flexibility score remained in the same ranking of 'flexible' percentile scores for the balanced domains both reduced with the cohesion score moving from *very connected* to *connected*. In the unbalanced domains the level of disengagement in the family rose from *very low* to *moderate* but the level of rigidity moved back from *high* to *moderate*. The plot profile at twelve months more closely resembled the *rigidly cohesive*

family type instead of *balanced*. Therefore interpretation of these data suggested healthy characteristics of family functioning continued to decline from Suzanne's perspective. However, despite this the *rigidly cohesive* family type is still classed by Olson and Gorall (2006) as one of the most well-functioning family types (see Box 6.1). In addition family communication and satisfaction reduced further to *low* and *very low* respectively.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	84	Very Connected	68	Very Flexible	18	Very Low	12	Very Low	45	Moderate	13	Very Low
3 months	80	Very Connected	62	Flexible	20	Very Low	14	Very Low	64	High	10	Very Low
12 months	58	Connected	50	Flexible	50	Moderate	14	Very Low	50	Moderate	26	Very Low

Table 6.3 Balanced and unbalanced percentile scores for Suzanne Barker

	Family Communication						Family Satisfaction					
	1 Month		3 Months		12 Months		1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level	%	Level	%	Level	%	Level
Suzanne	88	Very High	65	Mod	32	Low	84	High	23	Low	10	Very low

Table 6.4 Communication and satisfaction scores for Suzanne Barker (Higher scores Healthier)

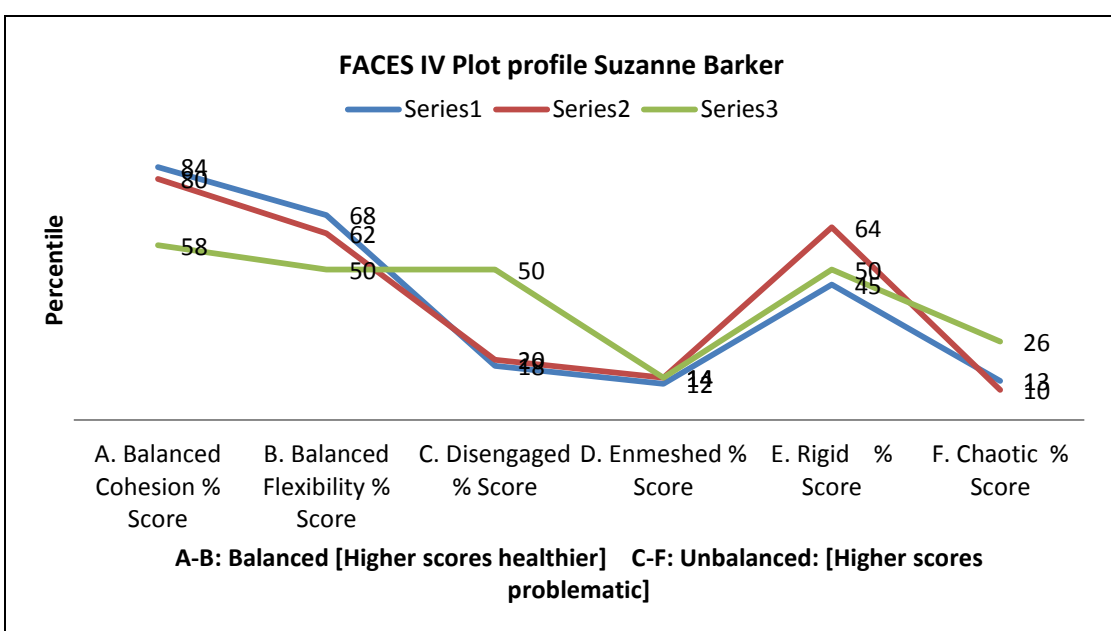


Figure 6.1 FACES-IV Plot profile for Suzanne Barker

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

FACES-IV data for Suzanne Barker showed a general pattern of higher scores for the balanced domains and lower scores for the unbalanced domains of family functioning. However, the plot profiles for Suzanne Barker indicated that the level of rigidity in the family system and reduction over time in cohesion and flexibility changed the family type from *balanced* to *rigidly cohesive* by twelve months. Although Olson and Gorall (2006) suggests this latter family type still has healthy family functioning they may struggle to adapt to change. However the most marked change in the data over time was the continued decrease in Suzanne Barker's family communication and satisfaction scores.

6.3.1.2 Emma Barker

One month: Scores for the balanced domains of the FACES-IV questionnaire were classed as *connected* and *flexible*. These scores were accompanied by *low* or *very low* percentile scores for all unbalanced domains of family functioning. The plot profile created from Emma Barker's data reflected a *balanced* family type. Percentile scores for family communication were classified as *moderate* and family satisfaction *low*.

Three months: There was a slight increase in the percentile scores for balanced domains and some decrease in the unbalanced domains suggestive of healthier family functioning. However, these percentile scores remained within the same rankings *connected* and *flexible* (see table 6.5) and the plot profile continued to be classed as *balanced*. Family communication and satisfaction remained unchanged and were evaluated again at *moderate* and *low* respectively.

Twelve months: Percentile scores for balanced domains reduce but once again stayed within the same ranking. Unbalanced domains *rigid* and *chaotic* showed some increase with the chaotic score moving from *very low* to *low*. Therefore Emma Barker's plot profile continued to be classed as *balanced*. Evaluation of family communication and satisfaction remained *moderate* and *low* respectively.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	58	Connected	55	Flexible	36	Low	16	Very Low	16	Very Low	24	Very Low
3 months	65	Connected	62	Flexible	34	Low	15	Very Low	14	Very Low	13	Very Low
12 months	60	Connected	55	Flexible	36	Low	15	Very Low	26	Very Low	36	Low

Table 6.5 Balanced and unbalanced percentile score for Emma Barker

	Family Communication						Family Satisfaction					
	1 Month		3 Months		12 Months		1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level	%	Level	%	Level	%	Level
Emma	61	Mod	61	Mod	50	Mod	35	Low	25	Low	30	Low

Table 6.6 Communication and satisfaction scores for Emma Barker (Higher scores Healthier)

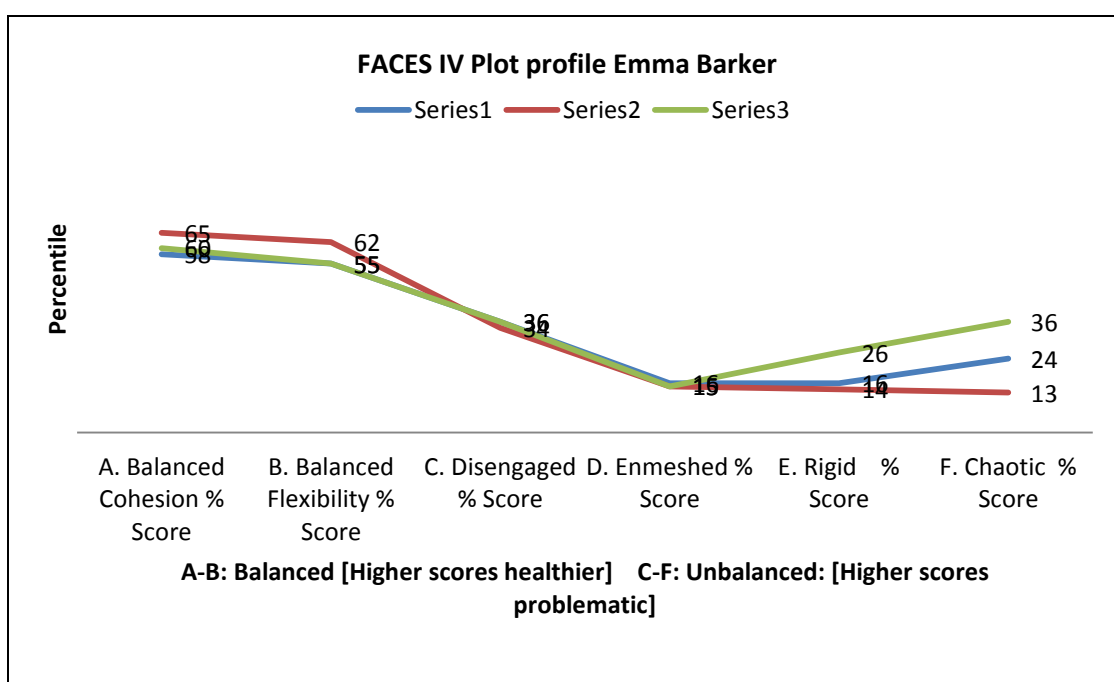


Figure 6.2 FACES Plot profile for Emma Barker

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

FACES-IV data for Emma Barker changed little within the year post-injury. Data suggest that family functioning remained stable over time. Although percentile scores for balanced domains showed some increase three months after injury these gains were not enough to move up the rankings from *connected/flexible* to *very connected/very flexible*. In addition these gains did not continue and were not retained by twelve months. Data for family communication and satisfaction also remained the same across the year.

6.3.2 Cohesion and flexibility dimensions scores

Cohesion and flexibility dimension scores were calculated from Suzanne and Emma's data at one month, three months and twelve months. These scores were then plotted onto the Circumplex Model and can be found in Appendix 15. Plotting these data showed how

Suzanne's FACES-IV data changed over time. Interpretation of these scores indicated that Suzanne felt the family was less connected and less flexible as the year progressed. In contrast to Suzanne's data Emma's evaluation of the family system remained relatively stable over time with some increase in cohesion three months post-injury that was lost by the one-year evaluation. Despite the differences between the data from family members all evaluations retained healthy levels of family functioning, as measured by FACES-IV, within the year post-head injury.

6.3.3 Circumplex Total Ratio scores

Circumplex total ratio scores were calculated from cohesion and flexibility ratios (see Table 6.7). All Circumplex Total Ratios within the first year of head injury were above the threshold of one indicating that both Suzanne and Emma evaluated the family having healthy characteristics of family functioning over time. However, Suzanne's scores gradually reduce from 3.97 to 3.19 to 1.56. These data indicate that healthy characteristics of family functioning reduced in the year-post injury. In contrast Emma's data showed some increase in family functioning at three months with ratio scores increasing from 2.49 to 3.62 this ratio score then decreased below the initial evaluation one year on (2.06).

	1 Month			3 Months			12 Months		
	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio
Suzanne	5.6	2.34	3.97	4.71	1.68	3.19	1.81	1.32	1.56
Emma	2.23	2.75	2.49	2.65	4.59	3.62	2.35	1.77	2.06

Table 6.7 Ratio scores for the Barker family (Total ratio scores above one are healthier)

6.3.4 Discussion

Over time FACES-IV data suggests Suzanne Barker's perception of family functioning changes. Although still classified as having healthy levels of family functioning one year after head injury data suggest there was a reduction in healthy characteristics of cohesion and flexibility and some increase in the unhealthy characteristics of being disengaged and rigid. However, Emma Barker's FACES-IV data indicated her perception of the family remained relatively stable over time. The family system was evaluated at all stages as having healthy family functioning. However there were some slight gains made in the balanced domains of cohesion and flexibility three months after injury that are not retained by the twelve-month point. Olson

and Gorall (2006) hypothesised that these family members would be well equipped to adapt to change.

Suzanne's family's communication scores reduced from very high (family members feel very positive about the quality and quantity of their family communication) to low (family members have several concerns about the quality of their family communication) and her satisfaction score dropped from high (family members are satisfied with most aspects of their family) to very low (family members are very dissatisfied and are concerned about their family). In contrast Emma's communication and satisfaction scores remained unchanged. Family communication was evaluated as moderate (family members feel generally good about their family communication, but have some concerns) and family satisfaction considered low (family members are somewhat dissatisfied and have some concerns about their family).

These data indicate that family members had different perceptions of how their family changed in the year post-TBI. The differences in these datasets suggest Suzanne was at greater risk from the effects of reduced characteristics of healthy family functioning. One obvious reason for this marked difference is that Emma is an adult child from her father's previous relationship and has lived outside of the family home for a number of years. This distance may act as a moderating effect on her evaluations of family functioning. In addition Suzanne is a step-mother and Sophie and Isabel are half-siblings which may affect how Emma defines her family and may make direct comparison to Suzanne's data problematic.

6.4 Hughes family functioning

Descriptive data are presented below for Diane, Bill and Lucy Hughes. However, data are missing from Diane Hughes at three months and Lucy Hughes withdrew before the twelve-month data collection point. In the year post-injury plot profiles and family communication and satisfaction scores were very similar between family members and over time data in all domains from all family members changed very little. The Hughes family was consistently evaluated by all family members as having characteristics of healthy family functioning within the first year post-injury.

6.4.1 Plot profiles and family communication/satisfaction scores

Percentile scores for the Hughes family can be viewed in tables 6.8, 6.10 and 6.12. Family communication and satisfaction scores are displayed in Tables 6.9, 6.11 and 6.13. Plot profiles are then illustrated figures 6.3-6.5. The interpretation of these longitudinal data is discussed below.

6.4.1.1 Diane Hughes

One month: FACES-IV scores for the balanced domains were indicative of *very connected* and *flexible* and all unbalanced domains were scored *low* or *very low*. This pattern of high and low scores on the plot profile classifies the family type as *balanced*. Percentile scores for family communication were *high* and family satisfaction *low*.

Twelve months: Scores for the balanced domains did not change and remained *very connected* and *flexible*. However the unbalanced domain, *rigid*, had increased to *moderate* levels suggesting there was less flexibility in the family system as a whole. Therefore Diane's plot profile remained relatively unchanged and was still classed as *balanced*. The family communication score remained *high* and family satisfaction remained *low*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	75	Very Connected	60	Flexible	26	Very Low	20	Very Low	30	Low	32	Low
12 months	68	Very Connected	60	Flexible	26	Very Low	20	Very Low	45	Moderate	20	Very Low

Table 6.8 Balanced and unbalanced percentile score for Diane Hughes

	Family Communication						Family Satisfaction					
	1 Month		3 Months		12 Months		1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level	%	Level	%	Level	%	Level
Diane	70	High			70	High	21	Low			23	Low

Table 6.9 Communication and satisfaction scores for Diane Hughes (Higher scores Healthier)

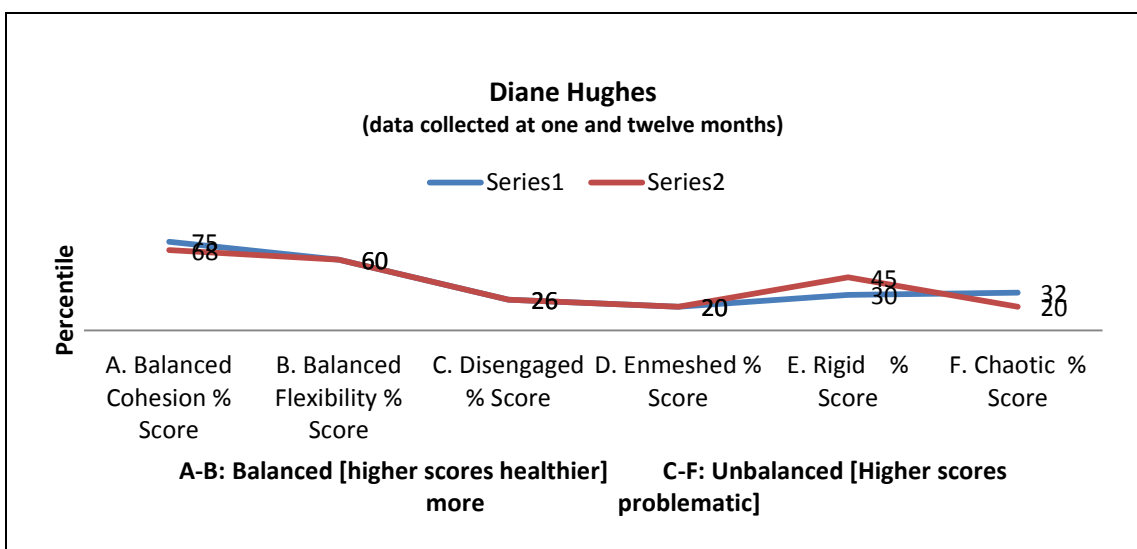


Figure 6.3 FACES Plot profile for Diane Hughes

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

Diane Hughes' evaluation of family functioning remained largely unchanged in the year post-injury. Firm conclusions about change are hard to draw because the three-month data are missing. However, data suggest Diane perceived there to be healthy characteristics of family functioning that were sustained over time. The FACES-IV data were very similar with little change from one to twelve months post-injury. However the level of rigidity did increase from *low* to *moderate* suggesting the ability of the family to adapt to change may have reduced. Despite these characteristics family satisfaction percentile scores remained in the *low* ranking.

6.4.1.2 Bill Hughes

One month: Scores for the balanced domains of FACES-IV were classed as *connected* and *flexible* while unbalanced domains were evaluated *very low* with the exception of rigidity that scored *low*. The plot profile created from these FACES-IV data was aligned to a *balanced* family type. The family communication percentile score was considered *moderate* and family satisfaction score *low*.

Three months: The FACES-IV data were very similar. However, the level of cohesion increased and moved to *very connected*, suggesting emotional closeness had increased. Bill's plot profile remained indicative of a *balanced* family type and family communication and satisfaction percentile scores remained *moderate* and *low* respectively.

Twelve months: Cohesion levels were retained at *very connected*; however the unbalanced domain, rigid, had increased over time to *moderate* levels. Increase in rigidity may indicate this family is less adaptable to change. Despite these small fluctuations Bill's FACES-IV data categorised the family as *balanced*. The family communication and satisfaction scores remained at *moderate* and *low*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	65	Connected	62	Flexible	26	Very Low	15	Very Low	40	Low	18	Very Low
3 months	68	Very Connected	55	Flexible	18	Very Low	20	Very Low	32	Low	20	Very Low
12 months	68	Very Connected	60	Flexible	20	Very Low	20	Very Low	45	Moderate	20	Very Low

Table 6.10 Balanced and unbalanced percentile score for Bill Hughes

	Family Communication						Family Satisfaction					
	1 Month		3 Months		12 Months		1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level	%	Level	%	Level	%	Level
Bill	58	Moderate	50	Moderate	61	Moderate	30	Low	23	Low	25	Low

Table 6.11 Communication and satisfaction scores for Bill Hughes (Higher scores Healthier)

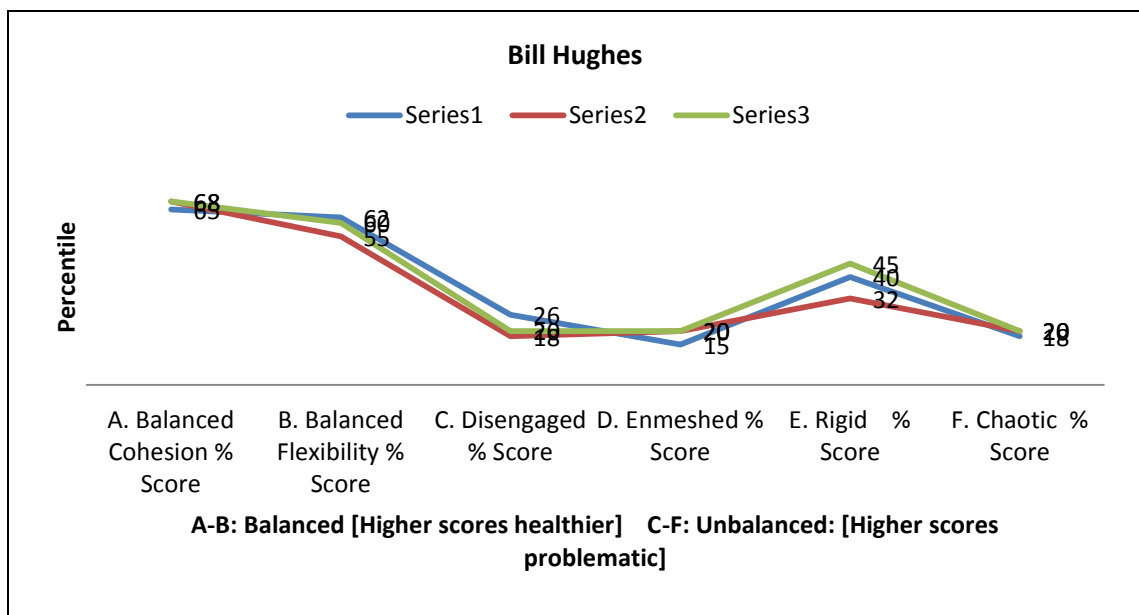


Figure 6.4 FACES Plot profile for Bill Hughes

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

The FACES-IV data from Bill Hughes showed that characteristics of family functioning remained relatively stable over time. Interpretation of these data would suggest Bill's perception of his family changed little in the year post-TBI. However, there was some gain in emotional closeness at three months that was sustained by twelve months. In addition, by twelve months the unbalanced domain, *rigid*, had increased within the family. Overall FACES-IV data indicate that from Bill's perspective this was a *balanced* family type with characteristics of healthy family functioning. Yet despite this, Bill's family satisfaction scores remained ranked as low throughout the year.

6.4.1.3 Lucy Hughes

One Month: FACES-IV data indicated balanced domains were evaluated as *connected* and *flexible* with the unbalanced domains scored as *very low* (disengaged, enmeshed and chaotic) and *low* in the rigid domain. On the plot profile these data are interpreted as *balanced* and

indicative of healthy family functioning. Communication and satisfaction percentile scores were evaluated as *moderate* and *low* respectively.

Three Months: FACES-IV data remained relatively unchanged; as such the plot profile created was very similar. However, data in the balanced domain of cohesion increased from *connected* to *very connected*. The family communication percentile score remained *moderate*; however the family satisfaction score increased from *low* to *moderate*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	60	Connected	60	Flexible	24	Very Low	24	Very Low	40	Low	15	Very Low
3 months	68	Very Connected	65	Flexible	32	Low	18	Very Low	36	Low	15	Very Low

Table 6.12 Balanced and unbalanced percentile score for Lucy Hughes

	Family Communication						Family Satisfaction					
	1 Month		3 Months		12 Months		1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level	%	Level	%	Level	%	Level
Lucy	61	Moderate	61	Moderate			35	Low	40	Moderate		

Table 6.13 Communication and satisfaction scores for Lucy Hughes (Higher scores Healthier)

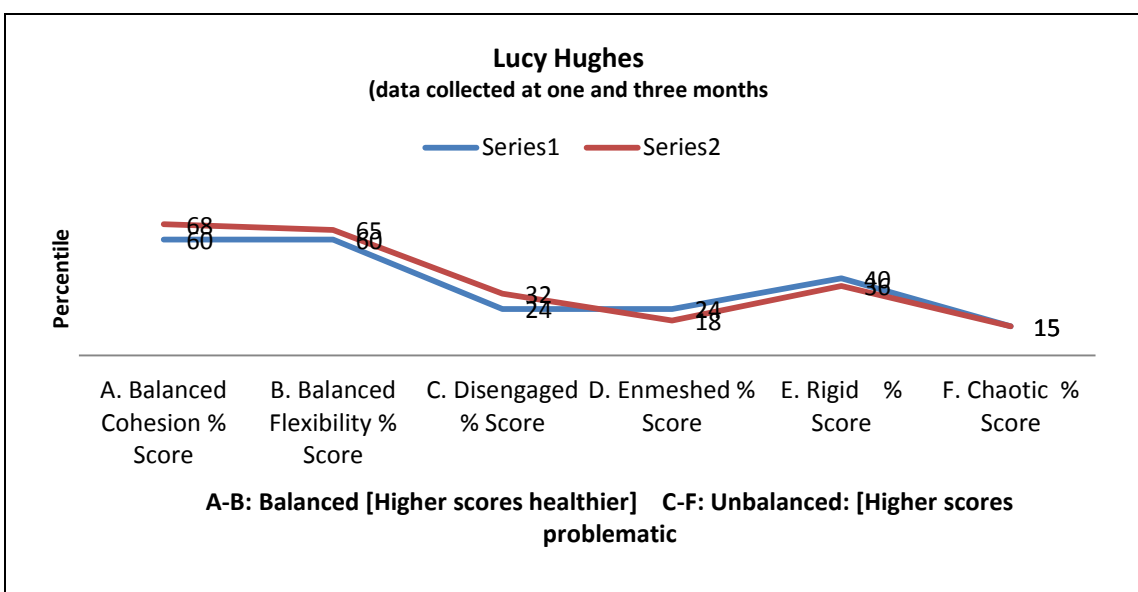


Figure 6.5 FACES Plot profile for Lucy Hughes
(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

Lucy Hughes' FACES-IV data remained relatively stable post-head injury. Interpretation of these data would suggest that Lucy's perception of her family changed little between one and three months. However, data also showed an increase in the healthy characteristics of cohesion as the family was perceived as *very connected* three months after injury. In addition, this increase in emotional closeness was accompanied by a rise in the family satisfaction score.

6.4.2 Cohesion and flexibility dimensions scores

Cohesion and flexibility dimension scores were calculated for Diane, Bill and Lucy at one month, three months and twelve months (when data were available). These scores were then plotted onto the Circumplex Model and can be found in Appendix 16. Plotting these data showed how stable Bill and Lucy's data were. In contrast, Diane's scores for cohesion reduced from *very connected* to *connected* one year later. Interpretation of these data would suggest that Diane's perception changed the most, when compared to Bill and Lucy's data, and this change was associated with an overall reduction in healthy characteristics of family system functioning.

6.4.3 Circumplex Total Ratio scores

Circumplex Total Ratio scores were calculated from cohesion and flexibility ratios and are displayed in Table 6.14. Data from all family members showed that Circumplex Total Ratio scores were always above the threshold of one. More specifically Diane's Circumplex Total Ratio scores reduced very slightly from 2.6 to 2.4. Bill's total ratio scores showed some increase three months after injury (2.65 to 2.85); however this gain was not retained 12 months after injury as the ratio score returned to 2.62. Lucy's total ratio score also showed a slight increase three months after injury (2.34 to 2.63).

	1 Month			3 Months			12 Months		
	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio
Diane	3.26	1.94	2.6				2.96	1.85	2.40
Bill	3.17	2.14	2.65	3.58	2.12	2.85	3.4	1.85	2.62
Lucy	2.5	2.18	2.34	2.72	2.55	2.63			

Table 6.14 Ratio scores for the Hughes family (Total ratio scores above one are healthier)

6.4.4 Discussion

The longitudinal FACES-IV data for all members of the Hughes family remain relatively stable over time. Interpretation of these data would suggest that family functioning is healthy at all times within the year post-injury. Healthy characteristics of cohesion and flexibility illustrated a family that was connected and flexible to change. Both Bill and Lucy's data indicate that at three months family functioning had increased due to a rise in the level of cohesion of the family system. In addition by the end of the year data from Bill and Diane indicated a slight rise in the unbalanced domain of rigidity; a feature of unhealthy family functioning.

Scores for family communication and satisfaction also remained relatively consistent. Diane's percentile scores for family communication scored *high* (family members feel good about their family communication and have few concerns) whereas Bill and Lucy's scores were *moderate* (family members feel generally good about their family communication, but have some concerns). All family members had percentile scores for family satisfaction that would indicate they were somewhat dissatisfied overall. Only Lucy reported an increase in family satisfaction percentile scores three months after injury. These findings do not support Olson's (2006) hypothesis that balanced families have high family satisfaction.

6.5 Wilson family functioning

Descriptive data are presented below from Mike Wilson and Kate, Peter and Helen Moore. These data showed that in the year post-head injury all family members evaluated family functioning as healthy and little change occurred in family communication and family satisfaction scores.

6.5.1 Plot profiles and family communication/satisfaction scores

Percentile scores for the Wilson family can be viewed in tables 6.15, 6.17, 6.19 and 6.21. Family communication and satisfaction scores are displayed in Tables 6.18, 6.16, 6.20 and 6.22. Plot profiles are then illustrated in figures 6.6-6.9. The interpretation of these longitudinal data is discussed below.

6.5.1.1 Mike Wilson

One month: FACES-IV data indicated that balanced domains were evaluated as *very connected* and *flexible*. Data for the unbalanced domains disengaged/enmeshed scored *very low* and rigid/chaotic *low*. The plot profile created from these data was classed as *balanced* and reflected healthy family functioning. Mike's percentile scores for family communication and satisfaction were both considered *high*.

Three months: Data from the FACES-IV questionnaire remained relatively unchanged as did Mike's plot profile. Percentile scores for family communication remained *high* and family satisfaction increased from *high* to *very high*.

Twelve months: Once again FACES-IV data remained relatively unchanged; however there was a slight decrease in the unhealthy domain, chaotic, from *low* to *very low*. Percentile scores for family communication were again considered *high* and satisfaction returned from *very high* to *high*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	85	Very Connected	60	Flexible	14	Very Low	24	Very Low	34	Low	40	Low
3 months	82	Very Connected	62	Flexible	13	Very Low	18	Very Low	36	Low	34	Low
12 months	84	Very Connected	65	Flexible	14	Very Low	16	Very Low	40	Low	26	Very Low

Table 6.15 Balanced and unbalanced percentile score for Mike Wilson

	Family Communication							Family Satisfaction					
	1 Month		3 Months		12 Months			1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level		%	Level	%	Level	%	Level
Mike	80	High	83	High	86	High		75	High	92	V. High	71	High

Table 6.16 Communication and satisfaction scores for Mike Wilson (Higher scores Healthier)

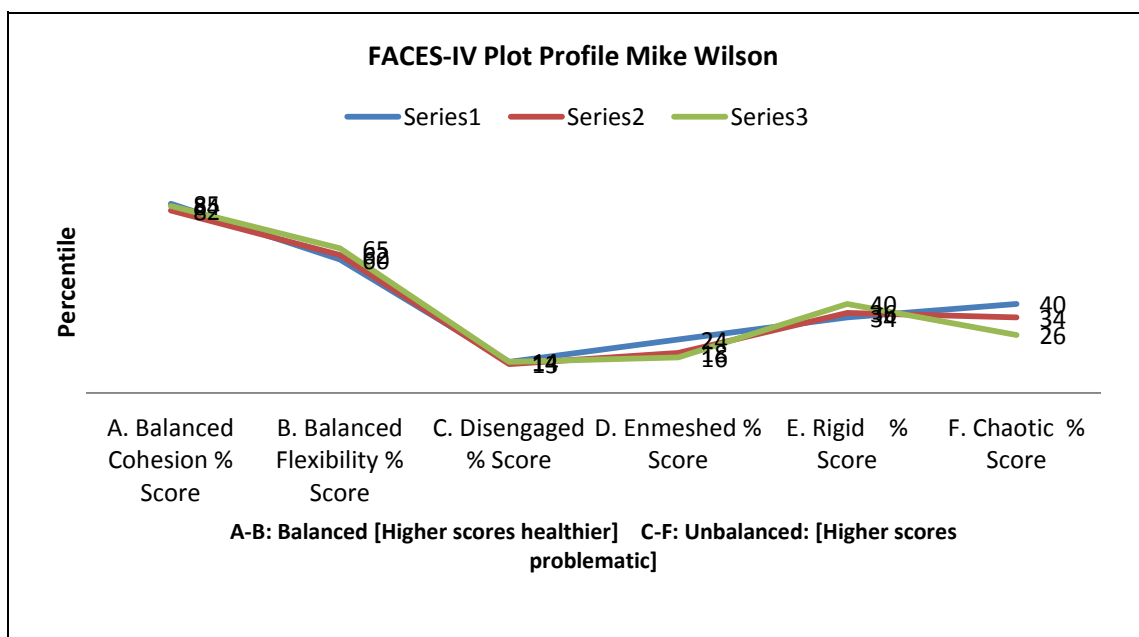


Figure 6.6 FACES Plot profile for Mike Wilson

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

Mike Wilson's data suggest very little change in his evaluation of the family system in the year post-TBI. Interpretation of these data suggested that Mike perceived his family to be functioning well in the first month after injury and these healthy characteristics were sustained over time. Family communication and satisfaction scores both remained high with some further increase in family satisfaction score at three months post-injury that was not retained by the twelve-month data collection point.

6.5.1.2 Kate Moore

One month: Scores for the balanced domains of the FACES-IV tool were evaluated as *very connected* and *flexible*. Data for the unbalanced domains were scored as *low* (disengaged) or *very low* (enmeshed, rigid, chaotic). The plot profile created was classed as *balanced* and indicated characteristics of healthy family functioning. The family communication and satisfaction percentile scores were both evaluated as *moderate*.

Three months: FACES-IV data and Kate's plot profile remained unchanged, as did scores for family communication and satisfaction.

Twelve months: Once again the FACES-IV data changed little by the one-year data collection point. However, the unbalanced domain 'disengaged' reduced from *low* to *very low*. Interpretation of data would suggest an increase in engagement between family members. The family communication percentile score remained *moderate*; however there was an increase in the family satisfaction score from *moderate* to *high*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	70	Very Connected	55	Flexible	30	Low	13	Very Low	13	Very Low	20	Very Low
3 months	70	Very Connected	50	Flexible	30	Low	10	Very Low	13	Very Low	24	Very Low
12 months	82	Very Connected	55	Flexible	20	Very Low	10	Very Low	12	Very Low	26	Very Low

Table 6.17 Balanced and unbalanced percentile score for Kate Moore

	Family Communication							Family Satisfaction					
	1 Month		3 Months		12 Months			1 Month		3 Months		12 Months	
	%	Level	%	Level	%	Level		%	Level	%	Level	%	Level
Kate	65	Mod	61	Mod	65	Mod		58	Mod	45	Mod	66	High

Table 6.18 Communication and satisfaction scores for Kate Moore (Higher scores Healthier)

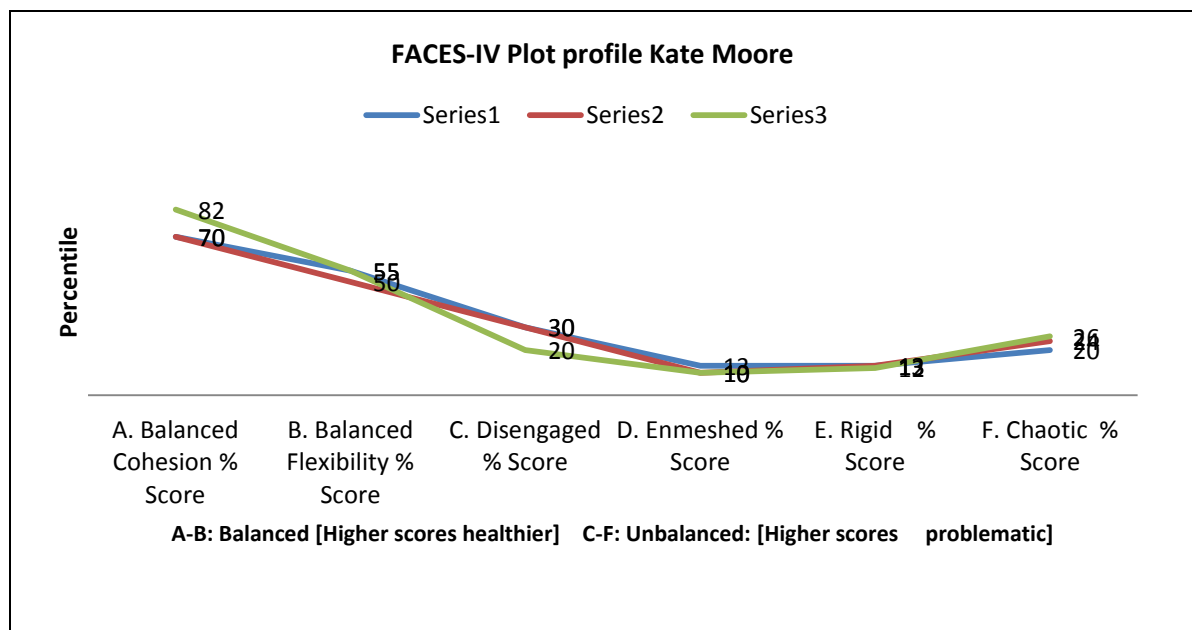


Figure 6.7 FACES Plot profile for Kate Moore

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

FACES-IV data for Kate Moore changed very little in the year post-injury. Interpretation of these data would suggest Kate perceived her family to have healthy characteristics of family functioning and these were sustained over time. However by the end of the first year Kate's overall family satisfaction score had increased. This could suggest that Kate was more satisfied with the way the family functioned one year post-injury.

6.5.1.3 Peter Moore

One month: Scores for the balanced domains were evaluated as *very connected* and *flexible*. Unbalanced domains disengaged/enmeshed were scored *very low* and rigid/chaotic considered *low*. The plot profile created from these data was classed as *balanced* and was indicative of healthy family functioning. The percentile scores for both family communication and satisfaction were evaluated as *moderate*.

Three months: The cohesion domain of the FACES-IV questionnaire reduced from *very connected* to *connected*. However the other balanced domain remained *flexible*. The disengaged domain went from *very low* to *low* and the chaotic domain changed from *low* to *very low*. The family communication and satisfaction percentile scores remained unchanged.

Twelve months: Scores for cohesion returned from *connected* to *very connected* and the level of flexibility remained unchanged. Within the unbalanced domains the disengaged score returned to *very low*, the rigid score moved from *low* to *very low*. Percentile scores for family communication and satisfaction increased from *moderate* to *high*.

Time since injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	80	Very Connected	60	Flexible	26	Very Low	13	Very Low	40	Low	30	Low
3 months	65	Connected	58	Flexible	32	Low	15	Very Low	40	Low	26	Very Low
12 months	80	Very Connected	58	Flexible	20	Very Low	13	Very Low	18	Very Low	20	Very Low

Table 6.19 Balanced and unbalanced percentile score for Peter Moore

		Family Communication							Family Satisfaction					
		1 Month		3 Months		12 Months			1 Month		3 Months		12 Months	
		%	Level	%	Level	%	Level		%	Level	%	Level	%	Level
Peter	65	Moderate	61	Moderate	70	High		40	Moderate	40	Moderate	75	High	

Table 6.20 Communication and satisfaction scores for Peter Moore (Higher scores Healthier)

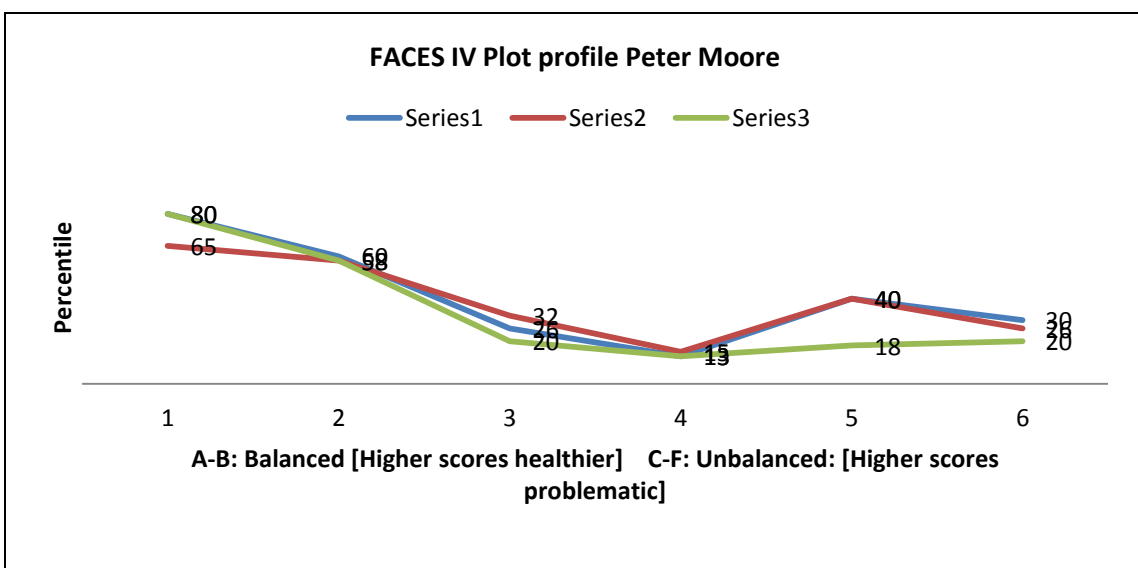


Figure 6.8 FACES Plot profile for Peter Moore

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

Interpretation of Peter Moore's Faces-IV data would suggest that his perception of family functioning changed little in the year post-TBI. Although data indicate that there was some reduction in healthy characteristics at the three-month data collection point these returned by twelve months. In addition by twelve months scores for family communication and overall satisfaction had increased. Interpretation of these changes could suggest Peter was more content with the way his family functioned post-injury.

6.5.1.4 Helen Moore

One month: Scores for the balanced domains were evaluated as *very connected* and *flexible* and all unbalanced domains were scored *very low*. This plot profile created from these data was classed as *balanced*. The percentile scores for family communication and satisfaction were both evaluated as *moderate*.

Three months: FACES-IV data remained relatively unchanged with one exception in the domain 'rigid' which went from *very low* to *low*. The family communication percentile scores remained *moderate*; however family satisfaction went from *moderate* to *high*.

Twelve months: Once again FACES-IV data remained unchanged as did the percentile score for family communication. However the percentile score for family satisfaction moved back from *high* to *moderate* levels.

Time since Injury	Balanced Cohesion % Score	Cohesion Level	Balanced Flexibility % Score	Flexibility Level	Disengaged % Score	Disengaged Level	Enmeshed % Score	Enmeshed Level	Rigid % Score	Rigid Level	Chaotic % Score	Chaotic Level
1 month	82	Very Connected	62	Flexible	14	Very Low	16	Very Low	26	Very Low	20	Very Low
3 months	84	Very Connected	62	Flexible	12	Very Low	15	Very Low	36	Low	18	Very Low
12 months	82	Very Connected	55	Flexible	14	Very Low	14	Very Low	40	Low	20	Very Low

Table 6.21 Balanced and unbalanced percentile score for Helen Moore

		Family Communication							Family Satisfaction					
		1 Month		3 Months		12 Months			1 Month		3 Months		12 Months	
		%	Level	%	Level	%	Level		%	Level	%	Level	%	Level
Helen	61	Moderate	61	Moderate	65	Moderate		40	Moderate	75	High	58	Moderate	

Table 6.22 Communication and satisfaction scores for Helen Moore (Higher scores Healthier)

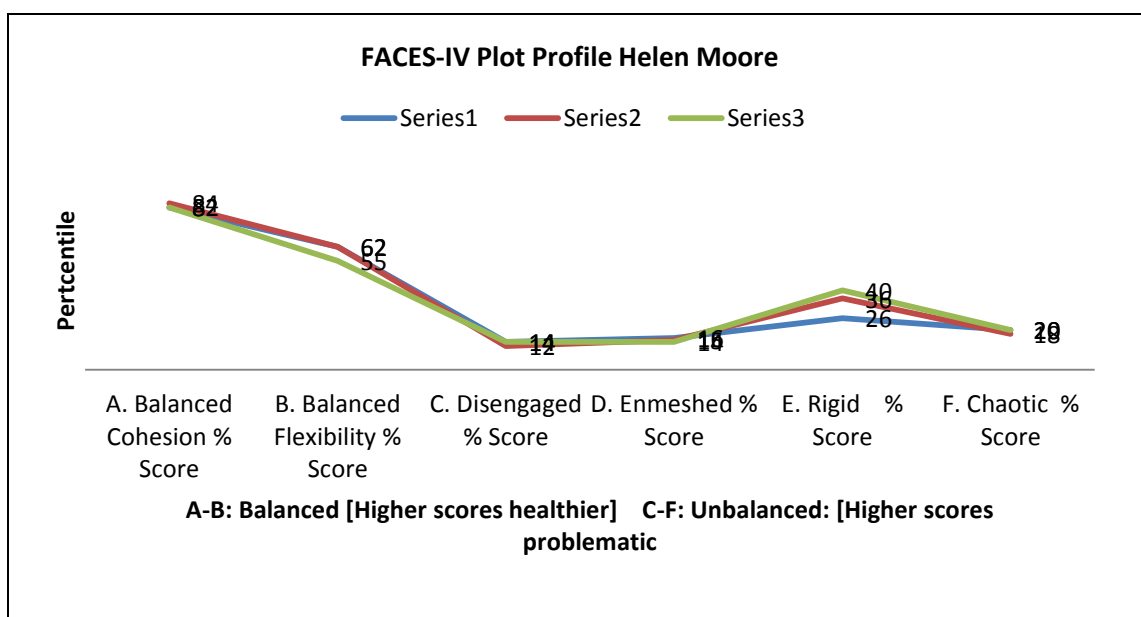


Figure 6.4 FACES Plot profile for Helen Moore

(Series 1: One month; Series 2: Three months; Series 3: Twelve months)

Helen Moore's dataset changed very little in the year post-TBI. Interpretation of this dataset would suggest Helen perceived her family to have healthy levels of family functioning that were sustained over time. Although data indicate that there were some gains in family satisfaction at the three-month data collection point this increase was not sustained by twelve months.

6.5.2 Cohesion and flexibility dimensions scores

Cohesion and flexibility dimension scores were calculated for Mike, Kate, Peter and Helen at one month, three months and twelve months. These scores were then plotted onto the Circumplex Model and can be found in Appendix 17. Plotting these data illustrated that cohesion and flexibility stayed relatively stable over time for most family members.

Comparing family members' datasets on the diagram the biggest change included Kate moving from *connected* to *very connected* by the end of the first year after head injury. Mike moved from an unbalanced level of cohesiveness to a more balanced level. Furthermore at three months Peter moved from *very connected* to *connected* but then moved back again and Helen moved from *connected* at one and three months to *very connected* at twelve months.

6.5.3 Circumplex Total Ratio scores

Circumplex total ratio scores were calculated from cohesion and flexibility ratios and are displayed in Table 6.23. Data from all family members showed that Circumplex Total Ratio scores were always above the threshold of one. More specifically Mike and Helen increased

their ratio score at three months; however Helen's score then decreased by twelve months (4.08; 4.26; 3.85) whereas Mike's score continued to increase (Mike 3.05; 3.53; 3.78). In contrast Kate and Peter's ratio scores decrease at three months but increased substantially by twelve (Kate 3.29; 3.1; 4.18; Peter 2.91; 2.26. 3.95).

	1 Month			3 Months			12 Months		
	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio	Cohesion Ratio	Flexibility Ratio	Total Ratio
Mike	4.47	1.62	3.05	5.29	1.77	3.53	5.6	1.97	3.78
Kate	3.26	3.33	3.29	3.5	2.7	3.1	5.47	2.89	4.18
Peter	4.1	1.71	2.91	2.77	1.76	2.26	4.85	3.05	3.95
Helen	5.47	2.7	4.08	6.22	2.3	4.26	5.86	1.83	3.85

Table 6.23 Ratio scores for the Wilson family (Total ratio scores above one are healthier)

6.5.4 Discussion

Interpreting the longitudinal FACES-IV data all members of the Wilson family perceived their family as very connected and flexible to change. Over time there was little change in their evaluation of the balanced and unbalanced characteristics of family functioning whereby these data remained at healthy levels throughout the first year. Data indicate there was an overall increase in the Circumplex Total Ratios for Mike, Kate and Peter. These data indicate that by the end of the year the family had adopted even more characteristics of healthy family functioning post-injury.

Throughout the year Mike evaluated family communication as *high* (family members feel good about their family communication and have few concerns). Whereas Kate, Peter and Helen considered it *moderate* (family members feel generally good about their family communication, but have some concerns). However by the end of the year Peter also scored it *high*.

Overall family satisfaction scores fluctuated over time. Both Mike and Helen increased their evaluation three months after injury indicating some immediate positive change; however these gains were not sustained over time. In contrast Kate and Peter's satisfaction did not increase at three months, but increased from moderate to high by the end of the year indicating they were satisfied with most aspects of their family life.

6.6 Evaluation of family functioning between cases

FACES-IV data suggest the cases recruited to this study were balanced families with healthy characteristics of family functioning and varying degrees of family satisfaction. Olson and Gorall (2006) suggest that these families are predicted to do well and are most able to adapt to changing circumstances. In support of this hypothesis, although each family made gains and losses in balanced and unbalanced domains of family functioning, data from all family members indicated these were *balanced* families and these evaluations were sustained over time. The only dataset to show a change in perception of family type was that of Suzanne Barker who moved from *balanced* to *rigidly cohesive* by twelve months post-injury.

Calculation of Circumplex Total Ratio scores revealed these were consistently above the threshold of one. Ratios above one indicate there are more balanced characteristics of adaptability and cohesion within the family system than unbalanced characteristics. These results suggest the family members recruited to this study maintained their assessment of the relative health of family system functioning within the first year of injury. Commonalties across the datasets included increases in levels of cohesion and scores for family satisfaction. Items taken from the domain that assesses levels of cohesion in the family include: 'family members are involved in each other's lives; family members feel very close to each other; and family members are supportive of each other during difficult times' (Olson 2010b, p5). It would be reasonable to assume that following head injury a family that had been living more independently comes together and supports each other in times of crisis. Supporting each other and increasing levels of emotional closeness may be responsible for some family members feeling more satisfied overall with their family post-injury.

In addition many evaluations contained increases in the unbalanced domain labelled rigid. Items in this domain include: 'our family is highly organized; our family becomes frustrated when there is a change in our plans or routines; once a decision is made, it is very difficult to modify that decision' (Olson 2010b, p6). It may be that families who have a family member with a head injury need to be more organised and adopt a more structured routine because of the needs of the injured person to attend follow-up appointments or deal with any physical limitations. Alternatively the injured person may have developed sequelae such as deficits in memory, concentration, attention or executive skills that demand a more routinized day-to-day life.

What was interesting to note was that overall, the family with the highest Circumplex Total Ratio scores both before and after injury, was the Wilson family, all ending the year with

scores close to four. In addition family communication and satisfaction were either moderate or high with some increases noted either at the three-month or one-year evaluation point. However Suzanne Barker's evaluation was similarly high at 3.97 one month after injury and yet it was her data that revealed the most significant deterioration to 1.56. The reduction in this ratio score was mirrored by reduction in family communication and satisfaction. In contrast the Hughes family's evaluation remained relatively unchanged during the year. Ratio scores were between 2.19 and 2.85 for the whole family. The FACES-IV tool hypothesises that balanced families will have higher family satisfaction; however this was not supported in the Hughes family as family satisfaction scores were ranked as low for all family members and family functioning remained healthy. This hypothesis was also not supported in Emma Barker's data whereby despite balanced family functioning family satisfaction was low.

6.7 Chapter summary

This chapter has considered the quantitative data from the FACES-IV questionnaire. Through a descriptive analysis of plot profiles, family communication/satisfaction scores, cohesion and flexibility dimensions and Circumplex Total Ratio scores it was concluded that FACES-IV data indicated these were all balanced family type with healthy levels of family functioning that was sustained throughout the year. The greatest decline in family functioning was shown in Suzanne Barker's data while the greatest increase was shown in the Wilson family. Overall FACES-IV data suggest family system functioning in these families changed little over the year. However, data did reflect different gains and losses in specific characteristics that perhaps were of limited magnitude to significantly change family functioning overall.

7 Discussion & Conclusions

7.1 Introduction

In this final chapter there is an opportunity to explore further the findings presented in Chapters Five and Six by drawing on additional literature from a range of theoretical contexts to enhance understanding of family in the context of TBI. The chapter is structured around the five key findings of this study which were: using narratives to understand the processes involved in the judgement of pre- and post-injury change; recognising and validating the stories of non-injured family members in their own right; working with narrative structures; identifying misaligned narratives and understanding the complexity of change in families post-TBI. The chapter comes to a close by reflecting on the limitations of the study, re-visiting the research questions and concluding with recommendations for practice and research.

7.2 Generating new insights

This study was underpinned by social constructivism and narrative theory. Therefore any new insights must be understood within this context. As was discussed in Chapter Four Section 4.3 social constructivism provided the platform for an investigation into accounts that were created, shaped and constructed through social interaction. This position enabled consideration of the non-injured family member and their family/social context. Within the context of our lives family is often a fundamental element of the way these interactions influence our interpretation of events. In that sense constructivism provided a platform for understanding some of these interactions and how the family shaped the individual experience. In addition to which the study did not have to be constrained by looking for one truth, one version of reality and valued the exploration of different embodied experiences. Furthermore, the use of narrative theory was a particularly useful way of examining the research questions. Head injury provided the cue for the creation of stories that clearly represented a past, a present and a future. Arguably, the field would continue to benefit from more studies being conducted in this way.

It was stated in Chapter Three that the current evidence base suffered from a picture of generalised family functioning that struggled to make sense of the complexity of family processes and the relevance of family context. Studies frequently used retrospective, cross-sectional designs and heterogeneous groups of participants with different injuries and considerable differences in time since injury. In addition participants were most commonly

recruited through rehabilitation or support groups through convenience sampling again limiting the perspective to those already known to follow-up services.

Within this study these concerns were addressed through the design of a prospective longitudinal study that enabled several family members from each family to take part. Instead of simply analysing the data together the study first examined the contribution that family members made to understanding each individual family system. As such family processes and family context were examined and explored in-depth. The insights gained by following these family members through their first year of head injury helped to illuminate important aspects of overall adaptation to post-injury life for the whole family.

Following an extensive literature search it is thought that this study is the first to use narrative inquiry with non-injured family members post-TBI. As such it contributes a unique insight into understanding the relevance of connections between the past, present and future for the family member themselves, their relationship with the injured person and the way they see their family as a whole. In contrast to much of the previous literature this study did not seek to focus on the problems people encounter post-TBI. Instead it enabled a view of both the positive and negative features of the experience and how people made sense of these through the stories they told.

7.2.1 Using narratives to understand the processes involved in the judgement of pre- and post-injury change.

The writings of Bury (1982), Williams (1984), Williams (2000) and Ellis-Hill and Horn (2000) made a substantial impact on the analysis and interpretation of the narrative threads. For the most part, theories of biographical disruption (Bury 1982), revision and reconstruction (Williams 1984) have been used to understand the lives of people with chronic illness (Lawton 2003). In contrast to the original studies of chronic illness these theories were used in this study to help make sense of the lives of non-injured family members. As such these people were not ill themselves but were experiencing the illness of others.

7.2.1.1 Biographical attendance

This study highlighted and explored a feature that has not been identified in earlier theories, namely 'biographical attendance'. Biographical attendance was identified in the narratives of non-injured family members and involved maintaining the injured person's identity while they were perceived as being unable to express it fully themselves. Therefore biographical attendance was especially noticeable within the early accounts and during periods of

unconsciousness and confusion. Often the need to attend to the injured person's identity was a direct consequence of being told the injured person would no longer be the same. Therefore biographical attendance involved family members actively looking for, and describing, known character traits. Personality traits that were important to the non-injured member were then identified to themselves and the family or to other people including healthcare staff.

Biographical attendance adds a new perspective to the biographical literature on narrative identity. However similar processes have been noted within the field of dementia. There are obvious parallels between dementia and head injury because both threaten to alter the known identity of the person with injury or illness. The difference is that head injury often causes an immediate effect whereas dementia involves gradual deterioration. Kitwood has written extensively about how this cognitive decline erodes personhood in people with dementia (Kitwood & Bredin 1992; Kitwood 1997; 1998). Personhood in this sense refers to dehumanisation through the lack of recognition, respect and trust (Kitwood 1997). In contrast family members in this study still treated injured relatives as people, still afforded them rights and respect, but their understanding of who they knew the injured person to be was under threat.

This process of biographical attendance helped family members in this study to make a connection to the injured person as the person they were before injury. As such, these acts helped to create positive representations of the future and assure the security of the whole family. Similarly Hasselkus and Murray (2007) found that when carers were able to maintain aspects of the person's pre-dementia identity it also helped to maintain the carer's own sense of self. Therefore, Nolan et al. (2004) suggests that personhood is best understood in the context of relationships and is vital in understanding how people and families live with conditions that threaten identity .

7.2.1.2 Biographical reinforcement, revision, reconstruction

Once character traits were identified, however small, the medical discourse of change was juxtaposed with the family perspective that they were the same. Within the family members' accounts biographical reinforcement was evident even during agitated or confused states where behaviours often served to reinforce family members' understanding that this was the same person. These were key moments within the narrative threads and acted as turning points within their stories denoting that recovery was possible and that the recovery process had commenced.

In previous studies this process of biographical attendance and later reinforcement may have been identified as ignoring the consequences of head injury. Verhaeghe et al. (2005) discussed the assumption by clinicians that family members who ignored such consequences were using denial as a coping mechanism. However, in the acute period the outcome is unknown in these situations and very little can be predicted with accuracy following TBI. Therefore, what was very evident within the narrative analysis was the conflicting discourse between families and healthcare professionals whereby change was treated as a certainty by many clinicians and something families were expected to face quickly.

Verhaeghe et al. (2005) warns that the term ‘denial’ can be seen as a judgemental statement that can threaten the therapeutic relationship between healthcare professionals and family members leading to a sense of distrust (Verhaeghe et al. 2007a). It may therefore be more helpful to suggest head injury can *challenge* the known identity of the injured person (Ellis-Hill and Horn 2008) and that family members must come to understand any revisions to this identity rather than predicting so early on that people will be different. Healthcare professionals need to recognise where families are in their journey of understanding head injury, and its consequences, and work with this rather than try to enforce early acceptance of their own clinical discourse.

As recovery progressed and post-injury limitations and sequelae were identifiable many family member accounts included features of biographical revision and reconstruction (Williams 1984). Family members in this study described the injured person as the same but certain personality traits were enhanced or subdued. These narrative features maintained a sense of coherence and continuity for the whole family post-injury and are thought to be strategies people employ when faced with a ‘biographically disruptive event’ (Lawton 2003). As such it is important to remember that these family members are using these conceptual strategies as a means to make sense of illness, and recovery, and also to underpin their sense of resilience and ability to cope in such traumatic times.

7.2.1.3 Biographical disruption

As discussed in Chapter Two Section 2.4 head injury is frequently associated with the perception that the injured person can fundamentally change (Lezak 1978; 1986; 1988). This is supported by the empirical literature that commonly reports family members perceive the injured member to be a completely different person post-injury (Brooks & McKinlay 1983; Chwalisz & Stark-Wroblewski 1996; Gosling & Oddy 1999). This study used the theory of biographical disruption as a way to make sense of this change in post-injury personhood.

Bury (1982) explains there are three core features of biographical disruption that are commonly present during the course of a chronic illness:

‘First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common sense boundaries [...] second there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation’ (Bury 1982, p169-170)

The theory that illness can make people reconsider who they think they are, and will be in the future, aligned well with head injury. The non-injured family members' accounts of TBI revealed how head injury attacked a 'taken for granted' part of their lives as roles, relationships, family functions and purpose were being renegotiated. In addition to which the known identity of the injured person was being called into question. These events meant that expectations and anticipated futures for the whole family had to be re-examined within this context. A similar argument was presented by Wuest et al. (1994) who characterised family members of persons with dementia as 'becoming strangers' over time. Hasselkus and Murray (2007) explored this further using biographical disruption to describe how caregivers perceived the identity of the person with dementia to have changed during their illness.

Biographical disruption in this sense was a feature of all family member narratives at different times. Biographical disruption was first predicted either by healthcare professionals in their discourse of change or a consequence of head injury of which family members were already aware. Biographical disruption was then challenged through features of biographical reinforcement, revision and reconstruction. Then, later, and only for some family members, biographical disruption was explicit in the account through direct references to the injured person being different from who they were pre-injury. However even in narratives that confirmed biographical disruption these sat within the context of aspects that had stayed the same (biographical continuity), aspects that were exaggerations of previous traits (biographical reinforcement) and those that had been redefined (biographical revision).

Where biographical disruption was present this feature of the narrative represented loss. In this context the pre-injury person was perceived as being lost and was replaced with someone different. Once again drawing on the chronic illness literature Charmaz (1983; 1999) identified a similar process when those with chronic disease felt their former self had been replaced with a new self. Charmaz (1983; 1999) used the term 'loss of self' to describe this feature and this aligns well to the notion of biographical disruption. These ideas were drawn upon and it was

thought that 'loss of person' would adequately describe this process whereby a non-injured family member perceived a former identity to be replaced with a new one. This 'loss of person' has been explored in the TBI literature as 'ambiguous loss' (Landau & Hissett 2008; Kean 2010). Ambiguous loss involves the difficult articulation of exactly what had been lost when there is no physical loss to objectify the account. In this context ambiguous loss refers to a person who is physically present but psychologically absent (Kean 2010).

Chapter Two Section 2.4 introduced the current thinking surrounding change of the pre-injured person post-head injury. It was argued that the biological view of personality change that can be attributed solely to organic damage is being challenged (Yeates et al. 2008). Papers that consider broader constructs include the need to understand the biopsychosocial construction of personality (Yeates et al. 2008) and the role of identity and social contexts (Cloute et al. 2008). The findings of this study add a new dimension to this literature by suggesting change, from the perspective of the non-injured members, could be considered in narrative terms. Identifying features of biographical attendance, reinforcement, revision and disruption can help to understand further how family members make sense of head injury and the life changes that follow.

7.2.1.4 Summary

The preceding debate centred on how the non-injured members created narratives about the injured person. In these biographical narratives it was illustrated how family members made sense of the threat that head injury posed to who they knew the injured person to be. Findings of this study contributed a new feature to the biographical literature, that of biographical attendance, and enhances our understanding of how narratives are used to create coherency during such biographically disruptive events.

7.2.2 Recognising and validating the stories of non-injured family members in their own right.

'Although family members 'live through' the trauma of brain injury, the rehabilitation literature does not depict their experiential perceptions and reactions from their vantage point' (Klonoff et al. 2008, p110)

The quote above from Klonoff et al. (2008) crystallises the point that we have not yet recognised and respected the journey the non-injured family members make in response to head injury. It would seem that relatives are treated predominantly as witnesses to other people's journeys of illness rather than embarking on a journey of their own. This study supports the literature that states non-injured family members are part of the illness journey

(Duff 2002; 2006; Klonoff et al. 2008; Kean 2010). Understanding the substantial effect that this journey can have on the lives of the non-injured members tells us these family members have needs in their own right.

Predominantly the literature to date has taken the view that change is set in motion by the injured person. This rests on the assumption that because the family has changed since injury, these changes should always be attributed to changes that can be identified in the injured person. This can be seen in literature that examines the correlations between injured person outcomes and non-injured person outcomes. For example the most common variable to have a significant relationship to family member outcomes has been the presence of cognitive or neurobehavioural sequelae in the head injured survivor (Perlesz et al. 2000; Connolly & O'Dowd 2001; Harris et al. 2001; Ponsford et al. 2003; Wells et al. 2005; Blake 2008; Jackson et al. 2009). Of course this is part of the story, but it is not the whole story. What has been missing in the literature is how non-injured family members change through their own personal journey in response to trauma, mortality, vulnerability, loss of control and engaging in, and with, unfamiliar worlds, people and places. Family members need to be recognised as active agents in this process of change and the complexity of this process suggests change should not be reduced to a limited number of discrete variables.

7.2.2.1 Trauma

Within this study narratives of trauma were identified as a core component of family member accounts. Trauma has been considered in the TBI family literature but has been restricted to the presence of post-traumatic stress symptoms (PSS) (Kieffer-Kristensen et al. 2011; Pielmaier et al. 2011). To examine the cause of trauma Pielmaier et al. (2011) considered the relationship between PSS and injury severity. However they did not examine anything else that could contribute to developing these symptoms. Although severity of injury can be defined through a number of indices like the Glasgow Coma Scale this score does not explain what it is really like to see the aftermath of injury, the reality of blood, swelling, broken limbs, open fractures, chest drains, artificial ventilation and having to face the reality of death in the critical care unit.

This study adds to this evidence base by examining the accounts of traumatic events. In Chapter Five Section 5.3.1 it was argued that, without exception, all family members experienced some degree of fear, helplessness or horror. It was then argued later in Section 5.3.1.4 that trauma narratives represented how head injury caused a rupture in daily experience. How family members then came to interpret and make sense of these events

ultimately underpinned many of their subsequent coping mechanisms and ability to adjust post-injury.

Harvey (2002) suggests a central concept of trauma is that described by Horowitz (1976) as *intrusive imagery*. After the events are over, memories continue to be present in everyday life through encountering stimuli that remind people of their experience. Examples of these intrusive images were noted in many of the narrative threads in this study. Intrusive images included memories of the accident site, the injuries sustained and scans that showed extensive brain damage. However, there was no indication that healthcare professionals had ever helped family members come to terms with what they had seen. Therefore family members in this study were attempting to make sense of these alone.

These findings are not dissimilar to the existing literature on patient experiences of the general intensive care setting. This environment is considered strange and hostile: Meriläinen et al. (2010) and Endacott (2011) suggest that patients are rarely left unaffected by their stay. Therefore much of the current literature relating to the development of post-traumatic symptoms refers to the impact of the ITU environment on the patient (Davydow et al. 2008; Kiekkas et al. 2010). However, as families also occupy this environment, sometimes for long periods, the effect of this environment on them has also been considered and the presence of post-traumatic stress symptoms has also been identified (Azoulay et al. 2005; Anderson et al. 2008). Where studies have considered the family, significant psychological problems have been recognised.

It may be that healthcare practitioners are desensitised to the environments they work in and their ability to identify trauma in others is limited. This may account for why very few units employ any interventions to help patients or families with the aftermath (Jones & Griffiths 2007). However, Jones and Griffiths (2007) suggest healthcare practitioners have a responsibility to help those people affected by their engagement in this unfamiliar environment.

Harvey (2002) explains that trauma is also a fundamental consequence of dealing with loss. The narrative findings in Chapter Five explored subjective forms of loss that were present in both recovery narratives (Section 5.3.2) and narratives of suffering (Section 5.3.4). Therefore if such losses are associated with causing trauma these findings further serve to illustrate the presence of trauma in the accounts of the non-injured members and that trauma can extend far beyond the intensive care setting.

7.2.2.2 Loss

Harvey (2002) defines loss as:

‘the loss of something in a person’s life in which the person was emotionally invested. The loss can involve an important person or some other entity. Emotional investment, then, becomes a key factor in defining major loss.’ (Harvey 2002, p5)

Head injury is representative of one such major loss. Losses in the narrative data were often cumulative and progressive over time. In circumstances where biographical disruption (Bury 1982) was present in narratives or indeed biographical reconstruction (Williams 1984) aspects of the pre-injury person had to be assigned to the past or reconsidered in light of current sequelae. The anticipated future of a family depends on the stability of all family members’ narratives. If biographical continuity of one member is threatened or disrupted the biography of all other family members is revised in this context. In some circumstances family members may have an emotional investment in the anticipated future of another family member. As the future changes for the injured person so it does the future for the whole family. Therefore as a cherished part of someone’s character is lost following head injury this demands that the non-injured person lets go of this part of their own biography as well.

Another loss present in the narrative data was that which included a crisis of ordinary meanings in the everyday world (Harvey 2002). This crisis involves the loss of the world we have come to know and understand and has been referred to as loss of the assumptive world (Kauffman 2002):

‘the assumptive world concept refers to the assumptions or beliefs that ground, secure, or orient people, that give a sense of reality, meaning or purpose to life. The assumption may be that I am a good person, that I will grow old with my spouse, that God is just, that others may be trusted, that things are or will be a certain way, that there is a future. Or it may be that an assumption is such a familiar aspect of one’s sense of reality that its disruption is hard to conceive, the loss of confidence in its truth putting one’s very sense of identity at risk.’ (Kauffman 2002, p1)

Therefore our assumptive world is what we know, or think we know about everything in our past, present and future lives. The presence of head injury challenges this world and when the world we understand fails to meet our expectations it can present a crisis of meaning (Landsman 2002).

The above debate presents quite a one dimensional view of head injury that concentrates on the negative effects. While it is essential to understand this perspective it is incomplete without the recognising the positive effects and the search for greater meaning that trauma and loss can prompt within a person’s life (Kauffman 2002; Landsman 2002).

For some family members in this study crisis was made sense of through the opportunity to find positive meaning within the experience. It was argued in Section 5.3.3 that these broad benefits of the experience aligned well to the theory of post-traumatic growth by Tedeschi and Calhoun (1996). The narrative data confirmed the presence of the three categories associated with post-traumatic growth. Specifically these were 'changes in self-perception' where the family member felt they were a better person because of the experience; 'changes in interpersonal relationships' where family members were more emotionally connected to each other or were more sympathetic of each other; and 'a changed philosophy of life' where family members looked towards an improved future for the whole family. These changes brought a sense of purpose to a potentially devastating injury.

However, for those family members in this study who failed to align their experiences to their assumptive world and then failed to use this crisis as a means for post-traumatic growth, these failures seemed to magnify their suffering. Being unable to make sense of trauma and suffering through the opportunity for positive change was perceived to be a lost opportunity and therefore represented yet another loss in the experience that had to be faced.

However, Landsman (2002) suggests that far from being mutually exclusive many survivors of trauma identify both positive and negative changes 'apparently coexisting without being offsetting' (p25). Narrative data confirmed the presence of coexisting features whereby there was a fluctuation of constructs that in one sense helped the person develop a progressive narrative and in another sense accounted for many of the narrative's regressive features. Landsman (2002) called this the 'paradox of good outcomes' (p25) and stresses that those who go on to adjust well also experience distress and despair. Therefore it is important not to dismiss narratives that represent good outcomes or positive change for there may well be unresolved issues that warrant attention.

7.2.2.3 Validation

It was argued earlier in this section that family members are too frequently treated as witnesses to the illness journey rather than embarking on a journey of their own. In Section 5.3.3 it was illustrated how the family members in this study were pulled into a medical world, became immersed in this world and were then expected to make the transition back to their own world. Trauma and loss are transforming and people learn new meanings from experiencing these (Harvey 2002). It is now argued that these experiences need validation as journeys in their own right:

‘the crisis of trauma is pervasive, altering emotional, cognitive, and behavioural experience.’ (Landsman 2002, p14)

‘All through life, each of us takes on new identities. Yet no stimulant of identity change is more potent than that of major loss.’ (Harvey 2002, p20)

Both of the above quotes remind us that being pulled into the experience of head injury, even from the position of a non-injured family member, has the capability to change who we think we are, how we see others and how we understand the world around us. Hasselkus and Murray (2007) identified a similar finding with a group of caregivers:

‘...for the caregiver-participants, the chronic illness was not their own, but we propose that its presence, nevertheless, caused disruption in their lives and forced major changes in their daily routines and ways of viewing their selves.’ (Hasselkus & Murray 2007, p16)

The narrative data in this study supported these ideas and showed how the non-injured family members redefined their own lives within these contexts.

7.2.2.4 Summary

Experiencing the acute illness of a family member can be a fundamentally life changing event. The changes a non-injured family member may feel after head injury are not a purely passive response to head injury sequelae or responding to the injured person’s needs. These changes are set in motion by trauma, loss, suffering, and can revise the family member’s sense of self even before the injured person is on the path to recovery. The family member may take both positive and negative meaning from the events and it is important not to dismiss negative outcomes where positive outcomes appear more dominant.

7.2.3 Working with narrative structures

Stories are an important part of everyday practice for healthcare professionals. However, in this context stories can be heard but not listened to. Personally I came to this study without prior knowledge of narrative inquiry but now feel filled with opportunity for how it can help in everyday practice and facilitate future research. Narrative is not simply about chronology, a potted history, but the fluidity of reflective practices that continually compare our current position to past experiences and future ambitions. These reflections orientate us to a familiar life. When this reflective position is not so coherent, so assured, so fixed, it causes us to question the taken for granted aspects of our lives. At this point there can be deep despair or immense opportunity for change.

7.2.3.1 Temporality and broken/incomplete narratives

It has been argued that a full narrative must contain the temporal features that connect past, present and future. Those narratives which do not conform to this structure have been referred to as anti-narratives (Frank 1995). In this study such narratives were referred to as broken or incomplete narratives. These narratives lacked coherence between past, present and future and were used by family members in this study to portray distress and meaninglessness. In Chapter Five trauma narratives and narratives of suffering were likened to chaos narratives (Frank 1995) and fracturing/enduring storylines (Brown & Addington-Hall 2008) for their lack of temporal structuring and sense making capabilities. A hallmark of these narratives was the feature of 'living through' and represented experiences that felt unfinished and 'of the moment'.

In the same way that trauma narratives represented an immediate threat to the future of the whole family, over time narratives of suffering represented the continuing dislocation of the future from the present (Frank 1995). As such many of these narratives developed regressive features whereby the story moved away from attainment of a value goal (Gergen & Gergen 1983; Robinson 1990). It was suggested by Brown and Addington-Hall (2008) that these types of storyline 'may be particularly challenging and uncomfortable to hear' (p206) and because of this, professionals may not know how to work with them. However there is an opportunity for healthcare professionals to identify these broken and incomplete narratives and help people to make sense of them and, where appropriate, reconnect their present to the past and future.

7.2.3.2 Hypothetical narratives

The notion that people lie, forget, become confused and get things wrong in the stories they tell was put forward in Chapter Four Section 4.9.2. However, despite these deviations from the actual events storytellers reveal narrative truths that expose more about the storyteller and their interpretation of events than could ever be understood by establishing if the account was indeed factually correct (Riessman 1993; 2008). Extending these ideas further, interpretation of the narrative data in this study was heavily influenced by the presence of hypothetical narratives.

These hypothetical narratives were not about real events and explored the 'what if's'. Often they were as powerful and as meaningful to the overall experience as what actually transpired. The importance of hypothetical narratives was explored by Patterson (2008):

'this notion of imagined experience, and it's juxtaposition in a narrative with past and present experience, was crucial to the development of my understanding of the

relationship between narration and coping in the aftermath of trauma. My data contained past, present, future and hypothetical narratives, densely interwoven. Through my analysis of imaginary, or hypothetical, narratives of what the traumatic event might have been [...] I came to understand that these 'narrative imaginings' were as crucial an aspect of the process of narration and coping, as were the narratives of the actual past events.' (Patterson 2008, p34)

In a similar way in this current study, hypothetical narratives were interwoven into past, present and future and played an important part of my interpretation of the data. Many of these hypothetical narratives had as much, and sometimes more, presence in the family member's account than the actual events. In a study of ITU families with severe head injury Kean (2010) suggested the future was an elusive concept and aligned well to the findings of this study. Reflecting during the time that the future was unknown, family members in this study used their imagination to build a mental picture of what it could be like. Some hypothesised a good outcome and others predicted the worst. Later when the outcome was less elusive and more assured hypothetical narratives still featured through accounts of how close the injured person was to death, coma or a persistent vegetative state. To dismiss these hypothetical stories as 'not real' invalidates their importance to how family members made sense of their experience.

7.2.3.3 Regressive/progressive/stable narratives

Utilising a framework for narrative movement enabled features in the narrative sequence to be identified as regressive, progressive or stable narratives (Gergen & Gergen 1983; Robinson 1990). This framework was helpful to defend interpretations of the data and show why a narrative felt destructive and harmful. Alternatively where narratives were progressive these helped the storyteller to show movement towards a valued goal and as such were used to draw positive meaning from the experience.

However not all narrative sequences had such clearly identifiable features dictating one direction of travel. Narratives sometimes lacked clarity or had mixed features, travelled one direction in one breath, and the other in another, as family members tried to bring a sense of coherence to the account. These features reflect the early debate in Section 7.2.2 regarding the paradox of good outcome by Landsman (2002) who stated both positive and negative changes often coexist. Therefore those who ultimately develop a progressive narrative will still have elements of the account that were regressive and/or stable.

This fluctuation within the narrative data may have been exacerbated in this prospective study because there was not enough time to assimilate and make sense of the experience before the

interviews. However, arguably the study may have been more able to capture the narratives before they had been more carefully formed and repackaged through the passage of time, retelling and reflection. In addition the direction of the narratives in this study were also influenced by the hypothetical narratives, which again, may be attributable to collecting stories before the end of the story was known and made sense of. Hypothetical narratives could be in the opposite direction to the 'real' narrative sequence and this was relevant to the overall meaning taken from the experience. Therefore the model of narrative direction taken from Robinson (1990) has been progressed in line with these findings. The arrows in opposite directions in Figure 7.1 denote the fluctuation of narrative direction and the broken line indicates a hypothetical narrative moving in the opposite direction from the narrative of the actual events.

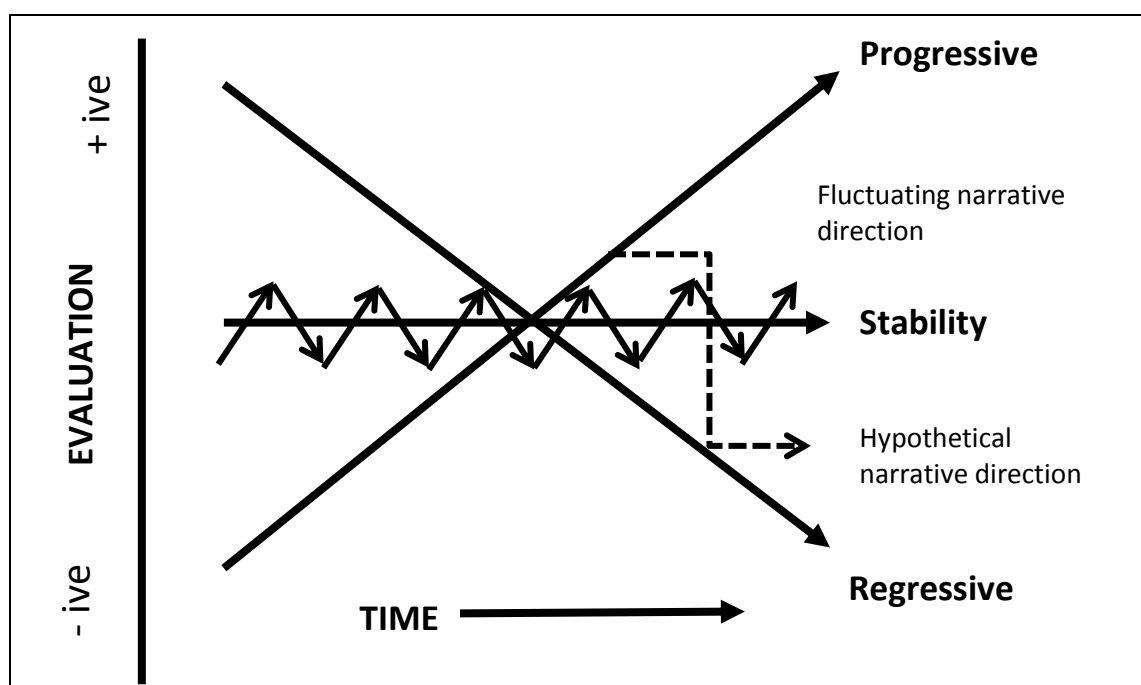


Figure 7.1 Advanced model of narrative direction adapted from Robinson (1990, p1176)

7.2.3.4 Summary

By listening to the temporal features of an account healthcare practitioners may become more aware of the family member's needs and their risk of experiencing distress over a prolonged period of time. Hypothetical narratives portray just how powerful the experience of head injury is and although many hypothetical scenarios are not realised they left a lasting impression on the family members in this study. Therefore it is important that hypothetical narratives are not overlooked or dismissed as they are an important part of how family members make sense of their experiences. Helping people to acknowledge these as valid

parts of their experience may be a useful way of helping them come to terms with their situation. Being aware of narrative direction may also help practitioners to understand how narratives are created to portray meaning. This meaning cannot always be easily articulated by the storyteller or identified by the healthcare practitioner but being aware of these narrative devices could improve our ability to actually listen to patients and families and identify where they need help.

7.2.4 Identifying misaligned narratives

In previous studies using narrative inquiry participant accounts are usually looked at in isolation from others. As such the integrity of the individual perspective is maintained. However this study considered both the individual narrative and how these were interwoven within a family context. What the data in this study suggested was that the symmetry between narratives was important. Where individual narratives in families were similar, or aligned, family members felt closer, united, and the family pulled inwards. Where individual narratives were different, or misaligned, this appeared to increase a sense of isolation and separation between family members. These misaligned narratives emphasised the division within families and illustrated how the family could be pulling apart.

Evidence of the implications of these misaligned narratives was shown in several narrative threads. First was in the recovery narratives where those who looked into the future conflicted with those who did not and those who could identify change in the injured person conflicted with those who could not. These features of the narrative isolated the family member and the subsequent effect of not sharing these narratives over time was then to exacerbate the family member's suffering.

Misaligned narratives were also evident between injured and non-injured members. It was suggested several times that the injured person would never be able to truly appreciate what the family went through and why they might feel different about themselves, their family and their lives. This misalignment made the injured person an outsider to their own experience. The impact of this on ITU patients was identified by Williams (2009):

‘Not knowing was like being an outsider in her own life, alienating her knowing self from her unknowing body. Constructing her story helped her not only to gain possession of the facts, but also to believe it actually happened to both her body and herself.’
(Williams 2009, p284)

The narrative data in this study showed how family members helped to realign the family's narratives by telling the injured person everything they could and helping them to complete

missing memories. However, sometimes there was then tension identified between family members who wanted to remember and those who wished to forget.

In addition the concept of misaligned narratives was also evident between hypothetical and actual narratives. Over time as the real deviated from the hypothetical narratives 'what actually took place' sometimes invalidated the earlier experience. For example as the injured person moved away from the possibility of serious deficits/disability post-injury the narrative of what actually took place made some family members wonder if they had misinterpreted the severity of injury or, in one case, exaggerated the severity of injury for sympathy. The impact of this misalignment was that some hypothetical narratives were afforded more status and importance than the actual events.

7.2.4.1 Summary

Considering the alignment of narratives in families may help to further understand what brings families together and what pushes them apart. Recognising the cumulative effects of misaligned narratives may help to identify those families in need of additional support.

7.2.5 Understanding the complexity of change in families post-TBI

One of the primary research questions underpinning this study (and discussed further in Section 7.5.1) concerned the changes reported by non-injured family members during the first year of TBI. Change was examined both in the evaluation of family functioning over time and through the narrative data. These insights provided different windows into the lives of non-injured family members. Changes represented in the narrative data were discussed in Sections 7.2.1-7.2.4 therefore the debate will centre on the quantitative insights and what was gained through the mixing of methods.

7.2.5.1 Evaluation of family functioning

Family functioning was assessed in this study using an outcome measure recommended in the literature (Godwin et al. 2011; Kaslow et al. 2011). The FACES-IV measure was useful in identifying broad characteristics of family functioning and, from the perspective of individual members, classifying the family on a continuum of balanced to extreme family types.

Direct comparisons of the FACES-IV data in this study to the findings of other studies are difficult to make with confidence for several reasons. Firstly the small sample size means that although there were nine participants only three families were being analysed. Secondly, although over 500 studies have claimed to used earlier versions of the FACES tool (Kouneski 2000) few have used version four. Thirdly, few studies used a research design with follow-up

data to examine how evaluations changed over time. The only example of a study using comparative data was by Curtiss et al. (2000) who asked respondents to complete questionnaires retrospectively for a stressful event that had occurred in the past and then again for their current situation following head injury. Retrospective data collected in this way are clearly limited as participants may not accurately recall family functioning during this time. In the 20 families recruited by Curtiss et al. (2000) it was concluded that balanced family types were more likely to move to a more extreme type following severe head injury. Data in this study did not support this conclusion as family functioning remained relatively stable over time with only one dataset from Suzanne Barker showing a change in family type from *balanced* to *rigidly cohesive*. In terms of assessing change in family functioning the conclusions drawn from the quantitative data would have to suggest the families in this study changed very little overall in the year post-injury.

A structured measure like FACES-IV may be a useful tool for clinicians to establish a base line measure of family functioning post-injury and to be able to understand the patterns involved in family functioning over time. However, although the FACES-IV tool may identify change of magnitude it is important to identify that it may not be sensitive enough to identify other more subtle, yet equally important, shifts in the family way of life.

7.2.5.2 Mixing methods

Discussion regarding change identified in both quantitative and narrative data present quite diametrically opposed conclusions. From one perspective families stay the same, from the other they change.

The choice of both an unstructured narrative interview and a structured questionnaire may seem unusual bedfellows in one piece of research and indeed this combination of methods has proved extremely challenging. It was stated in Section 4.7 that 'it was anticipated that the use of these two data collection techniques would together contribute to a greater understanding of the context of change and family functioning following TBI than could be achieved through one method alone'.

Arguably, this mixing of methods has been more informative than using one method alone if only to serve as a reminder that it is essential that people, and their experiences, are not reduced solely to constructs we think can be measured. Within this study it seemed that FACES-IV was not sensitive enough to detect the important experiences that were heard in the

stories family members told. The healthcare environment is dominated by the need to measure outcomes and this often conflicts with our more human need to tell stories.

7.2.5.3 Summary

It is important to understand how families change in the year post-TBI. However the findings of this study would suggest that family functioning is not the only change that should be considered. It is possible that to enable family functioning to remain constant required the family, and the individuals in it, to change accordingly and these changes are important to understand.

7.3 Revision of a metaphor

Chapter Two suggested a 'ripple effect' as a metaphor for understanding family in the context of head injury. In line with this suggestion family members recruited to this study had to find a way of living with the effects of head injury and re-stabilise the family system post-injury. This process of re-stabilising has been referred to as returning the family to equilibrium (Verhaeghe et al. 2005; Wongvatunyu & Porter 2005; 2008a; 2008b):

'When a family member suffers a TBI, this adversely affects each individual and the system (family) as a whole. A TBI constitutes a major violation of (and challenge to) family homeostasis. It demands that all individuals within the family and the entire family as a system adapt so that it may grow and develop into a subsequent equilibrium phase.' (Verhaeghe et al. 2005, p1007)

However, family systems theory reminds us that this equilibrium and desire for balance is not equivalent to a static position. Maitz (1991) explains that the family is a dynamic system that constantly evolves to meet its changing needs. The study by Wongvatunyu & Porter (2005; 2008a; 2008b) demonstrated this principle by showing how mothers in their study did not try to return their family to its pre-injury state but tried to reshape their family in response to the changes imposed by TBI.

The narrative findings of this study also emphasise that the year post-injury is a turbulent time of constant renegotiation within family systems. However, a ripple effect supports the understanding that the cause of change and disruption in families is the injured person and their needs. Whereas this study suggests the processes of change in families is more dynamic as the non-injured members cause their own ripples of change and these flow in different directions. Therefore change is not just in response to the needs of the injured person but also in response to the changes felt by the non-injured family members themselves.

In light of the study findings, we might need to think of this metaphor in a slightly different way. The metaphor used to replace the 'ripple effect' is 'rain on water'. Figure 7.2 shows a ripple effect. This image assumes the family is stable pre-injury and as the family is displaced by head injury ripples reverberate into every member's life. Those family members caught by the ripples respond accordingly to the need to change. Figure 7.3 illustrates rain on water. This image assumes the family is a dynamic ever-changing system with ripples created by all family members. These ripples clash and converge as they move in both similar and divergent directions. The image of rain on water may therefore be a more accurate representation of the family system responding to such a life changing event.



Figure 7.2 Ripple effect



Figure 7.3 Rain on water

(images taken from Microsoft Word 2007 clip art)

Common models of family adaptation include those by Lezak (1986), Kosciulek et al. (1993), Degeneffe (2001) and Powell (2004). These models often include stages of denial and unrealistic expectations as features of the early experience, developing into anxiety, guilt and despair with a final phase of sorrow and mourning with the necessity for role reorganization within the family system (Verhaeghe et al. 2005). Although not all family members are predicted to experience each phase these models represent linear progression through the process of adjustment. In addition to which these models reflect adjustment as a process that is reactive to head injury in isolation. Whilst it is essential that we understand these reactions it is also a constraining view to think that the only process involved is in response to the injured person and their needs.

Therefore this study contributes to the current evidence base by suggesting a less linear and more dynamic process of family adaptation to head injury. Findings of this study suggest family members are active agents in the process of change and have their own influence on the nature of family functioning post-injury. Adaptation and adjustment were part of an

iterative process involving simultaneous features of change and stability in how individuals felt about themselves, the injured person and other family members.

7.4 Limitations

7.4.1 Absent voices

‘all families are unique, they each have their own distinctive stories [...] stories that express the lives of their individual members, but that are also something more than simply the sum of those individual lives.’ (Pratt & Fiese 2004, p1)

The quote above suggests that the individuality of a family is reflected in the stories its members tell. Yet despite putting all these stories together there will still be something missing in how we come to know each family. This understanding gives rise to the first limitation of this study, that of absent voices. Although a number of family members were recruited from each family there were family members, both core and extended, who were not included. As such how their stories might have contributed to answering the research question is not known.

The most obvious voices that were absent in this study included those of the injured person and the non-injured children. Decisions regarding the exclusion of children were set out in Section 4.3.6. With reference to the families recruited to this study this meant that two young children in the Barker family (Sophie and Isabel aged 14 and 11) did not take part. The youngest sibling in the Hughes family was 17 and was not included based on age. In addition within the Wilson family the injured person’s brother was not identified by the rest of the family to take part, despite meeting the inclusion criteria.

This study set out to examine the experiences of the non-injured members. However family-centred investigations would be enhanced if the whole family participated as these other members would contribute another dimension to understanding the evolution of the family system. In addition it may be that the injured person’s views complement or conflict with those of the non-injured members and it would be interesting to explore how both scenarios affect wider family functioning.

7.4.2 Unfinished journeys

Although this study was a longitudinal study over the course of one year, one year is still a short period in people’s lives. Of course this study helps us to understand the importance of the first year but it does not tell us about the relationship of this first year to the subsequent years and the continuing process of adaptation and change.

Landsman (2002) reminds us that many of the stories we hear are unfinished. Interestingly the accounts from some members of the Barker and Hughes family felt unfinished by the end of the year, as if there was more to come as the months unfolded. In contrast many of the narratives from members of the Wilson family felt tied off, as if the story of head injury was complete and the family had reached a state of stability again. However there is no way of knowing if this was truly the case or if issues manifested in the future. It is important therefore to seek to understand how the subsequent years unfolded for all the families recruited to this study.

7.4.3 The 'balanced' family

As discussed in Chapter Six Section 6.6 the cases recruited to this study were all identified by the FACES-IV tool as balanced families. Quantitative data suggested that families were functioning well within the first month post-injury and qualitative data suggested that these family members were generally close to each other before injury. It is very possible that this study was affected by a selection bias that meant only well-functioning families were approached to participate. By a 'well-functioning' family I mean a family that looked to be coping reasonably well with their situation, a family receptive to the idea of participating in research and a family that was easy to approach. This meant that families that were struggling with their situation or indeed, struggling with each other would not have been asked about participating. In addition the criteria for recruitment meant that families already dealing with the presence of a prior head injury, psychiatric history, dementia, alcohol or substance abuse were excluded. Arguably therefore families with more dysfunctional characteristics of family functioning were not able to take part.

In addition Chapter Two presented a typical picture of head injury that was of a young male engaged in a high risk activity during circumstances that were avoidable and often complicated by the presence of alcohol. Interestingly none of the patients involved in this study fitted this typical picture in full. Only one was male who was aged 54 and the other two were young females. However there were other features of injury that did align with common demographics and those included the circumstances of injury for example falling from a high height, as in the Barker family, being the victim of a road traffic collision as a pedestrian, as in the Hughes family or driving without due care and attention, as in the Wilson family. All these injuries were sustained under preventable circumstances, whereby two were terrible accidents and in the Hughes family there was clearly someone responsible for the injury.

7.4.4 The recovered patient

In terms of injury severity only those with moderate or severe injuries, as defined by Glasgow Coma Scores on admission of 3-12, were identified as potential participants. This selection was left to the discretion of the nurse specialist for neuro-trauma and as such data on injury severity were not collected as part of this study. However all family members spoke about the injured person's medical condition that included periods of agitation/memory loss in the initial post-waking period that would be considered post-traumatic amnesia (PTA) (Powell 2004). Given these circumstances all patients in this study would be classified as having severe injuries corresponding to PTA of more than 24 hours (Powell 2004) and is considered most predictive of functional outcome (Sherer et al. 2008).

It is difficult to make definitive comments on patient recovery because these data were not collected in this study. Information about the patients' circumstances was gathered through the family members in interviews and also meeting with the injured member to obtain their consent. Through these interactions it became understood that all injured persons had regained mental capacity in the year post-injury. An outcome measure frequently used to assess recovery following head injury is the Glasgow Outcome Score (Jennett & Bond 1975). This score classifies outcome on a scale from dead to good recovery (resuming most activities with some minor residual deficits) (Jennett & Bond 1975). Following meetings with the injured person and discussion with their family member it is reasonable to assume that all injured persons would be classified as having achieved a 'good recovery'.

In terms of injury and outcome the patients recruited to this study were quite similar. All injured persons sustained severe injuries, all shared comparable clinical journeys through acute care and all appeared to achieve a broadly similar level of outcome as defined by the Glasgow Outcome Score. Therefore, this is not illustrative of all TBI patients many of whom may have been left with more severe physical, cognitive and or behavioural deficits post-injury. However this was a small selective sample to meet the needs of an in-depth case study investigation. Although it would not have been possible to represent the whole TBI population a larger sample may have provided greater variation. Despite the assumption of a 'good recovery', this study has shown the importance of listening to people's stories and understanding their journeys irrespective of the injured person's outcome.

7.4.5 The story re-told

There is never one story, nor one interpretation of a story, each is moulded and shaped in and through interaction and in this respect are always co-authored (Mishler 1995). In Chapter Four

Section 4.9.4 the potential effect that I may have had on the story re-told was discussed. It must be assumed that disclosure of personal and professional motivations for the research had an impact on the account and it is possible that the medical narrative was emphasised because I am a nurse. Bruner (1990) stated that stories always have a 'narratorial voice' and that events and experiences are always witnessed 'through a particular set of personal prisms' (p54). As such, the account shared by a participant will inevitably reflect an individual's own unique perspective (Carter 2008). Therefore it is also reasonable to assume that family members were also influenced by my gender, age, presentation, personality, behaviour and conduct during the research. Few of which were in my control and yet all were in part responsible for the narratives developing in a particular way. The story re-told was also influenced through my personal interpretation of the accounts and how I chose to re-story the data.

7.4.6 Summary

This research was a detailed in-depth case study that sought to understand the individual families that were recruited. Limitations included absent voices, unfinished journeys, the 'balanced' family, the recovered patient and stories re-told. Both the study design and the limitations discussed restrict the transferability of the findings to those in similar situations. Despite this there are implications for practice and research that move beyond the confines of this small study. These are explored in Section 7.6.

7.5 Response to the research questions

7.5.1 What are the changes reported by non-injured family members during the first year of a family member's traumatic brain injury

Within this study the understanding generated of the changes reported by non-injured family members in the first year of a family member's head injury depended solely on the tools used to identify these changes. If change can be evaluated through examining specific variables such as family functioning utilising a structured measure such as FACES-IV that objectifies aspects of family life like cohesion, adaptability, satisfaction and communication may be very useful. The measurement of certain features at different points in time enables a researcher to show if and when change in these specific variables has occurred. However data in this study suggested that although there were some subtle changes to note in the variables associated with family functioning these were not of a magnitude to suggest family functioning had been adversely affected in the first year post-injury. Therefore, it may be reasonable to suggest that either FACES-IV was not sensitive enough to show how the family was changing,

or that the variables associated with family functioning in the FACES-IV model do not adequately represent this dynamic process.

In contrast, if change is a more constant part of the life cycle that underpins the continual reshaping of our narrative sense of self, then change was a persistent feature of the stories people told. From a narrative perspective change occurred through making sense of new experiences, new knowledge, and the generation of new meaning through trauma and suffering. These narrative features cannot be measured by an outcome measure such as FACES-IV. They must be re-told for those outside the experience to hear and be brought into the storyteller's world. As has been shown through this study change measured by FACES-IV may be minimal but narrative change may be substantial. As such change should be seen as a constant throughout the first year following TBI as family members renegotiate, reconstruct and redefine all their lives.

7.5.2 Within one family what are the effects of traumatic brain injury up to one year following injury?

Within one family the effects of TBI in the short term are extensive. A family pulls together in the immediate phase where the life of a family member hangs in the balance. Life outside head injury is put on hold as much as possible and family members concentrate their efforts on the injured person's journey to recovery. Families are an integral part of the head injury journey and live through the unknown which is acutely distressing. Although immersed in the patient's treatment and care once the person starts to recover they are often removed from this journey. Changes in care environment, restricted access and reduced contribution to care decisions exacerbate this removal. Although the injured person owns the experience of head injury the non-injured family members own the narrative. However healthcare professionals do not appear to be truly appreciative of just how embedded people become in this experience and the disruption it causes when their active role is no longer required.

Clearly there comes a time when family members must take up their own lives again and in this period the family that pulled together starts to move apart again. However in this natural transition what was left within the three families was very different. Through their shared narratives, the Wilson family was left with a sustained bond between the non-injured members. Although the injured person did not share that narrative, efforts were made by all to give the injured person an active voice in their story and pull her into the experiences of the rest of family. The non-injured members in the Barker family also displayed how the shared experience had brought them closer. However, in contrast to the Wilson family the injured

person was increasingly separate through narrative misalignment with his spouse and daughters, and his wife's perception of biographical disruption. The Hughes family were all trying to adjust to their changed lives and were making efforts together to help Abigail reconnect her future to her past ambitions.

7.6 Implications

The aim of this study was never to try and generalise the findings to a larger population. Indeed it would be wrong to do so on the basis of a small study with a very specific group of families affected by head injury. Yet despite this there are lessons to be learnt that may help to inform similar situations and these are discussed below.

Healthcare practitioners need to rethink their assumptions that family members will not recognise the injured person as the same post-injury and consider how useful this prediction is during the acute phase of recovery. Although family members in this study expressed the desire not to be given false hope they were also clear about the importance of retaining some hope for their situation. In situations where predictions were not seen as reliable family members became wary of believing anything else from these sources.

Although the experience of head injury will always remain with the injured person the narrative also belongs to the non-injured members who occupy the story especially in the early phases of recovery. Healthcare practitioners need to understand why non-injured members become so embedded within the experience and have such an active presence in the narrative. These narratives need to be both valued and validated to help family members understand that they too are changing as a result of their experiences.

Healthcare practitioners are well placed to work with narratives. However, it is possible that either stories of this type are not elicited in clinical interactions or when they are stories are not listened to for narrative structures. Understanding how narrative structures are used by storytellers to convey meaning may help practitioners to actively listen to families and work with them in a more therapeutic way. Practitioners may then be able to identify where family members need help to come to terms with what they have witnessed and how they continue to deal with their experiences in the year post-head injury. Listening to incomplete or broken narratives is important in healthcare because it suggests narrative understanding has not yet been reached. There is then an opportunity to help families reconnect their present with their past and their future.

There is a need to understand the impact that misaligned narratives have on everyday life for the whole family. Understanding how shared narratives bring people closer and misaligned narratives cause division, separation and isolation could help those in rehabilitation to work with the stories of all family members. Families can then be supported to help realign these narratives so that the family feels more together and moving in the same direction.

Developing an understanding of how families change in the year post-TBI should not be restricted to what can be identified through the use of structured measures. It is very possible that while structured measures such as FACES-IV suggest that family functioning stays relatively stable the family is embarking on a series of changes to enable this to occur. The significance of these less obvious changes needs to be acknowledged.

7.7 Future directions

In direct response to the limitations of this study identified in Section 7.4 there are a number of areas that future research may wish to examine. Although this research contributed to an emerging field of TBI family literature there are still more questions to be answered to more fully understand what is meant by a whole family approach and how it can be achieved in healthcare settings. Therefore more research needs to be inclusive of injured and non-injured family members and those where there are children. The use of group interviews alongside individual interviews or as a single data collection method could possibly help to capture a more whole family experience. Future research may also like to consider how the findings of this study are reflected in families where there are more complex medical/social histories and where the injured person has had a less favourable outcome.

The findings of this research have also given rise to a number of areas that warrant investigation to facilitate in the development of sound evidence-based interventions. These include how to help family members understand their own narratives and, where these narratives are misaligned in families, how to facilitate their realignment. In addition studies need to examine what mechanisms are effective in resolving trauma and suffering following TBI.

7.8 Contribution to knowledge

In this final section of the thesis the key contributions this research has made to the existing knowledge and evidence base will be summarised. Specifically it considers contributions to: research in traumatic brain injury; research methodologies, in particular narrative research; the wider field of research with families; and key messages for practice.

7.8.1 Research in traumatic brain injury

The evidence base regarding TBI has traditionally presented a one dimensional view of post-injury consequences for the family by concentrating on the presence of stress, depression and anxiety in family members. By contrast this study enabled consideration of the multiple reactions possible post-injury and the complexity of family life by examining both positive and negative features of the experience. Research in TBI is predominantly drawn from retrospective and cross-sectional studies using mixed groups of participants that vary in time since injury from a few months to several years. In addition family based investigations frequently recruit single family members and extrapolate their findings to the wider family. Where studies do recruit multiple members of the same family they rarely consider how data from the same family compare to each other. This research has therefore contributed to the emerging field of family based studies within TBI through its use of a prospective longitudinal approach and the in-depth analysis of family context.

7.8.2 Research methodology and narrative approaches

This work has developed methods and ideas within narrative research by extending understanding of hypothetical narratives and introducing the concept of misaligned narratives (see Sections 7.2.3.4 and 7.2.4). The relevance of hypothetical narratives is not frequently discussed within the narrative literature. Their importance in this research may be attributable in part to the prospective design where the future was unknown. Future researchers using such an approach need to be attuned to how powerful and meaningful these can be to how people make sense of the events they experience. Therefore it is important not to dismiss them simply because they represented events that did not actually transpire. Narrative methods frequently focus on individual accounts encouraging the co-existence of multiple realities. Examining the contribution of individual accounts to the wider family system may explain why misaligned narratives were an important part of the findings. Misaligned narratives represented distance and division within families and their presence in family members' narratives created an isolating effect.

The qualitative data in this research was at times difficult to work with because of the acute trauma and sense of loss that permeated through the analysis. However when findings were presented as case studies their significance and power was reduced through detailed retelling and description. When the findings prioritised features of narrative theory instead this helped create a research product that was vivid, interesting, and evocative as well as credible. These features are essential in qualitative research to enhance their communicative power.

As discussed in Section 7.2.5.2 mixing methods is often advocated as a means of enhancing research, especially within case study designs. As a novice researcher using both approaches enhanced my understanding of research methods. However, the addition of a structured questionnaire contributed less to answering the research questions than might have been expected. Therefore although it may be tempting to combine qualitative and quantitative approaches, what can be realistically achieved through their use should be carefully thought through, and it should not be assumed that qualitative methods alone cannot produce powerful, compelling and robust findings.

7.8.3 Family research

Although family functioning has emerged as a key variable post-TBI, limiting investigations to variables such as cohesion and flexibility, as with the FACES tool, does not reflect the complexity and individuality of people's lives, their experiences and their unique family context. In addition, labels such as 'balanced' and 'healthy' may serve a purpose for a structured measure but have little resonance with the reality of family life.

When there is change in a family system family members respond by adapting their roles accordingly. As explored in Section 7.3 this model of change is supported by the metaphor of TBI causing a ripple effect whereby change in one member necessitates change in others. However researchers should also give consideration to other changes occurring within the family, changes which are not always directly attributable to the injured person. Where family members are active agents in the process of change they themselves influence the way the family functions. Therefore the metaphor of rain on water facilitates this view of family as a dynamic and changing system in its own right.

7.8.4 Key messages for practice

The implications of this study for clinical practice were explored in detail in section 7.6.

However they are summarised here to reiterate their importance:

- Family members are deeply affected by their experiences of head injury and these experiences need to be validated and family members supported in their own right.
- Predicting significant change post-TBI is not always helpful in the acute care setting. At this time family members are coming to terms the severity of injury and sustaining a vision of the pre-injury person helps them to create a positive representation of the future where they have not lost the person they knew.
- For at least one year after injury family members vacillate between aspects of the brain injured person that have stayed the same, been enhanced or subdued, and

sometimes changed. Working with these co-existing perceptions may be a more useful way of engaging with families post-injury.

- Recognising that, in a narrative sense, different family members are misaligned in their understanding or interpretation of events can provide an opportunity for healthcare practitioners. The term 'misaligned' is less restrictive than 'conflicted' and suggests the possibility of future realignment and the opportunity for families to be supported to come together once again.

In summary this study provides an opportunity to significantly shift the focus of future research and practice by raising the profile of narratives of health and illness to the level of biomedical and clinical discourse. In doing so, care provision for the support needs of the whole family may be more effective.

7.9 Concluding Remarks

This study contributes to a growing field of family-based studies that aim to examine the family system more closely. This study set out to understand family in the context of TBI from the perspective of non-injured members and supports the understanding that all family members can be affected by head injury. Chapter Seven defended the five core understandings reached in this investigation. Specifically these were: using narratives to understand the processes involved in the judgement of pre- and post-injury change; recognising and validating the stories of non-injured family members in their own right; working with narrative structures; identifying misaligned narratives and understanding the complexity of change in families post-TBI.

Original contributions included the identification of biographical attendance, understanding the implications of misaligned narratives and refining a common metaphor to further understand the dynamic processes involved when families are affected by TBI. It was also argued that limiting our view to that which can be measured in a structured way by instruments such as FACES-IV is restrictive and misses the opportunity to see in greater depth what it is that is shifting in people's lives and how this shapes their understanding of the world around them.

Traumatic brain injury remains a potentially devastating condition that can cause untold long-term consequences for the injured person and their families. Within this context these are brain injured families where the individual experience cannot be considered in isolation from the family. Working with families to validate their experience, resolve their trauma and

prevent suffering may go some way to help return the family system to a state of equilibrium and support them through this difficult period in their lives. In turn this may enable family members to positively adjust to life in the wake of head injury.

8 Appendices

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Appendix 1: Example Medline Search

1.	AB "head Injury" OR "head Injuries"	12496
2.	AB "Brain Injury" OR "Brain Injuries"	22631
3.	AB "Traumatic Brain Injury" OR "Traumatic Brain Injuries" OR TBI	14080
4.	AB "Cranio-cerebral trauma"	585
5.	(MM "Head Injuries, Closed") OR (MM "Head Injuries, Penetrating") OR (MM "Cranio-cerebral Trauma")	14619
6.	(MM "Brain Injuries")	29016
7.	Searches 1-6 Combine with OR	61143
8.	AB Family OR Families	473158
9.	AB Parent OR Parents	134540
10.	AB Spous*	10112
11.	AB Sibling OR Siblings	28492
12.	AB Mother OR Mothers	102238
13.	AB Father OR Fathers	19598
14.	AB Carer OR Caregiver	10929
15.	(MM "Family") OR (MM "Single-Parent Family") OR (MM "Family Relations") OR (MM "Nuclear Family") OR (MM "Adult Children") OR (MM "Family Characteristics") OR (MM "Parents") OR (MM "Siblings") OR (MM "Spouses")	52576
16.	(MM "Caregivers")	10778
17.	Searches 8-16 Combine with OR	710755
18.	Search 7 AND search 17	2659
19.	Limit English, 2001-2011,	1433
20.	NOT pediatric OR paediatric OR "shaken baby"	1214
	Title and abstracts reviewed for relevance	1214
	Full text obtained and reviewed	152

Appendix 2: Research Matrices of Selected Studies

Table 1: Primary Carer

<i>Study</i>	<i>Country</i>	<i>Question/Aim</i>	<i>Design</i>	<i>Data collection</i>	<i>Sample</i>	<i>Key findings</i>
Anderson et al. (2009)	AUS	Do the same neurobehavioural impairments act as stressors on both parents and spouses?	Quantitative survey	Structured interview: Neurobehavioral Problem Checklist; Family Assessment Device; Brief Symptom Inventory.	64 spouses and 58 parents caring for person with severe TBI (mean time since injury 41 months range 4-183).	Family functioning influences psychological distress. Social impairments led to more distress in spouses, thinking or cognitive impairments led to more distress in parents (despite more impairment being reported by spouses).
Blake (2008)	UK	Caregiver stress in traumatic brain injury.	Narrative literature review	CINAHL, Medline and PsychInfo; 1974-2007 Empirical studies and review articles.	No number of papers identified.	The fact that caregiving for persons with TBI can be a stressful role is undisputed. Physical deficits less likely to cause strain than cognitive and behaviour problems.
Chronister et al. (2010)	USA	To determine the degree to which stress-coping variables mediate or moderate quality of life and caregiving appraisal among caregivers of individuals with TBI.	Quantitative cross-sectional self-report survey	Modified Caregiving Appraisal Scale; Patient Competency Rating Scale – Relative Version; COPE; Family Needs Questionnaire; WHO-Quality of Life – Brief.	108 carers of adults with TBI at least 12 months post-injury (mean years since injury 8.62).	All variables, except emotion focused coping/health needs, avoidant coping, were related to QoL. Strongest associations were emotional support, tangible support and perceived burden ($p < 0.001$). Social support and family needs were important to QoL and stress appraisal.
Connolly and O'Dowd (2001)	IRE	Examine the association between disability stressors following a head injury and caregiver strain and stress.	Quantitative cross-sectional self-report survey	General Health and History Questionnaire; Caregiver Strain Index; Perceived Stress Scale.	N=70 caregivers (aged 22-76) of adult TBI at least one year post-injury (mixed severity mean time since injury 5.7 years).	Behavioural disabilities showed the strongest association with the Perceived Stress Scale ($p < 0.001$). Motor and cognitive disabilities showed the highest associations with the Caregiver Strain Index ($r = 0.60$ in both categories, $p < 0.001$).
Davis et al. (2009)	USA	To investigate the relation of pre-injury medical and psychiatric histories to perceived burden and emotional distress in caregivers of persons with TBI.	Quantitative follow-up survey	Structured interview 2 weeks and 1 year post admission: Brief symptom inventory; Perceived burden subscale of Modified Caregiver Appraisal Scale; Escape-avoidance/positive reappraisal subscales of Ways of Coping Questionnaire;	N=114 caregivers (aged 20-79) of persons admitted with TBI (mixed severity) to inpatient rehabilitation.	Those with significant medical illness and those treated for psychiatric illness both reported higher levels of distress ($p = 0.01$, $p = 0.05$); poorer functional status of person with TBI associated with greater burden (0.0001).

Ergh et al. (2002)	USA	To examine characteristics of persons with brain injury and their caregivers associated with caregiver distress and family dysfunction.	Quantitative cross-sectional survey	Multidimensional scale of perceived social support. Structured interview: GCS; Patient Competency Rating Scale; CAGE; Neuropsychology Behaviour and Affect Profile-Significant other form; Social Provision Scale; Brief Symptom Inventory; Family Assessment Device	N=120 60 pairs, one TBI individual (4 months-9 years moderate-severe injury) / one primary carer.	Social support did not moderate family dysfunction but did moderate psychological distress. Neurobehavioral disturbance predicted caregiver distress. Social support grouped into low, moderate high. The low social-support group showed significantly poorer adjustment than did the moderate and high social-support groups ($p<.001$). 60-68% of the sample had clinically significant levels of family dysfunction.
Ergh et al. (2003)	USA	To examine the extent to which caregiver social support moderates the influence of patient characteristics.	Quantitative cross-sectional survey	Structured interview: GCS; Patient Competency Rating Scale; Neuropsychology Behaviour and Affect Profile-Significant other form; Social Provision Scale; Satisfaction with Living Scale	N=120 60 pairs, one TBI individual (4 months-9 years moderate-severe injury) / one primary carer.	Social support grouped into low, moderate high. Low social-support had significantly poorer life satisfaction than moderate and high social-support groups (all $p<0.01$). Those with low support were more dissatisfied with their lives; 12.0% of those with moderate support, were slightly dissatisfied and none were very dissatisfied; high support, 21% slightly dissatisfied, 5.3% very dissatisfied.
Friedemann-Sanchez et al. (2008)	USA	To synthesize what is known about the information needs of family caregivers of patients with TBI.	Narrative literature review	Academic Search Premier, MEDLINE, and PsycINFO	19 papers (4 literature reviews, 2 educational programmes, 14 primary research; 6 quantitative, 7 qualitative).	Most studies address overall needs including rating scales for important and met needs. Requirement for clear, timely, accurate, honest and complete information. Information giving post discharge may be most useful.
Gan et al. (2010)	CAN	To broaden the understanding of ABI caregiver support needs.	Qualitative constant comparison analysis strategy	6 focus groups (two hours) and 12 key informant interviews	39 family carers of adults with ABI at least 12 months prior (mean 5.3 years) 12 programme representatives 4 researchers.	Focus group themes: Coping (feeling overwhelmed; Increasing separation from friends, family society), barriers (fatigue, stress, time), Support needed (educating the system, more support for ABI person, counselling respite) Support that worked, Ideal world (peer support network, accessible, responsive).
Harris et al. (2001)	NZ	To determine which variables mediate, and which variables moderate, the relationship of stressors resulting from TBI,	Quantitative cross-sectional self-report survey	Social Behaviour Assessment Schedule; Zung Self-rating Depression Scale; Self-completion in the presence of	58 carers of persons who had sustained a severe TBI. Sustained 6 months, 1 year, 2	23% of carers had clinically significant levels of depression. 84% were above the 'normal' score indicating higher rates of depression than the general population. Behavioural problems

		to the emotional adjustment of caregivers.		a counsellor.	years, or 3 years prior to study.	($p=0.003$), social role problems ($p<0.001$), and adverse effects on the family ($p<0.001$) all had significant correlation with depression scores.
Hart et al. (2007)	USA	To examine racial differences in patterns of caregiving in families affected by TBI.	Quantitative prospective, observational study; 1,2, or 5 years post-TBI	Structured interview: Caregivers: Brief Symptoms Inventory and Satisfaction with Life Scale. TBI patient: Disability Rating Scale; GOS-E; Functional Independence Measure.	N=256 (195 white, 61 African American pairs). Identified at follow-up 1, 2 or 5 years post injury.	Same patterns of parental care giving found between groups however less spouses and more 'other relatives' involved in care in the African American group. More African Americans were involved in intensive caregiving ($p<0.001$) however the African American group had more disability and less functional independence than the white group.
Jackson et al. (2009)	UK	To examine experiences of caring for adults with ABI and compare these with carers of adults with dementia.	Quantitative cross-sectional self-report survey	Barthel Index; Dependency Scale /Care Needs Assessment; Katz Index of Activities of Daily Living; Memory and Behaviour Problems Checklist; Caregiver Activity Survey; Carer Burden Interview; WHO Quality of Life-Brief; General Health Questionnaire-28.	222 carers of adults with ABI (mixed sample, median time since injury 5.6 years) 132 carers of those with dementia.	Similar frequency of behavioural problems. Negative carer reactions to problems were greater in the ABI group. ABI carers quality-of-life ratings were worse ($p<0.001$) overall and in all domains. Burden increased as the time spent caring per 'typical' day increased in both ABI ($p<0.001$) and dementia ($p<0.001$) groups. Behavioural problems were the strongest predictors of poor well-being in both groups.
Kreutzer et al. (2009)	USA	To describe frequency and magnitude of care-givers' emotional distress and life satisfaction.	Prospective collaborative cohort study	Structured telephone interview 1, 2 or 5 years post injury: Brief Symptom Inventory-18; Satisfaction with Life Scale; Functional independence measure; Disability Rating scale.	273 caregivers of adults with TBI (aged 16-88 time since injury 1-5 years).	17.6%-23.8% (subscales of BSI) exceeding scores for clinically significant emotional distress; 45.5-53.2% of these had received treatment. Satisfaction with life sample mean similar to normative data. 65.9% had no scores exceeding cut offs. No differences between caregiver roles. Vocational status associated with caregiver wellbeing.
Lefebvre et al. (2008a)	CAN	To examine the determinants of long-term social integration as well as the impact of TBI on family caregivers.	Qualitative, thematic content analysis	Semi-structured interviews (average 90 minutes)	22 TBI patients (aged 31-71 moderate or severe injury, time since injury mean 12.8 years) 21 caregivers.	45.5% satisfied with integration (others ambivalent or dissatisfied). Determinants: safeguarding/ developing family life, support from relatives; Barriers to social integration; not going back to work, depressive episodes, problems in relationships and TBI sequelae.
Livingston et al. (2010)	USA	To determine predictors of family caregiver life	Longitudinal multicentre	Satisfaction with Life Scale 1 and 2 years post injury;	336 caregivers (44% parents, 37%	Satisfaction with life was significantly lower both one year and two years post injury than comparison to

		satisfaction at one and two years after TBI.	cohort study	Functional Independence Measure; Disability Rating Scale; Neurobehavioural Functioning Inventory.	spouses) of adults with TBI (mixed severity TBI).	normative means (both $p < 0.001$). 39% dissatisfied 59% satisfied at one year, 41% dissatisfied 58% satisfied two years post injury. SWLS correlated most significantly with injury related (length of stay, disability) and neurobehavioral/level of functioning characteristics.
Machamer et al. (2002)	USA	To determine what is related to positive and negative significant other experience following TBI.	Quantitative correlation study, structured interview	Burden Questionnaire, Centre for Epidemiologic Studies-Depression scale; Functional Status Examination (only 83 completed this measure).	180 significant others of people with moderate to severe TBI 6 months post-injury.	Majority of SOs report positive aspects of caregiving, 93% felt happy to have had the opportunity to care for the subject and 92% felt good about their ability as a caregiver at least some of the time. SOs divided into groups of caregiver burden: negative, Intermediate, positive. The highest percentage of cases with severe head injury (i.e., GCS < 8) were found in the negative burden group (35%), followed by the intermediate group (23%) and the positive group (13%).
Man (2002a)	CIN	To examine if the coping process is affected by genders, relationships and/or coping resources of families.	Mixed methodology predominantly qualitative (content analysis) with some validated tools used for demographics, health and empowerment.	General Health Questionnaire; Empowerment questionnaire; short interview with 8 open questions; long interview (question guide given).	50 caregivers (82% female, 48% wives) of adults with ABI (mixed sample, time since injury 3 months – 7 years (mean 13 months). 4 families selected for long interview.	Coping methods: acceptance, rationalization, active seeking of solutions, planning activities. Caregivers were always so immersed in the caring process that they neglected their own physical and psychological health. Successful empowerment through personal expectations, desire to master situations, strong motivation, flexibility, active planning.
Man (2002b)	CIN	To further explore the difficulties and problems families are facing in caring for people with brain injury.	Mixed methodology predominantly qualitative (content analysis) with some validated tools used for demographics, health and	General Health Questionnaire; Empowerment questionnaire; short interview with 8 open questions; long interview (question guide given)	50 caregivers (82% female, 48% wives) of adults with ABI (mixed sample, time since injury 3 months – 7 years (mean 13 months). 4 families selected for long interview.	Coping mechanisms: acceptance rationalisation, seeking solutions, planning activities. Successful empowerment through personal expectations, desire to master situations, strong motivation, flexibility, active planning. Ability to cope is dependent on family structure.

Nabors et al. (2002)	USA	To assess the predictors of caregiver burden as it relates to physical, cognitive and affective/ behavioural impairments of the person with the TBI.	empowerment. Quantitative self-report surveys and follow-up telephone interview	Head Injury Family Interview; Family Needs Questionnaire; Family Assessment Device; Non-support scale of the; Personality Assessment Inventory. 22 caregivers agreed to a phone interview conducted utilizing the qualitative portion of the HI-FI (30-45 minutes).	N=45 (24 African American/ 21 White) caregivers of patients with moderate-to-severe TBI at least one year post injury (12-52 months).	African American and White caregivers exhibited similar patterns of adjustment. Negative relationship between affective/behavioural burden and percentage of needs met ($p=0.000$); Negative relationship between household income and affective/behavioural burden ($p<0.05$); Age was a significant factor in predicting what percentage of needs were met of the caregiver ($p=0.047$); Social support was significantly related to affective/behavioural burden ($p=0.009$). Telephone interviews: Frequent depression and anxiety, social isolation, heavy burden. Coping mechanisms problem solving/talking it out, prayer, walking away/time out education and counselling.
Prigatano et al. (2005)	USA	To examine the relationship between relatives' distress level and their ratings of impaired awareness for persons with TBI.	Quantitative cross-sectional survey	Barrow Neurological Institute for Higher Cerebral Functions; Patient Competency Rating Scale (relative form); rating of distress 0–10; rating of patient awareness of deficits 0-10.	25 relatives of TBI patients (mixed severity mean time since injury 10.5 months). Comparison groups: 16 probable dementia; 15 memory problems but no dementia.	The higher the level of distress that the relatives experiences, the less aware of difficulties they judge the person with TBI to be ($p=0.06$). Correlation was similar in the dementia group ($p=0.03$).
Riley (2007)	UK	To investigate whether the beliefs carers hold about the difficult behaviours of persons with TBI contribute to their distress.	Quantitative cross-sectional self-report survey	Responses to two descriptions of negative behaviours: Controllability Beliefs Scale; Care Control Scale; Problem Behaviour Checklist; Perceived Stress Scale; Zung's Self-Rating Depression Scale; Social Support Scale.	40 carers (mixed sample) of adults with TBI sustained at least 12 months post injury.	SR-depression scale mean 49.2; Perceived stress scale mean 34.8 (both results above population means). Those who felt less able to control the behaviour were significantly more likely to report stress. Depression was greater for those who believed the behaviour was under the control of the other person and/or motivated by negative intent for motivation variable but not for irritability and mood variables.
Rivera et al. (2007)	USA	To examine characteristics of caregivers living with	Quantitative cross-sectional	Social Problem-Solving Inventory; Caregiver Burden	60 carers (57 women, 3 men) providing care	29 (48.3%) had CES-D scores that met the criteria for being at risk for depression. No significant

		traumatic brain injury who may be at risk for depression.	self-report survey	Scale: The Pennebaker Inventory for Limbic Languidness (caregiver health): Centre for Epidemiologic Studies – Depression scale	for those with TBI for at least 6 months (range 36-298 months).	demographic differences between the at-risk and low risk groups. At risk had significantly higher negative problem-solving scores.
Rotondi et al. (2007)	USA	To determine the expressed needs of persons with TBI and their primary family caregivers.	Qualitative content analysis	Semi-structured telephone Interviews (4 phases: acute Care; in-patient rehabilitation; return home; community life.	80 adults with TBI and 85 family caregivers / support persons. No restriction for time post-TBI.	Theme reported by both groups in all phases was understanding injuries, treatments and consequences. Family emotional and mental health only identified in support person data. Insufficient education and preparation for the future.
Sander et al. (2007)	USA	To compare emotional distress, appraisals of burden, and use of coping strategies between White and Black/Hispanic caregivers of persons with TBI.	Quantitative follow-up study structured interview and self-report questionnaires.	Brief Symptoms Inventory; Ways of Coping Questionnaire; Modified Caregiver Appraisal Scale.	195 caregivers of TBI (mixed severity) patients 1-2 years post-injury (mean 13 months).	Black and Hispanic caregivers report lower income, lower education, and are more likely to be caring for an extended family member. Black and Hispanic caregivers use more emotion focused coping strategies distancing and accepting responsibility. However, neither race nor income predicted depression or anxiety scores.
Stebbins and Pakenham (2001)	AUS	To investigate the relation between irrational schematic beliefs and psychological distress in caregivers of persons with TBI.	Quantitative cross-sectional self-report survey	Irrational Beliefs Inventory; Brief Symptom Inventory; income satisfaction; personality/behaviour change	116 carers of adults with TBI (mixed sample).	68% clinically significant global distress. Of the caregiving situation only income satisfaction predicted global psychological distress. Irrational beliefs were related to psychological distress. Characteristics of injury were not related to distress.
Turner et al. (2007)	AUS	To examine the lived transition experiences of individuals with ABI and their family caregivers.	Qualitative interpretive phenomenology	Semi-structured (6 questions) in-depth Interviews average 45 minutes range 22-77 minutes.	N=24 13 ABI patients (mixed sample, mild-severe, time since discharge 15.2 months range 2–53 months) and 11 caregivers.	8 Themes: hospital experience; transition process; role of family caregivers; post-discharge services; friendship networks and community involvement; meaningful activities and time management; physical and psychological wellbeing; barriers and facilitators. Those maintaining support networks were more likely to describe a positive transition. Main burden fell on the closest family member, transition often overwhelming where strain could lead to crisis including relationship breakdown and other family disputes.
Vangel et al. (2011)	USA	To examine the predictive value of caregiver/family	Quantitative cross-sectional	Brief Symptom Inventory-18, Satisfaction With Life Scale;	109 pairs of adults with TBI and	For the person with TBI poor psychological outcome correlated with poor caregiver perceived social

		status to the well-being of persons with brain injury and to examine whether perceived social support to caregivers moderates their well-being.	self-report survey	Disability Rating Scale; Social Provision Scale, Family Assessment Device, and Disability Rating Scale.	caregiver.	support and poor familial behavioural control. Those with TBI who reported high disability were also more likely to have carers with poorer psychological symptomology. Social support of caregivers moderates outcome status for individuals with TBI.
Wells et al. (2005)	USA	To predict long-term outcome of those caring for family members who have sustained a TBI.	Quantitative cross-sectional self-report survey	Brock Adaptive Functioning Questionnaire; Caregiving Stress Questionnaire; Symptoms Checklist; Satisfaction with Life Questionnaire; The Methods of Coping Inventory.	72 pairs of adult TBI survivors (Injury sustained 1-40 years ago; mean 9.64 years, mixed severity) and primary caregiver.	Positive caregiving feelings were endorsed more than negative caregiver feelings ($p < 0.001$). Variance in depression accounted for variance in anxiety ($p < 0.001$). No significant differences between gender or kinship. Relying on family reduced internalised symptoms. self-reliance reduced externalised symptoms and increased positive care feelings

Table 2: Parents

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Fumiyo et al. (2009)	JAP	To elucidate the psychosocial adjustment process of mothers for 5 years following the injury to facilitate the social rehabilitation of both mother and son.	Qualitative modified grounded theory	Semi-structured interview 30-60 mins, 5 Questions given, one data collection point.	13 mothers (aged 30-50) caring for single sons (aged 15-30). Time since injury 11 months -3 years 5 months	5 stage adjustment process model: avoidance; closed; support seeking; withdrawal; reconstruction
Kao and Stuifbergen (2004)	USA	To describe the meaning of the experience of the relationship between young adult TBI survivors and their mothers.	Qualitative descriptive phenomenology	Semi-structured interview (2-4hrs), What is your experience of having a TBI child? One data collection point.	12 pairs of mothers (aged 44-58) and children (aged 18-25), severe TBI by MVA at least two years prior (range 2-11 years).	Sense of abnormality for the TBI survivor, period of uncertainty for the mothers; mother child relationship themes; dependency & autonomy, marital menace, maintaining harmony; Mothers often reluctant to express their feelings, in part because they perceived the necessity of being stronger than others.
Minnes et al. (2010)	CAN	To document (a) major issues of concern in a sample of older parents caring for a son or daughter with ABI in Ontario; (b) the relative stressfulness of these issues; and (c) service needs and	Quantitative and qualitative data collected cross-sectional	Checklist of Support and Service Needs and Family Stress and Coping Interview.	47 parents (aged 50-81) 42 female 5 male. Primary caregivers of adults with ABI (aged 25-59; time since injury 2-51 years.	Three issues identified on the FSCI as being particularly stressful. Diagnosis of brain injury (82%) 'obtaining information and understanding'; Feelings about the cause of the ABI (75%) 'responsibility, blame'; Planning for long-term accommodation (75%) 'inappropriate solutions'. Most needed and used services: social and recreational activities

		service use of these caregivers.				(83%), day programs (62%), residential placement (57 %), in-home support (51 %). No significant differences in parent stress ratings for level of disability.
Wongvatunyu and Porter (2005)	USA	To describe the essence of the experience of mothers who provide regular help for young adults who had suffered TBI at least 6 months previously.	Qualitative descriptive phenomenology	3 in depth interviews over 2 months, perceptions, actions, intentions related to helping young adults of TBI.	7 Mothers (aged 46-64) with young adult children (aged 20-36) with moderate to severe TBI (range 8 months – 20 years).	5 phenomena: reconnecting my child's brain (concern over cognitive problems magnified as they realised the extent and on-going nature of limitations, mothers took on the critical task of re-training and learning); Considering my child's safety (perceiving the young adults vulnerability to various threats); Making our lives as normal as possible (making a new normalcy in the family's changing life; "reinventing our families life") dealing with our biggest problem; advocating for my child.
Wongvatunyu and Porter (2008a)	USA	To describe the changes that seven mothers of TBI survivors perceived in family life six months or more after TBI.	Qualitative descriptive phenomenology	3 in depth interviews over 2 months, Life before and after injury.	7 Mothers (aged 46-64) with young adult children (aged 20-36) with moderate to severe TBI (range 8 months – 20 years).	Getting attention from each other for different reasons now: getting along with each other since the injury: facing new financial hurdles; going our separate ways down this new path; splitting the family apart against our will.
Wongvatunyu and Porter (2008b)	USA	What is the personal-social context of the experience of mothers who help young adult survivors of moderate or severe TBI?	Qualitative descriptive Phenomenology	3 in depth interviews over 2 months, Experiences as caregivers and life before and after injury.	7 Mothers (aged 46-64) with young adult children (aged 20-36) with moderate to severe TBI (range 8 months – 20 years).	5 life world features; having a child who survived a TBI as a young adult (unprepared, no answers devastation, developing on-going commitment); Perceiving that life has really changed (6-12months); having sufficient support/feeling bereft of any help; believing that my child is still able; believing that I can help my child.

Table 3: Spouse / marital relationships

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Anderson et al. (2002)	AUS	To test a model linking neurobehavioural problems of TBI, family functioning and psychological distress in spousal caregivers.	Quantitative cross-sectional self-report survey	General Health and History Questionnaire; Family Assessment Device; Brief Symptom Inventory.	64 spouse carers of adults with severe TBI (time since injury 5-184 months mean 43 months).	Three variables had significant effects of psychological distress: Social, behaviour, communication (all $p < 0.005$) Family functioning was a mediating variable ($p < 0.02$). Mean score of FAD indicated generalised unhealthy functioning. Strongest effects a) family functioning adversely

Arango-Lasprilla et al. (2008)	USA	To determine the predictors of continuous marital stability over 2 years post-injury and examine the moderating effects of ethnicity.	Cohort study	Admission, 1 and 2 year follow up, Marital status; Demographic characteristics; Injury characteristics.	977 TBI patients from national database (primarily moderate and severe). 751 Caucasians and 226 minorities.	affected by behaviour b) those with high levels of unhealthy family functioning more likely to report higher levels of psychological distress. 15% separated / divorced. Age, injury severity, cause of injury influence marital stability. 20.35% of minorities were unstably married at two years as compared to 12.92% of Caucasians ($p=0.0060$). The odds of being unstably married are 4.03-times greater for a patient with age 36.2 years vs. a patient with age 57.3 years, 1.95-times greater for males than for females and 2.99-times greater for violent injuries than for non-violent injuries, 2.27-times greater for moderate GCS than for severe but not significant between other severities.
Blais and Boisvert (2007)	CAN	To identify the personal characteristics of each couple partner that favour his or her psychological adjustment and marital satisfaction.	Quantitative cross-sectional self-report survey	Interpersonal Communication Skills Inventory; Ways of Coping Questionnaire; Hospital Anxiety and Depression Scale; General Well-Being Schedule; The Marital Adjustment Test; Kansas Marital Satisfaction Scale.	70 TBI couples, mixed severity, 1-8 years post injury mean 3.11 years). 70 control couples.	Characteristics for adjustment: positive attitude towards problems, infrequent use of avoidance coping strategies, positive perception of spousal communication skills. TBI couples had less of these characteristics than matched controls. Individuals who had a TBI use avoidance ($p<0.012$) and social support seeking coping strategies ($p < 0.005$) significantly more frequently than their control group as do caregiving spouses ($p<0.04$) TBI couples reported significantly more communication difficulties than control couples.
Bracy and Douglas (2005)	AUS	Do couples in which the husband has sustained a severe TBI differ significantly, with respect to perceptions of husbands' interpersonal communication skills?	Quantitative cross sectional self-report survey	Questionnaire completed in an interview with researcher La Trobe Communication Questionnaire.	25 TBI couples with severe injuries at least 2.5 years prior 2.6-15 years and 25 control couples.	TBI couples reported significantly more communication difficulties than control couples.
BurrIDGE et al. (2007)	UK	To examine spousal relationship satisfaction following an ABI to one partner.	Quantitative self-report survey Retrospective and current evaluations	The Relationship Questionnaire; The Cognitive Failures Questionnaire; The European Brain Injury Questionnaire; The Socio-Emotional Questionnaire.	20 ABI couples at least 1 year post injury mean 3.3 years, mixed severity). Two control groups: 20 pain couples/ 20 healthy couples	Partners and patients in the ABI group were less satisfied than healthy volunteers ($p=0.006$, $p=0.002$). ABI partners indicated a greater amount of reduced relationship quality from pre to post injury ($p=0.016$)
Eriksson et al.	SWE	To identify couples' joint	Quantitative	Questionnaire developed for	55 ABI couples	Couples classified as "happy", "discordant", and

(2005)		perception of their satisfaction with life as a whole when one of the persons in the couple had ABI between one and five years earlier.	cross-sectional Self-report survey	study and from aspects of several other measures, perceived, impairments, limitations and life satisfaction.	sustained 1-5 years prior.	“not happy”. In only 16 of the 55 couples both partners were satisfied with life as a whole. Joint satisfaction correlated with function in everyday life (especially leisure time, contact with other and ability to wash their own clothes).
Gill et al. (2011)	USA	To explore the experience of intimacy from the viewpoint of persons with TBI and their intimate partners.	Qualitative grounded theory approach to analysis	Semi-structured interviews (60-90 minutes), one data collection point.	18 persons with TBI at least 6 months prior (mean time since injury 4.78 years) and their partners.	Barriers to intimacy: injury-related changes, emotional reactions, sexual difficulties, role conflict and strain, family issues, social isolation, and communication. Relationships enhanced through unconditional commitment, spending time together, communication, strong pre-injury relationship, bonding through surviving the injury together, social support, family bonds.
Hammond et al. (2011)	USA	To examine how a spouse who has experienced TBI affects the marital relationship.	Qualitative grounded theory approach to analysis	Two gender specific focus groups.	10 spouses of persons with TBI (complex mild to severe) at least 4 years prior; range 6-12 years for wives/ 4-9 years for husbands.	Meta-codes: Staying married; temporality; spatiality; trust; communication; emotional attachment; caregiver responsibilities; financial responsibilities; reactions to added responsibilities. Changes in family dynamics and the way change is perceived affects pulling together or pulling apart. Hoping for change versus embracing the present; living in the past versus living in the present; coping through time away versus coping together.
Katz et al. (2005)	ISR	To examine the relation between time since husbands' TBI, wives' coping flexibility and wives' perceived burden.	Quantitative vignette based evaluation	Structured interview; After reading four vignettes, asked to complete: Ways of Coping Questionnaire; Perceived Burden questionnaire.	40 wives of TBI patients at least one year after discharge (range 1-32 years).	The hypothesis that the perceived burden of wives of men with TBI will increase with time was not confirmed. However women with little coping flexibility perceived burden did increase with time. The hypothesis that wives with greater coping flexibility will have less perceived burden than those with less coping flexibility was also not confirmed.
Kreutzer et al. (2007)	USA	To examine rates of separation and divorce after traumatic brain injury and identify factors relating to risk of marital breakdown.	Cohort study	General Health Questionnaire; Injury severity; marital status.	120 consecutive admissions aged 19-69 married at time of injury; follow up time since injury 2.5-8 years (mixed TBI severity).	75% remained married at follow up, 17% divorced 8% separated. No significant differences found in gender, education, post injury employment status or times since injury. Age at injury predicted relationship status ($p<0.001$) (older subjects less likely to be divorced or separated). Longer length of relationship also correlated with marital status

Layman et al. (2005)	USA	To explore the partner relationships of older couples faced TBI.	Qualitative participatory action research content analysis, one data collection point	Semi-structured interviews by telephone and face-to-face, (37–78 min).	N=15 (8 persons with TBI and 7 spouses aged over 50, at least 3 years post injury mixed severity) 6 controls.	(p<0.001). Three major themes: relatedness (many individuals with TBI and their partners attributed various relationship changes to ageing and age-related issues and not to the TBI; reduced sexual intimacy post TBI) relationship persistence (staying in the relationship despite difficulties); spontaneous reference to ageing (variability of relationship experiences was shown across individuals with TBI, partners and comparison participants. The presence of mood swings was the only factor that distinguished partners that were still together and those whom had separated (p=0.002). However this significance did not extend to aggression or temper.
Wood et al. (2005)	UK	To explore which neurobehavioural legacies of serious head trauma have the greatest impact on relationships and increase the risk of relationship breakdown.	Quantitative self-report survey	12 item questionnaire developed for study through interviews and a qualitative content analysis.	48 partners of severe TBI, together and separate groups (time since injury 5.57 and 5.94 years).	

Table 4: Siblings

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Degeneffe and Lynch (2006)	USA	To what extent do adult siblings of persons with TBI experience high levels of depression? Which factors are associated with depression?	Quantitative cross-sectional postal survey	Amount of Care Provided Scale; Cognitive-Behavioural Impairment Scale; Subjective Caregiving Burden Scale; Caregiving Demands Scale; Family Deprivation Scale; Future Concerns Scale; Gain Scale; Frequency of Family Coping Behaviours; Social Provision Scale; Centre for Epidemiological Studies Depression Scale.	N=170 over 18 (aged 18-72) siblings to injured person with TBI at least 6 months prior (mean 12.18 years).	The sample had a higher level of depressive symptomatology than a general sample. Cognitive behavioural impairment was not associated with depression; The less the non-injured sibling perceived the availability of support, the more she or he reported experiencing depression (p<0.001).
Degeneffe and Burcham (2008)	USA	What types of affective and instrumental caregiving do adult siblings of persons with TBI provide? What factors	Quantitative cross-sectional postal survey	Amount of Care Provided Scale; Cognitive-Behavioural Impairment Scale.	N=233 over 18 (aged 18-72) siblings to injured person with TBI at least 6 months	Affective care exceeds instrumental support. The average per item score across the three affective support items was 1.38. an outcome significantly higher (p<.001) than the mean score of .54 for the 7

		predict affective versus instrumental caregiving?				
Degeneffe and Olney (2008)	USA	To gain a comprehensive and contextual understanding of sibling future concerns.	Qualitative constant comparative analysis	Open ended question in a postal survey "what are your concerns regarding the future for your siblings?"	prior. Mean time since injury 12.6 years, Providing regular care for sibling. N=280 over 18 (aged 18-72) siblings to injured person with TBI at least 6 months prior.	areas of instrumental support. A stronger caregiving (both affective and instrumental caregiving) relationship occurs when the injured and non-injured siblings are of different genders. 8 themes identified 5 of which had most concordance with the whole group. Recovery: post injury impairments negatively affected the ability of their injured siblings to maintain relationships with family/friends: Future caregiver: most appeared willing take on the role of carer in the future but many had concerns: Independence: many siblings voiced concerns about the ability that their siblings had and would have to hold a job: professional care: satisfaction with quality of services: relationships and family; social isolation.
Degeneffe and Lee (2010)	USA	To examine sibling perceptions on the quality of life of their brother's and sister's TBI.	Qualitative constant comparative analysis	Open ended question in a postal survey "What is your feeling regarding your sibling's quality of life?"	N=279 over 18 (aged 18-72) siblings to injured person with TBI at least 6 months prior.	More negative (n=123) than positive (n=98) appraisals of quality of life. Positive themes: receives support; positive psychological adjustment; recovery from TBI. Negative themes: role strain; Negative psychological adjustment; quality of professional care.
Degeneffe and Olney (2010)	USA	To gain insight into how the lives of adult siblings of persons with TBI are different since the injury.	Qualitative constant comparative analysis	Open ended question in a postal survey "How is your life different since your sibling had a TBI?"	N=272 over 18 (aged 18-72) siblings to injured person with TBI at least 6 months prior.	Family impacts: growing up with a sibling with TBI and impact on family closeness; Caring: including caring for and about the family member; Making sense of the experience' through personal development, grieving, existential change, psychological distress and guilt.

Table 5: Child / Adolescent

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Butera-Prinzi and Perlesz (2004)	AUS	What has the experience been like post-trauma for a small sample of children whose father has an ABI?	Qualitative phenomenology	In-depth interviews (1-1.5 hours), Secondary data; observations in a family group programme and quantitative data from the	4 children (aged 7-12) with a father with ABI from 3 families (time since injury 2-4 years).	Living with their fathers' physical and psychological changes, experiences of loss and grief; Increased violence in the family following their fathers' ABI; All children expressed a sensitive empathy for their mothers' suffering; absence of social support; fears

				Behaviour Assessment System for Children.		of family disintegration and financial hardship. Data from BASC show that children were at risk with signs of anxiety, depression, hyperactivity, feelings of inadequacy, having atypical thoughts, over-compliant and experiencing difficulties at school and in their relationships with their parents and peers. Shock and freight (feeling numb); Coping and adaptation (avoidant and emotionally) focused methods i.e. anger and denial. Cohesion between the non-injured family members has probably helped them through; religion; positive meaning making (each of the participants found some positive meaning in the tragedy); lack of information; worry and anxiety about family and parenting; changes in self.
Harris and Stuart (2006)	South Africa	How does the offspring of a parent who sustained a TBI experience the situation?	Qualitative existential-phenomenology	Unstructured interviews, 45 minutes – 2hours.	4 adolescents (aged 17-19) time since injury 18 months–7 years. All fathers sustained severe injuries.	
Kieffer-Kristensen et al. (2011)	DEN	To examine post-traumatic stress symptoms (PSS) and psychological functioning in children with a parent with ABI.	Cross-sectional questionnaire	Children's Revised Impact of Event Scale; Beck Youth Inventory; Child Behaviour Check List.	35 children (aged 7-14) of mod-severe injured parents (mean time since injury 3.7 years). Comparative group with diabetes (N=20).	46% of the children in the brain injury group met the clinical diagnostic criterion for PTSD compared to 10% in the diabetes group ($p<0.01$). Parents reported more emotional and behavioural problems than published norms.

Table 6: Family Functioning

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Boyle and Haines (2002)	AUS	To assesses the effects of severe traumatic brain injuries on family members and functioning.	Quantitative cross sectional survey	The Family Environment Scale; Profile of Mood States	25 relatives of persons with severe TBI. Comparison group N=32.	FES and PMS scores indicate elevated rates of depression and decreased ability to express feelings, decreased time and energy for social and recreational activities, and increased control in comparison to families without a brain-injured member. Despite this, findings indicated families were coping adequately.
Carnes and Quinn (2005)	USA	How do family resources, coping, and family member perceptions of the crisis impact family adaptation?	Quantitative cross-sectional self-report survey	Brief Symptom Inventory; Family adaptation, partnership, growth, affection, and resolve; Family	123 family members of 65 ABI patients (mixed severity, time since injury 16 – 411	Higher coping scores related to lower levels of psychological distress ($p<0.05$). Positive coping skills were related to increased family functioning ($p<0.01$). Social support was positively related to

				Crisis Oriented Personal Evaluation Scale; Brain Injury Behaviour Scale; Memory and Behavior Problems Checklist, Intergenerational Solidarity Scale.	days mean 57.5).	decreased psychological distress and increased family functioning.
Gan et al. (2006)	CAN	To examine the functioning of a sample of families who are living with an individual with ABI.	Quantitative cross-sectional self-report survey	Family Assessment Measure; Problem Checklist; Competency Rating Scale; Caregiver Strain Index; Neuropsychological tests.	66 individuals with ABI (mixed severity mean time since injury 5.7 years range 0.2–29.5 years) and 148 family members.	FAM scores indicated families with ABI were more distressed than a normative sample ($p < 0.0005$). Kinship scores were significantly different, mothers, spouses and siblings scores were higher than normative sample fathers and offspring's were not. Spouses were generally more distressed than parents across all domains.
Gan and Schuller (2002)	CAN	To investigate family system outcome following ABI.	Quantitative cross-sectional self-report survey	Family Assessment Measure.	43 individuals with ABI, 92 family members (time since injury 3 months-25 years, mixed severity).	Non-injured family members reported significantly more distress and poorer family functioning in all domains than those with injury. Overall FAM score were significantly different than norm ($p < 0.001$). No correlation of scores with kinship, time post injury or level of injury.
Gregório et al. (2011)	AMS	To investigate how the functioning of family members and the coping styles they use are related to the psychosocial functioning both of the family members and of the person who has sustained a brain injury.	Quantitative self-report survey	Utrecht Coping List, Family Assessment Device; Life Satisfaction Questionnaire 9; Caregiver Strain Index; Stroke-Adapted Sickness Impact Profile 30.	61 families with ABI adults (mean time post-injury 2.8 years). 76 family members (61 caregivers, patient pairs and 15 other family members).	On average primary carers were satisfied with life. Despite this 38% reported low QoL, 39% experience high level of strain. Mean FAD scores for all family members showed 39% experienced unhealthy family functioning. Passing coping style of the primary carer was associated with more family dysfunction, lower quality of life, and higher strain.
Hanks et al. (2007)	USA	To examine roles of coping style, family functioning, perceived social support and the TBI survivor's functional status with respect to both positive and negative appraisals of caregiving.	Cross-sectional survey	GCS, Disability Rating Scale, Functional Independence Measure, Social Provision Scale, Coping Inventory for Stressful Situations, Family Assessment Device, Caregiver Appraisal Scale.	60 primary caregivers of TBI individuals (mixed severity, 6 months–15 years post injury mean 4 years).	As measured by CAS Most carers were dissatisfied with at least half of the areas assessed. Subscales perceived burden and caregiving mastery 89.2% and 92.3% of the sample were dissatisfied. Functional status did not correlate strongly with other variables. Higher levels of family dysfunction correlated with more negative feelings of perceived burden, relationship satisfaction, caregiving mastery.
Inzaghi et al. (2005)	Italy	To verify whether the same uneasiness elements as those	Quantitative self-report	Barthel ADL; Disability Rating Scale; Neuropsychological	16 adults with TBI and a family member.	15/16 Family members reported the number of friendships has significantly dropped. All family

		described by the numerous previous studies also existed in an Italian sample of TBI patients.	survey	assessment.		members retained a sense of worry for the future.
Norup et al. (2010)	DEN	To investigate emotional distress and quality of life in a sample of Danish relatives of patients with severe brain injury at admission to intensive rehabilitation in the sub-acute phase.	Quantitative cross-sectional survey	Short Form 36; Symptom Checklist depression/anxiety scales; GCS, Injury severity Scale; Rancho Los Amigos score; Function Independence Measure	31 Relatives of adults with severe ABI (mean 25.41 days post injury range 8-103).	QoL subscales: role emotion, vitality, mental health all lower than Danish population norms (all $p < 0.01$) indicative of worse QoL. Depression and anxiety higher than normative group. 61% of the sample were above the suggested cut off for both anxiety and depression. Patient condition/functional ability showed no correlation with relative's QoL variables. Only patient condition measured by EFA score correlated with fewer depression symptoms ($p = 0.04$). Only patient condition measured by RLA correlated with more symptoms of anxiety ($p = 0.04$). Kinship was not significantly correlated to QoL.
Pielmaier et al. (2011)	SWZ	To assess post-traumatic stress symptoms in proxies of survivors of STBI in the short-term and investigated stress-associated factors.	Quantitative prospective cross-sectional study	Impact of Event Scale– Revised; Abbreviated Injury Scale.	69 Relatives of severe TBI 14 days post injury (range 5-23, median 11).	36 (52.2%) had clinically relevant levels of PTS symptoms (IES-R total score 33 or higher). Women were reported significant higher levels ($p < 0.05$) however more than 2/3 of the sample were women. No difference in kinship (spouse vs other relationship). Severity of injury assessed by initial GCS was related to PTS symptoms. However injury severity was not consistently associated with distress.
Ponsford et al. (2003)	USA	To examine long-term family adjustment and emotional adjustment in a sample of close relatives of individuals with TBI.	Quantitative cross-sectional survey (structured interview)	Family Assessment Device; Leeds Scales for Self-Assessment of Anxiety and Depression; Structured Outcome Questionnaire; Craig Handicap Assessment and Reporting Technique; Sickness Impact Profile; Novaco Anger Control Questionnaire.	143 TBI survivors (mixed severity) and one close relative. Recruited at follow-up clinic 2,3 or 5 years post injury (mean 3.3 years).	Mean FAD score no different to healthy control. However 74% scored unhealthy in one subscale of the FAD. Those who reported cognitive and behavioural problems were more likely to report unhealthy FAD scores. Those with anxiety and depression were also more likely to be in the unhealthy family functioning group. 23% of spouses and 31% of parents obtained scores in the clinically significant range for anxiety and 25% of spouses and 23% of parents obtained scores in the clinically significant range for depression. No significant differences between spouses and parents in terms of

Ponsford and Schönberger (2010)	USA	To investigate family functioning and relatives' emotional state 2 and 5 years following TBI.	Quantitative follow-up survey	Structured Outcome Questionnaire, Family Assessment Device, Hospital Anxiety and Depression Scale, and the Craig Handicap Assessment and Reporting Technique.	Adults with TBI and their relative (301 at 2 years, 266 at 5 years post injury)	caregiver levels of anxiety and depression. Anxiety and depression was not significantly correlated with injury severity or independence in ADLs. FAD scores did not differ significantly from a normative group. However across the subscales a significant proportion had unhealthy scores. Those with TBI and their relative showed high rates of anxiety and depression. However little difference between FAD scores, anxiety or depression at 2 and 5 years post-injury. Neurobehavioral changes had most effect on FAD scores and distress even at 5 years post-injury.
Sady et al. (2010)	USA	To determine the contribution of preinjury caregiver and family functioning to community integration outcomes 1 to 2 years after injury.	Quantitative inception cohort study Structured interview	Family Assessment Device; Brief Symptom Inventory; Perceived Social Support; Craig Handicap Assessment and Reporting Technique; Community Integration Questionnaire.	141 carers and TBI survivors (mixed severity, time since injury mean 13.38 months). Carer measures within 2 weeks of admission, survivor 1-2 years post-injury.	No difference between injury severity. Those with severe injuries had greater productivity outcomes when the carer perceived higher levels of social support than those with severe injuries and lower levels of support. In mild/moderate groups healthy family functioning was related to independence in home activities ($P=0.033$). However this relationship did not exist for severe injuries. Those in mild/moderate injury groups carer distress was also lower in those with greater social integration ($p=0.031$).
Sander et al. (2002)	USA	To investigate the relationship of family members' functioning to patients' progress in a post-acute rehabilitation programme.	Cohort study	Admission and follow-up: Family Assessment Device; Disability Rating Scale.	37 survivors of TBI and their carers (70% parents, majority had severe TBI).	49% ($n=18$) reported FAD scores indicative of unhealthy family functioning. Persons from healthy family environments showed greater improvement than unhealthy families ($p<0.05$). over 1/3 of those reporting unhealthy FAD scores showed a decline on the DRS level of functioning scale, and only 28% showed improvement.
Sander et al. (2003)	USA	To characterize the pre-injury family environment of persons with TBI as a first step toward predicting post-injury adjustment.	Quantitative inception cohort study Structured interview	Brief Symptom Inventory; Perceived Social Support; Family Assessment Device.	191 caregivers of persons with TBI (mixed severity, time since injury no longer than 3 months), recruited within 2 weeks of admission.	37% of caregivers had BSI scores that showed symptoms of emotional distress that were probable of psychiatric diagnosis. 25%-33% of caregivers reported unhealthy functioning on one or more of the FAD scales. 92% reported overall satisfaction with social support, A greater percentage of those who earned less than \$10,000 per year reported

Schönberger et al. (2010)	AUS	To examine the level of family functioning after TBI and relatives' psychological state, measured in terms of symptoms of anxiety and/or depression, as they evolved between two and five years post-injury.	Quantitative longitudinal follow-up survey	Structured Outcome Questionnaire; Family Assessment Device-GFS; Hospital Anxiety and Depression Scale.	66 relatives of persons with TBI (mixed severity).	unhealthy family functioning, in contrast those with salaries more than \$50,000 per year reported healthy family functioning ($P=0.008$). No significant change in unhealthy FAD scores, anxiety and depression from 2 - 5 years. (FAD 36%-32%; anxiety 50%-42.2%; depression 22.7%-18.2%). FAD scores did not differ in sub-groups of relatives. Average FAD similar to normative sample.
Testa et al. (2006)	USA	To identify risk factors for poor family functioning and neurobehavioural problems after TBI.	Quantitative longitudinal follow-up survey (discharge and one year)	Family Assessment Device, Neurobehavioral Functioning Index GCS; Injury Severity Scale/Abbreviated Injury Scale.	Consecutive admissions with TBI (mixed severity) N=122 at discharge (time since injury mean 52.1 days) N=73 at follow-up (mean 421.6 days) and a family member. Compared to 44 orthopaedic injury patients as discharge, 33 at follow-up.	Approximately one third of all patients' family members (TBI and OI) reported an unhealthy or distressed level on the FAD-GF. Levels of distress and dysfunction remained fairly consistent across time in all groups. Very few reported impaired family functioning and depression. FAD-GF score at discharge reliably predicted outcome. Neurobehavioural function scales for depression, memory/attention also predicted family dysfunction. Injury severity was not related to family outcome.
Winstanley et al. (2006)	AUS	To investigate pathways associated with relative distress after a family member sustained a TBI.	Quantitative longitudinal follow-up survey (median 31 days post-trauma follow-up median 16 months)	Mayo- Portland Adaptability Inventory; Disability Rating Scale; Sydney Psychosocial Reintegration Scale; Family Assessment Device; Family Needs Questionnaire; General Health Questionnaire.	134 Severe TBI adults sustained within the previous 6 months and a close relative.	Relative's self-reported distress was not due to the direct impact of the neurobehavioral impairments. The effect of neurobehavioral impairments was mediated by the degree of community participation achieved. FAD-GF score at follow-up was slightly higher than admission to rehab but did not reach significance.

Table 7: Family Needs

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Arango-Lasprilla et al. (2010)	Columbia	To determine family needs in a group of family caregivers of individuals with TBI from Colombia.	Quantitative cross-sectional survey structured interview	Family Needs Questionnaire.	29 carers of adults with TBI (at least 6 months prior, mean time since injury 33 months).	The most highly rated need of importance was the health information subscale. The Instrumental Support sub-scale had the lowest mean importance rating. Of the specific needs identified six items from the health information subscale were in the top ten most important needs. Those ranked lowest were primarily items from the emotional support and community support network sub-scales. Over 50% of unmet needs came from the emotional support sub-scale.
Kolakowsky-Hayner et al. (2001)	USA	To characterise family member needs and perceived quality of life before injury and long-term after injury.	Quantitative self-report survey	Family needs questionnaire; quality of life assessed by "in general how satisfied are you with your life now" on a 5 point Likert scale.	57 caregivers of person with TBI (mixed severity) at least 4 years prior.	Family member life satisfaction was higher pre-injury (47.3% very satisfied, 40% somewhat satisfied) than post injury (23.2% very satisfied, 35.7% somewhat satisfied). The numbers who reported being somewhat, or very, dissatisfied increased nearly six fold. Health information (51.43%) and involvement with care (47.93%) needs were often rated as met. Instrumental support (31.52%) and professional support (28.38%) needs were most often rated as not met.
Lefebvre et al. (2008b)	CAN	To describe the information needs of family caregivers, their sources of information, their strategies for gathering information, and the impact of the information on their adjustment and their relationship with health professionals.	Qualitative focus group pilot study	Focus groups 2hrs, 3 main themes discussed about information.	6 ABI family caregivers (1-5 years post injury) 8 health care professionals.	Carers: mostly needed information was on how deficits would impact daily life, way to deal with deficits and the long-term consequences. Primary complaint was lack of information and method it was conveyed, especially in acute care.
Lefebvre et al. (2005)	CAN	To investigate the experiences of individuals who had sustained a TBI, their families and the physicians and professionals involved, from the beginning	Qualitative constructivism	Semi-structured interviews (guide given) approx. 90 minutes.	N=53 8 TBI Patients with moderate-to-severe TBI, 14 family members, 22 health professionals, 9 physicians. Time since	5 themes across all groups: information, which refers to communication and sharing of information: information transmission in each stage is limited but physicians were concerned about false hopes. Uncertainty: How will he be when he comes out of hospital? Will he even know me? Relationships

		of acute care to their reintegration in daily life.			injury (mean=2.8 years).	between the actors: The experience of the families shows that relations with physicians and professionals is positive when the families are recognized for what they know.
Leith et al. (2004)	USA	To learn what participants perceive their service needs to be and where they experience service gaps in the existing system of TBI services in South Carolina.	Qualitative focus group study	Four semi-structured focus groups (no more than six participants) 10 broad questions.	10 TBI persons (mixed severity sustained in the last 5 years) and 11 family members.	The need for: early, continuous, comprehensive service delivery; information/education (too much and too little information leads to confusion); formal/informal advocacy; empowerment of persons with TBI/families; and human connectedness/social belonging (extreme isolation, emotional support identified as a major need).
Murray et al. (2006)	CAN	To explore and describe the expressed needs of family members caring for a person with an ABI.	Quantitative self-report postal survey	Family Needs Questionnaire.	66 family member carers of those with ABI (age of survivor at time of injury 4 months-76 years, time since injury 5-174 months).	Health information scale of FNQ rated as highest importance, emotional support scale had the lowest. 8/10 of the highest needs were from the health information scale and two from community support. 6/10 met needs were also from the health information scale. 6/10 most unmet needs from emotional support category.
Paterson et al. (2001)	CAN	Why do families of survivors of TBI do not always perceive that their learning needs have been met by healthcare professionals.	Qualitative interpretive description	Semi-structured interviews and focus groups.	8 survivors of moderate-severe TBI (time since injury range 10-30 months) 8 family caregivers 4 groups of healthcare professionals (5-8 in each).	7/8 TBI family member pairs could not recall receiving information. HCP group all reported extensive information giving before discharge. HCP group believed severe anxiety inhibits learning. Family members said they were intimidated, foreign, daunting healthcare confused by different roles. Information is overwhelming and poorly timed.
Sinnakaruppan and Williams (2001)	UK	To appraise recent literature on the topic of perceived needs of family carers of head injured adult relatives.	Critical Review	Medline (1966-2000), Embase (1987-1999), CINAHL (1982-January 2000) and Psychlit (1967-1999)	13 Papers.	Most studies report the need for information regarding the head injury, its effects, and techniques for adjusting to the subsequent changes. Honesty from professionals was also important as was the need for hope. Studies reported needs of carers who rated personal carer support as relatively unimportant, in contrast needs prioritised were for the injured relative. Most unmet need was emotional support. Significant difference between parents and spouses. Where behavioural and

Turner et al. (2011a)	AUS	To explore the perspectives of individuals with ABI and their family caregivers concerning recovery and adjustment during the early transition phase from hospital to home.	Qualitative phenomenology	Semi-structured interview (average 33/36 minutes) pre-discharge, 1 and 3 months	20 adults with ABI and 18 family members.	affective changes were reported there were more unmet needs. Primary themes relevant to adjustment and recovery: Adapting to life in the real world; variations in recovery; the emotional adjustment rollercoaster and discovering the new me. Being at home was key milestone, accompanying sense of achievement, perceived as bringing closure.
Turner et al. (2011b)	AUS	To explore the service and support needs of individuals with ABI and their family caregivers during the transition phase from hospital to home.	Qualitative phenomenology	Semi-structured interview (average 33/36 minutes) pre-discharge, 1 and 3 months	20 adults with ABI and 18 family members.	Primary themes balancing the service and support equation; negotiating the rehabilitation maze; and working with or against 'the system'. Range of formal and informal support used only 5/20 used a formal support service at 3 months. Most valuable support provided by families and friends. Frustration continually expressed at 'the system'. System perceived as inconsistent, difficult to understand, bureaucratic, impossible to work with. Difficult and stressful transition was a consistent theme. Themes of the literature: perspectives regarding the transition process; outcome and service provision.
Turner et al. (2008)	AUS	To review the literature relating to the transition from hospital to home for individuals with ABI.	Literature review	Medline, PubMed, CINAHL, OT Seeker, PsychInfo, Cochrane Library	50 papers identified from 1986 onwards	
Verhaeghe et al. (2007a)	BEL	To explore the possibly intricate relationship between hope and information in family members of traumatic coma patients.	Qualitative grounded theory	Semi-structured interviews (24 interviews) range 30-295 minutes (mean=125).	22 family members of 16 patients in a coma.	Hope was a central theme in every interview. Concepts of hope and information were intertwined. Themes: The bad news: passively absorbing bits of information; Seeing the patient: trying to understand reality; Seeking help/foothold; Learning to deal with information. After some time, family members start trusting their own interpretation of the situation.
Verhaeghe et al. (2007b)	BEL	To examine the process that family members go through when they are confronted with traumatic coma.	Qualitative grounded theory	Semi-structured interviews (24 interviews) range 30-295minutes mean 125.	22 family members of 16 patients in coma (12 TBI 4 ICH)	Hope was a primary theme in each interview regardless of severity, kinship, or personality. However, they did not want to have false hope or delude themselves about the outcome. Self-protection by learning not to attach to more emotion with hope. Hope over time becomes stepped, remaining stable for a period of time then falls or rises dependant on information or events.

Table 8: Family Context

<i>Study</i>	<i>Country</i>	<i>Question/Aim</i>	<i>Design</i>	<i>Data collection</i>	<i>Sample</i>	<i>Key findings</i>
Duff (2006)	CAN	To determine family needs and concerns when a relative was in a state of post-comatose unawareness or minimal responsiveness following a severe TBI.	Qualitative grounded theory	1-3 Interviews and clinical observations of family units in two acute neuro trauma units.	25 family members from 11 families of adults with severe TBI in post-comatose unawareness or minimal responsiveness.	Basic Social Process: Negotiating. Negotiations between family members (revising roles and responsibilities for key facets of family life). Negotiating with members of the health care team (conflicted relationships identified between families and healthcare team). Negotiating with others. Negotiating the health care system. Those who had a supportive family were most cable of absorbing the impact of injury.
Duff (2002)	CAN	To discover the most salient concern of families who had a close relative who had suffered a severe TBI and how they dealt with the experience during uncertain trajectory of illness that followed coma.	Qualitative grounded theory	1-3 Interviews and clinical observations of family units in two acute neuro trauma units over 8 months.	36 participants (11 severe TBI patients and 25 family members).	Basic Social Process: Negotiating Uncertainty. Four processes: Willing survival (first phase, doctors consistently pessimistic about survival and outcomes); Attending to snow white (extended periods at the bedside); reconstructing the person (growing realisation of long-term effects, degree of recognition and acceptance of changes varied widely; making it better (occurs at different times realised it was impossible to make the injury go away).
Jumisko et al. (2007)	Sweden	To elucidate the meaning of close relatives' experiences of living with a person with moderate or severe TBI.	Qualitative hermeneutic phenomenology	Interview guide included themes pertaining to life before and after the injury (80 minutes).	Eight close relatives of patients with moderate – severe TBI median time since injury 8 years.	Naïve understanding: familiar world collapsed, great uncertainty, want to do everything to support the ill person, fear, anxiety, and disappointment, but also of gratitude, pride, and pleasure. Structural analysis fighting not to lose one's foothold getting into the unknown, becoming acquainted with the changed person, being constantly available, missing someone with whom to share the burden, struggling to be met with dignity, and seeing a light in the darkness. Comprehensive understanding: had to learn to know the ill person who had been changed by the TBI.
Kean (2010)	UK	To explore families who experienced an ambiguous loss following the patient's brain injury which resulted in	Qualitative constructivist grounded theory	Family group interviews, one data collection point.	12 adults and 12 children from nine families of persons with ABI (only	Ambiguous loss emerged in five families captured as 'the essence of who he is, is not there'. Unconsciously family members often talked in past tense but often retained hope of a good enough

		permanent brain damage.			findings from 5 families reported) 7 days to 3 week length of stay in ITU. Number of papers is not identified.	recovery. The on-going nature of the loss and the uncertainty that impacts on perceptions of the future for families.
Kneafsey and Gawthorpe (2004)	UK	To explore the long-term effect of head injury on adult head injured patients and their families.	Narrative literature review	CINHAL and Medline.		Carers may be vulnerable to stress and anxiety as a result of their caring role. Both mild and severe head injury may have devastating effects for both patient and family. For the family, the impact of changes in the relative may involve lifelong changes in their relationships, lifestyles and quality of life.
Verhaeghe et al. (2005)	USA	To create an overview of what is known about the psychological reactions of family members confronted with traumatic brain injury.	Literature review	Medline, PsycLit and CINAHL.	94 English language publications.	No relation has been found between feelings of depression and injury severity. Even after 10–15 years physical problems are less stressful than the patient's cognitive, emotional and behavioural problems. TBI threatens family stability. Demands are made that change the system and growth must follow for the family to reach equilibrium again.
Yeates et al. (2007)	UK	To identify dimensions of family (and wider) contexts that can be seen to influence the sense-making of change after ABI within families, and (2) to explore how diversity in accounts of disability is responded to and negotiated within families.	Qualitative social constructivism, discourse analysis	Open Interviewing using 3 themes; disability and change, meaning of change, managing different perspectives (60-90 minutes).	3 pairs of persons with ABI (mixed sample, times since injury 2 years for two ABI adults and 10 years for the other) and a family member.	Accessing sense-making resources: All struggled to make sense of injury related change. Service provision was perceived as unavailable, sparse or disrupted. Dominant social meanings in family accounts of change: language used associated with the portrayal of who the ABI person was or still is illustrated how family members made sense of change. Orientating and contesting accounts of change; not knowing what change should be attributed to brain injury and what would be present without the injury.

Table 9: Other selected literature

Study	Country	Question/Aim	Design	Data collection	Sample	Key findings
Brooks et al (1987)	UK	To identify the magnitude, evolution, and prediction of behavioural and other changes in the patient and to	Quantitative, structured interview	Questionnaire included behavioural, affective, social, leisure and vocational sequelae. Burden assessed on	134 patients with severe TBI and a close relative, time since injury 2-7 years.	Relatives report of burden: high 52% medium 37% low 11%. Distribution of burden was consistent at each time interval. Approximately 85% or more were in high-medium burden groups.

		relate these changes to the distress and burden in the patient's family.		a 7 point scale then grouped as low/medium/high.		
Brooks et al (1986)	UK	To identify the patterns of change in behavioural disturbance in the patient and distress in the family during the first 5 years after injury.	Quantitative, 5 year follow-up structured interview	Physical and mental state, behaviour, self-care abilities, and personality. Burden assessed by 7 point rating scale for carer strain (low/medium/high).	Close relative of 42 patients with severe TBI time since injury 5 years.	Most frequent problems in mental/behavioural areas, continuing personality change 60% at one year – 74% at five years. More relatives experiencing high levels of burden by five years (10% low 33% medium 56% high). Greater personality/behavioural change correlated with greater subjective burden.
Curtiss et al. 2000)	USA	To examine acute changes in family structure and coping responses pre- and post-TBI.	Quantative, self-report survey	FACES-II, coping Responses Inventory. Complete one for a stressful event 6 months prior and one based on how they were functioning since the TBI.	20 spouses of individuals with TBI (mostly severe injury), following admission to rehabilitation.	Large proportion of balanced-type families changed to extreme-type following TBI (70%). A substantial proportion of moderately balanced families (40%) also showed less cohesion and/or adaptability following TBI. Found significant change in family structure following TBI.
Chwalisz & Stark-Wroblewski (1996)	USA	To examine the subjective experience of spousal caregivers.	Qualitative content analysis	Open question added to survey: 'if you wish to share anything else feel free to write on the rest of this page'.	27 caregivers of persons with head injury.	My situation is different and/or easier than others; sources of support and assistance; changes in spouse with injury included various changes and losses that were mostly negatively perceived; Changes in marital relationship included loss of affection, thoughts of divorce; problems with advice from medical professionals.
Gosling and Oddy (1999)	UK	To explore sexual relationships following head injury from the point of view of the non-injured spouse.	Mixed self-report questionnaires and semi-structured interviews	General Health Questionnaire, Golombok and Rust Inventory of Marital State. Interview: 7 open ended questions.	18 heterosexual couples where a male partner had a severe TBI 1-7 years post injury.	Wives reported current marital relationship was significantly worse than before injury ($p<0.001$). Wives rated their own sexual satisfaction as significantly lower after the injury ($p<0.01$). Perception of sexual coercion was correlated with lower sexual satisfaction for the women ($p<0.05$). Wives reported much more dissatisfaction than their partners ($p<0.001$). Relationships no longer equal, sharing or providing companionship. Difficulty in identifying positive aspects in their relationship.
Kosciulek (1996)	USA	To assess the utility of the Circumplex Model and Marital and Family Systems for guiding family assessment	Quantitative self-report postal survey	Family Information Sheet; Family Adaptability and Cohesion Evaluation Scale-II; Family Assessment Device.	82 primary carers of a person with TBI at least one year post-injury.	Balanced families had significantly lower scores for general functioning and communication scales indicative of more effective functioning in these domains.

Kosciulek and Lustig (1999)	USA	and intervention following a member's head injury. What are the factors that differentiate Balanced, Mid-range, and Extreme brain injury family types?	Quantitative self-report postal survey	FACES II; Problem Checklist; Family Assessment Device-GF; Family Information Sheet.	76 primary caregivers of persons with TBI (times since injury mean 7.8 years).	Those classed as balanced had older primary caregivers, more effective family adaptation, and members with brain injuries with less problematic cognitive functioning. Those classed as Extreme had members with brain injuries with more problematic affective and cognitive functioning and greater time since injury. Extreme families were also more likely to have poorer family adaptation than the mid-range.
Kreutzer (1994)	USA	To explore the extent of caregiver psychological distress and impaired family functioning following the acute, inpatient phases of recovery from brain injury.	Quantitative, cross-sectional, structured interview	Brief Symptom Inventory, Family Assessment Device.	62 primary carers of adult TBI, mixed severity, time since injury 1.5-60 months (mean 16).	47% of carers exceeded criteria for 'caseness' for levels of emotional distress as measured by global severity index. FAD scores compared to normative data. 56% reported unhealthy general functioning. Subset of 48 carers less than 2 years post-injury to compares spouse v parents. Spouses reported more BSI symptoms, no difference in FAD scores
Livingston et al. (1985)	UK	Do relatives of severe head injury victims suffer significant psychiatric disturbance?	Quantitative, cross-sectional, structured interview	3 months post injury: Glasgow Outcome Scale, cognitive functioning, personality change; General Health Questionnaire, Leeds General Scale for Anxiety and Depression, Social Adjustment Scale, 25 item Burden Scale.	Relatives of 42 male patients with severe TBI 3 months after injury. Comparison group of mild head injury.	Mood disturbance and social role dysfunction. Perceived burden higher in severe head injury group $p=0.001$. Marital and family functioning worse in severe head injury group $p<0.01$. 45% scored beyond 'caseness' threshold for anxiety.
Maus-Clum and Ryan (1981)	USA	To identify the experiences of the primary family member in the immediate acute period post-injury.	Quantitative self-report questionnaire	Developed questionnaire (crude measure).	N=30 (19 wives / 11 mothers) of those with ABI.	Need for clear kind information first priority, followed by discussion of realistic expectations, emotional support important but not of immediate concern, all but three reported changed personality. Over 50% reported frustration, irritability, annoyance and almost 50% of wives felt depressed and angry. Married to a stranger 32%, married but don't have a husband 42%.
Oddy et al. (1985)	UK	Long-term follow-up of very severely head injured	Quantitative follow-up study,	Bond Neurophysical Scale; Raven's Progressive	34 severe TBI approximately 7 years	Personality change reported by 31/44 at two years, those unemployed at 2 years remained so at 7 years.

		patients.	structured interview	Matrices; Mill Hill Vocabulary Scale; relative's interview about social adjustment, memory and behaviour, Symptom checklist;	post-injury (44 patients at 2 year follow-up)	Social isolation was a major problem. 60% had no girlfriend or boyfriend. Two of five married couples had separated. Five TBI patients had married in-between follow-up.
Orsillo et al. (1993)	USA	To investigate the nature and extent of psychological distress in siblings of the head injured population.	Quantitative self-report postal questionnaire	Family Assessment Device, Problem Solving Inventory, Dysfunctional attitude Scale, Rational Behaviour Inventory, Attributional; Style Questionnaire, Ways of coping Checklist, Brief Symptom Inventory,	13 siblings aged 13-21 (8 female) of severe TBI (time since injury 1-149 months).	Sibling's global severity index, indicating presence of psychological symptoms, greater than normative data ($p < 0.001$). 10 met criteria for 'caseness'. Siblings had few behaviours/attitudes associated with effective problem solving and had more dysfunctional attitudes.
Panting and Merry (1972)	UK	The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family.	Quantitative follow-up survey	Injury severity, return to work, attacks of emotional rage, relationship status, work potential at review	30 TBI patients with mixed severity 2-7 years post injury	Husband-wife relationships are less stable than parent-child. Ten patients married at the time of injury, of these three divorced and one separated at follow-up 2-7 years post-discharge from rehabilitation.
Pessar et al. (1993)	USA	To examine the effects of parental brain injury on children's behaviour as reported by the uninjured parent.	Quantitative self-report survey	Child Information Form, Behaviour Rating Scale, Self-Report Symptom Checklist, Health and Activity Limitation Survey	24 married couples (children aged 2-23) 16 fathers injured (time since injury 16-84 months)	22/24 reported change in child behaviour: acting out, emotional problems; however relationship problems with injured parent was the most prevalent problem. 23/24 uninjured parents reported negative changes in injured parent's behaviour.
Tate et al. (1989)	AUS	To examine psychosocial disability in severe blunt head injury and compare the psychosocial outcomes of subgroups.	Quantitative, structured interview	Data collected on: employment, interpersonal relationships, functional, independence, social contacts and leisure interests; overall psychosocial disability	87 subjects and a close relative from a follow-up of 100 admissions post-TBI (mean time since injury 6 years).	Psychosocial reintegration: 24.1% Good, 42.5% substantially limited, 33.3% poor. Recovery based on GOS: Good $n=45$, Moderate disability $n=26$, Severe disability $n=16$. Breakdown of pre-trauma marriages: Good recovery = 5/12, Moderate Disability 7/11, severe disability 5/8.
Thomsen (1984)	DEN	To identify late psychosocial outcome in severe head injury.	Quantitative, structured interview	2.5 years post-injury, then 10-15 year follow-up: medical/demographic; neuro-psychological and psychological data.	40 TBI patients with severe blunt head trauma and their relative.	Social dependence increased social burden, changed personality / emotional behaviour presented greatest problem to families. Those who had divorced stated injured person was a stranger, nine married at 2.5 year follow-up 7 of these had

Uysal (1998)	USA	To examine the parenting skills of individuals with TBI, effects of parental TBI on children and effects of parental TBI on levels of depression.	Quantitative structured interview	Parent: Parent Behaviour Form, Parent Practices Questionnaire, Parenting Dimensions Inventory, Sources of Annoyance, Beck Depression Inventory. Child: Behavioural Rating Profile, Children's Depression Inventory, Parent behaviour Form, Parent Practices Questionnaire.	16 TBI families (at least 2 years post-injury range 2-39 mean 9.39 years) 10/16 two parent families 8/10 both interviewed, 16 comparison families.	divorced by the next follow-up. Parents with TBI reported their children to have less cognitive competence, less achievement, less conformity. Differences in parenting ability between injured and non-injured spouse were not confirmed by child reports. Both parents perceived as being more lax with rules, allowing them to disobey, ignoring bad behaviour than control families. No significant difference in frequency of problem behaviours between TBI children and control
Wood and Yurdakul, (1997)	UK	To record how frequently relationships break down in the years following TBI.	Quantitative self-report postal questionnaire	Demographic data; injury type, PTA; length of relationship prior; current relationship status; nature of the change.	41 patients with TBI over 21 married or living with partner for at least 1 year (mean time since injury 5.42 years).	Prior to injury: 75.57% married, 4.58 engaged, 19.84% common-law relationship. Approximately 8 years post injury: 39.69% married, 2.29% engaged, 3.05% common-law relationship. In total 48.86% reported divorce or separation from their partner.

Appendix 3: Interview Schedule

Guide for interviews with participants

Meeting No. 1

Exchange pleasantries

Introduce myself

Ask the participant where they would like to sit

Describe purpose of first meeting.

“Thank you for considering to take part in this research about the experience and support needs of families after head injury. In this meeting I will go through the information sheet with you and then I will show you a flow chart which illustrates each stage of the study. Should you have any questions you may stop me at any time so that I can respond to these. I will then go through the consent form which I will invite you to sign if you agree to participate in this study. Do you have any questions?”

Go through the information sheet and invite questions.

Go through the study flow chart and identify key stages of the research.

Show the participant the consent form and explain each point that they will be required to sign against.

Confirm understanding and invite the participant to sign the consent form.

If consent is given describe process for interview and questionnaire completion.

“When you are ready the interview will commence and should last approximately 60-90 minutes. Should the interview run over 90 minutes you will be informed of this and your preference established as to whether you wish to stop the interview or continue. Once the interview is complete you will be invited to take a short break and the questionnaire may be completed on your return. The questionnaire asks a total of 62 questions and invites you to respond to these by placing a tick beside one of five possible answers. Completion of the questionnaire takes approximately 15 minutes. Do you have any questions?”

Interview:

Re-iterate terms of confidentiality and discuss support mechanisms.

Describe purpose of the interview.

Explain the format of the interview.

Invite questions and confirm understanding.

Start digital recording and conduct interview.

Stage 1: Opening question to promote narrative response.

"I would like you to think about your (insert relationship)'s injury and what has happened in the time since the injury. Please tell me the story of this injury, all the events and experiences that have been important to you personally. Begin where you like, please take the time you need. I'll listen first, I won't interrupt. I'll just take some notes for after you've finished telling me about your experiences."

"Take your time and start when you feel ready".

Stage 2: Clarification and further questioning

Questions will be based on issues raised by the family member, in the same order they spoke of them and will reflect the same language used. Questions will typically be formulated using the following statements...

"When you spoke about (insert topic reflecting language used) can you please tell me more about this event?"

"You mentioned (insert topic reflecting language used) can you explain why this made you feel (insert emotion reflecting language used)?"

"Please could you describe in more detail (insert topic reflecting language used)?"

Stage 3: Further questions

The following questions will be asked only if these issues have not already been raised by the participant during stage one and two. These questions will address the following topic areas; relationships, key moments, needs, challenges and perceptions of the future. Questions will be framed using the appropriate opening such as ...

"Research suggests that head injuries can affect relationships within a family. Please can you tell me about the relationships within your family since your (insert relationship) had their injury?"

"Reflecting on (insert specific time frame) how would you now describe your support needs at this time?"

"Reflecting back on your experience to date what do you perceive as being an important moment in the recovery of your (insert relationship)?"

"It is impossible to know what will happen in the future however; what do you think will happen next and how do you feel about this?"

Close of interview:

Ask participant if there is anything else they wish to add?

Close interview with a statement of thanks.

Turn off digital recorder.

Discuss with participant how they feel now the interview is over.

Questionnaire completion:

Invite participant to take a 10 minute break before completion of questionnaire.

Show questionnaire and familiarise participant with completion instructions.

Invite participant to complete questionnaire.

Close of meeting:

Return to study flow chart and confirm next stage of the research.

Establish the participant's preference as to whether they wish to receive the questionnaire approximately one week prior to their next meeting, to complete at their own convenience, or at the meeting if they need to be supported.

Confirm participant has my contact details.

Thank participant for their time.

Meeting No. 2 & 3

Exchange pleasantries

Introduce myself

Ask where the participant would like me to sit

Inquire about completion of questionnaire.

Interview:

Follow guide for interview 1

Questionnaire completion:

If questionnaire has not been completed prior to the meeting the participant will be invited to take a 10 minute break before completion of the questionnaire.

Invite participant to complete questionnaire.

Close of meeting:

Confirm participant has my contact details.

Thank participant for time and confirm next stage of the research.

Appendix 4: Permission to use FACES**LIFE INNOVATIONS, Inc.®**

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Website: www.facesiv.com**Customer Service:** cs@facesiv.com**Storing & Scoring Data:** data@facesiv.com

I am pleased to give you permission to use the **FACES IV Package** in your research project, teaching or clinical work with couples or families. In order to use FACES IV, you must use the entire FACES IV Package which contains 62 items.

You may either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgement should be given regarding the name of the instrument, the developers' names, and Life Innovations.

In exchange for providing this permission, we would appreciate a copy of any papers, theses or reports that you complete using the **FACES IV Package**. This will help us to stay abreast of the most recent developments and research regarding this scale. We thank you for your cooperation in this effort.

Also, we are requesting that you provide us with a *set of your data* so that we can build a large and diverse norm base. We will acknowledge your contribution to the master data base. We will not use your data for individual studies on your topic or any topic. We would appreciate it if you used the format we have provided in an Excel spreadsheet (Microsoft).

In closing, I hope you find the **FACES IV Package** of value in your work with families. I would appreciate hearing from you as you make use of this package.

Sincerely,

David H. Olson, Ph.D.

Appendix 5: FACES-IV Questionnaire and Answer sheet

Family Experience of Traumatic Brain Injury.

Questionnaire

(FACES - IV Package © 2006 Life Innovations, Inc.)

The FACES-IV package was developed by David H. Olson, Dean M. Gorall and Judy W. Tiesel

Life Innovations
P.O. Box 190
Minneapolis, MN 55440
Version 3/07

REC Ref Number: 08/H0308/181

(Researcher use only)

R&D Number: A091364

Family Code:

Participant Code:

Background information

Age _____ Gender M / F Date: _____

Medical needs _____

Emergency contact number _____

Relationship to patient (*Please circle*)

Mother Father Son Daughter
 Brother (younger) Brother (older) Sister (younger) Sister (older)
 Aunt Uncle Grandmother Grandfather
 Other Please state _____

Ethnic group (*Please circle*)**White**

· British · Any other White background (Please describe)

Mixed

· White and Black Caribbean · White and Black African
 · White and Asian · Any other Mixed background (Please describe)

Asian or Asian British

· Indian · Pakistani
 · Bangladeshi · Any other Asian background (Please describe)

Black or Black British

· Caribbean · African
 · Any other Black background (Please describe)

Chinese or other ethnic group

· Chinese · Any other (Please describe)

Directions:

1. Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.
2. Please respond to each statement by placing a tick in the corresponding box. An example is provided below.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree
			✓	

1. Family members are involved in each others lives.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

2. Our family tries new ways of dealing with problems.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

3. We get along better with people outside our family than inside.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

4. We spend too much time together.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

5. There are strict consequences for breaking the rules in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

6. We never seem to get organized in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

7. Family members feel very close to each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

8. Parents equally share leadership in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

9. Family members seem to avoid contact with each other when at home.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

10. Family members feel pressured to spend most free time together.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

11. There are clear consequences when a family member does something wrong.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

12. It is hard to know who the leader is in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

13. Family members are supportive of each other during difficult times.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

14. Discipline is fair in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

15. Family members know very little about the friends of other family members.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

16. Family members are too dependent on each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

17. Our family has a rule for almost every possible situation.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

18. Things do not get done in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

19. Family members consult other family members on important decisions.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

20. My family is able to adjust to change when necessary.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

21. Family members are on their own when there is a problem to be solved.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

22. Family members have little need for friends outside the family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

23. Our family is highly organized.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

24. It is unclear who is responsible for things (chores, activities) in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

25. Family members like to spend some of their free time with each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

26. We shift household responsibilities from person to person.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

27. Our family seldom does things together.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

28. We feel too connected to each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

29. Our family becomes frustrated when there is a change in our plans or routines.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

30. There is no leadership in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

31. Although family members have individual interests, they still participate in family activities.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

32. We have clear rules and roles in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

33. Family members seldom depend on each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

34. We resent family members doing things outside the family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

35. It is important to follow the rules in our family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

36. Our family has a hard time keeping track of who does various household tasks.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

37. Our family has a good balance of separateness and closeness.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

38. When problems arise, we compromise.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

39. Family members mainly operate independently.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

40. Family members feel guilty if they want to spend time away from the family.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

41. Once a decision is made, it is very difficult to modify that decision.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

42. Our family feels hectic and disorganized.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

43. Family members are satisfied with how they communicate with each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

44. Family members are very good listeners.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

45. Family members express affection to each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

46. Family members are able to ask each other for what they want.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

47. Family members can calmly discuss problems with each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

48. Family members discuss their ideas and beliefs with each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

49. When family members ask questions of each other, they get honest answers.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

50. Family members try to understand each other's feelings

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

51. When angry, family members seldom say negative things about each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

52. Family members express their true feelings to each other.

Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

How satisfied are you with:

53. The degree of closeness between family members.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

54. Your family's ability to cope with stress.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

55. Your family's ability to be flexible.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

56. Your family's ability to share positive experiences.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

57. The quality of communication between family members.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

58. Your family's ability to resolve conflicts.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

59. The amount of time you spend together as a family.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

60. The way problems are discussed.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

61. The fairness of criticism in your family.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

62. Family members concern for each other.

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

Thank you for Your Cooperation!

FACES IV: Answer Sheet (Researcher use only)**REC Ref Number: 08/H0308/181****R&D Number: A091364****Family Code:****Participant Code:**

1	2	3	4	5
Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

1. _____	7. _____	13. _____	19. _____	25. _____	31. _____	37. _____	
2. _____	8. _____	14. _____	20. _____	26. _____	32. _____	38. _____	A. _____
3. _____	9. _____	15. _____	21. _____	27. _____	33. _____	39. _____	B. _____
4. _____	10. _____	16. _____	22. _____	28. _____	34. _____	40. _____	C. _____
5. _____	11. _____	17. _____	23. _____	29. _____	35. _____	41. _____	D. _____
6. _____	12. _____	18. _____	24. _____	30. _____	36. _____	42. _____	E. _____
							F. _____

1	2	3	4	5
Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree

43. _____	44. _____	45. _____	46. _____	47. _____	48. _____
49. _____	50. _____	51. _____	52. _____	SUM _____ = _____ %	

1	2	3	4	5
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied

53. _____	54. _____	55. _____	56. _____	57. _____	58. _____
59. _____	60. _____	61. _____	62. _____	SUM _____ = _____ %	

Appendix 6: Next of Kin Recruitment packs

Contents:

- Cover letter
- Consent form
- Information sheet
- Reply slip

Family Experience of Traumatic Brain Injury.

Dear Family Member

I would like to invite you to consider participating in a research study. The study is about the experiences and support needs of families following head injury. In this pack you will find four items which will assist you to make an informed decision regarding your participation in this study and then to contact me.

This recruitment pack contains : An information sheet
 A reply slip
 A consent form
 A Pre-Paid Envelope

You are invited to read the information provided which will tell you about why the study is being conducted and what it would mean if you decided to take part. Once you have had time to consider this information you may like to ask some questions. So that I can respond to these questions I will need your permission to contact you. The reply slip enclosed may be used to forward your contact details to me so that I can discuss the study with you.

Alternatively if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark
PhD Student with the University of Southampton

NEXT OF KIN CONSENT FORM**REC Ref Number: 08/H0308/181**

(Researcher use only)

R&D Number: A091364**Family Code:****Participant Code:****Title of Project: Family Experience of Traumatic Brain Injury.****Name of Researcher: Charlotte Jane Clark**

Please initial box

1. I confirm that I have read and understand the information sheet dated: 20/10/08 (version No. 2) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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

3. I agree to support this study by distributing recruitment packs to other family members.

Name of next of kin_____
Date_____
Signature_____
Name of person taking consent_____
Date_____
Signature***When completed, 1 for participant; 1 for researcher site file***

Family Experience of Traumatic Brain Injury.**Next of Kin Information Sheet****Invitation to join the study**

You are being invited to join a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

Recovery from a head injury can be as challenging for the non-injured family members as it is for the person who has had the injury. However, it is not yet understood how best to support family members at this time. Therefore, the purpose of this study is to further understand the family's experience of this injury and identify their support needs within the first year. (The study is being conducted as a requirement of the award of Doctorate of Philosophy (PhD) with the School of Health Sciences at the University of Southampton).

Why have I been invited?

You have been invited to join this study because you are the next of kin of a person who has had a head injury. I am particularly interested in how the family of this person has been affected by this injury and what their support needs are at this time.

Approximately four families in total will be recruited into the study.

Do I have to take part?

It is up to you to decide. If you do decide to take part, as the next of kin your specific role would be to support the study by identifying two – four family members who may wish to take part in the main study (this may or may not include yourself) and to give these members a study recruitment pack. This study aims to explore the family experience of head injury therefore any person who is identified by you as a member of your relative's family may have the opportunity to join the study. However, the family member must be known to the person with the injury, aware of the patient's diagnosis, over the age of eighteen and able to provide informed consent.

If you are willing to invite family members to join this study or would like to ask some questions please complete the attached reply slip and return it to me using the pre-paid envelope. These details will only be used so that I can make contact with you to respond to your questions. I will then ask to meet with you at a mutually convenient place, date and time to describe the study further and go through this information sheet. If you agree to the role outlined I will ask you to sign a consent form and then I will give you the recruitment packs to be distributed to the identified family members. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the services you or your relatives receive.

What will happen in the main study?

If the family members you identify would like to take part or would like to ask some questions I will ask them to return the reply slip contained in the recruitment pack so that I can explain the study further. Should you decide that you would also like to take part in the main study you are invited to keep one of the recruitment packs and to return a second reply slip.

The study will be conducted during the first year following the injury of your family member. Within this year those who take part will attend three interviews and complete a questionnaire three times. During the interview family members will be prompted to talk about their experience and support needs following the injury. Each interview will take approximately 60-90 minutes and will be digitally recorded to enhance the accuracy of reporting their story. The questionnaire asks a total of 62 questions and invites family members to respond to these by placing a tick beside one of five possible answers. Completion of the questionnaire takes approximately 15 minutes. The first meeting will be arranged within the first month after injury the second at approximately three months and the third at the end of one year.

During the study information about your relative with the head injury may be referred to. It is important therefore that your relative has the opportunity to consent to this information being used in this study. If it is appropriate to do so consent will have been requested from your relative prior to you receiving this information sheet, however, if their condition does not initially allow for this they will be given the opportunity later in the study. When consent is given those participating in the study may continue however if consent is not given family members will be withdrawn from the study along with any data already collected. In addition to this if at any time your relative expresses objection to the participation of their family in this research please inform the researcher so that the family may be withdrawn.

There are no expenses or payments available for participating in this study.

What are the possible disadvantages and risks of taking part?

It is appreciated that talking about this experience might not always be comfortable therefore the interview can be stopped at any time. Whilst it is not intended that the interview meetings should cause any distress, it would be helpful if those who take part identify someone who would be available for support. It has been agreed that Headway's national helpline will be available to offer any support if required. This number is: **0808 800 2244**.

What are the possible benefits of taking part?

The study is not designed to help those who take part. However, the information from this study has the potential to inform services supporting the needs of family members affected by head injury in the future.

What happens when the research study stops?

Once the study has been completed the information obtained will be analysed and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated at this time. Following completion it is expected that the information will be published in healthcare professional journals. You will not be identified in any report/publication unless explicit consent for this has been granted.

Will taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information will be handled in confidence. All information which is collected during the course of the research will be kept strictly confidential. Only authorised persons may have access to identifiable data such as collaborating researchers, sponsors & regulatory authorities. Your confidentiality will be maintained unless there is information of a criminal nature or a perceived threat to yourself or others in which case the researcher will be required to disclose this information to the appropriate body however you will be informed before any necessary action is taken. This principle is informed by the Nursing and Midwifery Council's Code of Professional Conduct (2008).

You and other family members will be given a research pseudonym to protect your anonymity and in addition to this all other identifiable data will be removed or changed. Despite these measures it is important you are aware that when this type of research is presented, e.g. in healthcare journals or at conferences, large pieces of original text will be displayed, and your contributions may be identifiable to those you have had contact with through language, familiar phrases used or situations discussed.

The interview transcripts will be stored securely in a lockable filing cabinet and will be destroyed after 15 years.

What will happen if a family member does not want to carry on with the study?

Any one who takes part in this study may withdraw any time and they do not have to provide a reason. This decision will not affect any services you or your family receives. Those who do not want to continue with the study will need to inform the researcher of their intention to withdraw so that they are not contacted again in the future. Should any person lose capacity to consent during the course of this study any information already provided will be used in accordance with the consent obtained.

What if there is a problem?

If you have a concern or a complaint about this study you should contact Ms Susan Rogers, Head of Research and Enterprise Services, in the Research Support Office at the School of Health Sciences (Address: University of Southampton, School of Health Sciences, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 7942; Email: ssr@soton.ac.uk). If you remain unhappy and wish to complain formally Ms Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Where can I seek independent advice?

The Patient Advice and Liaison Service (PALS) at Addenbrooke's hospital has agreed to provide independent advice about participating in this study. You can contact PALS on the following number: 01223 216756

Who is organising and funding the research?

The organisation supporting the research is University Campus Suffolk.

The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Cambridgeshire 2 Research Ethics Committee.

Contact for further information:

My contact details are as follows:

Charlotte Clark – University Campus Suffolk

Tel: 01473 338508

Email: c.clark@ucs.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Family Experience of Traumatic Brain Injury.**REPLY SLIP**

Thank you for reading the Next of kin Information Sheet and for considering participating in this research study about the experience and support needs of families after head injury. To help you decide whether you would like to join this study you may want to know more about the study and your involvement in it. So that I can respond to these questions I will need your permission to contact you.

Please complete the following details and return this form to me in the pre-paid envelope. Returning this slip does not mean you have to participate, these details will only be used so that I can make contact with you to respond to your questions. Please be assured that if you do join the study your contributions will be anonymous and confidential in any study reports.

If you return this reply slip I will contact you in the next few days. You will then be given at least 48 hours before a meeting is arranged so that you can think about the study and then have the opportunity to ask any further questions. You are always free to withdraw from the study at any time without giving reason.

Alternatively, if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark

PhD Student with the University of Southampton

Family Code: (Researcher use only)

Participant Code: NoK

Name (Please print)

Contact telephone number

Good times to phone

Times to avoid phoning

Please put this into the pre-paid envelope provided and put it in the post.

THANK YOU

Appendix 7: Participant Recruitment packs

Contents:

Cover letter

Consent form

Information sheet

Reply slip

Family Experience of Traumatic Brain Injury.

Dear Family Member

I would like to invite you to consider participating in a research study. The study is about the experiences and support needs of families following head injury. In this pack you will find four items which will assist you to make an informed decision regarding your participation in this study and then to contact me.

This recruitment pack contains : An information sheet
 A reply slip
 A consent form
 A Pre-Paid Envelope

You are invited to read the information provided which will tell you about why the study is being conducted and what it would mean if you decided to take part. Once you have had time to consider this information you may like to ask some questions. So that I can respond to these questions I will need your permission to contact you. The reply slip enclosed may be used to forward your contact details to me so that I can discuss the study with you.

Alternatively if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark
PhD Student with the University of Southampton

PARTICIPANT CONSENT FORM

Centre Number:	08/H0308/181	(Researcher use only)
R&D Number:	A091364	
Family Code:		
Participant Code:		

Title of Project: Family Experience of Traumatic Brain Injury.
Name of Researcher: Charlotte Jane Clark

*Please
initial box*

1. I confirm that I have read and understand the information sheet dated: 20/10/08 (version No. 2) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without medical care or legal rights being affected. ☐
3. I agree to having my responses audiotaped during interviews. ☐
4. I agree for extracts of my speech to be reported in research papers but my name will not be used and I will not be personally identifiable in any study reports. ☐
5. I understand that my confidentiality will be maintained unless during the course of the interview there is information of a criminal nature or a perceived threat to myself or others, in which case I will be informed by the researcher before any necessary action is taken. ☐
6. Should I lose capacity to consent during the course of this study I understand that I will be withdrawn from the study and that any information already provided with consent will be retained and used in accordance with the consent obtained. ☐
7. I agree for you to use the information I provide for this study for further analysis in the future. ☐
8. I agree to take part in the above study. ☐

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

When completed, 1 for participant; 1 for researcher site file

**Family Experience of Traumatic Brain Injury.
Participant Information Sheet**

Invitation to join the study

You are being invited to join a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

Recovery from a head injury can be as challenging for the non-injured family members as it is for the person who has had the injury. However, it is not yet understood how best to support family members at this time. Therefore, the purpose of this study is to further understand the family's experience of this injury and identify their support needs within the first year. (The study is being conducted as a requirement of the award of Doctorate of Philosophy (PhD) with the school of Health Sciences at the University of Southampton).

Why have I been invited?

You have been invited to join this study because a member of your family has had a head injury. I am particularly interested in how you and your family have been affected by this injury and what your support needs are at this time.

You may be involved in this study with up to three members of your family. Approximately three other families will also be invited to take part.

Do I have to take part?

It is up to you to decide. If you do decide to take part or would like to ask some questions please complete the attached reply slip and return it to me using pre-paid envelope. These details will only be used so that I can make contact with you to respond to your questions. I will then ask to meet with you at a mutually convenient place, date and time to describe the study further and go through this information sheet. I will then ask you to sign a consent form to show you have agreed to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the services you or your relatives receive.

What will happen to me if I take part?

The study will be conducted during the first year following the injury of your family member. Within this year you will be invited to attend three interviews and complete a questionnaire three times. During the interview you will be prompted to talk about your experience and support needs following the injury. Each interview will take approximately 60-90 minutes and will be digitally recorded to enhance the accuracy of reporting your story. The questionnaire asks a total of 62 questions and invites you to respond to these by placing a tick beside one of five possible answers. Completion of the questionnaire takes approximately 15 minutes. The first meeting will be arranged within the first month after injury the second at approximately three months and the third at the end of one year.

During the study information about your relative with the head injury may be referred to. It is important therefore that your relative has the opportunity to consent to this information being used in this study. If it is appropriate to do so consent will have been requested from your relative prior to you receiving this information sheet, however, if their condition does not initially allow for this they will be given the opportunity later in the study. When consent is given those participating in the study may continue however if consent is not given family members will be withdrawn from the study along with any data already collected. In addition to this if at any time your relative expresses objection to the participation of their family in this research please inform the researcher so that the family may be withdrawn.

There are no expenses or payments available for inclusion in this study.

What are the possible disadvantages and risks of taking part?

It is appreciated that talking about your experience might not always be comfortable therefore the interview can be stopped at any time. Whilst it is not intended that the interview meetings should cause any distress, it would be helpful to have a discussion with the researcher to identify someone who would be supportive to you should you need them following the interviews.

It has been agreed that Headway's national helpline will be available to offer any support if required. This number is: **0808 800 2244**.

What are the possible benefits of taking part?

I cannot promise the study will directly help you but the information I get from this study has the potential to inform services supporting the needs of family members affected by head injury in the future.

What happens when the research study stops?

Once the study has been completed the information obtained will be analysed and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated at this time. Following completion it is expected that the information will be published in healthcare professional journals. You will not be identified in any report/publication unless explicit consent for this has been granted.

Will taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information will be handled in confidence. All information which is collected during the course of the research will be kept strictly confidential. Only authorised persons may have access to identifiable data such as collaborating researchers, sponsors & regulatory authorities. Your confidentiality will be maintained unless there is information of a criminal nature or a perceived threat to yourself or others in which case the researcher will be required to disclose this information to the appropriate body however you will be informed before any necessary action is taken. This principle is informed by the Nursing and Midwifery Council's Code of Professional Conduct (2008).

You will be given a research pseudonym to protect your anonymity and in addition to this all other identifiable data will be removed or changed. Despite these measures it is important you are aware that when this type of research is presented, e.g. in healthcare journals or at conferences, large pieces of original text will be displayed, and your contributions may be identifiable to those you have had contact with through language, familiar phrases used or situations discussed.

The interview transcripts will be stored securely in a lockable filing cabinet and will be destroyed after 15 years.

What will happen if I don't want to carry on with the study?

You may withdraw from this study at any time and do not have to provide a reason. This decision will not affect any services you or your relative receives. You will need to inform the researcher of your intention to withdraw so that you are not contacted again in the future. Should you lose capacity to consent during the course of this study any information already provided will be used in accordance with the consent obtained.

What if there is a problem?

If you have a concern or a complaint about this study you should contact Ms Susan Rogers, Head of Research and Enterprise Services, in the Research Support Office at the School of Health Sciences (Address: University of Southampton, School of Health Sciences, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 7942; Email: ssr@soton.ac.uk). If you remain unhappy and wish to complain formally Ms Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Where can I seek independent advice?

The Patient Advice and Liaison Service (PALS) at Addenbrooke's hospital has agreed to provide independent advice about participating in this study. You can contact PALS on the following number: 01223 216756

Who is organising and funding the research?

The organisation financially supporting the research is University Campus Suffolk.

The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Cambridgeshire 2 Research Ethics Committee.

Contact for further information:

My contact details are as follows:

Charlotte Clark – University Campus Suffolk, Tel: 01473 338503

Email: c.clark@ucs.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Family Experience of Traumatic Brain Injury.**REPLY SLIP**

Thank you for reading the Participant Information Sheet and for considering participating in this research study about the experience and support needs of families after head injury. To help you decide whether you would like to join this study you may want to know more about the study and your involvement in it. So that I can respond to these questions I will need your permission to contact you.

Please complete the following details and return this form to me in the pre-paid envelope. Returning this slip does not mean you have to participate, these details will only be used so that I can make contact with you to respond to your questions. Please be assured that if you do join the study your contributions will be anonymous and confidential in any study reports.

If you return this reply slip I will contact you in the next few days. You will then be given at least 48 hours before a meeting is arranged so that you can think about the study and then have the opportunity to ask any further questions. You are always free to withdraw from the study at any time without giving reason.

Alternatively, if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for you time

Charlotte Clark

PhD Student with the University of Southampton

Family Code: (Researcher use only)

Participant Code:

Name (Please print)

Contact telephone number

Good times to phone

Times to avoid phoning

Please put this into the pre-paid envelope provided and put it in the post.

THANK YOU

Appendix 8: Patient information packs (prior to recruitment)

Contents:

Cover letter

Consent form

Information sheet

Reply slip

Family Experience of Traumatic Brain Injury.

Dear Patient

I would like to invite you to consider whether you would be willing to allow information about you to be used in a research study. The study is about the experiences and support needs of families following head injury and I would like to invite members of your family to join. In this pack you will find four items which will assist you to make an informed decision regarding the use of your information and then to contact me.

This information pack contains : An information sheet
 A reply slip
 A consent form
 A Pre-Paid Envelope

You are invited to read the information provided which will tell you about why the study is being conducted and what the implications are for you. Once you have had time to consider this information you may like to ask some questions. So that I can respond to these questions I will need your permission to contact you. The reply slip enclosed may be used to forward your contact details to me so that I can contact you to discuss the study with you.

Alternatively if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark
PhD Student with the University of Southampton

PATIENT CONSENT FORM**REC Ref Number: 08/H0308/181****(Researcher use only)****R&D Number: A091364****Family Code:****Participant Code:****Title of Project: Family Experience of Traumatic Brain Injury.****Name of Researcher: Charlotte Jane Clark**

Please initial box

1. I confirm that I have read and understand the information sheet dated: 20/10/08 (version No. 1) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that I am not required to take an active part in this study and that the consent I provide is given so that information about me can be used in this study. ☐
4. Should I withdraw my consent at any time I understand that my family will be removed from the study along with any data already collected. ☐
5. I agree for information about me to be used in this study. ☐
6. I agree for you to use the information provided for this study for further analysis in the future. ☐

Name of patient_____
Date_____
Signature_____
Name of person taking consent_____
Date_____
Signature***When completed, 1 for participant; 1 for researcher site file***

Family Experience of Traumatic Brain Injury.**Patient Information Sheet****Invitation**

I would like to invite members of your family to join a research study. Although you will not be required to take an active part in this study it is important that you also understand why the research is being done and what the implications are for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish information about you to be used in this study.

Thank you for reading this.

What is the purpose of the study?

Recovery from a head injury can be challenging for the non-injured family members as well as for the person who has had the injury. However, it is not yet understood how best to support family members at this time. Therefore, the purpose of this study is to further understand the family's experience of this injury and identify their support needs within the first year. (The study is being conducted as a requirement of the award of Doctorate of Philosophy (PhD) with the School of Health Sciences at the University of Southampton).

Why do you want to invite my family?

I would like to invite your family to join this study because you have had a head injury and I am particularly interested in how members of your family have been affected by this injury and what their support needs are at this time.

Up to four members of your family may be involved in this study. Approximately three other families will also be invited to take part.

Do my family members have to take part?

Your family members will only be invited to join this study if you are willing that information about you may be used in this study.

Do I have to agree to the use of my information in this study?

It is up to you to decide. It is important that you have the opportunity to decide whether you would be willing for this information to be used in the study because if members of your family do take part information about you may be referred to. If you decide you would be willing for information about you to be used you will be invited to give your consent for this. So that I can explain the study and respond to your questions I will need your permission to contact you. This can be done by completing the attached reply slip and returning it to me by putting it in the pre-paid envelope and either handing it to the Clinical Nurse Practitioner or asking a family member to put it in the post. These details will only be used so that I can make contact with you either by phone or in person to respond to your questions. You will then be given at least 48 hours before a further meeting is arranged at a mutually convenient place, date and time to describe the study further and go through this information sheet. I will then ask you to sign a consent form to show you have agreed for information about you to be used in this study however, you are still free to withdraw this consent at any time and without giving a reason. A decision to withdraw your consent at any time will not affect the services you receive.

What will happen in the study?

If you give your consent we will then contact your next of kin to discuss the study further. We will then invite your next of kin to identify members of your family who may like to take part and to give these family members a recruitment pack for the study. If these family members agree to take part they will be involved in the study during the first year of your injury and will be invited to attend three interviews and complete a questionnaire three times. During the interview family members will be prompted to talk about their experience and support needs following your injury. Each interview will take approximately 60-90 minutes and will be digitally recorded to enhance the accuracy of reporting their story. The questionnaire asks a total of 62 questions and invites family members to respond to these by placing a tick beside one of five possible answers. Completion of the questionnaire takes approximately 15 minutes. During the interview family members will be prompted to talk about their experience and support needs following your injury. The first meeting will be arranged within the first month after injury the second at approximately three months and the third at the end of one year.

There are no expenses or payments available for participating in this study.

What are the possible disadvantages and risks of taking part?

It is appreciated that when your family members talk about their experience it might not always be comfortable therefore the interview can be stopped at any time. Whilst it is not intended that the interview meetings should cause any distress, it would be helpful if those who take part identify someone who would be available for support. It has been agreed that Headway's national helpline will be available to offer any support if required. This number is: **0808 800 2244**.

What are the possible benefits of taking part?

The study is not designed to help those who take part. However, the information from this study has the potential to inform services supporting the needs of family members affected by head injury in the future.

What happens when the research study stops?

Once the study has been completed the information obtained will be analysed and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated at this time. Following completion it is expected that the information will be published in healthcare professional journals. No participant will be identified in any report/publication unless explicit consent for this has been granted.

Will taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information will be handled in confidence. All information which is collected during the course of the research will be kept strictly confidential. Only authorised persons may have access to identifiable data such as collaborating researchers, sponsors & regulatory authorities. Your confidentiality will be maintained unless there is information of a criminal nature or a perceived threat to yourself or others in which case the researcher will be required to disclose this information to the appropriate body however you will be informed before any necessary action is taken. This principle is informed by the Nursing and Midwifery Council's Code of Professional Conduct (2008).

You and other family members will be given a research pseudonym to protect your anonymity and in addition to this all other identifiable data will be removed or changed. Despite these measures it is important you are aware that when this type of research is presented, e.g. in healthcare journals or at conferences, large pieces of original text will be displayed, and contributions may be identifiable to those you have had contact with through language, familiar phrases used or situations discussed.

The interview transcripts will be stored securely in a lockable filing cabinet and will be destroyed after 15 years.

What will happen if I do not want information about me to be used in this study?

If you do not wish information about you to be used in this study your family will not be approached to participate. If you initially give your consent you may also withdraw this at any time and do not have to provide a reason your family will then be removed from the study along with any data already collected. You will need to inform the researcher of your intention to withdraw your consent so that your family members are not contacted again in the future. This decision will not affect any services you receive

What if there is a problem?

If you have a concern or a complaint about this study you should contact Ms Susan Rogers, Head of Research and Enterprise Services, in the Research Support Office at the School of Health Sciences (Address: University of Southampton, School of Health Sciences, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 7942; Email: ssr@soton.ac.uk). If you remain unhappy and wish to complain formally Ms Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Where can I seek independent advice?

The Patient Advice and Liaison Service (PALS) at Addenbrooke's hospital has agreed to provide independent advice about participating in this study. You can contact PALS on the following number: 01223 216756

Who is organising and funding the research?

The organisation supporting the research is University Campus Suffolk.

The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Cambridgeshire 2 Research Ethics Committee.

Contact for further information:

My contact details are as follows:

Charlotte Clark – University Campus Suffolk, Tel: 01473 338508 Email: c.clark@ucs.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Family Experience of Traumatic Brain Injury.**REPLY SLIP**

Thank you for reading the Patient Information Sheet and for considering how information about you may be used in this research study about the experience and support needs of families after head injury. To help you decide whether you would be willing for information about you to be used in this study you may want to know more about the study and how this information will be used. So that I can respond to these questions I will need your permission to contact you.

Please complete the following details and return this form to me by putting it in the pre-paid envelope and handing it to the Clinical Nurse Practitioner. Alternatively you may be able to ask a family member to put it in the post for you. Returning this slip does not mean you have given your consent for information about you to be used in this study and these details will only be used so that I can make contact with you to respond to your questions. Please be assured that any information about you will be anonymous and confidential in any study reports.

If you return this reply slip I will contact you in the next few days. If you are unable to provide a contact telephone number because you are in hospital you may prefer to invite me to the meet with you. Following this initial discussion you will then be given at least 48 hours before a further meeting is arranged so that you can think about the study and then have the opportunity to ask any further questions. Once I have responded to your questions satisfactorily you will be invited to sign a consent form. You are always free to withdraw your consent from the study at any time without giving reason.

Alternatively, if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark (PhD Student with the University of Southampton)

Family Code: _____ (Researcher use only)

Participant Code: PtP

Name (Please print) _____

Please tick the appropriate box and complete the information requested.

☐ Please contact me by telephone my number is _____

☐ Please visit me in hospital the name of the ward is _____

Good times to phone / visit _____

Times to avoid _____

Please put this into the pre-paid envelope provided and either hand it to the Clinical Nurse Practitioner or you may prefer to ask a family member to put it in the post for you.

THANK YOU

Appendix 9: Patient information packs (following recruitment)

Contents:

- Cover letter
- Consent form
- Information sheet
- Reply slip

Family Experience of Traumatic Brain Injury.

Dear Patient / Service User

Members of your family are currently participating in a research study about the experiences and support needs of families following head injury. During this study information about you may have been referred to by the participating family members. As I was initially unable to talk to you about the research it is important that you now have some time to consider whether you would be willing for this information to be used in this study. In this pack you will find four items which will assist you to make an informed decision regarding the use of your information and then to contact me.

This information pack contains : An information sheet
 A reply slip
 A consent form
 A Pre-Paid Envelope

You are invited to read the information provided which will tell you about why the study is being conducted and what the implications are for you. Once you have had time to consider this information you may like to ask some questions. So that I can respond to these questions I will need your permission to contact you. The reply slip enclosed may be used to forward your contact details to me so that I can discuss the study with you. If the reply slip is not returned it will be assumed that you do not wish information about you to be used and your family will be removed from the study along with any data already collected.

Alternatively if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for your time

Charlotte Clark

PhD Student with the University of Southampton

PATIENT CONSENT FORM**REC Ref Number: 08/H0308/181**

(Researcher use only)

R&D Number: A091364**Family Code:****Participant Code:****Title of Project: Family Experience of Traumatic Brain Injury.****Name of Researcher: Charlotte Jane Clark**

Please initial box

1. I confirm that I have read and understand the information sheet dated: 20/10/08 (version No. 1) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that I am not required to take an active part in this study and that the consent I provide is given so that information about me can be used in this study.
4. Should I withdraw my consent at any time I understand that my family will be removed from the study along with any data already collected.
5. I agree for information about me to be used in this study.
6. I agree for you to use the information provided for this study for further analysis in the future.

Name of patient_____
Date_____
Signature_____
Name of person taking consent_____
Date_____
Signature***When completed, 1 for participant; 1 for researcher site file***

Family Experience of Traumatic Brain Injury.**Patient Information Sheet****Invitation**

Members of your family are currently participating in a research study about the experiences and support needs of families following head injury. Although you are not required to take an active part in this study it is important that you understand why the research is being done and what the implications are for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish information about you to be used in this study.

Thank you for reading this.

What is the purpose of the study?

Recovery from a head injury can be challenging for the non-injured family members as well as for the person who has had the injury. However, it is not yet understood how best to support family members at this time. Therefore, the purpose of this study is to further understand the family's experience of this injury and identify their support needs within the first year. (The study is being conducted as a requirement of the award of Doctorate of Philosophy (PhD) with the School of Health Sciences at the University of Southampton).

Why was my family invited?

Your family was invited to join this study because you had a head injury and I am particularly interested in how members of your family have been affected by this injury and what their support needs are at this time.

Up to four members of your family may be involved in this study. Approximately three other families will also be invited to take part.

Why am I being invited to agree that information which refers to me may be used in this study?

During this study situations may be discussed which contain information about you and your injury. Therefore it is important to seek your permission to use this information in this study.

Do I have to agree for this information to be used?

It is up to you to decide. The research will be suspended and no more data will be collected until your preference has been established. If you do decide that information about you may be used in this study you will be invited to give your consent for this. So that I can explain the study and respond to your questions I will need your permission to contact you. This can be done by completing the attached reply slip and returning it to me using the pre-paid envelope. These details will only be used so that I can make contact with you to respond to your questions. I will then ask to meet with you at a mutually convenient place, date and time to describe the study further and go through this information sheet. I will then ask you to sign a consent form to show you have agreed for your information to be used however, you are still free to withdraw this consent at any time and without giving a reason. A decision to withdraw your consent at any time will not affect the services you receive.

What happens in the study?

Family members who take part in this study are invited to attend three interviews and complete a questionnaire three times. The first meeting was conducted within the first month after injury and subsequent meetings arranged for approximately three and twelve months. During the interview family members are prompted to talk about their experience and support needs following the injury. Each interview takes approximately 60-90 minutes and is digitally recorded. The questionnaire asks a total of 62 questions and invites family members to respond to these by placing a tick beside one of five possible answers. Completion of the questionnaire takes approximately 15 minutes.

There are no expenses or payments available for participating in this study.

What are the possible disadvantages and risks of taking part?

It is appreciated that talking about this experience might not always be comfortable therefore the interview can be stopped at any time. Whilst it is not intended that the interview meetings should cause any distress, those who take part are encouraged to identify someone who would be available for support.

Headway's national helpline is also available to offer any support if required.

This number is: **0808 800 2244**.

What are the possible benefits of taking part?

The study is not designed to help those who take part. However, the information from this study has the potential to inform services supporting the needs of family members affected by head injury in the future.

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Once the study has been completed the information obtained will be analysed and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated at this time. Following completion it is expected that the information will be published in healthcare professional journals. You will not be identified in any report/publication unless explicit consent for this has been granted.

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contributions may be identifiable to those you have had contact with through language, familiar phrases used or situations discussed.

The interview transcripts will be stored securely in a lockable filing cabinet and will be destroyed after 15 years.

What will happen if I do not want information about me to be used in this study?

If you do not wish information about you to be used your family will be removed from the study along with any data already collected. If you initially give your consent you may also withdraw this at any time and do not have to provide a reason. You will need to inform the researcher of your intention to withdraw your consent so that your family members are not contacted again in the future. This decision will not affect any services you receive.

What if there is a problem?

If you have a concern or a complaint about this study you should contact Ms Susan Rogers, Head of Research and Enterprise Services, in the Research Support Office at the School of Health Sciences (Address: University of Southampton, School of Health Sciences, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 7942; Email: ssr@soton.ac.uk). If you remain unhappy and wish to complain formally Ms Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

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The Patient Advice and Liaison Service (PALS) at Addenbrooke's hospital has agreed to provide independent advice about participating in this study. You can contact PALS on the following number: 01223 216756

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The organisation supporting the research is University Campus Suffolk.

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Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Cambridgeshire 2 Research Ethics Committee.

Contact for further information:

My contact details are as follows:

Charlotte Clark – University Campus Suffolk, Tel: 01473 338508

Email: c.clark@ucs.ac.uk

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Family Experience of Traumatic Brain Injury.**REPLY SLIP**

Thank you for reading the Patient Information Sheet and for considering whether information about you may be used in this research study about the experience and support needs of families after head injury. To help you decide whether you would be willing for this information to be used in this study you may want to know more about the study and what the implications are for you. So that I can respond to these questions I will need your permission to contact you.

Please complete the following details and return this form to me in the pre-paid envelope. Alternatively you may be able to ask a family member to put it in the post for you. Returning this slip does not mean you have given your consent for information about you to be used in this study and these details will only be used so that I can make contact with you to respond to your questions. Please be assured that any information about you will be anonymous and confidential in any study reports.

If you return this reply slip I will contact you in the next few days. If you are unable to provide a contact telephone number because you are in hospital you may prefer to invite me to the meet with you. Following this initial discussion you will then be given at least 48 hours before a further meeting is arranged so that you can think about the study and then have the opportunity to ask any further questions. Once I have responded to your questions satisfactorily you will be invited to sign a consent form. You are always free to withdraw your consent from the study at any time without giving reason.

If you return this reply slip I will contact you in the next few days. You will then be given at least 48 hours before a meeting is arranged so that you can think about the study and then have the opportunity to ask any further questions. You are always free to withdraw your consent from the study at any time without giving reason.

If you do not return this reply slip it will be assumed that you do not wish information about you to be used and your family will be automatically removed from the study along with any data already collected.

Alternatively, if you would like to contact me directly please telephone: 01473 338508 or email at c.clark@ucs.ac.uk

Thank you very much for you time

Charlotte Clark

(PhD Student with the University of Southampton)

Family Code: (Researcher use only)

Participant Code:

Name (Please print)

Please tick the appropriate box and complete the information requested.

☐ Please contact me by telephone my number is

☐ Please visit me, the name of the hospital is

The name of the ward / department is

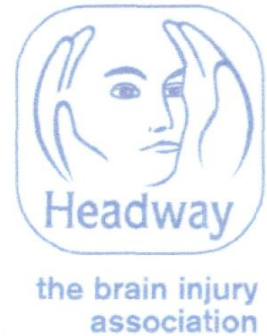
Good times to phone / visit

Times to avoid

Please put this into the pre-paid envelope provided and put it in the post. Alternately you may prefer to ask a family member to put it in the post for you.

THANK YOU

Appendix 10: Permission from Headway



Charlotte Clark

24th April 2008

Dear Charlotte,

Thank you for explaining the purpose and design of your study to us, and offering to place our details on your support materials.

Whilst we would like to make it clear we have no involvement in the study itself, Headway would be happy for you to offer our freephone helpline number to the participants. The helpline offers information, sign-posting and support to anyone affected by brain injury, and can provide details of local Headway services as well as helping people to work through their situation.

Headway is a UK-based registered charity (no 2346893) whose aim is to promote understanding of all aspects of brain injury and to provide information, support and services to people with a brain injury, their families and carers. Further information on the work we do is available on our website, www.headway.org.uk.

Yours Sincerely,

Andrew Taylor

Communication Services Executive

Telephone: 0115 924 0800
Minicom: 0115 950 7825
Fax: 0115 958 4446
www.headway.org.uk

4 King Edward Court
King Edward Street
Nottingham
NG1 1EW

Appendix 11: Generic Layout for transcripts**Interview One:**

Participant: Suzanne Barker

Participant Code: 05A

Date: 5th August 2009

Time: 10:30 – 12:00

Location: Home

Biographical Details:

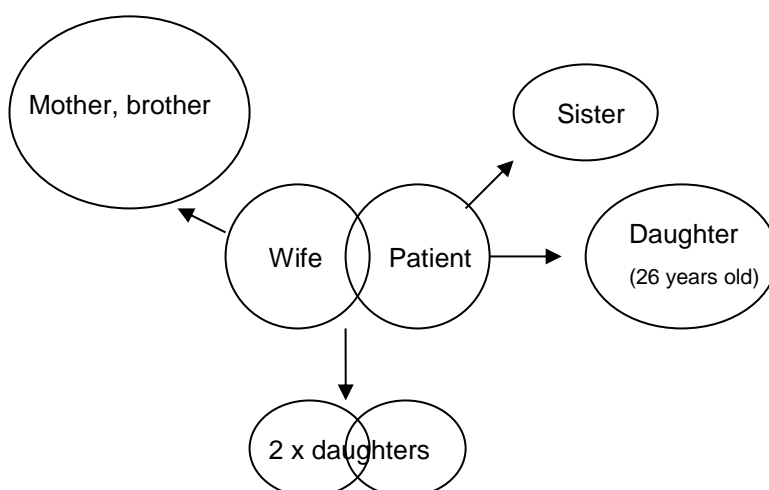
Family characteristics: Suzanne 36 married to Dave 58 two children 14, 11. Step-daughter 26 lives away. Dave's first wife died prior to the marriage. Suzanne and Emma have not always had a good relationship. Works part time as a teacher. Dave is self employed, works from home, works long hours.

Life stage: Children at school, youngest changing to middle-school.

Day-to-day function: Suzanne runs the house, looks after the children, Dave takes care of the finances, split responsibilities, defined roles.

Injury: Fell six or seven metres whilst at work, fractured base of skull, cerebral oedema, conscious on arrival, confused, agitated, sedated intubated in the critical care unit. pneumothorax, chest drain, allergic reaction, woken from sedation within two weeks, ready for rehabilitation but no beds available. Self-discharged at one month post injury.

Change: Suzanne has had to adopt the role of her husband within the business and the finances whilst dealing with her normal responsibilities. Emma has come home to help and has been taking care of the children.

Family Diagram:

Ref	Notes	Transcript	Notes
1:24:59	CC	<i>So that's recording...ok...so I'd like you to think about your husband's injury...</i>	

Appendix 12: Examples of matrices supporting narrative analysis

The purpose of presenting these matrices is to illustrate the process of narrative analysis. Therefore to preserve anonymity of the family member matrices have been substantially condensed and reduced. Original versions spanned many pages and contained all the narrative data collected.

Narrative thread	Suzanne Barker T1 Matrix	
Is my husband the same or different?	Codes	Exemplar quotes
	<p>Knew it was bad; search for information; told he won't be the same; what will be lost; discontinuity; things will change; the way he put his hands</p> <p>Memos</p> <p>Worried straight away about the brain injury and what it would mean ??suggests lay knowledge of serious outcome/problems ahead.</p> <p>Why do we tell people that 'he will be different' so early on? How does it help them? What does it do to their hope/their experience?</p> <p>So quick to tell them about difference and yet so restricted with information. How can someone be so desperate for information and then get told off for looking in the medical notes? How can you tell someone off when their husband is critically ill? Why do we get so protective?</p> <p>Suzanne then considers how 'different' he will be what will be lost, what will he forget. Although small things anchor her decision 'he is the same' there is obviously still a question over his personality because of the many other references to Dave being different than before or not yet back to normal.</p> <p>How does PTA play a role? Why do we tell them about difference during PTA? PTA is transient so ?? pointless looking for signs during this time.</p>	<p>and I thought awww [nervous laughter...] it doesn't look too good I mean it looked really serious and everyone was sitting down and he said "right...your husband had a major fall we think that, he fell probably from six or seven metres high so it's a very high height to be falling from and basically he's got, severe internal injuries, severe bleeds, severe head injuries, he got a fractured skull and he's got swelling to his brain and he's got a fractured leg..."^{22:1-8}</p> <p>I mean at the time the fractured leg wasn't an issue because I was really worried about the brain...^{23:1-2}</p> <p>...and I didn't know where I was standing and whether it was their job to do so. I didn't know. We don't...no-one tells us anything. You have to... I don't know what we were meant to be doing...you know if, I was meant to interrupt the doctors, or if I could ask the nurse or if I mean, we were trying to read the notes but we got told off one day so...[laughs]... well I just wanted information, without being too...you know...^{68:1-7}</p> <p>After his ten days of being sedated they tried to, to wake him up, and the last time it worked so we were pleased with this and erm...so he was still in intensive care and he woke up and er... he managed to say his name where he was, if he knew where he was...he said yes. You know, are you in any pain? He said no. What's your name? Dave... He couldn't remember where he lived at this stage but then it all came back, so that was quite encouraging. What I wasn't prepared for was the er...although I was told...when one of the surgeons er, spoke to me and he said, you know, when he's gonna wake up his face might just be distorted. And...you know, he might, he might look aggressive and violent but I thought well may be but...[telephone rings]...and er...when he woke up he was actually quite vocal and frontal and he said "right... er, right... er" well he couldn't remember where he was...and then he kept saying "oh right get me my clothes...take my clothes in the cupboard here and right we're going home, we're going home". And I said well Dave you can't just go home you know you're in hospital you had a nasty...I had to explain everything all the time so he'd say "oh alright, alright then lets go" [laughs]. So that was quite funny, I mean I did right a few things down that he said because they were so funny. Though it wasn't funny, but those things he said were funny in the intensive care...^{76:1-22}</p> <p>But I think he got a bit too agitated and he really wanted to go home at some stage he actually physically wanted to walk off. So we had to... I think they had to calm him down with some pills or something. Not sedation but something similar and er...and he calmed down slightly. But each time he would see me he would get really agitated. And I mean he would remember my name but he was very vocal and er, you know "get me out of here". You know...as if he was in a prison or something you felt really yeah he felt like he was restrained you know. Like somebody was holding him or something...prisoner or something like that. That was quite hard I wasn't prepared for that. Though they had warned me but not...not that well I thought, I thought I was not prepared that well^{77:1-12}</p>

Suzanne Barker Longitudinal Matrix			
Narrative thread	One Month	Three months	Twelve Months
Recovery, change and loss	Exemplars	Exemplars	Exemplars
	When he first woke up, you know, I mean I could see that... even when he was asleep, the way he was putting his hands... and I thought... oh... yes, you know, that's him... I was really worried that he would not be him at all... that was one of my worst fears, that you know if he's not like his old good self, will I still love him, and will he still love us? Will he remember what we've been through... <small>91:7-12</small>	Suzanne [T2] "And he hasn't... when they say... you know, you're husband's probably gonna be different... you know with his frontal injuries and everything... er... I don't think his personality's changed that much... he's probably more... not self-centred but he likes talking about himself... and if somebody comes and sees me for example... he would just come limping and say 'ohhh, I'm not too well or you know... do you want to hear what happened to me?' ... and I mean I do understand but he doesn't see the other, he wouldn't... make a proper conversation... he... still rather focuses ... on... 'oh what happened to me, me, me'... but... it's hard for him to... er... ask questions... for example, or to be aware, you know of how people would feel..." <small>11:1-10</small>	that's when we sort of find that... under stress doesn't cope as... as well as before... because he's sort of, sort of a calm person and... he would just deal with it you know really well... I think now he just gets really vocal and... Sometimes you know if you walk into his office and you say something her just... BURST... or he snaps or he slams or he... breaks or... that's something that you know... he never used to do before... ^{25:1-6} So we know it's not his fault... and you know put it down to... er... the accident but that's, that's the thing that... that's the sort of concern for us really... that's the only little thing that's left over from the accident... ^{26:1-3}
	Memos	Memos	Memos
	Change is predicted early, exposed to information about change and told by nurse he will be changed. What does 80% mean? What is truly too different to cope with? Making sense of predicted change by bargaining, establishing continuity and using discontinuity when needed to explain behaviours during PTA	Some slight changes are considered but not causing a problem, the most frustrating characteristic is made sense of in terms of his normal/pre-injury personality. Making sense of change by rationalising normal characteristics, age related.	Definite change identified at T3. Recovery is separated into physical-no worries, and emotional/social/behavioural. Exacerbated by hiding from clients, friend family. ?? leaves Suzanne isolated. Still underpinned by a small aspect of his character. Making sense of change as difference, unwelcome, hidden, cause for concern, left the family scarred
	Codes	Codes	Codes
	Knew it was bad, told he won't be the same, what will be lost, "he's not my husband", it almost looks like him, discontinuity, things will change, the way he put his hands, search for information.	maybe it wasn't that bad, we still don't know, he's really, really well, loss of smell, planning skills intact, worries about seizure tablets, headaches, walking, so many questions, we didn't know, need to put the pieces together.	So much improved, skills are there, looks the same, no worries, amazing, hasn't realised what's possible, working really hard, people think he's the same, don't want to disappoint.

Diane Hughes T2 Matrix		
Narrative thread		
Let down	Codes	Exemplar quotes
	Reacting to medication, useless, disillusioned, 'Get on with it', he won't be punished, the worst thing, be grateful, awful, had to fight, all we needed, constant,	initially she was reacting to her medication, to her epileptic medication... and erm... she came out of hospital basically... still allergic to the phenotoin she'd been put on... which like had an impact on us because... she was giddy all the time... she was... nauseous... she felt ill... erm... she was, had quite a problem over sorting her out being seen by the GP... and he kept saying... 'well I suspect an all[ergy]' erm he didn't say allergy he thought possibly a viral thing... even though I said that I felt it was probably an allergy to the phenotoin... and... he said you've just got to get on with it, it will clear up... and until we actually saw the neuro doctor... erm... in [name of place]... the neuro-rehab doctor and that was about three
	Memos	
	Diane talked about the good recovery but all is not well and	

	<p>you can tell this is difficult. The home is a 'sick bay' and she's the nurse.</p> <p>This issue of reacting to the medication is so traumatic for Diane. She knew something more than viral was wrong with her daughter but couldn't get her GP to acknowledge her concerns. The idea that someone would say 'get on with it' devalues her concerns.</p> <p>Diane calling her home a sick bay brings to mind the image of everything revolving around Abbey being ill, vomit bowls, the wheelchair. What does it do to you when you can see your daughter is not improving, after all you have been through to get where you are, and no one seems to give you the time. What Diane talks about needing is not very 'big' in her eyes 'all we needed' and that probably makes it even worse.</p>	<p>weeks after discharge... and she said... 'ah, get her bloods checked and... I'll speak to your GP' and it... he, they then changed her medication... which was fine for about... a week... and it all started again... she was... physically throwing up and... covered in a rash and it was the new medication so we changed to tegratol... she's now on epilim... so with that sorted... erm...^{7:1-14}</p> <p>you know the worst thing, I just think when I look back... the doctors don't actually come and see you at home any more... mmm... [crys]... [pause]... even if, you know, when she was sick... err,[crys]... they just don't come and see you... you ring them up... they don't answer your phone or say they'll get him to ring you later and he doesn't ring back... then you get told 'OH WELL, terrible accident'... [sniffs]... er... 'thank God she's doing well'... and er... just be grateful... grateful that she's improving... and I just can't get over how awful they are... [sniffs]... I mean years ago... you got in from hospital... you handed your letter in... and the doctor came to see you at home and he knew what she was like from a bit from discharge... and they saw you at home...^{43:1-18}</p> <p>I think we had... I didn't even get a phone call... nothing... it wasn't until... I rang them and said I was worried about her medication I didn't think I'd been given tablets correctly... and he said 'oh I'll get'... he said 'can you bring her to the sur[gery], bring her, take her... to get her blood taken at the hospital'... or erm... 'would you like the district nurse'... I said oh I think we'll have the district nurse... so they did check her blood levels and as it happened... that was fine there wasn't a problem... but he never saw her once... I can't get over how dreadful, dreadful... I just think God... I can't get over how the NHS is so awful... to people when they're at home... even all over with my mum... I just can't get over it... I've been nursing since I was seventeen ... [crying]... and I know I trained in the days when you had matron... and it was, you had district nurses... you had doctors that saw you... when you went sick... if you had child who was ill they came and saw you... [finding it difficult to speak]... I just don't... I've had to fight all the time... and it's nothing majorley wrong with her... that she's got over the accident... there's no thanks to them... I don't think so really... and to think my GP is the head of the... the practice... and he's telling me every single complaint that she had, and it was on the list of allergies... was a viral infection... I could not get over it... I just... I just could not get over it, even when I said she's covered in a red rash... he couldn't, he couldn't even accept that it could be an allergy to her medication...^{44:1-19}</p>
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Diane Hughes Longitudinal Matrix			
Narrative thread	One Month	Three months	Twelve Months
The shifting shape of family life	Exemplars	Exemplars	Exemplars
	<p>Er.... Er... I think... I think, what's come out of it, well I suppose you say 'ooo yes we got closer', but I think it's become more...obvious in some way, it, it can't be helped I mean obviously that Abigail has become more important, if you know what I mean...^{141:1-4}</p> <p>But I feel, it's brought the others, it's has brought them all closer together again, which they probably started to grow apart a little bit with college and things... and Lucy's been... both girls have been the same but... but I think, yeah Elizabeth's been like glued to the bed... at one point we couldn't get her away, we used to have to make her go and have a break... or take her away for a walk, go off and have a cup of tea... but the girls have been very, like, we're all very close...^{144:1-7}</p>	<p>Yeah but the family... yeah the same, the dynamics, had had changed in their... family how... the younger girl was... having to drive the older sister around... and take her shopping... and stay with her and look after her sister... because her sister was too frightened to go out ... 'cause she was frightened about being attacked again... well I mean Abbey hasn't got that but ... the same thing as... Liz's sort of saying do you want me to pick you up if she's over at her boyfriend's over at [name of place]... 'shall I pick you up Abigail... you know there's that kind of consideration always has to be thought of now... but Abbey has to rely on the family more... than she did in the past and erm...^{23:1-9}</p>	<p>when they were small... Abigail and Lucy were like together and Liz used to get the grotty dolly... [laughs]... because they were like together... so maybe that's... it's a shock for Lucy to realise that either... they're not as good as they were... in the past...^{104:3-6}</p> <p>I think... I think looking back... you know with everything I think... we've coped quite well as a family I think.... And I think Abbey has done really well... but she doesn't really understand how well she's done... she's doesn't seem to... although she watched the programme... it was almost like well... that was them... I'm me... and...^{23:1-5}</p>
	Memos	Memos	Memos

	All together through recovery, life stage of the family is moving on and moving away but the injury brings them closer and Abbey becomes more important. Being brave, being together, being there	Family adjusting getting back to normal, Abbey takes centre stage to help her recover, but not sleeping. Getting back to normal, more adjusted, but affected	Relationships between sisters has changed, Lucy hadn't realised, everything has utterly changed for the family, like a ripple on pond that keeps going, will it stop, would it have been easier if she had been more severely injured? It's completely changed everything for the whole family
	Codes	Codes	Codes
	going home, normality, brave, coping, good unit, seeing others	It has affected everybody, Will we get on, getting back to normal, more adjusted, not sleeping,	Looking back , seem alright, coped well, she doesn't understand, future not the same, don't look too far, pebble in the water, changed everything

Appendix 13: Description of Six family types from FACES-IV (Olson & Gorall 2006, p 8)

Cluster 1, *Balanced*, is characterized by the highest scores on the balanced subscales of Cohesion and Flexibility, and the lowest scores on all of the unbalanced scales except rigidity, where the scores are near the lowest. This combination of high balanced and low unbalanced scores indicates a family type with high levels of healthy functioning and low levels of problematic functioning. These families are hypothesized to be able to best handle the stressors of daily living and the relational strains of changes in the family over time. This family type is the least likely to be seen in therapy.

Cluster 2, *Rigidly Cohesive*, is characterized by high closeness and rigid scores, moderate change and enmeshed scores, and low disengaged and chaos scores. This family type has as its hallmark high degrees of emotional closeness and high degrees of rigidity. This family type would be hypothesized to function well at times given their high degree of closeness. However, they may have difficulty making the changes required by situational or developmental changes due to their high rigidity.

Cluster 3, *Midrange*, is characterized by moderate scores on all of the subscales with the exception of the rigid subscale. The cluster values of the rigid scale fall into two groups, high and low, apparently due to the bi-modal distribution of the percentile values for this scale. Thus the rigid value, even for this midrange cluster, falls into either a high or low grouping. This family type would be hypothesized to function adequately, displaying neither the high levels of strength and protective factors tapped by the balanced subscales, nor the high levels of difficulties or risk factors tapped by the unbalanced subscales.

Cluster 4, *Flexibly Unbalanced*, cluster is characterized by high scores on all of the subscales other than Cohesion, where moderate to low scores are characteristic. The high scores on the unbalanced subscales combined with the low to moderate scores on Cohesion, would seem to indicate problematic functioning, however the high scores on the Flexibility subscale may indicate that these families are able to alter these problematic levels when necessary. Of all the family clusters this one is the hardest to characterize clearly.

Cluster 5, *Chaotically Disengaged*, is characterized by low scores on the balanced subscales, low scores on the enmeshed and rigid subscales, and high scores on the chaotic and disengaged subscales. These are hypothesized to be high problem families based on the lack of emotional closeness, indicated by the low closeness and high disengaged scores, and the high degree of problematic change indicated by the high chaos and low change scores. This family type may be as problematic as the unbalanced type discussed below as the two indicators of lesser problems for this type, low enmeshed and low rigid scores, are also the two subscales which are the least effective in differentiating between problem and non-problem groups.

Cluster 6, *Unbalanced*, is almost an exact mirror image of the balanced family type. The unbalanced family type is characterized by high scores on all four of the unbalanced scales, and low scores on the two balanced scales. These families are hypothesized to be the most problematic in terms of their overall functioning. They have problematic functioning, indicated by high scores on the unbalanced scales, and lack the strengths and protective factors tapped by the balanced scales. This is the family type most likely to be seen in therapy.

Appendix 14: Circumplex Model (blank)

Circumplex Model & FACES IV

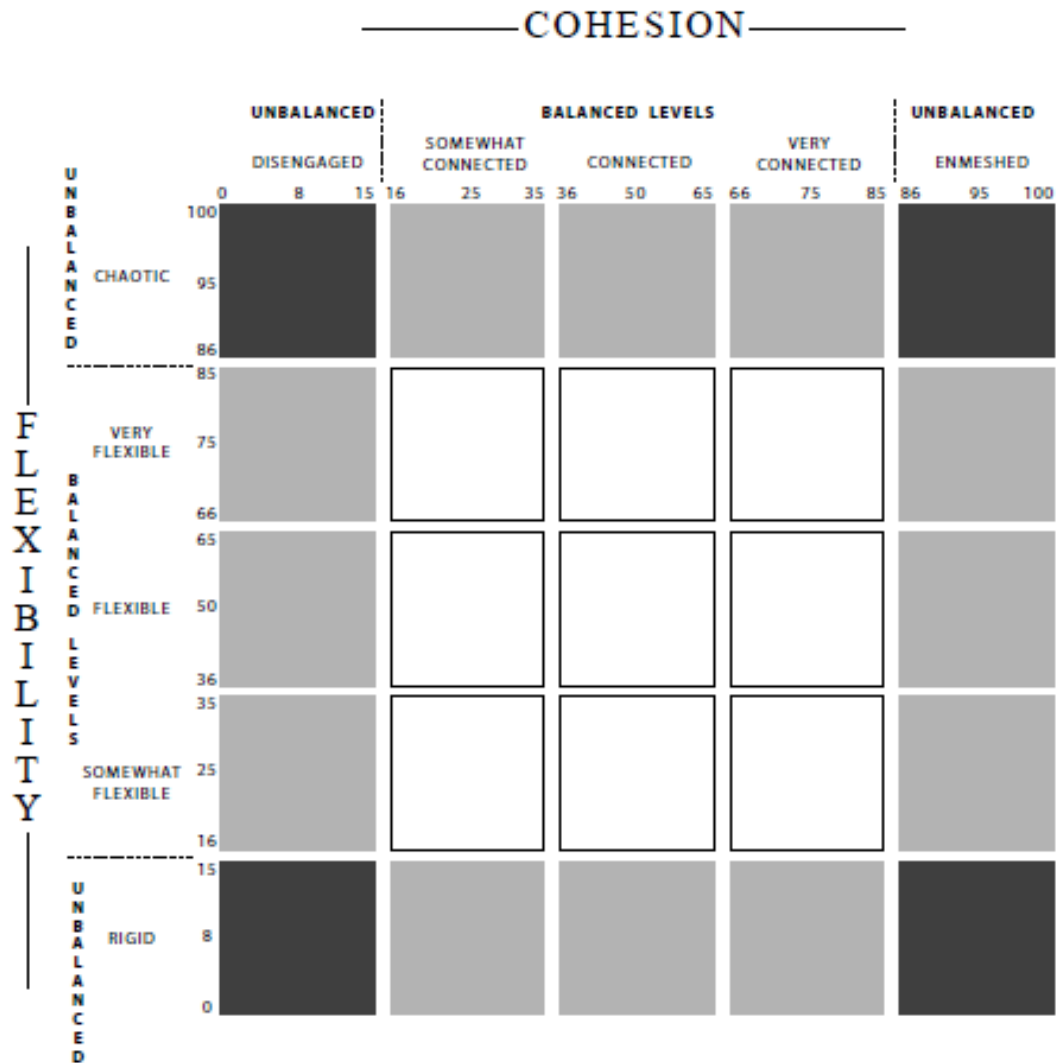
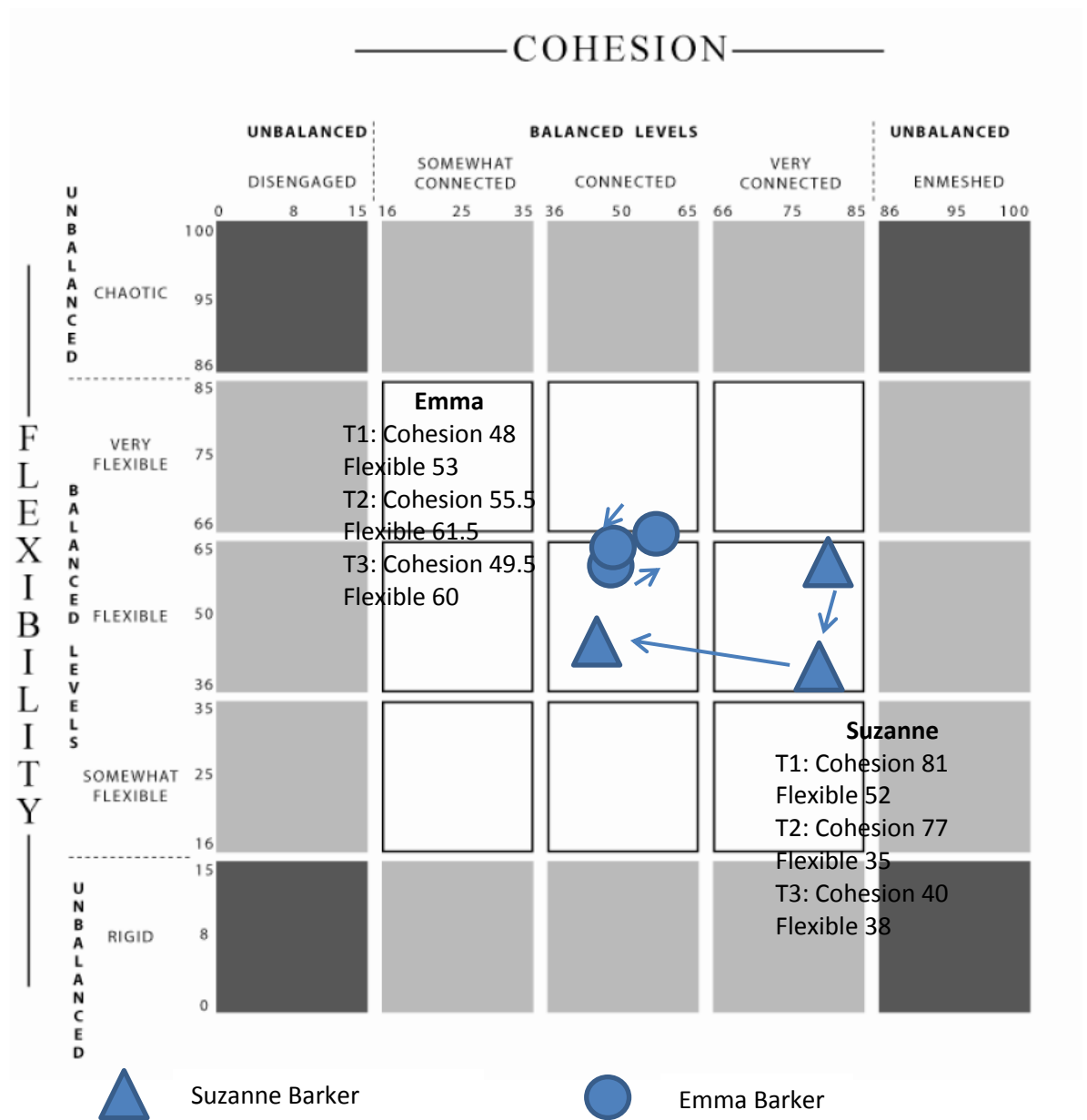


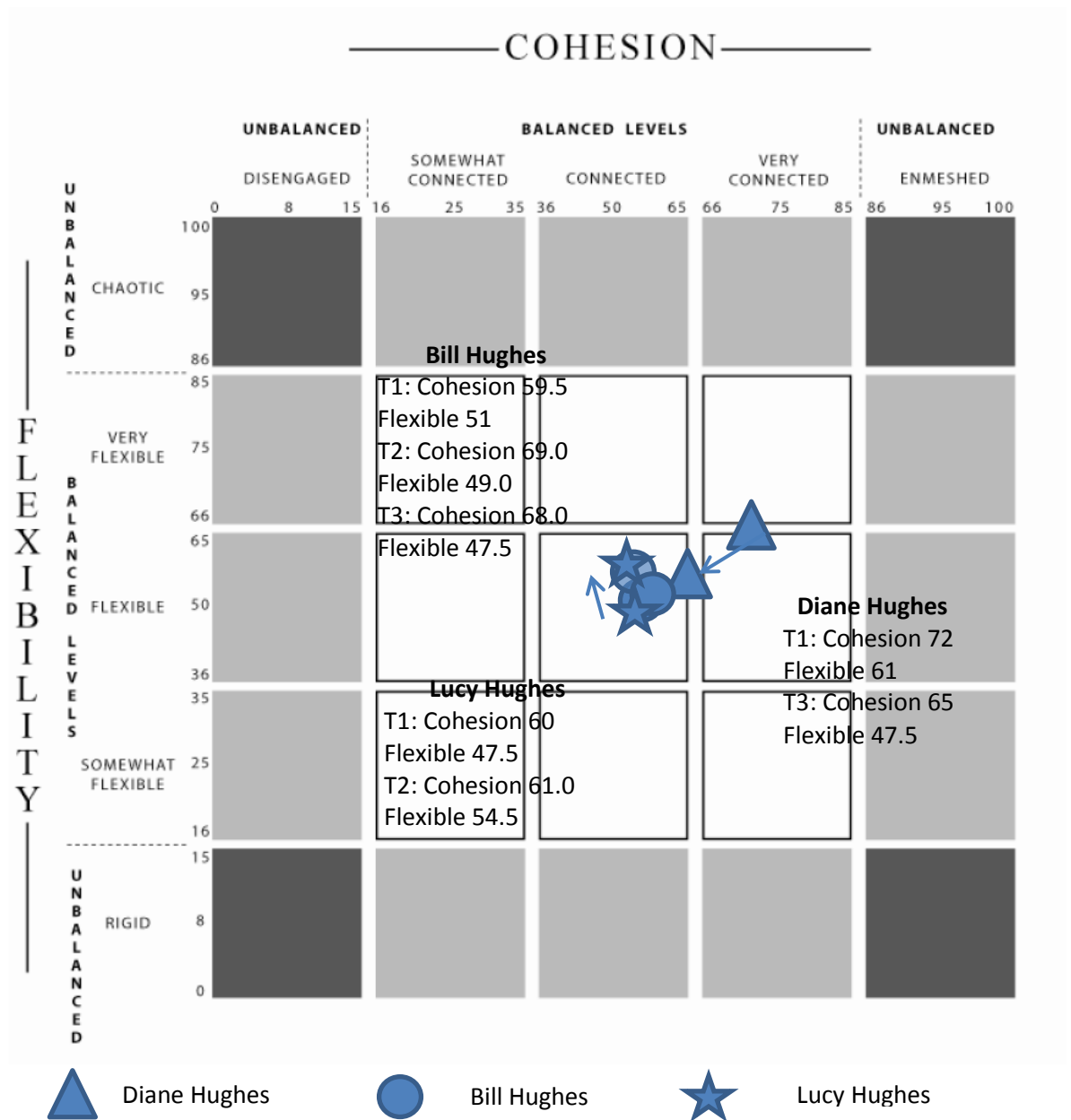
Figure 3.7 Circumplex Model by Olson et al 2003 (reproduced with kind permission of Life Innovation Inc.)

Appendix 15: The Barker Family Circumplex Model



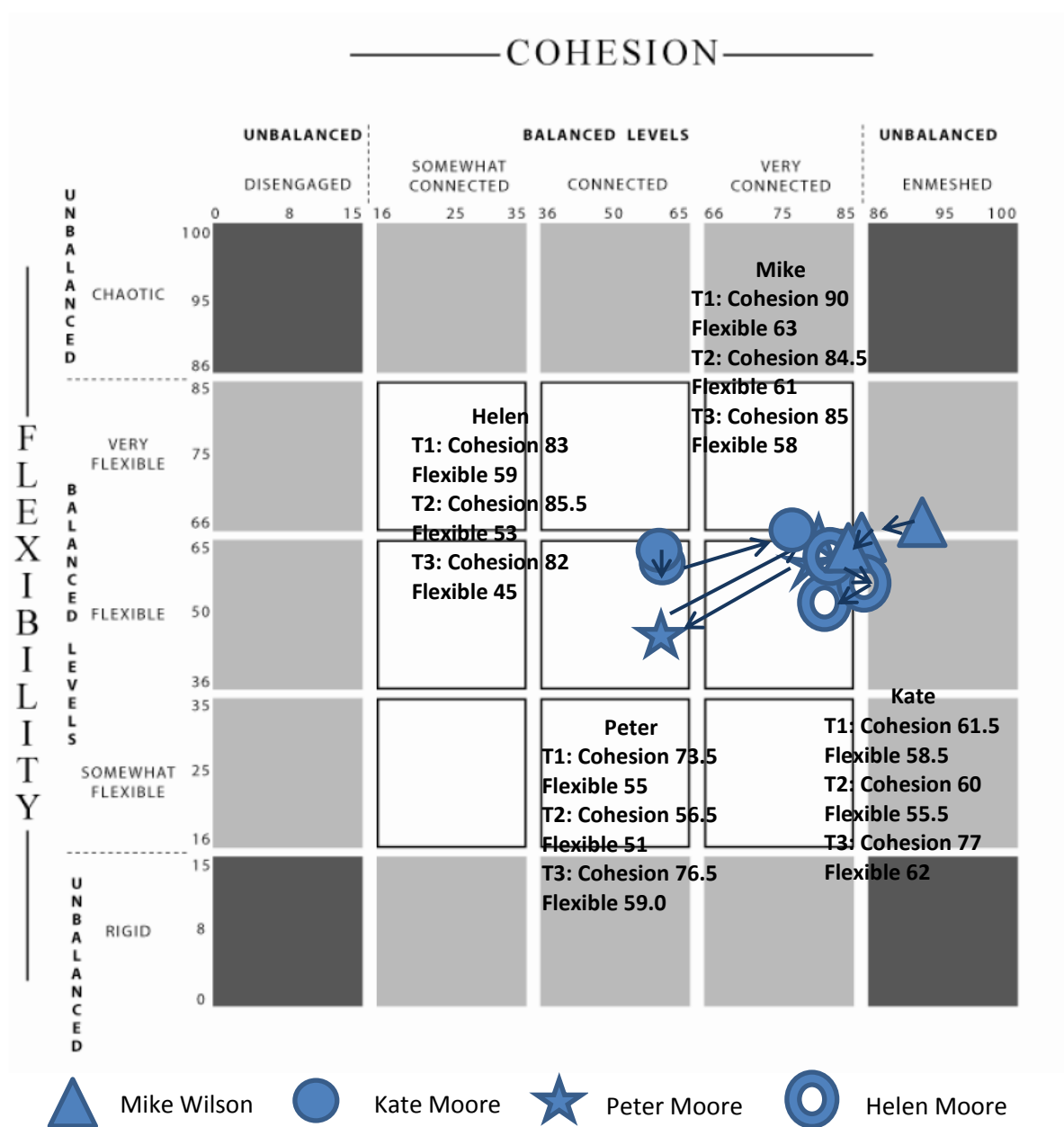
T1: one month T2: three months and T3: twelve months

Appendix 16: The Hughes Family Circumplex Model



T1: one month T2: three months and T3: twelve months

Appendix 17: Wilson Family Circumplex Model



T1: one month T2: three months and T3: twelve months

Appendix 18: Reprint of **Clark, C., Brown, J., Bailey, C. and Hutchinson, P. (2009)** Supporting families in the context of adult traumatic brain injury, *British Journal of Neuroscience Nursing*, 5(5) 216 – 220

CLINICAL

Supporting families in the context of adult traumatic brain injury

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Families are fundamental to the wellbeing, quality of life and functional and/or social outcomes of individuals who sustain traumatic brain injury (TBI) (Turner-Stokes, 2003). However, the family is often vulnerable and at risk from the challenge of supporting an individual who has been left with long-term neurological disability. In 2007, Jumisko et al argued there was a general lack of understanding about the challenges faced by families affected by TBI. This lack of knowledge may account for why health services appear limited in their capacity to effectively help such families (Ellis-Hill, 2001). A 'whole-family approach' to managing TBI is a new innovation recommended by the National Service Framework for Long-term Conditions (NSF-LTC) (Department of Health (DH), 2005), but there needs to be greater clarity about what this approach is and how it can be supported in practice. This article aims to bring together the evidence base in relation to this whole-family approach and its application in practice. Both family systems theory and family-centred care will be explored

as possible frameworks to achieve a whole-family approach. The implications of family-centred care will be discussed and recommendations will then be made for how the evidence base may be developed in the future.

Brain injury

An injury to the brain occurring at any time after birth is classified as an acquired brain injury (ABI) (Cree, 2003). ABIs are characteristically sudden-onset conditions that are followed by varying degrees of recovery (DH, 2005). Nontraumatic injuries are caused by strokes or infections and are therefore different from traumatic injuries that may be caused by falls, assaults or road traffic accidents (Hickey, 2003). Hospital episode statistics for 2005–2006 show head injuries to account for approximately 150 000 admissions per year to NHS hospitals in England (Hospital Episode Statistics Online, 2007). Those who sustain head injuries are predominantly men; some figures suggest a 2:1 ratio of male to female (Hospital Episode Statistics Online, 2007) and others estimate a ratio of 3:1 or higher (Powell, 2004). Age is also known to be associated with a higher risk of head injury with a large number sustained in the younger population (between 16–25 years) (Sorenson and Kraus, 1991). The association between head injury, age and gender has been attributed to the increased likelihood of these groups engaging in more high-risk behaviour (Powell, 2004). TBI therefore poses a major challenge for healthcare services (Engberg and Teasdale, 2004).

Many of those who recover from a TBI never return to their previous life and will have some change to their previous level of functioning. Wood et al (2005) suggested that diverse and complex physical or cognitive changes are a 'frequent legacy' of brain injury. These changes can require small adjustments in daily routines or complete dependency on others for every activity of daily living. Sequelae range from deficits in motor and physical ability, psychosocial and emotional challenges (Donnelly et al, 2005) to memory loss and attention difficulties (Engberg and Teasdale, 2004; Wood et al, 2005). As young people are frequently affected, the resulting conditions can have a significant emotional and financial burden for families and services providing for their long-term needs (Gottesman et al, 2003). Furthermore, life expectancy is

ABSTRACT

Families are fundamental to the wellbeing, quality of life and functional and social outcomes of individuals who sustain traumatic brain injury (TBI). However, the family is often vulnerable and at risk from the challenge of supporting an individual who has been left with long-term neurological disability. Considering the young population often affected, the resulting conditions can have significant emotional and financial burden for families and service providing for their long-term needs. The National Service Framework for Long-term Conditions acknowledges that the whole family is affected by neurological disability and it suggests that a 'whole-family' approach to managing TBI may be useful. This paper will argue that both family systems theory and family-centred care are frameworks that may be helpful in achieving the 'whole-family' approach in practice. However, future research is needed that will assess the efficacy of these and other approaches so that health-care services know the true value of any such intervention.

Key words

■ Traumatic brain injury ■ Whole-family approach ■ Family-centred care ■ Family systems

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usually only minimally reduced, so the individual and the family will live with the consequences for many years.

The importance of family

The importance of a supportive and well-functioning family often emerges as a key finding regarding the experience of living with, caring for, or being affected by another person's TBI (Wells et al, 2005; Hanks et al, 2007; Jumisko et al, 2007; Yeates et al, 2007). Wells et al (2005) surveyed 72 family members who identified themselves as the primary carer. Although caring was generally regarded more positively than negatively, it was the family as a support mechanism that featured as a significant moderator of negative feelings about caregiving and also for feelings of anxiety and depression. In a study of 60 primary caregivers, Hanks et al (2007) also found the family to be important. Hanks et al observed a strong relationship between both effective family functioning and social support with appraisals of caregiver burden, relationship status and sense of caregiving mastery.

The experiences of 170 caregiving siblings were investigated by Degeneffe and Lynch (2006) who identified a significant relationship between the perceived lack of social support and increased levels of depression. Within the qualitative literature Wongvatuny and Porter (2005) interviewed seven mothers of young adults with TBI. Their results showed that support from the rest of the family can act as a moderator of depressive symptomatology such as anxiety, stress and sleep disturbances.

A supportive and well-functioning family system is therefore a crucial component of positive experiences following TBI for both injured and noninjured members. However, Duff (2006) identified that much of the relevant literature in this field used a cross-sectional design to investigate family outcomes and thus these are limited to only a snapshot of the experience. Duff suggested that research has not yet established how the family evolves over time, and has only just started to explore the complexity of family contexts, family capacity, resilience, and the process of family adaptation.

Policy

In March 2005 the NSF-LTC was launched and focused on neurological conditions, although it can be applied to anyone with a long-term condition (DH, 2005). The NSF quality recommendation 10 (QR10) outlines the government's strategy to support families and carers. Although QR10 initially identified the need to support carers both in this role and as people in their own right, it went on to acknowledge that the whole family is affected by TBI. It then suggested that a 'whole-family approach' to managing TBI may be helpful (DH, 2005). In contrast to previous policy (DH, 1999; 2000) and statutory acts of law—Carers (Recognition and Services) Act 1995; Carers (Equal Opportunities) Act 2004—which imply there is a 'carer' and a 'cared-for', the NSF-LTC recognized that TBI and other long-term conditions affect more than just the identified primary carer. Therefore it would seem rea-

sonable for services to reflect this and address the support needs of the whole family.

More recently, Lord Darzi's review of the NHS set out an agenda for the future of health and health care (Darzi, 2008). The review included long-term conditions as a priority and advocated that all those with a long-term condition should have a personalized care plan. The care plan would organize services around the service user's individual needs. This personalized care was previously outlined in the White Paper, *Our Health, Our Care, Our Say* (DH, 2006); however, Lord Darzi's review suggests that in the next 2 years, all of the 15 million people in the UK with long-term conditions should be offered a personalized care plan. These plans are dependant on partnership working between service users and the professionals who deliver those services. Lord Darzi's review states that:

Personal care also considers the needs of the patient within the context of their support network, including carers, family and employers.

This statement identified the need to consider the family context of the person whose health-care needs are of primary concern. Understanding family dynamics is therefore an important consideration in planning care of individuals with TBI. Working more closely with families may therefore help achieve more effective and individualized care. Planning care in this way may improve not only the life of the injured person but also the lives of the rest of the family who are also affected by the injury.

Working with families

Defining the family is traditionally problematic and definitions are often restrictive. This may be one reason why working with the family is challenging. The family structure may be nuclear or extended, traditional or contemporary and it is difficult to apply one single definition (Broderick, 1993). However, Shields et al (2007) developed Nixon's 1988 definition of family to include 'significant others' who do not usually cohabit with the family. Further to this, the definition also allows those in nontraditional family roles, i.e. guardians, to be considered as an integral part of the family structure. Nixon's inclusive definition (Nixon, 1988; Shields et al, 2007) may therefore be useful to health-care practice:

The family is a basic social unit having at its nucleus two or more persons, irrespective of age, in which each of the following conditions are present:

- a) the members are related by blood, or marriage, or adoption, or by a contract which is either explicit or implied
- b) the members communicate with each other in terms of defined social roles such as mother, father, wife, husband, daughter, son, brother, sister, grandfather, uncle, aunt
- c) they adopt or create and maintain common customs and traditions.

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Table 1. Key points of family systems theory

A family's structure and organization are important factors determining the behaviour of family members
Family functioning cannot be fully understood by simply understanding each of the parts
The parts of the family are interrelated
One part of the family cannot be understood in isolation from the rest of the system
From: Walker and Akister, 2004.

One of the strengths of this definition is that it makes clear that families have unique ways of existing together. One approach to improve collaboration with families is to explore and understand these unique dynamics and the wider family context. A family systems approach may be helpful in achieving this and improving family support (Kosciulek, 1996; Kosciulek and Lustig, 1999; Curtiss et al, 2000; Gan et al, 2006; Yeates et al, 2007).

It is also possible that family-centred care could provide a practical framework for brain injury services to achieve the whole-family approach advocated by the NSF.

Family systems

Family systems theory views the family as consisting of structure, rules of operating and established methods of communicating (Maitz and Sachs, 1995). Family systems theory also illustrates how one part of the family cannot be understood in isolation from others. This enables examination of how changes in one member cause changes to occur in other family members and how the system as a whole then responds to this change (Maitz and Sachs, 1995; Walker and Akister, 2004) (*Table 1*). Although a conceptual framework, the model adopted by Turnbull and Turnbull (1991) may be helpful to understand the family within the context of TBI (*Figure 1*). This model places family members at the centre and starting from this point, family characteristics, the family lifecycle and family functions are considered.

Boschen et al (2007) explained that, although a systems approach is often advocated within the literature, few studies have actually employed this within their research design. However, Yeates et al (2007) did apply a systems approach in a qualitative piece of research where both the injured person and the primary carer were interviewed. They identified that family members used previous knowledge of the injured person as a resource to make sense of what was seen or experienced after injury. This knowledge

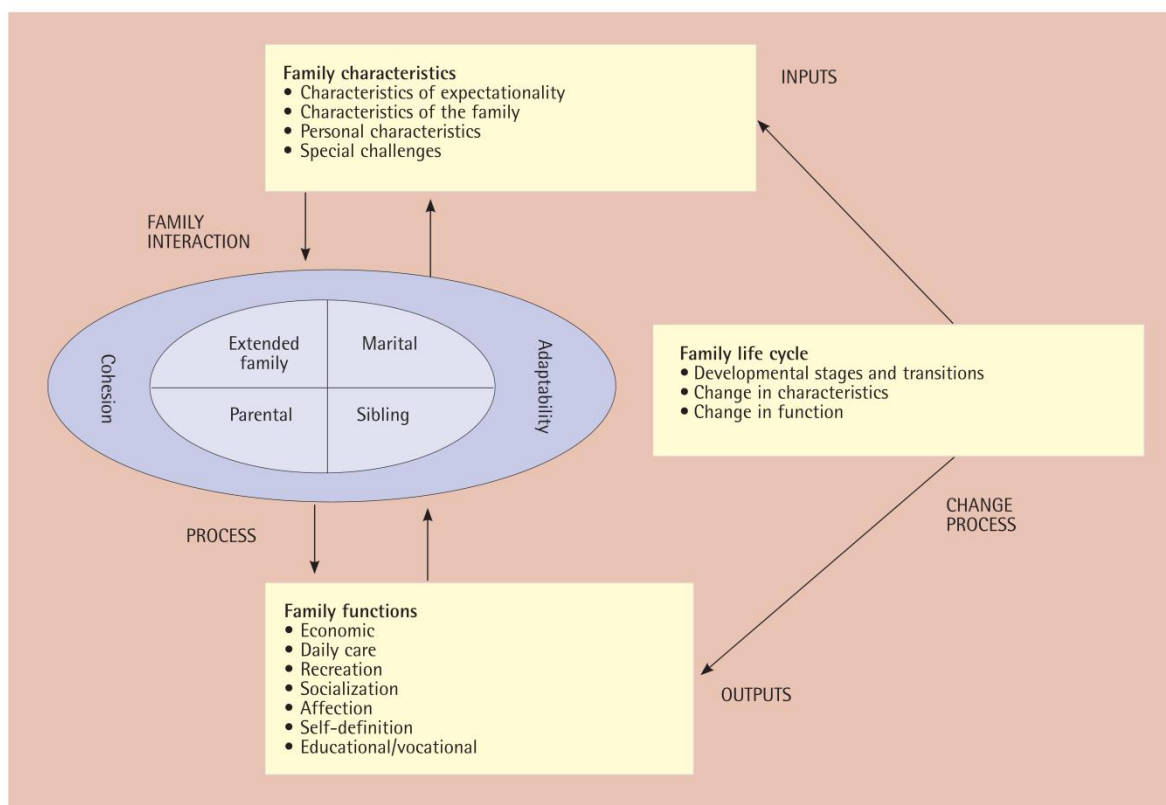


Figure 1. Family systems conceptual framework (Turnbull and Turnbull, 1991: 39).

was contextually bound within the family system and as such family context was a significant feature of the family member's ability to make sense of brain injury and the subsequent life changes that followed. This study illustrates the importance of the exploration of family contexts and the family system in order to understand the family experience of TBI.

Family-centred care

The publication 'People first: A shared vision and commitment to the transformation of adult social care' (DH, 2007) described how services should be personally tailored to meet individual needs. MacKean et al (2005) argued that, by comparison with other fields of nursing, children's services are far closer to this personalization agenda because of the well-established use of family-centred care. Family-centred care within children's nursing is promoted as the underpinning philosophy of the care of children (DH, 1991; Audit Commission for England and Wales, 1993) and emerged through the understanding that the presence of parents was beneficial to the sick child's recovery (Hutchfield, 1999). Family-centred care helps parents to continue in their established caring role (Brunner and Suddarth, 1989). Later in the child's life, as parental roles change, older children are expected to take more of an active role in their own care (Shields et al, 2008). Family-centred care accepts that a child's health is interdependent on family members, specifically parents, and this collective effort aims to support attainment of the child's desired health and social outcomes. Similarly in

TBI the family is required to care, support and adapt in response to the needs of the injured member. Therefore, although family-centred care is not applied in the same way in the adult setting, a holistic approach to care should involve consideration of, and collaboration with, the family.

Definitions of family-centred care vary greatly (Hutchfield, 1999) and they usually refer to care of the child; however, the definition from the Institute for Family-Centered Care (2008) illustrates how the theory can extend beyond the paediatric setting:

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practised in any health care setting.

Family-centred care is said to consist of nine elements that assist health professionals to work with parents and families to improve the care received by children (Shelton et al, 1987; Johnson, 1990). It would not be appropriate to transfer these principles directly to the care of an adult, however, further development of these principles suggest how family-centred care may be applied within the context of brain injury (Table 2). These should be viewed as principles of good practice and used as a framework to managing TBI within the context of the whole family.

It is important to acknowledge that not all family-centred care is implemented well. Darbyshire (1994) and Coyne (1996), for example, reported that the roles of family members and professionals are not always negotiated or clearly understood. This can lead to poor communication and lack of satisfaction with care. Shields et al (2006) suggested that nurses may be taking parental participation in care for granted and this is causing parents to feel resentment. If family-centred care were to be adopted in brain injury services, careful implementation would be required so that the same problems are not encountered. Finally, although there is a large amount of anecdotal evidence regarding the value of family-centred care of children, a Cochrane review concluded that insufficient rigorously-conducted research was available and that it was not possible to measure the efficacy of this approach (Shields et al, 2007). Careful studies of the potential role and effectiveness of family-centred care in brain injury services is therefore a prerequisite of any change.

Conclusions

Applying a family systems approach to understanding family dynamics and the family context may help practitioners plan more individualized and effective care. Using family-centred care is one possible framework to develop care delivery. However, there is currently little evidence to suggest family-centred care within the adult setting will be helpful. Future research is needed that will suggest ways in which the whole-family approach to managing

Table 2. The elements of family-centred care

Recognizing the family as a constant in the patient's life, while the service systems and personnel within those systems fluctuate
Facilitating family-professional collaboration at all levels of health care
Honouring the racial, ethnic, cultural, and socio-economic diversity of families
Recognizing family strengths and individuality and respecting different methods of coping
Sharing complete and unbiased information with families on a continuous basis
Encouraging and facilitating family-to-family support and networking
Understanding and responding to patient and family needs as part of health-care practices
Adopting policies and practices that provide emotional and financial support to meet the needs of families
Designing health care that is flexible, culturally competent, and responsive to family-identified needs
From: Adapted from Shelton et al, 1987; Johnson, 1990.

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TBI can be achieved. Qualitative research will help in the early stages of understanding family in the context of TBI. Evidence developed in this way may reveal a framework for modelling interventions which are responsive to the needs of the whole family. The efficacy of any such model should then be rigorously evaluated through a quantitative research design. Health-care services may then know the true value of any such intervention for patients and families affected by TBI.

BJNN

Acknowledgments: Figure 1 is adapted by permission of Paul H. Brookes Publishing Co., Inc.

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Conflict of interest: none

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KEY POINTS

- A whole-family approach is required to manage long-term neurological disability
- A supportive and well-functioning family is an important component of positive experiences following traumatic brain injury
- Understanding the family system may help care providers to plan individual and effective care
- If carefully implemented, family-centred care may provide a framework to assist practitioners to work with the whole family
- Future research is needed to evaluate interventions that are used to manage traumatic brain injury in the context of the whole family

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