

Investigating the Family in Traumatic Brain Injury (TBI)

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1:1 Introduction

The research thesis will be outlined to provide a summary of the structure and underlying themes.

Unlike the two research papers, this introduction is not intended for publication. Referencing for this section and the concluding section will be in American Psychological Association (APA) format, 6th edition. A summary of the subject area will now be provided followed by a breakdown of the thesis sections.

Traumatic brain injury (TBI) belongs to a classification of injury called Acquired Brain Injury (ABI). ABIs are brain injuries that have occurred since birth with possible causes including stroke, haemorrhage and infection (Powell, 2004). TBIs are a result of insults to the brain from external forces. TBI can lead to altered states of consciousness along with impairment of cognitive, physical, and psychosocial functions (Dawodu, 2011). The current research base has often recruited people with a variety of ABIs. This has been a criticism of the literature as ABIs do not affect individuals in the same way, with survivors presenting with a wide range of impairments which family members must adapt to (Newby & Groom, 2010). This thesis will focus on TBI as a distinct sub-group.

Literature referring to TBI will primarily be used. The empirical study will recruit family members of those specifically with a TBI. The narrative review will review papers primarily derived from TBI literature alongside those that explicitly refer to TBI.

Both ABI and TBI have significant psychological consequences for the individual and the wider family system (Panting & Merry, 1972; Lezak, 1986; Carnes & Quinn, 2005; Holm, Schönberger, Poulsen, Caetano, 2009; Braine, 2011). Research focused on the family in ABI /TBI has advanced in recent years, yet there is still much to learn about family functioning post injury, and equally how research can advance understanding of the best interventions to aid family members (Oddy & Herbert, 2008). This thesis will be divided into three sections and each will have a specific focus. The overarching theme will be considering how research and practice in TBI can be understood as a social phenomenon. Bowen, Yeates and Palmer (2010, p. 304) discuss that there is a need to see “brain

injury as existing within the spaces between people”. A focus on systemic thinking in conceptualising brain injury will first be applied to a narrative review.

Section 2: Adult Traumatic Brain Injury (TBI): A narrative review of family therapy as a conceptual model in research with family members.

This paper is formatted for submission to *The Journal of Head Trauma Rehabilitation*. Referencing is in the style of the American Medical Association Manual (AMA). A narrative review enables the collection and summarising of a large volume of literature in a subject area. A narrative method was preferred to a systematic review due to the paucity of empirical studies within this area. To ensure transparency in identifying papers a systematic review method of searching was selected. The rationale for the review centred on the relative lack of studies within the TBI and family literature which use underpinning epistemologies or conceptual frameworks to support their inquiries. The review addressed two research questions:

- What are the essential attributes of the model of family therapy when applied to TBI?
- How could this model be applied as a conceptual framework in TBI research?

The findings will propose that, family therapy could provide a conceptual framework to guide research and give it greater coherence. A guiding conceptual framework is presented which is then discussed in relation to its implications for research and practice.

Section 3: Sense-making through observation and action: A grounded theory study investigating how family members of traumatic brain injury (TBI) patients construct an understanding of injury

Following on from the narrative review will be a grounded theory empirical study. The paper is formatted for submission to *Brain Injury*. The referencing is Council of Science Editors (CSE) format. The study aimed to address some of the considerations for future research in the narrative review, primarily that there is a greater need “to have an appreciation of the family as more than a collection of individuals living together in the same physical or psychological place” (Leaf, 1993, p.

543). Additionally, that current theory is stronger in terms of understanding the consequences of brain injury but relatively lacking in terms of understanding the family's response (Perlesz, Kinsella & Crowe, 1999). The rationale for the study is outlined before the methodology is delineated. An epistemological position of constructivism was used to try and investigate a number of aims centring on how family members make sense of TBI. The paper will present a model of sense-making that developed from a grounded theory design as set out by Strauss and Corbin (1998). The empirical paper will discuss the findings in terms of their implications for practice and research alongside strengths and limitations of the study.

Section 4: Concluding section – Subsections 4:1, 4:2, 4:3.

The concluding section will use the APA style. This section is aimed at expanding upon the research papers and providing a more in-depth exploration of the work. It will be split into three sections:

4:2: Extended discussion

The first section will provide a general overview of the empirical study and the narrative review. The methodological considerations of both of these papers will be discussed in relation to process issues, strengths and limitations. There will also be an expanded discussion on the papers' relevance for theory, research, and practice.

4:3: Lay summary

It is well understood that academic work should be widely shared to be most beneficial. It needs to be determined how non-specialists can access the work (Rowan, Gale, Whaley & Tovar, 2005). A short lay summary of the empirical research will be provided that could be used for wider dissemination of the research. This summary is intended for publication in the charity *Headways*' newsletter.

4:4: Research proposal: Dynamic influences in sense-making processes within families of Traumatic Brain Injury (TBI) survivors

The research proposal will outline the general background and rationale for the study. The aim will be to address some of the criticisms of the empirical paper. The main critical point to address will be the empirical paper's focus on individual sense-making as opposed to collaborative sense-making. The methodology of analytic induction (Znaniecki, 1934) will allow hypotheses from the empirical study to be investigated. The research questions will be:

- How do families interactively make sense of TBI?
- What specific interactional behaviours contribute to the interpretation process?

The proposal will outline the hypotheses, methodology, ethical issues and the manner of data analysis.

This concludes the thesis overview and the sections described will now be presented in order.

1:2 References

- Bowen, C., Yeates, G., & Palmer, S. (2010). *A Relational Approach to Rehabilitation: Thinking about Relationships after Brain Injury*. London, LD: Karnac books.
- Braine, M. (2011). The experience of living with a family member with challenging behaviour post acquired brain injury. *Journal of Neuroscience Nursing*, 4, 156-64.
- Carnes, S.L., & Quinn, W.H. (2005). Family adaptation to brain injury: Coping and psychological distress. *Families, systems and health*, 23, 186-203.
- Dawodu, S.T. (2011). Traumatic Brain Injury (TBI) - Definition, epidemiology, pathophysiology. . Retrieved from Medscape reference website <http://emedicine.medscape.com/article/326510-overview#showall>.
- Godwin, E. E., Kreutzer, J. S., Arango-Lasprilla, J. C., & Lehan, T. J. (2011). Marriage after brain injury: Review, analysis, and research recommendations. *The Journal of Head Trauma Rehabilitation*, 26, 43-55.
- Holm, S., Schönberger, M., Poulsen, I., Caetano, C. (2009). Patients and relatives' experience of difficulties following severe traumatic brain injury: The sub-acute stage. *Neuropsychological Rehabilitation*, 19, 444-460.
- Leaf, L. E. (1993). Traumatic brain injury: Affecting family recovery. *Brain injury*, 7, 543-546.
- Lezak, M.D. (1986). Psychological implications of traumatic brain damage for the patient's family. *Rehabilitation Psychology*, 31, 241-250.
- Newby, G., & Groom, C. (2010). Evaluating the usability of a single UK community acquired brain injury (ABI) rehabilitation service website: Implications for research methodology and website design. *Neuropsychological Rehabilitation*, 20, 264-288.
- Oddy, M., & Herbert, C. (2008). Brain Injury and the Family: A Review. *Psychological Approaches to Rehabilitation after Traumatic Brain Injury*, 429-448.

Panting, A., & Merry, P.H. (1972). The long-term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabilitation*, 38, 33-37.

Perlesz, A., Kinsella, G., & Crowe, S. (1999). Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology*, 44, 6-35.

Rowan, K.E., Gale, C., Whaley, BE., Tovar, L. (2005). How well can scholars explain their research to a lay audience? A study of explanatory writing skills among scholars in three countries. Retrieved from Stanford University website: <http://www.stanford.edu/group/i-rite/nca2005.pdf>.

Strauss, A., & Corbin, J.M. (1998). *Basics of Qualitative Research Second edition: Techniques and Procedures for Developing Grounded Theory*. New York, NY: Sage publications.

Znaniecki, F. (1934). *The method of sociology*. New York, NY: Farrar & Rinehart.

**Adult Traumatic Brain Injury (TBI): A narrative review
and synthesis of the family therapy literature as a guiding
conceptual model in research with family members**

For submission to '*The Journal of Head Trauma Rehabilitation*'

2:1 Abstract

Background: Family members of those with a Traumatic Brain Injury (TBI) have been identified as being at significant risk of experiencing emotional distress. Understanding in this area is still developing and there is a lack of evidence based interventions. Many current research papers do not provide underpinning epistemologies or conceptual foundations to support their inquiries. Family therapy models, using systemic frameworks, are an emerging area of research and may provide a guiding conceptual framework from which to conduct research.

Objective: The study aimed to investigate:

- What are the fundamental concepts of family therapy when applied to TBI?
- How could these concepts applied as a conceptual framework for research?

Design: A narrative review using systematic methods was conducted. Twenty-one articles were identified in the systematic search. Articles were analysed to identify the main concepts and sub-concepts. A hierarchy was created with higher order conceptual points discussed first then more specific themes considered in the context of these higher order concepts.

Results: Two fundamental overarching themes were strength-based research and family members as participatory co-workers in research. A theoretical flexibility and integration of other models was also discovered. The findings indicated the application of a constructivist epistemology to underpin the research. The major assumption of the family therapy model to be used within these broad foci was interdependence. Interdependence can be seen functionally through the family system and acted out within the concepts of organisational patterns, roles, narratives and communication. All these concepts occur within a temporal continuum.

Conclusion: The family therapy model can provide organising concepts which could be used to guide the development of research which is grounded in a clear epistemological and conceptual position.

2:2 INTRODUCTION

It is proposed that the theoretical framework of family therapy could provide a conceptual framework to guide TBI family research, giving it greater coherence and focus. The current literature will be discussed to set this idea in context. The methodology is a narrative review with systematic principles and this will be outlined. The concluding section will set out the findings and present the conceptual framework. The conceptual framework will aim to provide the fundamental concepts of the family therapy model when applied to the TBI phenomenon and consider the relationships between them¹.

2:3 CURRENT LITERATURE

2:3:1 Defining Traumatic Brain Injury

Traumatic brain injury (TBI) belongs to a classification of head injury called acquired brain injury (ABI). ABIs are injuries to the brain which are not degenerative, hereditary or induced by trauma at birth. TBI is the largest sub-group of ABI². TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull causing lacerations, internal trauma and damage to brain tissue³. The data for 2009-2010 in the UK suggest that there were 23,162 hospital episodes recorded for head injuries⁴. Although incidence is high, the mortality rate from TBI is low⁵. It is recognised that the family of the individual who has suffered the TBI, will also experience adverse consequences and these will now be discussed.

2:3:2 Impact of ABI and TBI on the family

TBI has been considered to be distinct from other types of neurological impairment and ABI due to the unique challenges faced by family members⁶. However, few papers select participants specifically with TBI and so much of the background literature encompass the wider diagnosis of ABI.

Implications of ABI for family members have been investigated since the 1970s. Panting and Merry⁷ identified the impact of TBI on the family, finding that 60% of family members required stress related medication. Further research efforts began to focus on the subjective burden of family members^{8, 9, 10} and found links with depression, anxiety, poor concentration, isolation and feeling overwhelmed post brain injury. The impact on social and occupational circumstances, as well as the disruption to the

family life cycle has also been investigated^{11, 12, 13}. Lezak¹⁴ studied family members' needs in depth and identified the relationship between brain injury and adjustment. Lezak began the first exploration of the family as a system engaged in understanding and coping with TBI. Research then began to focus on the predictor variables of emotional distress. Findings implicated a range of family factors including financial resources, perceived social support and coping style^{15,16,17,18,19}. Qualitative research has also been used to elucidate the lived experience of family members' accounts of TBI^{20, 21}. From this initial inquiry, interventions began to develop to meet the identified need.

2:3:3 Interventions

Given the potential for negative psychological outcomes for family members, the focus of research endeavoured to think of interventions to reduce distress. There are an array of interventions including family support groups and peer support^{22, 23}, provision of information^{24, 25, 26}, family online community support systems²⁷ and manualised training²⁸. However, despite some positive outcomes a review in 2003 noted that there was no direct evidence concerning the efficacy of intervention approaches for family members²⁹. A review by Boschen et al in 2007³⁰ found similarly that the field is "still in its infancy" (p.35) and a systematic review carried out by these authors only identified four randomised control trials in the field of ABI. Reasons for this paucity will now be considered.

2:4 Methodological difficulties

It may be considered that much of the intervention literature has some methodological difficulties. Overall criticisms of the ABI/TBI literature have focused on the small and mixed sample sizes used in the research and the confused definitions of ABI/TBI and head injury^{31, 32}. This review identifies the need to go beyond these criticisms and consider the underpinning assumptions which guide the study designs. For the purpose of this review two criticisms will be considered; the semantics of the use of the word family, and the lack of guiding epistemological frameworks. These points will be considered in turn.

2:4:1 The family

Many papers identify the family as a focus for intervention or exploration. Most lay people might consider the family as a unit of people who are related through blood or emotionally bound. However there is often a research focus on the internal and individual world of one family member not the whole unit^{33, 34}. There are also few considerations of cultural and social constructions despite the fact that the use of the word family might allude to this as a significant topic^{35, 36}. Additionally, caregivers are often the focus of the intervention but the literature around family impact is referenced.

Caregivers might have a specific viewpoint and role in the person with TBIs life. Purely interviewing caregivers can be problematic in terms of interventions evolving from one person's particular phenomenological viewpoint. Focus on family members defined as caregivers might also exclude the needs of family members such as siblings³⁷. Research has shown that siblings often have the longest relationship, from birth to death, with the person with TBI³⁸. This recruitment problem can also be highlighted through the use of assessment instruments. Often when using measures such as the McMaster model of family functioning, one family member completes it for the whole family³⁹. This is then taken as an indication of functioning for the whole family. However, it has been found across family members there are often substantial discrepancies in perceptions of family functioning⁴⁰. Asking one member to complete measures for the whole family unit naturally ignores the roles and dynamics of subsystems within the family. The second criticism is the lack of guiding epistemological frameworks.

2:4:2 Epistemological frameworks

One example of the importance of epistemological frameworks is in the area of information provision. Provision of information is a recurrent theme in the literature with family members identifying greater information as a need. However there is often a static focus on quantity of information transmitted, as opposed to how this information is being received and constructed⁴¹. It has been shown that there is discrepancy between what families feel they receive and what is felt to have been provided by professionals⁴². The issue may however be not on the quantity or quality of information being given but how it is being interpreted within families. Cultural and societal factors may also impact upon the

consumption of the information. Taking these points into account it is worth noting that several attempts have been made to utilise conceptual models to frame and organise TBI research. A discussion of these models will now be provided.

2:5 Conceptualising the family in TBI

Existing conceptual models of TBI were outlined in a review paper in 2003²⁹. The review identified that there were numerous conceptual frameworks which all targeted different domains of experience. Some of these frameworks have arisen from research specifically with TBI family members^{43, 44} and some have been adapted from other areas of research⁴⁵. Although grounding research within a framework can be helpful, some conceptual frameworks may limit the research by the conceptualisation chosen. For example, Coco, Tossavainen, Jämskäinen and Turunen⁴⁶ reviewed the TBI family literature to distinguish what in healthcare constitutes an intervention. They used a conceptual framework of social support. The use of a conceptual model of social support is interesting as it focuses on the reciprocal exchange of information. Therefore this framework might not consider the systemic context that occurs around the two way exchange. It might be questioned that family members not only construct personal ideas about what this information means but share these interpretations and co-create them within the family system.

The most comprehensive advance in terms of theoretical frameworks for family members comes from Bowen, Yeates and Palmer⁴⁷ who advocate framing the rehabilitation of those with a brain injury in relational terms alongside the more dominant neuropsychological approach. They take the position that a 'brain injury is imbued with meaning at a social and relational level' (p150). This review aims to build upon this focus and propose how the family therapy model may enable future research to place a greater focus on co-constructed family interpretations of TBI. A definition of a conceptual framework will now be presented before the review methodology and findings are delineated.

2:6 Defining a family therapy framework

A conceptual framework explains either graphically or in narrative form the main elements of a phenomenon to be studied. There are three criteria which must be present for a coherent conceptual framework: articulating the essential criteria to be included; being comprehensive and encompassing the relevant variables within the domain to be studied; and identifying the epistemology or core scientific premises of an area of enquiry⁴⁸. Family therapy is a broad church of ideas and different schools have different theoretical boundaries. However, there are fundamental concepts that underlie all family therapy approaches⁴⁹. This paper will not seek to explain the whole area of family therapy other than outline the key findings in the current published literature on family therapy and TBI. To this end the research questions will now be defined.

2:7 RESEARCH OBJECTIVES

The aim of this narrative review is to systematically search for the available literature on the use of family therapy models in the field of TBI. The literature will then be critically analysed and the following questions considered:

- 1) What are the essential attributes of the model of family therapy when applied to TBI?
- 2) How could this model be applied as a conceptual framework in TBI research?

2:8 METHOD

The review design is a narrative review using systematic search methods. This review is not a classic example of a narrative review rather follows similar attempts at synthesising the literature to provide a conceptual framework for future research⁵⁰. A narrative review was conducted due to the relative paucity of studies in this area, particularly the lack of quantitative studies. The methodologies used are outlined below.

2:8:1 Search strategy

The literature search was conducted between July 2012 and February 2013. The following databases were searched: Psych INFO, Medline, Scopus and Web of Science. Reference lists of relevant

articles were searched in order to identify other potentially relevant studies. The journals '*Brain Injury*' and '*The Journal of Head Trauma Rehabilitation*' were hand searched from the past ten years. Authors of the key papers were contacted (Kreutzer, Yeates, Bowen, Yeates etc.) to see if they could contribute to the list of identified studies. Five authors included those noted, responded with updates on their work and feedback on this review topic. The search terms were 'Traumatic Brain Injury', 'Acquired brain injury', 'Family therapy', 'systemic' 'systemic psychotherapy', 'reflecting teams', 'relational', and 'family systems'. The search generated 639 papers across the three databases. The search term 'relational' highlighted a large number of papers which were rejected on title alone as being about other diverse subjects. (600). When this term was removed 151 papers remained which were more closely focused on the area of brain injury. Papers were either included or discarded based on title, abstract or contents. Those rejected on title were about topics other than TBI and merely included one of the search words. Those rejected on abstract often did not discuss family therapy. Those accepted offered a discussion of both family therapy and TBI. As this was only a small selection of papers all were included. Twenty-one papers ^(6, 28, 47, 53-54, 56-59, 61-63, 67-71, 74, 76-78) were identified in total and the findings of the papers will now be presented.

2:9 Findings

The findings were developed by making detailed notes on each journal paper and highlighting headings and key words. The major headings were then noted on separate sheets of paper. Major headings were decided based on the headings used in the papers i.e. communication was used several times in titles and sub-headings, so it became a major heading. The notes were then systematically read through to identify the key concepts discussed under each major heading. A hierarchy was created with higher order conceptual points discussed first and then specific themes considered in the context of these higher order concepts. It should be recognised that an element of social construction has been brought to interpreting what the key concepts were felt to be and this will be discussed in more depth. The findings will now be reported answering the research questions in turn at each point.

1 2:9:1 Epistemology

1:1 The findings indicate constructivist epistemologies are the main worldview applied to TBI. Family therapy has a varied background beginning with the intellectual climate of modernism in the 1940's which allowed family therapy to develop. In the mid-1970s to mid-1980s different models developed including post-modern ideas⁵¹. Constructivist ideas also developed in the 1980s placing an emphasis on the active process of meaning-making and the role of the therapist in bringing their own presuppositions to the data. Second order cybernetics also influenced the discipline using the study of abstract principles of organisation within complex systems like the family. Cybernetics brought a focus on, not what family systems consists of but how they function. The majority of the papers identified used a constructivist epistemology to frame their discussions.

1:2 In terms of the second research question, a conceptual framework for research would need to be underpinned by the idea that the term TBI is a social and cultural construction. Social constructions are powerful and people will have assumptions, presuppositions and preconditioned ideas about what TBI means for them. Much research in TBI is taken from an expert healthcare opinion with professionals holding the objective reality of TBI. However, some studies found nursing staff had major misconceptions about areas of brain injury such as recovery⁵². The assumption that researchers

are the holders of true knowledge is also reflected in the widespread use of screening measures developed for mental health populations. These often show a discrepancy in specificity of the questions asked and have developed from theory and models that may not relate to TBI.

Participatory action research may be one way of overcoming this focus on the objective professional selecting what they feel is important. Foster et al⁵³ endeavoured to use this method alongside considering the different interpretations of family in New Zealand culture. This fits in with another key finding in the literature, that of co-working, which will now be discussed.

2. 2:9:2 Co-working – user led or participatory

2:1 Complementary to a greater focus on looking at the families' constructed reality is the finding of co-working. Most papers emphasised the need for an uncompromised acceptance of families on teams as the first step⁵⁴. The core idea is of working with families as colleagues and not casting them inappropriately as patients. This point fits in with a finding in Collins and Kennedy's paper⁶ that the problem should be considered to be within the system and not in individuals; therefore a non-pathologising approach should be taken.

2:2 As inferred in the title one obvious way to apply this principle is to involve family members more actively in designing research from its inception to completion. Participatory action research has already been discussed as a means of involving people, who are concerned about or affected by an issue, taking a leading role in producing and using knowledge about it⁵⁵. However criticisms of this type of research design have included the idea that it can be a tokenistic form of inclusion. Survivor led research principles may have utility in involving families more fully in designing research. The next overarching finding in the literature is a focus on family members' strengths. This is related to the idea of considering families as active, empowered participants in research.

3. 2:9:3 Strengths based research

3:1 An important finding in the literature was the discussion of strength-based approaches and the setting of goals. This is discussed as means of facilitating coping in the face of adversity⁵⁶,

reframing unhelpful ways of discussing common family processes⁵⁷ and focusing more on positives and less on deficits⁵⁸. As mentioned previously, family therapy endeavours to situate the problem within the system and not in individuals. Moving away from underlying causes of psychological disturbance and towards solutions can help move away from a brain injured identity. The finding of goal setting for families to facilitate with their family member was a recurrent theme in the literature and a method to achieve a more strengths based focus. It also indicates the cross-over between neuropsychological approaches and family therapy⁵⁹.

3:2 The current family literature on TBI has a general bias towards focusing on negative emotions and little is known about resilience, positive emotions and incidents where people cope and achieve⁴⁴. The current field of positive psychology has much to offer in terms of thinking of people's areas of strength and resilience⁶⁰. Research that is conceptually guided by focusing not only on why people struggle and suffer but incidents where they have thrived would add much to our understanding of TBI and positive growth. The inclusion in the literature of the integration of other theories such as solution-focused theory and positive psychology introduces the next key theme which is that of a theoretical flexibility.

4 2:9:4 Theoretical flexibility

4:1 Throughout the literature there are examples of other theoretical models being integrated into the family therapy model. Flexibility as a general principle is important within family therapy given the need to adapt the model to family groups who may present differently. One example of theoretical flexibility is discussed by Byard⁶¹ who presents developmental understanding, of both brain and physical development, being considered alongside systemic ideas. Additionally, the brain injury family intervention (BIFI) developed by Kreutzer and colleagues uses a family systems framework to underpin the curriculum, with cognitive-behavioural approaches and solution-focused theory incorporated²⁸. This is a large area within the literature with Bowen, Yeates and Palmer⁴⁷ provide a discussion of the integration of neuropsychological theory and relational approaches. Larøi sums up this finding by noting that theoretical rigidity should be avoided⁵⁶.

4:2 Theoretical flexibility inevitably adds to the complexity of the conceptual framework by introducing the idea that, as long as defined and fully integrated, a number of other theories can be incorporated alongside family therapy principles. Within all of these points there is a notion that they may change across time therefore another overarching concept is the consideration of temporal context.

5 2:9:5 Temporal changes and the life cycle

5:1 An important model identified in the family therapy literature is the life-cycle model. This model has a good fit with another finding concerning being sensitive to the temporal context of the family. Disruption at different stages of the family life cycle can have diverse consequences⁶². The person with TBI should not be considered a static entity and new life stages will mean new challenges for them and the family⁶³. Considering the dynamic implications of this, Rolland⁶⁴ has developed a model for chronic illnesses which considers how the family are affected by psychosocial dimensions, time-related stage and key family life cycle issues.

5:2 Conceptually, there is a need for research to be more responsive to changes in the family system that could be impacting at different time points. The National Service Framework for long term conditions⁶⁵ states that quantitative methods of data collection may not be best suited for conditions where long term outcomes are involved. It notes that longitudinal studies and qualitative work are equally valued. Use of research designs that follow family members across time, are sensitive to individual's life cycle challenges, and consider social-contextual processes may be better placed to consider temporal changes.

6 2:9:6 Inter-dependence

6:1 A key finding in the literature was the idea of the family system as constructed of individual members with relationships between them. The group of family members is considered to be interdependent and inter-related. DePompei and Williams⁵⁴ describe the family system as 'like a house of cards' (p68) if one card is disrupted the effect will be felt throughout the 'house'. Within this

concept is the idea of circular causality, that each family member's behaviour is caused by and causes the other family members' behaviours. Although the concept of circular causality is not mentioned specifically, in many of the papers the idea of inter-dependence is crucial. Within this finding are two separate themes (6:1:2-3) which emerged in the literature as central concepts to consider in TBI. These will now be discussed.

6:1:2 *Family structure and organisational Patterns*

The family therapy literature has different models which place differing degrees of emphasis on the idea of structure in families. Families are thought to, with varying degrees of success, arrange themselves into a functioning group in order to achieve goals and shared needs⁶⁶. The structural branch of family therapy particularly emphasises this perspective and case examples of the use of this perspective were found in the search. The literature discusses the idea that families often have subsystems within them such as the parental subsystem and the child subsystem⁶⁷. One study looking at family structure found that 60% of families experienced a change in family structure following TBI. Kosciulek and Lustig⁶⁸ believe that it is important to understand the underlying patterns of family systems as previous patterns may predict future responses⁶⁶. Within family structure and response patterns the concept of roles is central.

6:1:3 *Roles*

Roles are defined in the literature as 'the expected pattern of behaviour associated with occupancy of a distinctive position in society'^{69(p.)}. There are a number of ways in which roles are presented in the literature. As previously mentioned roles can change over time and due to roles changing family members may need to face role transitions, reorganize roles⁶ and redistribute them⁶². Depompei and Williams⁵⁴ present a positive example of how family members can play important roles in the hospital process. They describe how family members can be perceived as information providers, advocates and active participants in treatment. Within the concept of roles, the concept of power is situated. Maitz and Sachs⁶² discuss how the power equilibrium can be disrupted within families. Professionals also tend to hold power in relation to families.

6:2 The manner in which these essential concepts could inform research is in two important ways. The first manner is to place an increased emphasis on researching the family system as a whole as opposed to individuals who are being termed the family. If the family system can be considered to hold a set of beliefs, values, goals and priorities⁷⁰ and are interdependent it makes sense to conduct research within the system. This fits in with the broad premise that a focus on the whole family could consider circular causal explanations in trying to understand what each person is doing to sustain the problem. A simple focus on one family member being distressed by the TBI can lead to a more linear causal explanation. Here the person with TBI is considered passive and as causing the psychological distress in their relative. Secondly, there is not much consideration of roles in the literature on TBI outside of considering the role of caregiver or wife.

7 2:9:7 Communication and narratives

7:1 The constructionist perspective considers language to be an essential part of how we construct our realities⁷¹. Communication as a finding in the review focused on verbal communication as an important mode of families constructing a narrative around TBI. Within this there is communication within the family and with professionals. Communication in TBI is recognised as being a major barrier which can lead to social isolation and reduced quality of life⁷². A study by Jorgensen and Togher⁷³ examined how those with TBI co-construct narratives with their family members. Narratives are ways of making sense of what is happening, and those narratives which are felt to be meaningful and manageable by family members are considered to be predictive of them positively appraising events⁷⁰. Another important finding was the communication that takes place between families and professionals. The co-ordinated management of meaning theory is mentioned in the literature and looks at how messages are transmitted and how they are received by people⁷².

7:2 The concepts of communication and narrative are clearly significant themes in conceptual thinking in family therapy. They are means of understanding the way that families construct their needs and express them. Methodologies that specifically seek to consider the narratives, transmission and interpretation of communication between people would be helpful in being able to understand

what the family members' individual perceptions of TBI are and what the co-constructed meaning is. Studies which use questionnaires may be missing out on important aspects of meaning making.

The major findings in the research literature have now been explored. These concepts have been ordered graphically to depict the key themes and will now be summarised

2:10 CONCLUSION

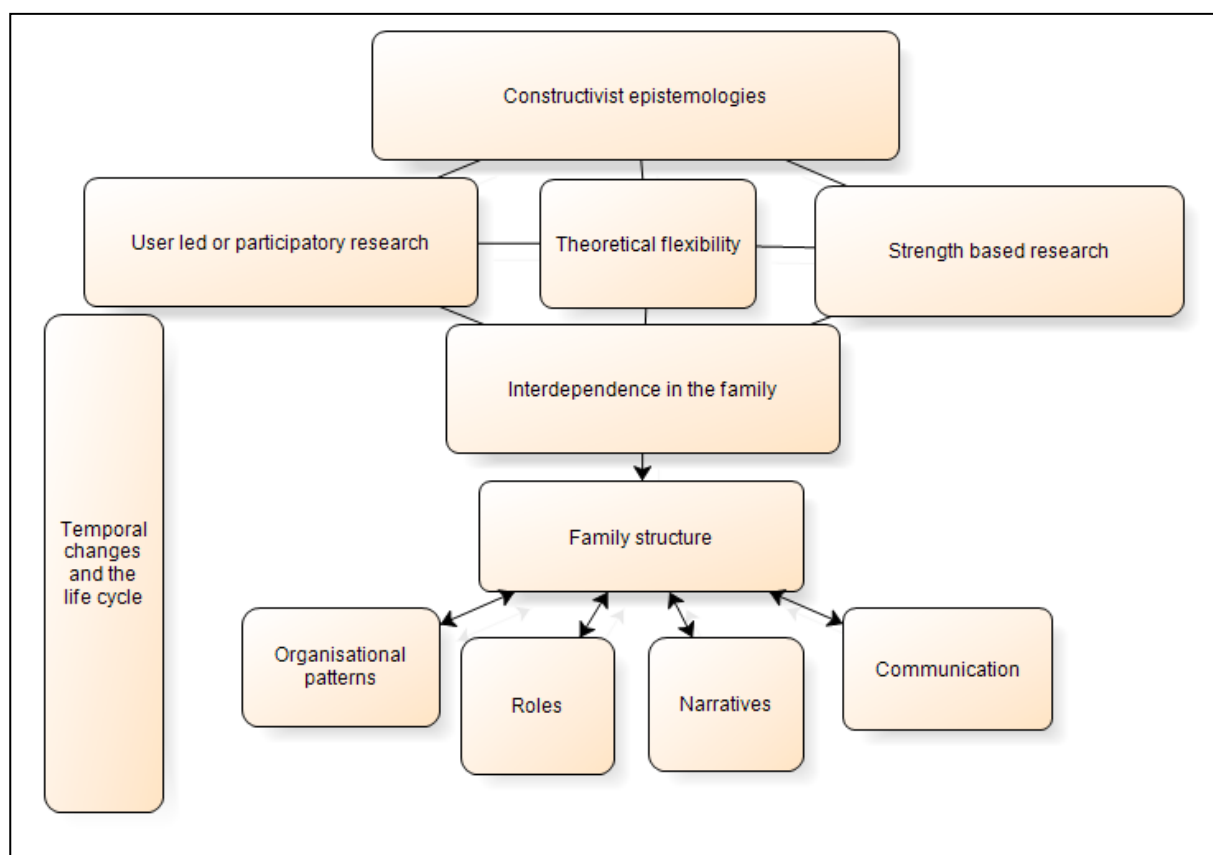


Figure One: Conceptual framework

The most vital finding of the model of family therapy in TBI is its epistemological underpinnings. The underpinnings of the constructivist model hold that people's constructed reality should be the focus of study. Therefore it might be considered that families who are the focus of study may be better placed to develop research. The ideology of user participation has been suggested as a means of practically achieving this. A parallel concept to greater user involvement is the focus on strengths as

opposed to deficits. People naturally strive for positive well-being and a focus on strengths as opposed to deficits might elucidate areas of strength based intervention. Theoretical flexibility is an important concept that relates to each of these core areas as the literature suggests the family therapy model is complementary to other theoretical models. The concept of temporal continuum underlies all the phenomena as there needs to be an acceptance that what is being measured is not static and will change over time.

Under these higher order concepts is the necessity to incorporate the central tenet that the family system is more than a collection of individuals rather that it is an interdependent whole with its own identity and dynamics. This principle would enable research to move away from generalising one family member's viewpoint to the whole family system. The four points underneath this principle might be considered the concepts whereby process can be studied and even measured. These areas are operational family patterns, roles, communication and narratives.

2:11 DISCUSSION

A conceptual framework needs to provide the key factors, concepts or variables of a phenomenon and describe what the presumed relationship among them is. This review has taken the main findings of the papers identified in the area of TBI and family therapy and proposed a way of conceptualising the area. It can be seen that the review has articulated the essential criteria that need to be included, aiming to comprehensively encompass the relevant variables within the domain to be studied. It has also identified what the epistemology or core scientific premises of the area of enquiry are. The review however has several limitations.

The most significant limitation with the current literature on family therapy and TBI is the quality of the published literature. Almost all of the papers identified are clinical opinion or case study articles. Only a few studies focus on one aspect of the literature, such as communication, and use empirical methodology. Given the paucity of studies the main findings of this review have been limited. There may be certain themes that are important from the family therapy literature which have not been

included in this review due to them not being discussed in depth in the papers. Additionally, given the importance of considering this field within a constructivist framework, it should be recognised that this is one interpretation of the literature. The review might be influenced by the reviewer's own thoughts. Another criticism is that it may have been helpful to review the work with the assistance of a co-reviewer to try and ensure greater reliability in the findings. However, it should be noted that the second author checked over the findings that had been drawn from the papers.

A significant strength of the family therapy model is the clear underpinning themes that appear consistently across most studies. The clinical opinions offered in the literature are from authors who have been working in the field of TBI for a considerable length of time and many suggestions are made on the basis of case reviews and good practice. It would appear that despite the paucity of literature there are clear common sense principles that can be taken from the studies. Another significant strength of the model is its ability to fit flexibly alongside other important theoretical areas within TBI such as developmental models. The review has identified potential areas of clinical application and recommendations which will now be provided.

2:11:1 Clinical applicability

A key advantage of the family therapy model is its ability to underpin both research and clinical practice. Current NHS neuropsychology services are often developed and run based upon medical objectivist diagnoses and services are offered dependent on a TBI/ABI diagnosis, along with age and severity criteria. Therefore, there is a problem-centred focus, with assessment often aiming to identify deficits in physical, neuropsychological and occupational functioning. Using strength based approaches, assessment could be less problem-focused with testing focusing on strengths and preserved skills rather than just deficits. Interventions could focus on families' desire to find solutions rather than identify problems. Possible ideas are to adopt a narrative listening manner to hear solutions families have and to enrich their coping narratives. As noted in the positive psychology literature, there could be a focus on points of resilience rather than just points of weakness. While family therapy cannot practicably be conducted in all cases of TBI, family therapy principles and

systemic consultancy could be offered throughout the hospital journey. Clinical Psychologists are often trained in systemic approaches and could offer consultation and training. Small scale service evaluations in addition to full scale research projects may also be able to use family therapy principles to conceptually underpin their investigations.

2:11:3 Recommendations

It is the opinion of this review that studies, particularly those developing interventions, should endeavour to make it clearer that they are being guided by a sound epistemological framework. Research trialling interventions for those with TBI could aim to involve those they seek to support at an earlier stage in line with the principles of co-working in family therapy. A greater inclusion of all family members in the study and a focus on the dynamic elements of family members making sense of the brain injury would add much to our understanding. Finally, given the conceptual model proposed it would make sense that this model is explored with family members of those with TBI to consider their views on its worth.

2:12 REFERENCES

1. Miles MB, Huberman AM, eds. *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd ed. London, LD: Sage Publications; 1994:18.
2. Braine ME. The experience of living with a family member with challenging behaviour post acquired brain injury. *J Neurosci Nurs*. 2011;43(3):156-164.
3. National Institute of Neurological Disorders and Stroke (NINDS). Traumatic Brain Injury Information Page. <http://www.ninds.nih.gov/disorders/tbi/tbi.htm>. Accessed April 9, 2013.
4. Hospital Episode Statistics (HES) online: Traumatic brain injuries. The Information centre for health and social care. <http://www.hesonline.nhs.uk/Ease/ContentServer?siteID=1937&categoryID=1207>. Accessed 7 January 2013.
5. Kay A, Teasdale G. Head injury in the United Kingdom. *World J Surg*. 2001;25(9):1210-1220.
6. Collins RC, Kennedy MC. Serving families who have served: Providing family therapy and support in interdisciplinary poly-trauma rehabilitation. *J Clin Psychol*. 2008;64(8):993-1003.
7. Panting A, Merry P. The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabil*. 1972;38-33.
8. Brooks DN, Campsie L, Symington C, Beattie A, McKinley W. The five year outcome of severe blunt head injury: a relative's view. *J Neurol Neurosurg Psychiatr*. 1986;49:764-770.
9. Knight RG, Devereux R, Godfrey, HPD. Caring for a family member with traumatic brain injury. *Brain Inj*. 1998;12(6):467-481.
10. Douglas JM, Spellacy FJ. Indicators of long-term family functioning following severe traumatic brain injury in adults. *Brain Inj*. 1996;10(11):819-840.
11. Koskinen S. Quality of life 10 years after a very severe traumatic brain injury (TBI): the perspective of the injured and the closest relative. *Brain Inj*. 1998;12(8):631-648.
12. Wood RL, Yurdakul LK. Change in relationship status following traumatic brain injury. *Brain Inj*. 1997;11(7):491-501.

13. Lefebvre H, Cloutier G, Josee Levert M. Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Inj.* 2008;22(7-8):535-543.
14. Lezak M. Brain damage is a family affair. *J Clin Exp Neuropsych.* 1988;10(1):111-123.
15. Carnes SL, Quinn WH. Family adaptation to brain injury: Coping and psychological distress. *Fams Syst Health.* 2005;23(2):186-201.
16. Hanks RA, Rapport LJ, Vangel S. Caregiving appraisal after traumatic brain injury: the effects of functional status, coping style social support and family functioning. *Neuropsychol Rehabil.* 2007;22(1):43-52.
17. Hawley CA., Joseph S. Predictors of positive growth after traumatic brain injury: a longitudinal study. *Brain Inj.* 2008;22(5):427-435.
18. Harris JKJ, Godfrey HPD, Partridge FM, Knight RG. Caregiver depression following traumatic brain injury (TBI): a consequence of adverse effects on family members? *Brain Inj.* 2001;15(3): 223-228.
19. Livingston LE, Kennedy RE, Marwitz, JH, et al. Predictors of family caregivers' life satisfaction after traumatic brain injury at one and two years post injury: a longitudinal multi-center investigation. *NeuroRehabil.* 2010;27(1):73-81.
20. Jumisko E, Lexell J, Soderberg S. Living with moderate or severe traumatic brain injury. *J Fam Nurs.* 2007;13(3):353-369.
21. Holm S, Schönberger M, Poulsen I, Caetano C. Patients and relatives' experience of difficulties following severe traumatic brain injury. *Neuropsychol. Rehabil.* 2009;19(3):444-460.
22. Hibbard MR, Cantor J, Charatz H, et al. Peer support in the community: initial findings of a mentoring program for individuals with traumatic brain injury and their families. *J Head Trauma Rehab.* 2002;17(2):112-131.
23. Malec JF, Smigielski JS, DePompolo RW, Thompson JM. Outcome evaluation and prediction in a comprehensive-integrated post-acute outpatient brain injury rehabilitation programme. *Brain Inj.* 1993;7(1):15-29.

24. Junque C, Bruna O, Matara M. Information needs of the traumatic brain injury patient's family members regarding the consequences of the injury and associated perception of physical, cognitive, emotional and quality of life changes. *Brain Inj.* 1997;11(4):251-258.
25. Bowen A, Tennant A, Neumann V, Chamberlain MA. Neuropsychological rehabilitation for traumatic brain injury: do carers benefit? *Brain Inj.* 2001;15(1):29-38.
26. Morris KC. Psychological distress in carers of head injured individuals: The provision of written information. *Brain Inj.* 2001;15(3):239-254.
27. Rotundi AJ, Sinkule J, Spring M. An interactive web-based intervention for persons with TBI and their families: use and evaluation by female significant others. *J Head Trauma Rehab.* 2005;20(2):173-185.
28. Kreutzer JS, Kolakowsky-Hayner SA, Demm SR, Meade MA. A structured approach to family intervention after brain injury. *J Head Trauma Rehab.* 2002;17(4):349-367.
29. Oddy M, Herbert C. Intervention with families following brain injury: Evidence-based practice. *Neuropsychol Rehabil.* 2003;13(1-2);259-273.
30. Boschen K, Gargaro J, Gan C, Gerber G, Brandys C. Family intervention after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. *NeuroRehabil.* 2007;22(1):19-41.
31. Brain Injury Network. Definitions of ABI and TBI. Brain Injury Network.org.
<http://www.braininjurynetwork.org/thesurvivorsviewpoint/definitionofabiandtbi.html>.
Accessed 8 January 2013.
32. Bach LJ, David AS. Self-awareness after acquired and traumatic brain injury. *Neuropsychol Rehabil.* 2006;16(4):397-414.
33. Leatham J, Heath E, Woolley C. Relatives' perceptions of role change, social support and stress after traumatic brain injury. *Brain Inj.* 1996;10(1):27-38.
34. Sander SM, Caroselli JS, High WM, Becker C, Neeses L, Scheibel R. Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Inj.* 2002;16(8):649-657.

35. Pappadis MR, Sander, AM, Struchen, MA, Leung P, Smith DW. Common misconceptions about traumatic brain injury among ethnic minorities with tbi. *J Head Trauma Rehab.* 2011;26(4):301-311.
36. Sander AM, Davis LC, Struchen MA, et al. Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *NeuroRehabil.* 2007;22(1):9-17.
37. Hassan STS, Wan-Fei K, Raman RA, Jamaludin H, Riji HM. Review on family caregiving and rehabilitation of traumatic brain injury. *J Soc Develop. Net new environ.* 2012;6(7);2423-2434.
38. Degeneffe CE, Olney M. 'We are the forgotten victims': perspectives of adult siblings of persons with traumatic brain injury. *Brain Inj.* 2010;24(12):1416-1427.
39. Serio CD, Kreutzer JS, Gervasio AM. Predicting family needs after brain injury: implications for intervention. *J Head Trauma Rehab.* 1995;10(2):32-45.
40. Anderson MI, Simpson GK, Morey PJ, Mok MMC, Gosling TJ, Gillett LE. Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): multi group analysis. *Brain Inj.* 2009;23(12):931-43.
41. Braga LW, Da Paz Junior, AC, Ylviksaker M. Direct clinician-delivered versus indirect family supported rehabilitation of children with traumatic brain injury: a randomized controlled trial. *Brain Inj.* 2005;19(10):819-831.
42. Lefebvre H, Levert MJ. Breaking the news of traumatic brain injury and incapacities. *Brain Inj.* 2006;20(7):711-718.
43. Harris JKJ, Godfrey HPD, Partridge FM. Caregiver depression following traumatic brain injury (TBI): a consequence of adverse effects on family members? *Brain Inj.* 2001;15(3):223-238.
44. Wilson B, Gracey F, Evans JJ, Bateman A. *Neuropsychological Rehabilitation: Theory, models, therapy and outcome.* Cambridge Medicine; 2009:1-377.
45. Lazarus RS, Folkman S. *Stress appraisal and coping.* Springer publishing co inc; 1984:1-445.

46. Coco K, Tossavainen K, Jämskäinen JE, Turunen, H. Support for traumatic brain injury patients' family members in neurosurgical nursing: a systematic review. *J Neurosci Nurs.* 2011;43(6):337-48.
47. Bowen C, Yeates G, Palmer S. *A relational approach to rehabilitation: Thinking about relationships after brain injury.* London: Karnac books; 2010:11-277.
48. Pinsof WM. A conceptual framework and methodological criteria for family therapy process research. *J Consult Clin Psychol.* 1989;57(1):53-59.
49. Hecker LL, Wetchler JL. *An introduction to marriage and family therapy.* The Haworth Press; 2003:1-625.
50. Leamy M, Bird V, Le Boutillier, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiat.* 2011;199(6):445-452.
51. Dallos R, Draper R. *An introduction to family therapy: Systemic theory and practice.* 3rd ed. Open University Press; 2000:1-249.
52. Ernst WJ, Trice AD, Gilbert JL, Potts BS. Misconceptions about traumatic brain injury and recovery amongst nursing students. *J Head Trauma Rehab.* 2009;24(3):213-220.
53. Foster AM, Armstrong J, Buckley A. Encouraging family engagement in the rehabilitation process: a rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disabil Rehabil.* 2012;34(22):1855-62.
54. DePompei R, Williams J. Working with families after TBI: A family-centered approach. *Top Lang Disord.* 1994;15(1): 68-81.
55. Pain R, Whitman G, Milledge D. *Participatory action research toolkit: An introduction to using PAR as an approach to Learning, Research and action.* Durham University; 2010.
56. Larøi F. The family systems approach to treating families of persons with brain injury: a potential collaboration between family therapist and brain injury professional. *Brain Inj.* 2003;17(2):175-187.

57. Larøi F. Treating families of individuals with traumatic brain injury: Presentation of clinical cases approached from a structural therapy perspective. *J Fam Psychotherapy*. 2000;11(4):69-186.
58. Johnson BD, Crane SC, Tatekawa, L. Communication on both sides of the mirror: Helping a family cope with a traumatic brain injury. *Family J*. 2004;12(2):178-183.
59. Bowen C. Family therapy and neuro-rehabilitation: Forging a link. *Int J Ther Rehabil*. 2007;14(8), 344-349.
60. Seligman MEP. *Authentic happiness: Using the new positive psychology to realize your potential for lasting fulfilment*. The Free Press: 2002.
61. Byard K. Taking a developmental and systemic perspective on neuropsychological rehab with children with brain injuries and their families. *Clin Child Psych*. 2011;16(2):165-184.
62. Maitz E, Sachs P. Treating families of individuals with traumatic brain injury from a family systems perspective. *J Head Trauma Rehab*. 1995;10(2):1-11.
63. Dausch BM, Saliman S. Use of family focused therapy in rehabilitation for veterans with traumatic brain injury. *Rehabil Psychol*. 2009;54(3):279-287.
64. Rolland JS. *Families, illness and disability: An integrative treatment model*. New York: Basic books; 1994:2-320.
65. Department of Health. *The national service framework for long term conditions*. Crown copyright, 2007.
66. Goldenberg H, Goldenberg I. *Family therapy, 8th ed*. Brooks Cole; 2012:2-15.
67. Tyerman A, Booth J. Family interventions after traumatic brain injury: a service example. *NeuroRehabil*. 2001;16(1):59-66.
68. Kosciulek JF, Lustig DC. Differentiation of three brain injury family types. *Brain Inj*. 1999;13(4):245-254.
69. Bay EH, Blow AJ, Yan X. Interpersonal relatedness and psychological functioning following traumatic brain injury: implications for marital and family therapists. *J Marital Fam Ther*. 2012;38(3):556-567.

70. Hallett JD, Zasler ND, Maurer P, Cash S. Role change after traumatic brain injury. *Am J Occup Ther.* 1992;48(3):241-246.
71. Kosciulek JF. Relationship of family schema to family adaption to brain injury. *Brain Inj.* 1997;11(11):821-83.
72. Berger PL. Luckmann T. *The Social Construction of Reality.* Garden City, N.Y.: Anchor Books; 1967.
73. Snow PC, Douglas JM, Ponsford JL. Narrative discourse following severe traumatic brain injury: a longitudinal follow up. *Aphasiology.* 1999;13(7):529–551.
74. Jorgensen M, Togher L. Narrative after brain injury: a comparison of monologic and jointly produced discourse. *Brain Inj.* 2009;23(9):727-740.
75. Cronen VE. Coordinated management of meaning: practical theory for the complexities and contradictions of everyday life. the status of common sense. In J. Siegfried, ed. *Psychology.* Norwood, NJ: Ablex Press, 1994:183–207
76. Gan C, Gargaro J, Kreutzer JS, Boschen KA, Wright FV. Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families. *Brain Inj.* 2010;24(4):651-663.
77. Groveman AM, Brown EW. Family therapy with closed head injured patients: utilizing Kubler-Ross' model. *Fam Syst Med.* 1985;3(4):440-446.
78. Charles N, Butera-Prinzi F, Perlesz A. Families living with acquired brain injury: a multiple family group experience. *NeuroRehabil,* 2007;22(1):61-76.

**Sense-making through observation and action: A grounded
theory study investigating how family members of traumatic
brain injury (TBI) patients construct an understanding of injury**

For submission to '*Brain Injury Journal*'

3:1 Abstract

Primary objective: The study investigated how family members of those with a traumatic brain injury (TBI) constructed an understanding of the injury.

Design: A qualitative design was applied using grounded theory methodology.

Method and process: 14 family members were interviewed using a semi-structured interview schedule. Sampling and interviewing occurred alongside analysis, in line with the analytic procedures of Strauss and Corbin. NVIVO-9 was used to organise the data analysis.

Results: Findings indicated that family members try to make sense of TBI in a context that is personally applied. In the perceived absence of information, family members engage in central processes of observation, interpretation and initiative. Professionals can support these learning processes by scaffolding initiative, providing personalised TBI information and a sense of hope; in an approachable manner. Desirable outcomes are progress for the family member with the TBI, a shared narrative, a good perception of professional support and understanding the next step to recovery.

Conclusions: Families actively construct an understanding of TBI through processes that exceed the simple provision of information from professionals. Misunderstandings in interpreting information can lead to negative outcomes and a conflicted understanding between professionals and within families.

3:2 Introduction

The understanding that following traumatic brain injury (TBI) family members have a number of needs is not disputed. However, despite an increased focus since the 1970s on the effect of TBI on families there are still gaps in our knowledge. Negative outcomes are still reported by family members and there are few UK nationwide standards for intervention. Studies often include mixed samples of acquired brain injuries (ABI) and sample sizes are often small. Additionally, despite the focus being on the family there are too few studies which seek to include different family relations in the research. In terms of the underpinnings of the research there is rarely discussion or signposting to an epistemological framework. This leaves it difficult to determine the lens knowledge has been produced through. In ascertaining family members' needs there is a use of pre-defined questions or measures developed in other areas such as mental health, which are not always suitable. Studies investigating need from a qualitative viewpoint rarely encapsulate their findings within a theoretical framework. Often descriptive thematic outcomes are reported with less attention to process issues around how families reached that point. There is little in-depth understanding in the literature about where and how families' understanding of TBI develops. This would be helpful in order to consider where interventions could be better targeted to meet needs. The current research will now be considered with reference to these points before a rationale for the grounded theory investigation is proposed.

3:3 Background information

TBIs have been referred to as the 'silent epidemic' and are considered to be one of the most serious public health problems facing the developed world [1]. Current statistics are hard to obtain, however data for 2009-2010 in the UK suggest that there were 23,162 hospital episodes recorded and in the past decade there have been a total of 163,748 hospital episodes [2]. In addition to the person with the TBI experiencing significant social, psychological and physical difficulties [3, 4] it has been recognised that families are often the hidden victims. Current UK policy is beginning to recognise the severity of this problem.

3:3:1 Policy context

Policy context recognises the need to offer family members support and advice throughout the injury continuum. Many policy documents outline the broad areas of support that family members need.

The National Collaboration centre [5] notes that information, counselling and psychological support can reduce the psycho-emotional outcomes experienced by the family. Family involvement with the rehabilitation and discharge process is also recommended yet there is little practical evidence-based policy documentation which outlines how best to do this.

3:4 Research history

Research into family members of those with TBI has been developing since the 1970s [6, 7, 8]. There have been several phases of research within the area. Initially the focus of research was on subjective burden in family carers [9, 10]. The outcomes showed that brain injury led to increased burden in carers and attempts were made to measure this. This focus has since been criticised for being simplistic and overly negative [11]. Alongside this work was identification of negative psychological symptoms in family members post injury and predictor variables [12, 13]. Chwalisz [14] was the first to use structural equation modelling to propose a theoretical model of caregiver stress; derived from stress-appraisal coping theory. However, the conceptual focus was on the caregiver and did not consider the wider system or shared sense-making. Considering what needs arise from these outcomes then became the focus of research.

3:4:1 Family need

Often fixed measures such as the family functioning measure [15] have been used to ask family members what they feel their needs are. There are two difficulties inherent here. Firstly, and a major criticism of the area as a whole, is there has been little attempt to include all family members in the research process. As Bowen, Yeates and Palmer [11, p291] note a ‘truly systemic approach would probably require individual family members to fill in a questionnaire each’. Research has therefore often been confined to theories of individual subjective experience as opposed to family inter-subjective experience. A second criticism is the large amount of information that is missed around the

process of family members reaching the point where they feel a need is not being met. There is no cause and effect explanation, merely an effect is identified as a simplistic result of TBI.

3:4:2 Interventions

Despite these limitations, numerous intervention studies began to attempt to address the identified needs [16, 17, 18, 19]. There have been numerous interventions trialled falling into different types including family support groups, peer support, provision of information and online community support systems. Although the link between the identified needs and intervention strands of research appears common sense, it should be noted that prior to the interventions being created there has perhaps not been enough focus on determining the underpinning concepts and epistemology that will guide the intervention. As Boschen et al [20, p36] noted, following a systematic review of the intervention literature, ‘the constructs used to study the field (quality of life, family functioning, satisfaction with services) vary and there has been no consensus over what is best to study’. In addition, some of the early research that is cited to support these interventions is heavily focused on negative psychological emotions with little focus on positive emotions and resiliency.

3:4:3 Information provision

One illustrative example is the consistent finding across studies suggesting that there is a need for ‘honest, accurate, comprehensive information’ [21, p.575]. Family members commonly state that they do not feel they receive enough information on prognosis, consequences or aftercare. Bowen, Tennant, Neumann and Chamberlain [22] attempted to provide early intervention and information for family members through a new service called the Leeds Head Injury Team (HINT). There were three conditions in the study, ‘early’ which was intervention before discharge, ‘late’ which was after discharge and ‘control’ which was existing services only. This study highlights the areas of methodological and conceptual difficulty. Firstly, methodologically there was a focus on a sole carer not the family network. This is problematic as family members will understandably interpret what they have been told within the family system. Secondly, this interacts with the idea that while family members state they need information, it is often unclear the processes by which they are consuming

and constructing an understanding of this information. The study had 46 carers refuse to participate; indicating there may be other dynamic issues present and the intervention was not accessible to a number of families for an un-investigated reason. A narrative review of the communication of information to poly-trauma patients, focusing on the TBI literature, identified that there is a continued need to identify effective approaches to communicate information [23]. It was discovered that although studies look at what information families say they want there is little guidance for how staff members can practically do this.

An example of a study which did focus on the transmission of knowledge is a study by Braga, Da Paz and Ylvisaker [24]. The aim of their intervention was to change the service delivery culture in a child brain injury service to make it participatory. The study trialled two methods of service delivery. There was an indirect family supported intervention whereby families were trained and supported to deliver rehabilitation and; one whereby family members received support but were not directly involved in the care of the child. The results showed that the indirect family supported group achieved better outcomes on cognitive and motor development scales. A discussion point was that greater involvement of the whole family may decrease the potential for inconsistent messages from staff members. The study discussed the need to create a context-sensitive non-compartmentalized treatment approach. Given some of the challenges reported there has been a refocusing in the literature on whole systems approaches. These approaches will now be described briefly.

3:4:4 Family systems

Whole systems research such as family therapy has a strong underpinning philosophy and epistemological standpoint. Family therapy and systems research within TBI has been present since the 1950's. Until recently however the main method of reporting this research has been through case study or clinical opinion [25, 26, 27, 28]. There are few rigorous empirical studies in this area which is a criticism; however this is starting to change. A recent review has proposed the use of marital family therapy (MFT) as a framework for investigating the marital relationship post injury [29]. This counters some of the criticisms made in this introduction as it makes use of a social constructionist

epistemology that frames relationships as a development of reality within the social interchanges between two people.

3:4:5 Summary

In summary, current theory is stronger in terms of understanding the consequences of brain injury but relatively lacking in terms of understanding the families' response. There are as yet unanswered calls for a theoretically coherent framework by which to understand family adaptation after brain injury [30]. Additionally 'although there are proposals that advocate for the strategic utilisation of the family in the care-giving process the wide range of variables operating in families of those with TBI has yet to be sufficiently explored' [30, p.32].

3:5 Family members and information consumption

Grounded theory methodology proposes the use of a 'delayed' literature search taking place during the inquiry, in order to build theoretical understanding of emerging concepts [31]. However, due to the need to identify the area of inquiry as worthwhile for investigation a general scoping search was conducted. This identified over 100 papers on 'TBI' and 'family members'. From this search several papers were identified which focused on the broad area of family members and information consumption. These studies will now be discussed briefly before the methodology is discussed.

A study by Paterson, Kieloch, Gmiterek [32] looked at family members' perception of information delivery in the post-discharge period. The study highlighted the disparity between what TBI families feel they have been told, which is very little, and what professionals feel they have told them, which is considerable amounts. The study highlighted the role of interpretation in understanding, noting that families' interpretations of information can be distorted by emotions and other factors. The study identified that; the amount and consistency of the information; the timing of the content; and the relevance of the content were all important factors. A criticism of the research is that the questions were phrased in negative terms, asking family members to discuss why their learning needs had not been met. Participants therefore did not discuss the strategies or approaches that were helpful in teaching them.

Simpson, Mohr and Redman [33] aimed to look at how people from Italian, Lebanese and Vietnamese backgrounds, living in Australia, understand TBI. They interviewed 39 people with TBI alongside their family members. The family members were of three relationships; siblings, spouses and parents. Other viewpoints within the family were thus possibly missed out. An inductive thematic approach was used which aims to categorise findings into different themes. The study identified themes around reporting symptoms of TBI, valued qualities in service providers, barriers to communication and stigma. This method stops short of comparing narratives for differences or linking concepts to create a theoretical model. One interesting finding within this study, where exploration of difference would have been interesting, was the theme looking at ‘understanding’. The authors’ findings indicated that participants’ understanding ranged from “sophisticated explanations, through to those who appeared to comprehend little about the rehabilitation processes” [p136]. A greater analysis of the specific learning mechanisms in individuals could help professionals discover how they could best intervene.

Verhaeghe et al [34] aimed to investigate the relationship between information provision and hope. The study focused on traumatic coma, which encompassed injuries sustained by traffic accidents, but was not solely focused on TBI. Therefore not all of the findings may apply to the present study. However, the study provided a focus on the mechanisms through which family members learn about traumatic coma. The study found that at first family members are passive in receiving information as they are overwhelmed by the volume of incoming new information; nevertheless after a while they begin to seek out information upon which they can build hope. Interpretations of the information they are being given by professionals then occurs. If these interpretations are not set into context by professionals, family members begin to create their own system by which to understand what is happening. The study by Verhaeghe et al provides some interesting findings in terms of how family members actively use information. However, despite the use of grounded theory, the research did not provide a clear idea of why the participants might differ or be similar in terms of the levels of hope they might have, the interpretations they might make and what information they might select based on their individual characteristics. Additionally, despite recruiting some family groups into the study

there is no discussion of what this method of recruitment found in terms of interpretations within families.

To conclude ‘the TBI literature still lacks unifying conceptual models, therapeutic methods and outcome studies regarding effective treatment of families’ [35]. The methodology for the current study will now be outlined.

3:6 Methodology

Grounded theory aims to ‘get through and beyond conjecture and preconception to discover the underlying processes of what is going on, so that professionals can intervene with confidence’ [38, p.5]. This description fits with the research questions below. The research questions will endeavour to consider the processes through which families learn about TBI and how professionals can intervene using this knowledge:

- 1) What did family members know about TBI prior to the traumatic injury?
- 2) How did family members experience the traumatic event and the process of hospitalization?
- 3) Where was or is information acquired from and how is it being interpreted?
- 4) How has information been used to construct an understanding of recovery?

3:6:1 Design

A qualitative design was applied using grounded theory methodology. Grounded theory was developed in the 1960’s by sociologists Glaser and Strauss [36]. It was developed due to criticisms of qualitative research being unscientific and too open to subjective judgements [37]. Grounded theory aims to collect rich data about the social world, whilst providing explicit guidelines over how to collect and analyse, leading to a more rigorous process and structure. The NSF [38] for long term conditions notes that the gold standard of randomised control trials and quantitative studies for treatment testing are not as relevant due to the complex and longitudinal factors involved in conditions such as brain injury. The NSF comments that qualitative work can be seen on equal

footing to quantitative. As well as being recognised as a good way to research the social world, grounded theory has strong epistemological foundations. The epistemological underpinnings of grounded theory initially aimed to position the researcher as an objective observer. However, Charmaz [39] has criticised Glaser and Strauss's version of grounded theory saying that it is too prescriptive and aligned with positivist principles. Charmaz proposes that data in grounded theory are actually a co-construction between the participants and researcher. By undertaking a constructivist enquiry there will be an assumed position of mutuality between researcher and participant, which necessitates a rethinking of the grounded theorist's traditional role of objective observer [40].

3:6:2 Participants

Grounded theory aims to reach theoretical saturation by constant comparison of the narratives of a heterogeneous sample of people, to contrast their unique viewpoints, until no new themes are emerging. The focus is on speaking to the selected people on characteristics that appear to be emerging as salient to the way a phenomena is being described. A demographic information sheet was used to collect several key characteristics about participants [Appendix 5]. Most studies have included severity of injury as measured on the Glasgow Coma Scale on admission [41]. This information was not included because the epistemological position suggests that, how the person interprets severity is most important, and this will materialise in the interview. Secondly, at the point of recruitment it will be known by the clinician how serious the injury was and this can be used as a guide to select based on severity should this emerge as important. The inclusion criteria were: being a family member of somebody who has suffered a TBI; being in the Greater Manchester area; over 18 years of age and able to speak English. It was hoped that several clusters of related family members could be recruited in order address some of the criticisms raised in the introduction. Also, to explore how family members within the same unit might jointly or individually interpret information. The first five participants were selected based on opportunity as there were no pre-existing conceptions about what characteristics might be important. The iterative process of analysis guided the selection of further participants by opening up avenues of interest and concepts that needed to be investigated further. Once the initial interviews had been analysed, participants began to be selected based on

emerging salient characteristics, for example role. There were three phases of recruitment which mapped onto the three stages of analysis: Open coding, axial and selective. The participants' demographics can be seen in table one.

Table 1: Participant characteristics

Participant's code	Age (Mean = 43.7)	Gender	Relationship to injured family member	Cause of incident Date of incident	Person entered rehabilitation unit post hospital	Injured persons current housing status
A	53	F	Mother	Fall Jan 2009	Y	At family home
B	48	F	Mother	Car accident April 2012	N	Hospital
C	49	F	Mother	Unknown Mar 2011	N	At family home
D	47	F	Wife	Assault May 2012	N	Hospital
E	63	M	Father	Assault Nov 2009	Y	At family home
F	26	F	Partner	Pedestrian accident Mar 2007	N	At home
G	54	M	Father	Car accident July 2011	N	At family home
H	55	F	Mother	Pedestrian accident Nov 2008	Y	At family home
I	50	F	Wife	Fall Aug 2011	Y	At home
J	61	M	Father	Pedestrian accident Nov 2008	Y	At family home
K	45	F	Wife	Climbing accident April 2010	N	At home
L	18	F	Sister	Pedestrian accident Nov 2008	Y	At family home
M	28	F	Sister	Assault Nov 2009	Y	At family home
N	35	M	Brother	Cycling accident April 2008	Y	Independently
O	24	M	Son	Cycling accident April 2008	Y	Independently

The interview schedule was semi-structured and developed over the course of the study. There were two changes to the initial questionnaire [Appendices 7, 14, 17]. The initial interview schedule had broad questions such as ‘tell me about how your family member got injured? The aim was to focus on areas that the participants felt to be important. After the open coding stage the interview schedule was altered to focus on emerging concepts. A third interview schedule was developed after the axial coding stage. This was to focus more specifically on understanding the relationships that had emerged between the concepts and to test the strength of evidence for the emerging model.

3:6:3 Procedure

The study was approved and funded through the University of Liverpool as part of a Doctoral qualification in Clinical Psychology. Ethical consent was gained from London Imperial College’s integrated research application system (IRAS) committee. Consent was obtained to recruit from two neuropsychology departments within NHS trusts in the North West and through the charity organisation BASIC (Brain and Spinal Injury Charity). A poster [Appendix 3] and information sheet [Appendix 4] were available within the reception areas of these organisations. The participant information sheet outlined the rationale for the study and defined the inclusion criteria. Once an expression of interest was recorded on a demographic information sheet the researcher contacted the participant to discuss any questions they had. A meeting was then set up for the researcher to interview the participant. The interviews took place at the participants’ homes and procedures around safe visiting were followed. Prior to interview participants read and signed a consent form [Appendix 6] and were assigned a numerical code. Participants were aware that they could withdraw at any time. Participants were also aware that if they became distressed they could be referred to see one of two Clinical Neuropsychologists supervising the project. The interviews took between thirty minutes to two hours. Once the interview was over the researcher asked the participant whether they would like to receive a copy of the final study. All participants said that they would.

3:6:4 Data analysis

Data analysis took place using the framework provided by Strauss and Corbin [42] and was situated in the constructivist stance of Charmaz [39]. Data collection and analysis ran concurrently. There were three stages to the analytic process; open coding, axial coding and selective coding. The first five transcripts were analysed using open coding. Strauss and Corbin describe how data are exploded at this point with the use of line by line coding. NVIVO-9 was used to create nodes for each code [Appendix 8]. Following line-by-line coding a narrative account of each participant was created alongside a flow chart detailing the most significant themes [Appendix 9]. After each transcript was analysed, questions were asked about what was not known from the existing data, and aims and hypotheses considered. After the third interview the transcripts were still considered line-by-line, but coding into new nodes, occurred only where new salient themes emerged, and references were used to populate existing nodes. The constant comparison method was used to consider the similarities and differences between the participants. A flowchart and narrative summary were created for the first six interviews. Hypotheses were drawn about what needed to be explored further to begin to create links between the emerging concepts (Axial coding) [Appendix 10, 11, 12, 13]. The interview schedule was adapted to narrow the focus onto important emerging concepts [Appendix 14]. A further six interviews were conducted using the participant selection described. These transcripts were also analysed and a narrative summary and flow chart were created, along with hypotheses and aims for the next interview. Axial coding aims to develop links at the conceptual level to link categories at the level of properties and dimensions. Nodes in NVIVO-9 began to be organised into properties with various dimensions as child nodes, organised underneath the main property [Appendix 15]. Finally selective coding endeavoured to select and identify the core categories and relate them to other categories [Appendix 18]. NVIVO-9 was still used, but much of this final organisation of the model was carried out using pen and paper and Microsoft word [Appendix 19]. There was a focus on questioning the relationships between categories and integrating them together to arrive at the grounded theory. A story line was explicated and a visual model created to map onto this story line [Appendix 20, 21].

Supervision was sought throughout the analytic process. Selected transcripts and the coding processes were shared with the second author to ensure that interpretations were appropriately grounded within these data. Memo writing was also utilised throughout the analysis to record operational, theoretical and reflective ideas. Through these memos and supervision it was important to examine personal preconceptions and consider the role of self in the creation of data.

3:6:5 Participant authentication

Glaser and Strauss [39] note that a grounded theory enquiry should be able to meet certain criteria. These are; fit, relevance, workability, and modifiability. Checking whether the theory resonated with the family members was used to gather feedback on the individual narratives. It was also used to gain feedback on the final model to ensure the model fits with the participants' experiences, that it seems relevant to them and that each participant can identify their story within it. The results of the data analysis shall now be reported.

3:7 Results

An overview of the model will first be provided, before the concepts are considered in order and with reference to the initial research aims and questions.

3:8 Overall story line of model

At the time of injury most family members say they have no experience or knowledge of TBI, though they have some basic knowledge of medical vocabulary (coma, resuscitation etc.). Those who do have knowledge of TBI, for example through work, appear to feel they start from a similar point to those who know nothing. This is because it emerged that the sense-making process is primarily about understanding how TBI relates personally to a family member; Generic facts are not as helpful as personally applied understanding. There are several general factors which should be considered as exerting an impact on the sense-making process, but that are not easy to predict per individual; emotional fluctuations; practical difficulties; and other family stressors.

Immediately after the injury there is a distinction between some family members feeling involved and informed by professionals and others feeling that 'nothing' is being explained. Nonetheless most family members feel positive about the information being delivered in intensive care (ICU). They describe starting to become 'expert' at monitoring the machines and considering their meaning for their family member. The families all have a similar view of the goal in ICU which is to get through the life and death crisis and there is a rough understanding of the next stage i.e. the person 'waking up'. However, after ICU families often report feeling they are not told enough, even those who previously felt involved. This leads to an increased reliance on other ways to take in information. Observation of the ward, injured family member and professionals is complemented by reading sources and asking questions. Hoping for progress and thinking spiritually are selected as mind sets.

After the person with the brain injury is out of danger there are a number of strategies which become more important. Observation is still the foremost way that most people seem to be building an understanding of what is happening. Furthermore, people appear to realise that previous experiences can be helpfully applied in the brain injury setting, for example, using parenting experience to help the family member re-learn skills like reading. The person with the brain injury can also start to communicate important information about how they feel and what would be helpful. After the initial stage of life or death there is also a shift to focusing on the future. Family members try to make sense of how their role in relation to the person is changing. The future is envisioned in terms of how it might look practically. Observation is also important here as people compare their family member pre and post injury, in ways that professionals cannot, to consider how things might have changed. Family members described two characteristics in regards to the future; how confident they felt with the changes in their role; and how responsible they felt for their continued involvement. Those who feel they can manage the change in role and feel responsible for the person are motivated to use what they are learning to improve the situation for the person. A form of experiential learning takes place where family members 'try things out', for example giving the person a ball to squeeze to improve strength. Those who feel less confident might sit by the bedside interpreting incoming information but feel more reliant on professionals to explain what they are seeing and what to do. Those who do not

feel responsible for the person, and so are less involved (friends or distant family members), will rely more on other family members' interpretations to guide their understanding.

The desire to check interpretations appears due to the limited understanding of what the next stage is and how serious the injury is. Professionals are valued by families to support their on-going interpretations. Professionals can help families using a supportive 'bedside manner' to offer personalised TBI information, guide their initiative and facilitate hope. Additionally, families also share knowledge and interpretations within the family. There seems to be the need for a shared sense of what to do next and agreement over how serious the injury is. Where there is agreement within families and between families and professionals, there are a number of outcomes. There is a greater confidence in the knowledge or 'expertise' that is being formed; a positive or shared view of steps to progress; a joint understanding of the next step and a positive perception of professionals' competency.

Conversely, where families seek to check interpretations with staff members and other family members, and find unwillingness or disagreement in opinion, this can lead to a conflicted understanding. Professionals here are felt to have an unsupportive bedside manner; only offer generic information on TBI without personalising it; are felt not to scaffold family initiative and not to facilitate hope. Outcomes here are professionals being seen to have an unsupportive 'bedside manner'; not feeling as confident in their developing 'expertise'; a sense of individual or conflicted narratives of what is happening; and an unclear or different view of steps to progress

Family members were interviewed at different stages throughout the injury continuum and it emerged that a common process was reflecting on previous events in hindsight. Family members felt they frequently considered the accident and hospital phase using emerging 'expertise' to ground previously confusing or hard to understand comments, sights or actions. The full process that has been described was similar whilst family members were in hospital and several years post discharge. Years after discharge from hospital, interpretations within families take precedence over interpretations with

professionals. Expertise years after the injury is increased. However observation, reading, previous experience and talking to the person with the TBI are all still important strategies.

The story line summarises the model with the highlighted headings providing the elements of the model which hold it together and constitute the context for the other sub-categories. Quotes from the transcripts will be provided to bring the data to life and situate the model in the data.

3:8:1 Experience of TBI

Research question one aimed to look at what family members knew about TBI prior to the traumatic injury. The broad answer from the majority of participants was that they knew nothing. The early stages are categorised by families desperately trying to make sense of what is happening. Those who have a rudimentary medical knowledge try and apply this to make sense of what is happening. Those who have more understanding do not seem to find this helpful at the point of injury as there a sense that what is occurring is a very unique situation. There is a feeling that the personal element of TBI is most important and so the expertise developed can only be generalised so much:

M: 'You could have a room full of people that have all had brain injuries, not one of them would be the same. I think it's important, if you were ever in that situation again, not to expect any two people with brain injury to be the same'.

An important factor that comes to light later on in families' journeys are that they have resources, experiences and skills. These start to become useful once the initial life and death crisis is over and families have greater capacity to think clearly. When describing these processes family members do not seem aware that they are intelligently using previous resources to help their family member. These resources are grouped into experiences and skills. Examples of experiences are living through other difficult situations like other family member's deaths. Skills are those such as being able to apply principles of parenting to the person's recovery or personal skills such as being a good communicator.

I: 'We've got him reading, we've got him writing again. We got some of my daughter's old books out from when she was a baby. I used to take him out of the main room and go back to his room and we used to work with him. And, because I felt that the therapists there weren't doing enough with him to bring him on'.

3:8:2 Relating medical to personal

As mentioned previously, a higher order concept is the central idea that families do not want to learn about Traumatic Brain Injury (TBI) per se rather they want to relate the medical to the personal. There was a feeling expressed that at times professionals provide the medical information but not the personal link. This is the core sense-making goal that occurs throughout the person with TBIs lifetime. These quotes summarise this central theme:

N: 'And you were kind of seeing the person rather than the medical concern I suppose'.

O: 'They're giving you information more on a medical level aren't they and maybe with a little bit of their own jargon whereas you want information on a personal level. Obviously they can't give you that because they won't know the individual beforehand'.

At the beginning there is a desperate need to take in the enormity of what has happened and try and begin to assess how serious the situation is and what can be done to help. Although these themes and tasks also take place later in the model, they are considered distinct at the start of the TBI journey as there is a clear divide in family narratives over how intensive care units are perceived and how information delivery is perceived around this point.

3:8:3 Early experience of information delivery

Family members have a desire to be both informed and involved in their family members' care. The stage of the recovery journey that appears to realise this best is the intensive care (ICU) stage. Family members feel happiest when they are offered personal information about their family member, guided to do something to help and where their hope is facilitated. This is also noted later in the model when trying to access information and check interpretations becomes more important. It may be that in ICU

staff members are better able to realise these goals, as at this life and death stage all parties are united in the same goal of preserving life. Family members and staff are also united in the desire not to think too far ahead:

D: 'It was more the kind of medical side of it just the actual being out of danger bit that's what you tend to focus on because I don't think your mind can cope with thinking ahead as well'

Moreover, it is easier to personalise information through explaining what the machines around the bedside are recording. This also gives family members a concrete and observable task to undertake. This is summarised in participant K's quote:

K: 'So I was just monitoring and watching it go up and go up all the time and at some points it wasn't as much as that. I felt like saying 'Well why not? Just give him something else now'. So I did become completely obsessed with the machines around R's bed'.

The vast majority of participants experienced ICU in a positive manner. It is after the family member comes out of ICU that there is a more negative perception. Family members start to feel less guidance about how they can help their family member progress. Participants describe feeling that there is a lack of explanations. This leads to families feeling that there is a greater need for them to learn and try to progress their family member themselves. As participant A summarises:

A: 'Intensive care did (explain). HDU and the wards went through the motions of the medical side but not actually explaining anything'.

A: 'If you don't explain these things to people then sometimes it's a massive slap in the face for the family and people that have to deal with it. Cos' like when things come later on and you think 'well nobody told me about this and nobody said'

It is important to note that some professionals are highly praised and every narrative singled out a professional and praised them for the work they did. The characteristics of these professionals will be described later. Observation appears to be the main method of learning that family members engage in when they perceive an absence of information. This will now be explored further.

3:8:4 Observation

Families are constantly engaged in a process of watching the family member and the environment to try and understand what has happened. Observation is the easiest way of taking in personally related information and families become sensitive to noticing small signs:

M: 'Because you find yourself just sitting there watching, like almost waiting for something to happen really'.

G: 'We just kept on looking at him. Seeing his movements and that, and then he just flickered his eyes, you know, and just moved his head a little bit and they said he's starting to come round now'.

Observation is a means of maintaining a positive hopeful mind-set via looking for signs of improvement. Spirituality and praying for signs of improvement can also be seen as tied to observation. The process of initiative can follow very quickly after families observe something. A form of early initiative is going away from the hospital and reading up on something that has been observed to try to make better sense of it. Another form of initiative is action-orientated which comes from a desire to improve the situation for the family member. This quote combines the three themes of observation, hope for progress and initiative:

B: 'He twitched his finger! I'm sure he just twitched his finger!', 'did you see that he...tw...he'. And kept going round to the left hand side and stroking him, pinching him a little bit and see if he reacts'.

Observation appears to always be an important strategy for understanding what is happening. The focus shifts slightly when family members begin to become more alert and verbally able. Families begin to compare their family member pre and post injury, trying to make sense of the future.

Participant L here considers her observations three years post injury:

L: 'I mean he always seems to be smiling. He doesn't seem upset. So I'd like to think he's not. I mean recently he's been feeling his head there, obviously thinking himself about it'.

The theme of action-orientated initiative will now be considered.

3:8:5 Action-orientated initiative

As previously mentioned initiative is an important concept in families' sense making. It appears to occur like a form of experiential learning, whereby trying things out can lead to an exploration of the consequences and a better understanding of what to do next time. There is a high premium placed on activity and doing something to improve the situation for the family member. Initiative can lead straight from an observation as described by A:

A: 'It was only co-incidence one day that I had this ball and erm he had opened his eyes and, I was stood at the end of his bed and I said to him catch the ball, and I went like this (Indicates throwing motion) and he did. And it was like little things like that, I know they are poorly, but if they are waking up and you do get that little moment then it's like 'try it''

One of the qualities that staff members are prized for is their ability to help the family scaffold their initiative and do something with the family member that ties into their personal goals and values.

Participant I provides an example of this:

I: 'I was told then that the best thing I could do was to stimulate him. And there are different forms of stimulation; I bought some Star Wars snap cards cos he used to like Star Wars'.

Initiative can also be influenced by how a person feels about their abilities to respond to visual cues.

This is tied into the theme of thinking about the future which appears to occur after the family member is out of the initial crisis point.

3:8:6 Future orientated thinking

Future orientated thinking occurs at different times for different people. Some people soon after hospitalisation begin to make interpretations that the person may not survive and so start thinking to the future. If the sense is that they will survive, the shift to future focused thinking tends to occur after the person has been given this prognosis. D summarises this shift in thinking from a life or death focus to the future:

D: 'Initially you're just thinking about whether a person will live or die and you try not to think about the future, that's all you want at that stage but as it becomes apparent they are going to live then you start thinking what is going to be next what's long term implications you know so'

Two areas appear to be at the forefront when thinking about the future these are 'how will life be different' and 'how will the relationship you had with the person be different'. Thinking about how life will change necessitates some information from professionals about what could conceivably happen. Here there is often a point of conflict as professionals cannot always guarantee what will happen next. Family members appear to be aware of this but retain a sense of needing to understand what the potential stages to recovery might be. Participant A discusses this:

A: 'Nobody sits you down and says right ok, this is where you are at this stage now, so your next stage will be here, and then here so you will progress, and that's how it should work. I mean obviously there's blips where you might end up back but a rough idea would help'.

Much of the thinking about roles and relationships occurs at an individual level, although aspects may be shared within the family. This can be seen where family clusters were interviewed and participants H and J both emphasised the same point:

H: 'I think Ryan's found it- I found it hard as a mum. But Ryan was not only his dad but his friend'.

J: 'Me and Simon was close (Sic). I used to take him to the football. We used to go to home and away matches'.

When considering the different participants' accounts, it appeared that two factors were important. Firstly people feel differing degrees of responsibility for their family member. In some cases, such as a mother who was always close to their child, the sense of responsibility is overwhelming. Others, such as wives, may have a sense of responsibility formed through marital vows.

I: 'I was devastated because we didn't know what his potential was, erm, and I'd been married to him a long time and I thought 'How could I put my husband in a home?' So that's why I was determined to get him as well as I could and hopefully have him home'.

The other theme present when family members considered their changing role was how comfortable they were with this. Some people appear to experience a dilemma in that they are unsure how comfortable they feel with the idea of being a carer, however they feel very responsible for the person. This appears to necessitate a greater need for involvement from professionals. Others feel comfortable in the shift in role and so perhaps more happy to act on initiative, for example O talking about the shift from being protected to being a protector:

O: 'It's, obviously there was a change and it's significant and it kind of feels strange but it didn't, in the context of obviously family and people you love it didn't, it wasn't too outlandish or too strange, it was just kind of, you know, what you'd expect people to do I suppose'.

Considering role appears to be important in terms of how vital seeking support from staff to make interpretations is.

3:8:7 Interpretations

Whether family members take initiative or not, they are constantly wondering what is happening, why it is happening and what can be done. Family members have a real need to check their interpretations with professionals and within their family. Participants noted that although they can make observations and take initiative, that this can at times, be dangerous if they come to the wrong conclusions:

M: 'I think you can learn a lot from watching but you can also, it can also be quite detrimental because you might see something that you think, like 'oh my god he's just done that' and actually, it's not even significant'.

Professionals are felt to be the holders of knowledge and information and it is felt important for them to share this with families. As A notes here there can be a sense of professionals holding back information:

A: 'If you're not going to give me the information you're going to have to put up with how I react. Because I am not prepared for this, I am not prepared for all these stages because nobody has told me so if you're not going to tell me then you are going to get this reaction; I came to my own conclusions'.

Family members also share their interpretations within the family unit and with the person with the TBI. Generally it appears that family members share their observations with each other, but perhaps do not always share what interpretation they make. In some cases family members have conflicting interpretations and this can lead to conflict in the family. K remembers an incident where she felt that ward staff were not being careful enough with her husband:

K: 'His mum didn't deal with that very well. Didn't like some of the things I was asking the nurses, didn't think I should be asking them'.

The person with the TBI is often coming from a disadvantaged position when trying to make sense of what has happened to them. They have missed much of the early stages when they were unconscious. Here, the family can jointly try to construct an understanding. However, it is often the case that professional input would also be welcomed to fully understand the medical context.

B: He's trying to make sense yeh, and erm and he sort of said well 'did I have tubes, what tubes did I have in my mouth... I think he wants to know that from a medical point of view and I have I've explained to him...'

3:8:8 Professionals' support

The process being referred to is the families' sense-making and professionals are talked about as undertaking, or not undertaking, a number of important tasks with family members. The underpinning characteristic professionals need to have is a good bedside manner. This appears to earn good will

with families and enable information to be delivered in a more palatable manner. Participant E provides a summary of this point:

E: 'Their ability and willingness to interact with, you know and again that well used phrase it's bedside manner and it's not about being able to tell me what someone's blood pressure is but it's the way you handle people'.

A second key characteristic of professionals is whether they are able to provide a personalised service to the family and information that is relevant to what is happening for their family member. Generic information about TBI is felt to not be as helpful and families can feel their expertise about their family member is being disregarded.

K: 'They found out who I was, what I was about, how I functioned, what Tim was about, what our relationship was about, but they never asked me any questions. Now that sounds really bizarre. I never felt like they were asking me any questions and yet they knew- '.

A third important way in which professionals can support families is being involved in scaffolding their initiative. Professionals who are seen to be 'doing something' to help are regarded positively. This feeds into family members' needs for progress and their desire to do something to help, as opposed to sitting by the bedside feeling helpless:

B: 'One of the nurses said to me 'if you want to bring something, some moisturising cream in for his arms and his feet because his skin was getting a bit dry'.

M: 'They would try and reduce his assisted breathing. And when you were there they would involve you in it and just say "talk, just talk to him quietly" and stuff like that and, that was really good because it gives you a better understanding of what they're trying to do'.

A final positive characteristic of professionals is for them to maintain a sense of hope through the provision of information about the next step. Family members appear to have a great desire to understand what might happen next and what to look for. Participant A describes the negative impact of receiving no information:

A: 'I don't think the professionals make it easy and I think that's a problem. They need to explain things, and it should be a clear path and you shouldn't have to keep sort of deviating and going places and getting knocked back and fighting'.

Much of the future focused information family members desire is on a smaller scale than professionals might think. It appears that family members understand they cannot be told the future outcome but a sense of hope and a way of progressing is helpful. Unlike professionals, families will have to keep faith that the person's situation can improve, as they will be with them day to day trying to achieve this. L talks here about the conflicting information, that on the one hand the families cannot be told the future, yet professionals are often dismissive of progress:

L: 'I'd probably think about what they said but then think 'You're wrong'. I wouldn't just ignore it because I didn't want to hear it. I'd just probably think well you don't know for sureit's unknown. Every brain injury is totally different. So it's just the unknown'.

Previous knowledge, observation, initiative, interpretations and professional input all come together to create a number of outcomes.

3:8:9 Sense-making outcomes

The outcomes of the sense-making process are evolving and changing incident by incident. This model is not a linear progression, rather it will repeat cyclically as new incidents emerge and understanding is integrated together. New incidents lead to knowledge development; which family members seem to want to check with professionals and other family members. This links to the first outcome that there is a sense of 'expertise' evolving in relation to their family member and how to manage day to day incidents. This expertise can then be applied to situations in the future:

G: 'About brain injury? Yeah, yeah. I could tell you quite a lot about brain injury. Erm, you know, what it actually does and what happens and how it erm...how it repairs itself and things like that'.

Family members seem to be either confident about their emerging expertise if they have had professional approval or less sure if they feel they have had little feedback from professionals.

Similarly, if there is disagreement in the family over interpretations there seems to be less certainty about the knowledge being developed. A second outcome is the development of a narrative of what has happened and what TBI means for the family. This narrative is shared to a greater or lesser degree with the other family members and with professionals. The more the narrative is shared, the more aware the family are of each other's struggles:

K: 'There's a shadow there that- neither of us want to upset each other.....I think maybe at some point in the future it suddenly will need to be dealt with'.

From this narrative emerges a shared or individual sense of what needs to happen for the person to continue to progress. These steps can be disagreed about between the family and professionals.

Where there is a sense of agreement about the next step, with clear goals being put in place, there is a greater sense of unity and positivity about the future. G describes how goals became an important concept from hospital which was continued at home:

G: 'You know and that's what he still talks about that now. About goals, what he wants to do, like. He wants to get back driving and he wants to go back to work'.

Interviewing family clusters was helpful in that it could be seen that often the different members had different interpretations of what had happened and therefore what the next step or way of managing a situation should be. The interviewer was in a privileged position to be able to hear these stories and reflect with the different family members how much of their relations' stories they felt they knew. Throughout the brain injury journey it was clear the families were developing their own individual narratives and also sharing some elements of the narrative. Participant H illustrates how differing family narratives about the injury can lead to different views on how to progress the person.

H 'A fine example is when he's hoisted, he holds onto the hoist. 'Now he must feel secure'. Cos he's holding on. And someone will say 'oh no you shouldn't do that, don't do that. "Take your hands off, take your hands off". If he needs to "why?"'.

Another outcome of the sense-making journey is the perception of professionals that the family holds. Family members appear to have differing views of professionals' competencies and feel that simple changes in professionals' manner could mean a lot to how they experience TBI. Participant C discusses her current impression of staff support which is very negative and G describes feeling a positive perception of staff members on ICU:

C: 'I was in shock at the change in attitude and approach to me after we left ICU I was in shock how appalling it was, absolute disgrace, caring profession excuse me but, bull shit'.

G: 'Yeah, the doctors and the nurses were brilliant. They explained to me everything what could happen and, you know, what, you know the worst...erm...scenario (Sic)'.

3:8:10 Hindsight

The model is cyclical in that everything that the family has been through will then be considered in hindsight. People will reconstruct what has happened in light of their new understanding. Family members can look back on observations they made and consider them within the context of new learned information. Interviewing clusters allowed for an understanding of how family members might reflect back and bring their new understanding of an incident to their family members' attention:

J: 'We discussed things with each other and all that cos S would say "Oh do you remember what such and such a body said?", "Oh yeah I did but I had forgotten. I remember now". Cos I can be told stuff and then I forget it'.

The findings of the study will now be discussed in relation to how they answer the initial research questions and how they support or refute current theory.

3:9 Discussion

The research aimed to answer four questions which considered how family members come to construct an understanding of TBI. As in all grounded theory inquiries, the focus can shift slightly as

the research topics are guided by the participants. However, the results of the study answer the initial research questions. Additionally, although many other interesting topics arose, such as emotional fluctuations, the research questions provided a clear focus to guide the interviews. An important caveat that can be added to the questions is that it is not TBI family members wish to construct an understanding of, but their family member's individual TBI. It was hoped that different family relations could be recruited alongside clusters of family members. Both of these aims were met with a good degree of success. The research questions will be considered in turn within the context of the existing research base. This will allow for an exploration of the literature closely connected to the findings in order to build upon strengths and limitations in these areas.

3:9:1 Research questions one and two

Research question one aimed to look at what family members knew about TBI prior to the traumatic injury and research question two asked how family members experience the process of hospitalisation. The sense-making literature can provide an existing research base from which to consider the findings of this study. Frank's [43, p1] description of 'serious illness as a loss of the destination and map' that had previously guided the ill person's life fits well with what was discovered from family members' narratives. It appeared that initially there is a perceived absence of knowledge reported by family members. The sense-making literature similarly notes that, in the critical period there will be a gap in peoples' knowledge [44] and prior assumptions are likely to be shattered [45]. To overcome these feelings of helplessness individuals are described as needing to engage in sense-making, not only in order to figure out what to do next, but also to deal with the anxiety and fear that may accompany the experience. The present research found a similar process, with family members initially in shock and then becoming more active in the sense-making process. The mechanisms of learning will be discussed further within research questions three and four.

3:9:2 Research question three

Research question three aimed to consider where information is acquired from and how it was interpreted. Previous research in TBI has often stopped short of fully investigating this. Simpson,

Mohr and Redman [33] speculated why some people have less knowledge, for example low education, or services not being culturally sensitive, but did not investigate the individual processes fully. Additionally, several studies have investigated information needs but focused on topics family members feel they want to know more about and not looked at processes taking place pre-discharge [46]. The present study interviewed several clusters of family members and found that, different pre-existing experiences and skills were important sources of information, which can vary across family members. Complementary to the idea of existing characteristics, Weick [47] proposed seven inter-related properties by which sense-making is organised. Weick [47] felt that sense-making is grounded in identity; this means that ‘who’ we are gives us a particular view on the world, and we use our personal experiences to give meaning and make sense of the present. Different family roles in TBI appear to bring different prior experiences which can be utilised in different ways, for example a mother using parenting techniques and feeling comfortable doing so. This is also illustrated in the literature on serious illness. Friesen, Pepler and Hunter [48] studied family members of those given a cancer diagnosis using a qualitative design. The study found that a major mechanism of learning was through families reviewing the past, gathering and interpreting information, and sharing experiences. A later strategy used to learn about TBI was asking the family member themselves. This is not often indicated in the TBI research as studies tend to interview TBI survivors or family members, not both together. Blais and Boisvert [49] did interview partners, one of whom had a TBI, and found that communication and problem solving were the biggest factors in psychological and marital adjustment processes. They note that both partners must modify or learn new behaviours, solve specific problems in response to new life situations and renegotiate their roles within the relationship.

Related to the idea of learning from the family member with TBI is another of Weicks’ [47] properties which notes that sense-making is a social phenomenon. This means that the sense-making process is contingent on our interactions with others. This has been discussed in the work of Bowen, Yeates and Palmer [11]. Interactions will impact on an individual’s sense-making activities and provide routines or scripts for appropriate conduct. When routines or scripts do not exist, for example if they are not provided, as is often the case in TBI, the individual is left to fall back on his or her own ways of

making sense. This appears to link with methods of information collection family members use when they feel there is an absence of information from professionals. The processes of observation and initiative will now be described.

3:9:2:1 Observation and initiative

Family members appear to engage in observing their family member, to take in information, and then act upon that information using initiative. The early literature search identified an emphasis on written and verbal information from staff members [17, 21, 46]. However, little attention has been paid to how family members use visual information to construct an understanding. Verhaeghe et al [34] did however note that, observations are one source of information family members' use, but did not locate this as a central element in their model. The present study found family members use observation as the primary method of sense-making and once they observe something they then feel compelled to check their interpretation of it with professionals. Braga, Da Paz and Ylviksaker [24] discussed in their study how greater involvement of the whole family may decrease the potential for inconsistent messages from staff members. Davidson [50, p31] also notes that 'sense-making is more than providing information; it is providing an interpretation of the situation and the surroundings from the environment that can be interpreted by family members'. In practice this can mean explaining events as they happen and then using reflective inquiry at the end of each visit to clarify misconceptions about the events of the day

3:9:3 Research question four

Research question four aimed to investigate how information was used to construct an understanding of recovery. The present study found that family members are keen to act upon the information they have taken in, and this is because they wish to progress their family member, which is the ultimate goal of taking in information and learning about TBI. It appears information is being taken in to try and construct a positive view of the future. Professionals are prized for helping achieve this vision and initiative is one process which is used to achieve a positive feeling about the future. In terms of the initiative that follows observation, parallels can be drawn with the experiential learning literature. Itin

[51] has described experiential learning as the process of meaning making from direct experience. Kolb's [52] work on experiential learning has contributed greatly to expanding the philosophy of experiential education. Kolb has created a widely known four-step experiential learning model (ELM) which maps well on to the idea of family members observing something in the moment, acting upon it, observing the consequences and refining the techniques they use. As widely mentioned in the paper by Verhaeghe et al [34] there is a need to use information to conceptualise a positive future and hope was found to be an important concept.

3:9:3:1 Hope

Snyder [53, p249] in his seminal paper on hope theory notes that 'hope is defined as the perceived capability to derive pathways to desired goals and motivate oneself via agency to use these pathways'. In the majority of cases in the present study the goal of progress and recovery had high levels of personal value and meaning to an individual. Hope theory can help elucidate why family members feel they need to understand the pathway to achieve progress and prize those professionals who aid this. Furthermore, some family members will feel more comfortable with the change in role they are experiencing. Those who adapt to their new role and have high motivation to engage in rehabilitating their family member appear more positive about the future and so may have higher levels of hope. Verhaeghe et al [34] carried out a grounded theory study looking at hope and information. The findings of their study indicated similar conclusions in terms of family members beginning to actively work on information and learning what to build hope on. Families in Verhaeghe's [34] study indicated they needed information that was accurate and understandable and left room for a realistic hope. The conceptual implications of the study will now be discussed.

3:9:4 Conceptual implications

A number of critics have noted that there is limited consensus over which concepts to use to study the field of family members and TBI [20, 30, 35]. Additionally, critics note there is often a focus on deficits and distress as opposed to resiliency and coping. This study has shown that a limited focus on deficits and a focus on family members' needs can ignore the resilience and ingenuity that families

are applying to understanding TBI. A greater focus on assessing family members' strengths and opening up dialogue with the whole family unit may help avoid a narrow focus on measuring distress and improving outcome measures. Family members and professionals will all interact to make sense of an individual's TBI. It is therefore important to consider how each person within the family system is constructing an understanding of the injury. A focus only on the injured party may lead to the family members' needs being ignored. TBI can be a complex phenomenon to understand and as each case is likely to be unique, the family will want to know about personal consequences and staff members can help apply their expertise in a personalised and flexible way. Leaf [54, p543] notes that 'traumatic Brain Injury (TBI) comes in as a roaring lion, devouring and changing systems and the support and the cohesiveness that the family knew before the event causing injury'. There is a need to understand and focus on roles within families in order to support family members in their transitions in role throughout the TBI continuum. A focus on individual family members in research and practice misses out on the complexity of dynamics within the family.

3:9:5 Strengths of the study

The strengths of the study are the use of a grounded theory methodology to compare and contrast the processes that family members go through to learn about TBI. The study used a clear epistemological framework which attempts to understand the accounts as a product of social construction. The study did not merely describe the findings rather it aimed to consider the relationships between concepts. All participants expressed interest in the project and appeared to find it helpful to be able to discuss freely their struggles in coming to understand what was happening for their family member. The study recruited different family relations and also three clusters of family members. The study provides an exploratory basis from which the theoretical model can be further explored.

3:9:6 Limitations and further research

The study has a number of methodological limitations. The participants recruited all asked to participate in the study, therefore there may be a bias in terms of families with a particularly positive or negative perception that they wanted to share. Secondly, point of recruitment was via Neuropsychology departments therefore these family members were all in contact with professionals in some manner throughout the process. A criticism of Bowen et al [22] was that the model did not address the issues of those choosing not to engage and investigating the reasons behind this. It may be that some family members are less inclined to engage with professionals and so are missed within the present study. In terms of the sense-making literature there is a distinction noted between studying collaborative sense-making and individual sense-making. Koenig and Trees [55] studied joint storytelling or collaborative narration and note how the study of these joint narratives can help families make sense of traumatic experiences. An outcome in the present study that was felt to be salient was the extent to which a joint narrative was felt to have been produced. Although an attempt was made to recruit different family relations into the study the model to an extent remains a model of individual sense-making as opposed to truly investigating active collaborative sense-making. This is a possible direction for future research, as there may be value in unpicking the factors associated with conflicting and unified understandings in the family in greater depth.

3:9:7 Implications for clinical practice

The model suggests that family members are active in the process of understanding TBI and bring skills and knowledge that could be utilised by professionals. Given that family members have important skills they could use in the rehabilitation process, it would be helpful if staff members had a greater idea of who was involved and their relationship to the person. Family books at the bedside with family trees would enable professionals to understand the system around the patient. Raising changes in role earlier in the rehabilitation process might enable family members to consider how this may affect them. The study also helps diminish some of the myths suggesting that family members want specific information about the future that can often cause uncertainty in professionals [56]. The

study indicated that families need a sense of hope and a validation that the future is not as bleak as it seems. Within this, families like to be given an idea of what they can do to help and what the next step might be so that they can plan for this. The main processes appear to be use of pre-existing knowledge, observation, initiative and checking interpretations. Many of these processes are amenable to intervention which may lead to more positive outcomes such as better perception of staff, a more cohesive family narrative and a better defined pathway to recovery. Davidson's [50] discussion of facilitated sense-making in ICU provides examples of how nurses can provide families with concrete activities. These activities are ones which the family may not necessarily have thought of on their own. They include meaningful activities at the bedside, such as applying lip balm, assisting in passive range of motion exercises, or giving a hand and foot massage, which give them a purpose in emerging new roles.

3:10 Conclusion

The sense-making model indicates that families have a desire to learn about TBI in a context that is personally applied to their family member. In the absence of information they will rely on observation and their own initiative to learn what is happening. Initiative can help families feel involved in aiding progression for their loved one. Family members will also use previous experience and their family member with TBIs lived experience. Staff members can help by scaffolding this initiative, providing personalised TBI information and providing a sense of hope; all of this done in an approachable manner. Desirable outcomes are progress for the family member, a shared narrative emerging, a sense of knowing what the next step is and a good perception of professional support.

Referencing

1. Winslade WJ, Brady JC. Confronting traumatic brain injury: Devastation, hope, and healing.
London: Yale University Press; 1999
2. Hospital Episode Statistics (HES) online: Traumatic brain injuries. The Information centre for health and social care. [Internet] [Date 21 Jan 2013]. Available from:
<http://www.hesonline.nhs.uk/Ease/ContentServer?siteID=1937&categoryID=1207>.
3. Brown D, Lyons E, Rose E. Recovery from brain injury: Finding the missing bits of the puzzle.
Brain injury 2006;20:937-946.
4. Chamberlain DJ. The experience of surviving traumatic brain injury. Journal of Advanced Nursing
2006;54:407-417.
5. National Collaboration Centre for Acute Conditions. 2002. Head injury: assessment, investigation
and early management of head injury in children and adults. London: NCC-AC, National Institute
for Clinical Excellence.
6. Panting A, Merry PH. The long-term rehabilitation of severe head injuries with particular reference
to the need for social and medical support for the patient's family. Rehabilitation 1972;38:33-37.
7. Lezak MD. Psychological implications of traumatic brain damage for the patient's family.
Rehabilitation Psychology 1986;31:241-250.
8. Rosenthal, M., & Young, T. (1988). Effective family intervention after traumatic brain injury:
Theory and practice. Journal of Head Trauma Rehabilitation 1988;3:42-50.
9. Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 1 year following severe
traumatic Brain injury 1998;12:1045-1059.
10. Knight RG, Devereux R, Godfrey, HPD. Caring for a family member with traumatic brain injury.
Brain injury 1998;12:467-481.
11. Bowen C, Yeates G, Palmer S. A relational approach to brain injury: Thinking about relationships
after brain injury. London: Karnac books; 2010

12. Anderson MI, Simpson GK, Morey PJ, Mok MMC, Gosling TJ, Gillett LE. Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): Multi group analysis. *Brain Injury* 2009;23:931-43.
13. Hawley CA, Joseph S. Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury* 2008;22:427-435.
14. Chwalisz K. The perceived stress model of caregiver burden: Evidence from spouses of persons with brain injuries. *Rehabilitation Psychology* 1996;41:91-113.
15. Kreutzer JS, Kolakowsky-Hayner SA, Demm SR, Meade MA. A structured approach to family intervention after brain injury. *J Head Trauma Rehabilitation* 2002;17:349-367.
16. Tyerman, A, Booth, J. Family interventions after traumatic brain injury: a service example. *Neurorehabilitation* 2001;16:59-66
17. Rotundi AJ, Sinkule J, Spring M. An interactive web-based intervention for persons with TBI and their families: Use and evaluation by female significant others. *Journal of Head Trauma Rehabilitation* 2005;20:173-185.
18. Wade SL, Wolfe C, Brown TM, Pestian JP. Putting the pieces together: Preliminary efficacy of a web-based family intervention for children with traumatic brain injury. *Journal of Paediatric Psychology* 2005;30:437-442.
19. Hibbard MR, Cantor J, Charatz H, Rosenthal R, Ashman T, Gundersen N, Ireland-Knight L, Gordon W, Avner J, Gartner A. "Peer support in the community: initial findings of a mentoring program for individuals with traumatic brain injury and their families." *The Journal of head trauma rehabilitation* 2002;17:112-131.
20. Boschen K, Gargaro J, Gan C, Gerber G, Brandys C. Family intervention after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. *NeuroRehabilitation* 2007;22:19-41.
21. Murray HM, Maslany GW, Jeffery B. Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury* 2006;20:575-585.
22. Bowen A, Tennant A, Neumann V, Chamberlain MA. Neuropsychological rehabilitation for traumatic brain injury: do carers benefit? *Brain injury* 2001;15:29-38.

23. Friedemann-sánchez G, Griffin JM, Rettmann NA, Rittman M. Communicating information to families of polytrauma patients: A narrative literature review. *Rehabilitation Nursing* 2008;33:206-213.
24. Braga LW, Da Paz Junior, AC, Ylvisaker M. Direct clinician-delivered versus indirect family supported rehabilitation of children with traumatic brain injury: A randomized controlled trial. *Brain Injury* 2005;19:819-831.
25. Larøi F. The family systems approach to treating families of persons with brain injury: A potential collaboration between family therapist and brain injury professional. *Brain Injury* 2003;17:175-187.
26. Larøi F. Treating families of individuals with traumatic brain injury: Presentation of clinical cases approached from a structural therapy perspective. *Journal of Family Psychotherapy* 2000;11:69-186.
27. DePompei R, Williams J. Working with families after TBI: A family-centered approach. *Topics in Language Disorders* 1994;15:68-81.
28. Maitz E, Sachs P. Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation* 1995;10:1-11.
29. Godwin EE, Kreutzer JS, Arango-Lasprilla JC, Lehan TJ. Marriage after brain injury: Review, analysis, and research recommendations. *The Journal of Head Trauma Rehabilitation* 2011;26:43-55.
30. Perlesz A, Kinsella G, Crowe S. Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology* 1999;44:6-35.
31. Carnes SL, Quinn WH. Family adaptation to brain injury: Coping and Psychological distress. *Families, systems and health* 2005;23:186-203.
32. Paterson B, Kieloch B, Gmiterek J. 'They never told us anything': Postdischarge instructions for families of persons with brain injuries. *Rehabilitation Nursing* 2001;26:48-53.
33. Simpson G, Mohr R, Redman A. Cultural variations in the understanding of traumatic brain injury and brain injury rehabilitation. *Brain Injury* 2000;14:125-40.

34. Verhaeghe STL, van Zuuren FJ, Defloor TD, Duijnste MSH, Grypdonck MHF. How does information influence hope in family members of traumatic coma patients in intensive care unit? *Family nursing* 2006;16:1488-1497.
35. Collins RC, Kennedy MC. Serving families who have served: Providing family therapy and support in interdisciplinary poly-trauma rehabilitation. *Journal of Clinical Psychology* 2008;64:993-1003.
36. Glaser BG, Strauss, AL. *The Discovery of Grounded Theory: strategies for qualitative research*. New York: Aldine De Gruyter; 1967.
37. Silverman, D. *Qualitative research*. New York (NY): Sage Publications; 2010.
38. Department of Health. *The National Service Framework for Long term conditions*. Crown Copyright; 2005.
39. Charmaz K. *Constructing grounded theory: A Practical Guide through Qualitative Analysis* (Introducing Qualitative Methods series). New York (NY): Sage Publications Limited; 2006.
40. Mills J, Bonner A, Francis K. Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice* 2006;12:8-13.
41. Lankova A. The Glasgow Coma Scale: clinical application in Emergency Departments". *Emergency Nursing* 2006;14:30-5.
42. Strauss A, Corbin JM. *Basics of Qualitative Research Second edition: Techniques and procedures for Developing Grounded Theory*. New York (NY): Sage Publications; 1998.
43. Frank, AW. *The wounded storyteller: Body, illness, and ethics*. London: University of Chicago Press; 1995.
44. Dervin, B. Sense-making theory and practice: an overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, 1998;2:36-46
45. Janoff-Bulman R. *Shattered assumptions: towards a new psychology of trauma*. Free Press; 1992
46. McPherson KM, McNaughton H, Pentland B. Information needs of families when one family member has a severe brain injury. *International journal of rehabilitation research* 2000;23:295-301.
47. Weick KE. *Sense-making in Organizations*. London: SAGE Publications; 1995.

48. Friesen F, Pepler C, Hunter, P. Interactive family learning following a cancer diagnosis. *Oncology Nursing Forum* 2002;6:981-987.
49. Blais MC, Boisvert JM. Psychological adjustment and marital satisfaction following head injury. Which critical personal characteristics should both partners develop? *Brain Injury* 2007;21:357-372.
50. Davidson JE. Facilitated Sense-making: A Strategy and New Middle-Range Theory to Support Families of Intensive Care Unit Patients. *Critical Care Nurse*, 2010;30:28-39.
51. Itin CM. Reasserting the Philosophy of Experiential Education as a Vehicle for Change in the 21st Century. *The Journal of Experiential Education* 1999;22:91-98.
52. Kolb D. *Experiential Learning as the Science of Learning and Development*. New Jersey (NJ): Englewood Cliffs, Prentice Hall; 1984.
53. Snyder RC. Hope theory: Rainbows in the mind. *Psychological Inquiry* 2002;13:249-275.
54. Leaf LE. Traumatic brain injury: Affecting family recovery. *Brain injury* 1993;7:543-546.
55. Koenig JK, Trees, AR. Finding Meaning in Difficult Family Experiences: Sense-Making and Interaction Processes during Joint Family Storytelling. *Journal of Family Communication* 2006;6:49-76.
56. Lefebvre H, Levert MJ. Breaking the news of traumatic brain injury and capacities. *Brain Injury* 2006;20:711-718.

Chapter 4: Concluding Discussion

4:1 Introduction

There have been two papers presented for the reader. The overall theme of the work has been the subject area of family members of those with a Traumatic Brain Injury (TBI). Underpinning this work has been a focus on understanding these areas within the epistemological framework of constructivism. The first paper was a narrative review of the use of family therapy as a conceptual framework for research with TBI families. The second paper was a grounded theory study which produced a theoretical model of sense-making processes in family members of those with a TBI. This chapter will discuss this work in more depth. It will be split into three parts:

- 1) The first section will be an extended discussion of each piece of work in turn.
- 2) Following this will be a lay summary of the grounded theory research for participants for dissemination in the charity newsletter Headway.
- 3) Finally a proposal for a further empirical study will be outlined.

4:2 Extended discussion

4:2:1 Overview

The narrative review will be discussed at each point in turn followed by the grounded theory study, where appropriate, similarities between the two will be discussed.

The narrative review aimed to evaluate the literature on the use of the family therapy model in TBI. It aimed to discuss whether the model could be applied as a guiding conceptual framework for research into family members with TBI. After reviewing twenty-one papers a narrative outline and graphic model were presented. The model pulled the key findings together with higher order concepts overarching more specific, focused concepts. The higher order categories within the model are; a constructivist epistemology; interdependence; the user as an active participant ; a focus on strengths. These factors need to be considered alongside a theoretical flexibility and a consideration of change across time. There are several concepts beneath these higher order concepts which were discovered as

being important in studying processes within the family. These are, family structure, organisational patterns, roles, communication and narrative.

The second paper was a grounded theory study which aimed to explore: what family members knew about TBI prior to the traumatic injury; how they experienced the event; where they acquired information from and; how they interpreted it to construct an understanding of recovery. The model that emerged was a sense-making trajectory. The sense-making model indicated that families aim to learn about TBI in a context that is personally applied to their family member. In the absence of information they will use observation and their own initiative to learn. Initiative can help families feel involved in aiding progression for their loved one. Family members will also use previous experience and their family member with TBIs lived experience. Family members' feelings of responsibility in relation to their role and the degree of comfort they feel in their new role have implications for how confident they feel in acting on initiative. Professionals can help by scaffolding initiative, providing personalised TBI information and a sense of hope; all of this done in an approachable manner. Desirable outcomes are progress in rehabilitation for the family member, a shared narrative emerging, an idea of what the next step is and a good perception of professional support. Both pieces of work had a number of methodological issues which will now be discussed.

4:2:2 Methodological concerns

When considering methodological concerns, it is first worth considering process issues which emerged throughout the investigations.

4:2:2:1 Process

It should be noted that the narrative review was undertaken after the grounded theory investigation. This is in part due to grounded theories' standpoint that the literature review does not need to occur before the investigation (Strauss & Corbin, 1998). Additionally, due to the way the thesis was organised, the empirical proposal was submitted at an earlier stage. Then while the grounded theory investigation took place the narrative review was conducted in parallel. This meant that some

interesting findings from the narrative review could not be included in the inception of the grounded theory study. One finding was the need to ensure family members are involved from the point of development of the research study. It would have been useful to have participants give feedback on the initial research questions and interview schedule, possibly through a focus group. However grounded theory is helpful in ensuring participants' views are considered as participants are encouraged to lead the interview to topics they feel are most salient. Another area in which the grounded theory study fell short of addressing the recommendations was that although it did promote greater inclusion of all family members in the study, including family clusters, there was less explicit investigation of the dynamic elements of family members' sense-making. This criticism will be addressed further in the follow on proposal.

A process issue within grounded theory studies is the importance of considering ones' own preconceptions and how they impact on the data. The constructivist epistemology requires us to see humans as "observers, participants, and agents who actively generate and transform the patterns through which they construct the realities that fit them" (Hickman, Neubert & Reich, 2009, p.40). The use of a reflective diary, alongside memos, was important as it enabled me to consider how my own experience might impact upon my interpretations. A personal experience memo (Appendix A) was created to give the reader context for the investigation and so I could reflect on my pre-conceptions and where they are grounded. One example of the utility of reflection was in the theme of family members' perceptions of information delivery. Having had my own bad experience of professional information delivery in TBI, I was expecting to note others felt the same and at first it was disquieting when people did not share that belief wholeheartedly. However, after a while I began to move too far towards ignoring negative stories of information delivery as I noted the positive more readily. This then led me to ignore the increasing emphasis on the theme of 'nobody told us'. Another interesting process issue was the emergence of observation as a strategy. Prior to the study I would never have cited observation as a strategy. This appears to be similar to family members in the study, possibly because it is almost too obvious a theme and people do not stop to consider the power of visual information and how they use it. After the theme emerged I was able to reflect on multiple occasions

where observation and then initiative were present within my family. The power of the methodology in seeking out explanations that lie between the lines of what people are saying was exciting to witness. These issues were also discussed in supervision and in a reflective diary. Transcripts were also checked to consider the questioning style and reflect on whether the questions being asked were targeting the themes under investigation. A criticism of questioning at first was my tendency to ‘fill in’ the end of a participant’s sentence thus leading them into using a particular term. A final point about process was that at times throughout the investigation it felt the data was too overwhelming and that nothing could ever emerge from the multiple stories and long transcripts. Through the use of techniques such as creating narrative and diagrammatic summaries for each participant (Appendix B) imaginary radio interviews (Appendix C) and using NVIVO -9 (Appendix D-F), the data began to take shape and generate further lines of inquiry and new hypotheses (Appendix G).

4:2:2:2 Other methodological issues

It has been noted that there are no perfect research designs (Marshall & Rossman, 2011). Indeed the narrative review had a number of limitations in terms of identifying and interpreting the data. The review articles came through extensive literature searches on three data bases, checking reference lists and contacting eminent authors. However, some literature is not well signposted in terms of the key terms used and several papers were identified by chance (Friedemann-sánchez, Griffin, Rettmann, Rittman, 2008). Given the amount of papers that refer to the family, but then do not discuss systemic elements, there was a need to be strict with the inclusion criteria. There was an element of subjectivity over which papers to include, dependent on how much they explicitly referenced the family therapy model. Given that a theme throughout the thesis has been the standpoint of constructivism, it should be recognised that the narrative review findings are one interpretation of these data. It would have been preferable to have a second reviewer to examine the papers and then have a joint discussion about our findings. Unfortunately, this was not possible due to time constraints and the difficulty of finding a joint-reviewer to conduct this work. Finally, another methodological consideration is that the literature is largely clinical opinion and case study papers. Should better

controlled empirical studies be conducted on the use of the family therapy model in TBI, other themes may emerge as more important within a conceptual model.

The grounded theory study has a number of limitations in terms of recruitment, design and interpretations. Recruitment for the study was first based on opportunity sampling. This led to a large number of expressions of interest from mothers and wives. The study aimed to access opinions from diverse family relations and so, when appropriate, the interested family member was asked whether other family members would participate. There appears a strong desire by mothers and wives to participate in research studies. This could be hypothesised from the model as due to the high levels of responsibility and comfort these relationships have towards the injured party, and thus desire for involvement. It raises interesting questions about why males are possibly less forward in participating in research. The study only recruited those who were accessing support services from neuropsychology or the charity organisation. This means that those who feel less involved in rehabilitation or are marginalised by services are not included, missing important perspectives on how to support these families. In terms of design it has been discussed that the study actually still investigates individual sense-making not family sense-making. There are important dynamic elements missing about how collaborative sense-making occurs. However, this is not necessarily a flaw of the design as the aim did not make explicit that family sense-making was the central concern.

In terms of interpretations Glaser and Strauss note that a grounded theory investigation should be able to meet certain criteria, these are: fit; relevance; workability; and modifiability (Glaser & Strauss 1967). The fit of the data is how closely concepts align with the incidents they are representing. Every effort was made to re-analyse the data following each new stage of coding and consider whether the diagram and the final story memo could account for each of the participant's experiences. Participant C and F were considered good to use as comparisons as they had polar opposite examples of how they felt.

One way in which to look at Glaser and Strauss' criteria of a good grounded theory is through the use of checking whether the theory resonates with the participants. When showing participants their individual narrative summaries there was a positive response with participants noting that; 'I think you have captured it perfectly' (Participant A). Nonetheless, this may not tell the full story as it was felt not possible to feedback to participants my entire interpretations of their interview. The Johari window proposed by Luft and Ingham (1950) notes that, we as humans have a blind self, or blind spot, which is what is unknown by the us but which others know. At times it may be that the interpretations would be too difficult to hear, for example one participant came across as quite distressed and the analysis was that this impacted on the overt negativity in her dialogue. However I needed to note these impressions in terms of the analysis. Memos were kept about these impressions to allow me to consider whether some of the statements were outliers from the rest of the data. Supervision was used to reflect on this process. Participants were shown the full and uncut version of the model and story narrative at the end of the research. The feedback gathered by seven family members was positive and all fourteen participants expressed an interest in receiving a copy of the full write up of the study. The positive feedback indicates that the relevance of the data may be high; it accurately deals with the real concerns of participants. It was felt that the theory is workable for all the participants interviewed. Even when there was considerable variation between participants, the model appears to explain the differing processes that family members went through.

The final criterion is modifiability which means that theory can be altered when new data are compared to existing data. A grounded theory is never right or wrong, it just has more or less fit, relevance, workability and modifiability (Glaser & Strauss, 1998). It would be very difficult to say that the study reached data saturation point as there are possibly concepts above and beyond observation and initiative that could have been explored further, an example being emotions. However, the interviews answered the research questions posed and it was felt the model was sufficiently developed to finish interviewing. Given the scope of the area under inquiry it was felt that this research provides a good exploratory beginning for which to develop future research from.

4:2:3 Relevance to theory

The narrative review has direct relevance to the theory from which it has developed. The narrative review was able to draw together some of the more well-known literature in the field and synthesise the key components into a model. The literature on TBI has begun to place a greater emphasis on TBI as dynamic and relational; existing in the spaces between people (Bowen, Yeates and Palmer, 2010). The model provides a way in which this could be practicably realised in research. The review findings tie into the grounded theory study as they place an emphasis on strengths within families. There is a sense that family members have skills and knowledge that can help them throughout the brain injury journey and which professionals could support. The literature has tended to focus on negative responses by family members and how they suffer following TBI. The present research is empowering in terms of showing how family members can develop an expertise around TBI and their family member. The research also draws focus to considering what epistemology research is being conducted from and the need to be clearer about the world view that is being investigated. The empirical paper will now be considered in the context of implications for theory.

The use of literature in grounded theory was disputed between Glaser and Strauss (Strauss, 1987; Glaser, 1992). Strauss felt that literature could be looked at in the early stages to sensitise the researcher to ideas, whereas Glaser disagreed. In general for PhD studies a focus on the literature needs to occur at an early stage to justify the research enquiry. There were a number of areas of literature which appeared relevant to the model which emerged from the study. The main areas of literature that the sensitising process made me aware of are sense-making, observational and experiential learning and hope. A full discussion has been provided of the links to Weick's (1995) model and the observations of other theorists in this field (Jannoff-Bulman, 1992; Frank, 1995; Dervin, 1998). Out of these, the TBI and family literature has looked at hope but not paid as much attention to the other fields. A focus on sense-making in TBI has not always been able to link in with existing literature and has at times focused on giving family members information and not considering other processes by which learning might take place.

The study can add to the literature in terms of exploring the specific processes that family members go through in order to sense make. Degeneffe and Olney (2010) found that siblings made sense of the experience in terms of considering their new relationship to the family member and by grieving for the person they knew before TBI. These findings are similar to my study in terms of roles and relationships being felt to have an influence on the sense-making process. However, Degeneffe and Olney (2010) do not indicate pathways to how this sense-making is accomplished. The present study felt that participants used other, more concrete methods, of gathering information to use for reflection over changes in role and relationships. Verhaeghe, van Zuuren, Defloor, Duijnste, and Grypdonck (2006) carried out a grounded theory study looking at hope and information. The findings of that study indicated similar conclusions in terms of family members beginning to actively work on information; learning what to build hope on. They also noted the crucial role professionals have in helping families interpret information in context. A study by Gan, Gargaro, Brandys, Gerber, & Boschen (2010) similarly noted an initial satisfaction with the information provided in hospital but then a lack of practical information thereafter. The present study backs up these findings by noting that it is the on-going practical suggestions that help shape sense-making. The role of helping family members make these interpretations cannot be underestimated as caregiver appraisals have been implicated in terms of mastery and burden in caregivers (Hanks, Rapport and Vangel, 2007). This element of active working of information adds to the literature on information provision which will now be discussed.

Actively working with information both visual and verbal yields family members ingenious intervention solutions to help their family member. These interventions are often felt to be more relevant to their family member than what professionals are seen to be doing. This does much to add to the literature on resilience and coping in families (Bowen, Yeates and Palmer, 2010). The link between professionals supporting this process is important and previous research has found that professionals often view family members as potential barriers to working with a patient due to their needs and expectations (Levack, Siegert, Dean & McPherson, 2009). This can lead to tension and family members being excluded from the rehabilitation process. As previously mentioned, the study

indicates family members often do not require specific information, more a guiding framework of how they can help achieve progress for their family member. These issues will be considered further within the implications for clinical practice.

4:2:4 Relevance to research

The narrative review has specific recommendations for research with family members with a TBI. Firstly, a greater focus on defining the conceptual framework and epistemological standpoint is recommended. When considering domains of knowledge and information it appears critical to know what standpoint this knowledge is being considered from, as opposed to presuming one individual phenomenological viewpoint can account for the whole family's experiences. For this reason more research looking at interdependence and involving whole family units would also be helpful and fit with current as yet unresolved calls for a more theoretically coherent framework from which to study family experience (Perlesz, Kinsella & Crowe 1999). The review identified that there could be greater attention paid to involving family members of those with TBI in the inception of research and in data collection. There are too few studies within the TBI field which are participatory and this is at odds with the idea of co-working in family therapy. A focus on strengths as opposed to deficits was also indicated in the conceptual model. This point fits well with the finding in the grounded theory study which indicates family members are resilient and keen to make use of previous experiences and available resources. This also fits with a greater call in the literature for studies to focus on resilience and positive coping in family members (Bowen, Yeates & Palmer, 2010).

The grounded theory research has identified that the core goal of families is to construct knowledge about the personalised impact of the family members' TBI. This is in order to facilitate and conceptualise progress. Two areas of learning whereby research efforts could focus on developing interventions are in the domains of observation and initiative. It has been the case that some interventions, whilst helpful and well-meaning, do not accurately explain why they chose the specific components of family support that they did (Albert, Bremner, Smith & Waxman, 2002).

Interventions targeted at aiding observational learning and helping to scaffold initiative would be

helpful. These interventions could potentially be small scale and carried out on wards. Additionally, the specific qualities that families appear to desire in terms of professionals are amenable to training which could be developed and trialled.

4:2:5 Relevance to practice

It has been noted that although policy context recognises the needs of family members, there are few practical evidence-based suggestions over how to intervene. Both papers have specific implications for clinical practice and also some overlapping features. For this reason both will be discussed together at this point. These points were outlined in the empirical paper but will be expanded upon here.

The narrative review places emphasis on staff members and family members co-working to understand the person with the TBI. This is similar to the findings that emerged in the grounded theory investigation. Both papers have a similar conclusion that the family do not make interpretations based on single occurrences but that there are multiple interpretations being made. Professionals working alongside families to understand the narratives they are creating might create a greater coherence of approach and a better understanding of what to do to help. Davidson (2010, p. 31) also makes this point stating that ‘sense-making is more than providing information; it is providing an interpretation of the situation and the surroundings from the environment that can be interpreted by family members’. In practice, Davidson (2010) says this can involve explaining events as they happen and then using reflective inquiry to clarify misconceptions about the events. Practical solutions might be to have an appointed key worker to direct questions to or to have more frequent meetings to ask for advice from staff. A paper by Holland and Shigaki (1998) discusses these issues noting that there should be emphasis on the process of information giving not being a static process. The present research also has implications for how staff members’ conceptualise the family in interventions. Leaf (1993, p. 543) notes that ‘traumatic Brain Injury (TBI) comes in as a roaring lion, devouring and changing systems’. There is a need to support family members in their transitions in role throughout the TBI continuum. Family members in the empirical paper reported suffering adverse psychological

health consequences due to their difficulties in accepting the change in role that had occurred. Additionally, some participants specifically remembered professionals telling them early on how much the injury would change the relationship. The model indicates that some family members feel less comfortable for taking initiative and so may start to feel unsupported and lost in their efforts to help. Given that often family members have important skills they could use in the rehabilitation process, it would be helpful if staff members had a greater idea of who was involved in the recovery process and their relationship to the person. Families could be encouraged and enabled to provide a brief family tree and summary of their relationships to the person to help staff members provide person-centred care. One participant remembers a specific ICU went out of their way to find out who she and her husband were as people. It appears this hospital's ethos was aimed at finding out the patient and family member's specific needs and tailoring support to meet these needs. Evidently the procedures in place to accomplish this have succeeded in making that individual feel this vision has been realised.

A finding specific to the grounded theory study was the idea that family members use observational learning and experiential learning to construct an understanding. This is a very practical finding that can be supported by professionals. It particularly implicates professionals that are involved in the day-to-day care of those with TBI being better trained and supported to enable them to help family members feel as though they can do something to help their loved one. Davidson (2010) provides examples of how nurses can provide concrete activities to support family members, such as applying lip balm, assisting in passive range-of motion exercises, or giving a hand and foot massage.

In conclusion, the two studies have complementary findings which are; to frame research within a epistemological framework which takes into account individuals unique perspectives and constructions of TBI; to consider the whole family in any research or practice; focus on strengths as opposed to deficits. Family members of those with a TBI have a wealth of skills that should be celebrated and utilised in the rehabilitation process.

4:3 Lay persons summary

Fourteen different family members of people who have had a Traumatic Brain Injury (TBI) were interviewed. A TBI is an injury to the brain which is caused by a blow to the head that causes damage. The research looked at how families understood what had happened to their family member. The idea was to consider whether members of staff could do more to help develop this understanding. The family members all told different stories but there were common ideas that came out of the interviews. The common ideas were put together in a visual model which described how family members make sense of TBI.

Generally, family members felt they did not receive enough information about what was happening. Family members specifically want to learn how the injury will affect their family member, but find they are provided with more general TBI information. Families tend to rely on watching their family member and the environment to try and understand what the effects of the brain injury are. Families also have to show a lot of initiative and read and look on the internet to find information. Different family members feel more or less confident in what they think is going on. Some feel responsible for trying to improve the situation for their family member by creatively designing ways to help. Everyone feels they need to ask staff members to make clear whether they have a good understanding of what is happening. Family members can also disagree between themselves about what they are seeing and what might be best for the person with the injury. Later on it is important that the whole family including the person with the TBI have a shared understanding.

Staff members are felt to be helpful when they help the family make sense of how TBI is particularly affecting their family member. Helpful staff members also have a good bedside manner; encourage positive progress by carrying out and suggesting activities the family members could do; and build hope. The ultimate outcomes of understanding are to develop a good knowledge of the family members' TBI and also to have agreement within the family and with staff members about the story that is being told about the injury. A shared sense of how to progress the person and a good feeling of unity with professionals are also desired.

4:4 Follow-on study

Title: Dynamic influences in sense-making processes within families of Traumatic Brain Injury (TBI) survivors.

4:4:1 General background

Previous research has indicated that family members of those with TBI often experience a number of negative outcomes (Brooks, 1991; Florian & Katz, 1989; Livingston, Brooks & Bond, 1985; Marsh, Kersel, Havill & Sleigh, 1998). Research thus far has progressed through a number of stages (Bowen, Yeates and Palmer, 2010). This research has done much to highlight the needs of family members (Junque, Bruna & Matara, 1997), consider predictor variables (Anderson et al, 2009; Ergh, Rapport, Coleman & Hanks, 2002), explore their experiences (Braine, 2011; Jumisko, Lexell & Söderberg, 2007) and begin to consider differences within the family (Degeneffe & Olney, 2008). There have been criticisms of some of this research for not focusing on systemic factors within families (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). Additionally, there have been broad criticisms of the research noting that it ‘lacks unifying conceptual models, therapeutic methods and outcome studies regarding effective treatment of families when a family member has a significant TBI’ (Collins, 2008, p.995). More recent research has aimed to look at family processes and has investigated family therapy (Bowen, 2007; DePompei & Williams, 1994; Larøi, 2000;2006) and martial therapy (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011) as ways of researching and intervening with family members. As a caveat to this research Broderick and Smith (1979) discuss how family systems theory can only advance as studies of family processes and structure are carried out. In order to successfully apply family systems theories to TBI the underlying processes should be investigated. A core area of family need that emerges from the literature is the area of information provision (McPherson, McNaughton & Pentland, 2000, Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck, 2006). This is also an area where the investigation of process has been limited with only a few studies investigating how information is transmitted and received for family members in TBI (Braga, DaPaz & Ylvisaker, 2005). Families are constantly engaged in processes of interpreting TBI through their

lens of past and current experience. An important area of literature to set the scene for this proposal is the sense-making literature which will now be discussed.

Receiving information and then making interpretations is critical to sense-making. Sense-making can be divided into individual sense-making and collaborative sense-making. Collaborative sense-making has been less well researched than individual sense-making. Although some researchers (De Jaegher & Paolo, 2007; Weick, 1995) have theorised the importance of interactions in sense-making, few have explored empirically how these interactions lead to the creation of a shared understanding. One example of a study of collaborative sense-making is by Koenig and Trees (2006). Koenig and Trees (2006) described how narratives help individuals make sense of their experiences and that this is particularly true for people trying to make sense of difficult or traumatic experiences. The study offers an approach to aid in identifying communication behaviours that accompany and differentiate the sense-making process in jointly told family stories. This study was a retrospective look at difficult family events however and did not look at active sense-making. Nadeau (1998) has investigated active family sense making about death. She notes that researchers sometimes falsely assume they have researched family sense-making, when only a few family members have been interviewed. It has been noted that the grounded theory study carried out looking at how family members construct an understanding of TBI fell into this description. The rationale for the proposed study will now be considered within this general background.

4:4:2 Rationale for proposed study

The grounded theory empirical study attempted to recruit family members of different relationships. This was partly based on the literature review noting that this was important and following the emergence of role in the family as a contributing factor to sense-making. However, family units were not interviewed together and therefore, whilst trying to address the criticisms of the previous research, the study stopped short of explicitly investigating dynamic sense-making processes and focused on individuals within the family making sense. Although three close family units were interviewed separately, it was felt that interesting findings that emerged from this work that could be investigated

further. Within the empirical model an interesting section which has yet to be expanded upon is how interpretations are actually made within a family and how this then leads to the different outcomes that were identified. Although these outcomes were drawn from the interviews with individual family members it would be interesting to see whether they are explicit when speaking to a whole family group or if other processes of interpretation occur. The narrative review can also help guide the proposed study and will now be considered.

The narrative review proposed that TBI research needs to be guided by a more theoretically coherent framework. The review suggested a conceptual framework of research which is underpinned by the constructivist model. This holds that people's constructed reality should be the focus of study. Within the model there was an understanding that the family system is more than a collection of individuals, it is an interdependent whole with its own identity and dynamics. The grounded theory study did use an explicit epistemological framework and the researcher's influence on this process was considered in line with social constructivist philosophy. The principle of interdependence means that there is a need to consider that understanding the phenomenological experience of one family member does not mean this is true for all family members and there may be factors that only occur in joint sense-making. The narrative review noted that ways in which to study this might be through looking at communication, narratives, operational patterns and roles. This study will aim to consider these processes when speaking to whole family units. The aims of the study will now be outlined.

4:4:3 Aim

The aim of the study will be to interview five whole family groups in an exploratory study to further investigate the sense-making processes that occurs within the family at different stages of recovery from TBI. The research question will be:

- How do families interactively make sense of TBI?
- What specific interactional behaviours contribute to the interpretation process?

4:4:4 Hypotheses

It is anticipated that similar processes as described in the grounded theory model will be discussed namely that;

- Observation and initiative will be processes through which learning occurs and is shared within the family.
- Family members begin to use pre-existing skills and experiences post-injury and different family members might have different skills and experiences.
- Family members will feel different degrees of comfort and responsibility with their changing role.
- How readily observations are acted upon, behaviourally in the form of initiative, will depend on how comfortable and responsible family members feel.
- There will be a desire to check interpretations within the family group and with professionals.
- Conflicting interpretations will lead to: Family members not being confident in developing 'expertise', individual/conflicting narratives emerging, unclear different views of steps to progress, and negative/differing perceptions of professionals.
- Unified understandings will lead to: Feelings of 'expertise' developing in the family, a shared narrative of TBI emerging, a positive/shared view of steps to progress, and a positive or shared perception of professionals.

4:4:5 Design

The design will be qualitative and use the methodology of analytic induction (Znaniecki, 1934).

Analytic induction has been chosen as it gives the researcher an opportunity to begin with a theory, in this case the empirical model, and build upon the hypotheses, developing and changing them as new information comes to light. Becker's (1958) description of analytic induction notes that data analysis begins whilst data are being gathered and the analyses are tentative and provisional only becoming comprehensive once the data are completely collected. Glaser and Strauss (1967) have in the past been critical of analytic induction and noted that it involves generating theory and testing theory in a

conditional manner, whereas grounded theory stresses the generating function without testing. Other critics have dismissed analytic induction due to its links with the realist, positivist philosophies of science (Robinson, 1951; Vidich & Lyman, 2000). Gilgun (2001) however has argued that grounded theory uses analytic induction without sufficient acknowledgment from Glaser and Strauss (1967). She has noted that ‘though analytic induction also can produce typologies and rich descriptions, the procedures themselves call for developing, testing, and falsifying hypotheses throughout the research process’ (p. 31). This methodology is as such considered to be a good choice to investigate the previous sense-making theory in a more dynamic manner.

4:4:5:1 Participants/sampling/access

Participants will be five family groups recruited from Salford Royal Neuropsychology department. Ideally the family group will consist of three or more people to fully explore different family positions and dynamics. Inclusion criteria will be; families containing two or more individuals including the person with the brain injury should they be willing; able to consent to participation; English speaking; over 18 years of age; and living in the Greater Manchester area. Excluding criteria will be; age under 18; outside of the Greater Manchester area; non-English speakers; and individuals who wish to participate without their family. Sampling will be guided by a desire to interview a family group at five distinct stages of the recovery process. However, given that recruitment of whole family groups may be difficult there will be an element of opportunity sampling. Access will be secured through the hospital trust by a supervisor on the project who will be a neuropsychologist.

4:4:5:2 Procedure

Participants will be recruited via the Neuropsychology department at Salford Royal hospital and the charity organisation BASIC. A poster will be present in the reception areas of both bases alongside a participant information sheet. Alongside this spontaneous recruitment, the neuropsychologist at the hospital will approach family members who might be interested in taking part. For the study to truly investigate family sense-making, all family members living in the home or all family members felt to make up the family unit will need to be willing to participate. The study will aim to look at five

different time points; intensive care; post emergence from coma; rehabilitation ward; rehabilitation unit; and home/independent living. These time points have been chosen as the grounded theory study indicated them to be distinct stages that all family members identified throughout the TBI journey. It may be that different processes of interpretation occur at each stage that the grounded theory model was unable to tease apart. Family members will be interviewed as a group either at home or in a small room at Salford Neuropsychology building. Safe visiting policies and procedures will be followed at all times. A camera tripod will be set up in the room and switched on when the interview begins. Before the interview begins all participants will have the chance to ask any questions and the consent form will be gone through again in detail. The interview will begin with the researcher asking ‘Please tell me about something you are currently trying to understand about your family members’ traumatic brain injury?’ It is anticipated that family members may have different topics and the conversation will be allowed to continue naturally. The researcher may ask prompt questions throughout such as ‘Is there anything else you were thinking?’ It is anticipated the interviews will last no more than an hour. After this point all participants will be thanked and the video tape will be stopped. The video transcript will then be created alongside an analysis of the different non-verbal behaviours that occurred throughout the hour.

4:4:5:3 Ethics

Ethical consent will be applied for from the relevant bodies including integrated research application system (IRAS). There are ethical concerns that may arise in this work. It may be that nobody wishes to participate at the intensive care stage and that this would be too distressing, if this is the case then this phase will be dropped and a family who are at a later stage in the hospital journey will be selected. In order to ensure participants are protected from harm, and that issues raised within their discussions are dealt with appropriately, all families will have access to a neuropsychologist afterwards to de-brief. Should individuals wish to speak further with a neuropsychologist a one hour session will be provided. All families will also be given information about Headway, the brain injury charity, and BASIC, the brain and spinal injury charity.

Measures/materials

The recruitment materials will include a poster, a participant information sheet, consent form and a demographic information sheet. The materials for the interview will consist of a digital camera recorder and stand. A semi-structured questionnaire will include the question to ask at the beginning of the discussion and some prompts. A pad of paper will be used to record observations and process memos as the discussions are taking place. The software package NVIVO-9 will be used to organise the data.

Data custodian: Will be a named supervisor on the project

Data analysis

The data analysis is intertwined with the previous study due to the desire to use the sense-making empirical model and test it from a dynamic perspective. Bulmer (1979) encourages the idea of interplay between data and classification that is guided by the researchers own notions as well as previous data. The data analysis process is explained in the following steps by Cressey (cited by Robinson, 1951):

- 1) A phenomenon is defined in a tentative manner,
- 2) A hypothesis is developed about it
- 3) A single instance is considered to determine if the hypothesis is confirmed,
- 4) If the hypothesis fails to be confirmed either the phenomenon is redefined or the hypothesis is revised so as to include the instance examined,
- 5) Additional cases are examined and, if the new hypothesis is repeatedly confirmed, some degree of certainty about the hypothesis results, and
- 6) Each negative case requires that the hypothesis be reformulated until there are no exceptions.

Katz (1983) discusses the difficulties in deciding when the revisions of the hypotheses can be said to be complete. Katz (1983) notes that an obvious difficulty is that the quest for universal explanation is elusive. He believes that the test of success is not a comprehensive explanation, but rather the degree

to which changes in constructs and hypotheses explain the phenomenon with few exceptions. As this study is an exploratory study it is hoped that five cases will allow for suitable examination of the hypotheses.

References

- Anderson, M. I., Simpson, G. K., Morey, P. J., Mok, M. M., Gosling, T. J., & Gillett, L. E. (2009). Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): Multi-group analysis. *Brain Injury*, 23, 931-943.
- Becker, H. S. (1958). Problems of inference and proof in participant observation. *American Sociological Review*, 23, 652-660.
- Bowen, C., Yeates, G., Palmer S. (2010). *A relational approach to rehabilitation: Thinking about relationships after brain injury*. London, LN: Karnac Books.
- Bowen C. (2007). Family therapy and neuro-rehabilitation: Forging a link. *International Journal of Therapy and Rehabilitation*, 14, 344-349.
- Braga, L.W., Da Paz., A.C., & Ylvisaker, M. (2005). Direct clinician-delivered versus indirect family supported rehabilitation of children with traumatic brain injury: A randomized controlled trial. *Brain Injury*, 19, 819-831.
- Braine, M. (2011). The experience of living with a family member with challenging behaviour post acquired brain injury. *Journal of Neuroscience Nursing*, 4, 156-64.
- Broderick, C., & Smith, J. (1979). The general systems approach to the family. *Contemporary theories about the family*, 2, 112-129.
- Brooks, D.N. (1991). The head injured family. *Journal of Clinical and Experimental Neuropsychology*, 13, 155-188.
- Bulmer, M. (1979). Concepts in the analysis of qualitative data. *Sociological review*, 27, 651-677.
- Charmaz, K. (2006). *Constructing Grounded Theory: A practical analysis through qualitative analysis*. New York, NY: Sage Publications.
- Davidson, J.E. (2010). Facilitated sense-making: A strategy and new middle-range theory to support families of intensive care unit patients. *Critical Care Nurse*, 30, 28-39.
- Degeneffe, C.E., & Olney, M.F. (2008). Future concerns of adult siblings of persons with traumatic brain injury. *Rehabilitation Counselling Bulletin*, 51, 240-250.
- Degeneffe, C.E., & Olney, M.F. (2010). 'We are the forgotten victims': Perspectives of adult siblings of persons with traumatic brain injury. *Brain Injury*, 24, 1416-27.

- De Jaegher, H., and Di Paolo, E. (2007). Participatory Sense-Making: An enactive approach to social cognition. *Phenomenology and the Cognitive Sciences*, 6, 485-507.
- Department of Health. (2007). *The national service framework for long term conditions*. London, LD: Crown copyright.
- Dervin, B. (1998). Sense-making theory and practice: an overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, 2, 36-46
- DePompei, R., & Williams, J. (1994). Working with families after TBI: A family-centered approach. *Topics in Language Disorders*, 15. 68-81.
- Ergh, T.C., Rapport, L.J., Coleman, R.D. & Hanks, R.A. (2002). Predictors of caregiver and family functioning following traumatic head injury. *Journal of Head Trauma Rehabilitation*, 17, 155-174.
- Florain, V., Katz, S., Lahav V. (1989). Impact of traumatic brain damage on family dynamics and functioning: a review. *International Disability Studies*, 13,150-157.
- Frank, AW (1995). The wounded storyteller: Body, illness, and ethics. *London: University of Chicago Press*.
- Friedemann-sánchez G, Griffin JM, Rettmann NA, Rittman M. (2008). Communicating information to families of poly-trauma patients: A narrative literature review. *Rehabilitation Nursing*, 33, 206-213.
- Gan, C., Gargaro, J., Brandys, C., Gerber, G., & Boschen, K. (2010). Family caregivers' support needs after brain injury: A synthesis of perspectives from caregivers, programs, and researchers. *NeuroRehabilitation*, 18, 5-17.
- Gilgun, J.F. (2001). *Case-Based Research, Analytic Induction, and Theory Development: The Future and the Past*. Conference presentation: The 31st Annual Theory Construction & Research Methodology Workshop of the National Council on Family Relations. Rochester, NY, November 2001.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. New York, NY: Aldine.

- Glaser, B. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Godwin, E. E., Kreutzer, J. S., Arango-Lasprilla, J. C., & Lehan, T. J. (2011). Marriage after brain injury: Review, analysis, and research recommendations. *The Journal of Head Trauma Rehabilitation*, 26, 43-55.
- Hanks, R.A., Rapport, L.J., & Vangel, S. (2007). Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation*, 22, 43-52.
- Hickman, L.A., Neubert, S., & Reich, K. (2009). *John Dewey between pragmatism and constructivism*. New York, NY: Fordham University Press,
- Holland D, Shigaki CL. (1998). Educating families and caretakers of traumatically brain injured patients in the new health care environment: a three phase model and bibliography. *Brain Injury*. 12. Pp.993-1009.
- Janoff-Bulman, R. (1992) *Shattered assumptions: towards a new psychology of trauma*. New York, NY: Free Press.
- Jumisko, E., Lexell, J. & Söderberg, S. (2007). Living with moderate or severe traumatic brain injury: The meaning of family members' experiences. *Journal of Family Nursing*, 13, 353-369.
- Junque, C., Bruna, O., & Matara, M. (1997). Information needs of the traumatic brain injury patient's family members regarding the consequences of the injury and associated perception of physical, cognitive, emotional and quality of life changes. *Brain Injury*, 4, 251-258.
- Katz, J. (1983). A theory of qualitative methodology. In R. M. Emerson (Ed.), *Contemporary field research: A collection of readings* (pp. 127-148). Prospect Heights, Ill.: Waveland.
- Koenig, K.K. & Trees, A.R. (2006). Finding meaning in difficult experiences: Sense-making and interaction processes during joint family storytelling. *Journal of family communication*. 6, 49-76.
- Larøi F. (2000). Treating families of individuals with traumatic brain injury: Presentation of clinical cases approached from a structural therapy perspective. *Journal of Family Psychotherapy*, 11, 69-186.

- Larøi F. (2003). The family systems approach to treating families of persons with brain injury: A potential collaboration between family therapist and brain injury professional. *Brain Injury*, 17, 175-187.
- Leamy, M., Bird, V., Le Boutillier, W.J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, 199, 445-452.
- Levak, W.M., Siegert, R.J., Dean, S.G., & McPherson K.M. (2009). Goal planning for adults with acquired brain injury: how clinicians talk about involving family. *Brain Injury*, 23, 192-202.
- Livingston, M.G., Brooks, D.N. & Bond, M.R. (1985). Three months after severe head injury: psychiatric and social impact on relatives. *Journal of Neurology, Neurosurgery and Psychiatry*, 48, 876-881.
- Luft, J.; Ingham, H. (1950). The Johari window: A graphic model of interpersonal awareness. *Proceedings of the western training laboratory in group development*. Los Angeles, LA: UCLA.
- McGhee, G., Marland, G.R., & Atkinson, J.M. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60, 334-342.
- Marsh N.V., Kersel, D.A., Havill, J.H., Sleight, J.W. (1998). Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury*, 12, 1045-1059.
- Marshall, C., Rossman, GB. (2011). *Designing qualitative research*. (5TH Ed.). New York, NY: Sage Publications.
- Nadeau, JW. (1998). *Families making sense of death*. New York, NY: SAGE Publications.
- Perlesz A, Kinsella G, & Crowe S. (1999). Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology*, 44, 6-35.
- Prigitano, G.H. (1989). Bring it up in milieu: Toward effective traumatic brain injury rehabilitation interaction. *Rehabilitation Psychology*, 34, 135-144.
- Robinson, W.S. (1951). The logical structure of analytic induction. *American Sociological Review*, 16, 812-818.

- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, England: Cambridge University Press.
- Strauss, A. & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory. New York, NY: Sage publications.
- Verhaeghe, S.T.L., van Zuuren, F.J., Defloor, T.D., Duijnste, M.S.H., & Grypdonck, M.H.F. (2006). How does information influence hope in family members of traumatic coma patients in intensive care unit? *Family nursing*, 16, 1488-1497.
- Vidich, A.J. & Lyman, S.M. (2000). Qualitative methods their history in sociology and anthropology. In N.K. Denzin & Y.S. Lincoln (Eds.). *Handbook of qualitative research*. (2nd ed. Pp. 37-49). Thousand Oaks, CA: Sage.
- Weick, K. E. (1995). *Sensemaking in organizations*. Thousand Oaks, CA: Sage.
- Znaniecki, F. (1934). *The method of sociology*. New York: Farrar & Rinehart.

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Appendix 1: Reflective memo – Personal experience

Memo: Reflective

Topic: Personal experience

Date: 26/03/2012



When I first started on the path to becoming a Clinical Psychologist there was one single factor inherent in my drive and desire to do so. My current role as a Trainee Clinical Psychologist has essentially arisen out of my own personal experience of being ‘a family member of somebody with a Traumatic Brain Injury’ (TBI). This was never a label I would have associated with myself at the time. I had little knowledge or understanding of the impact of a TBI. However, I have since come to understand more about how trauma to the brain can alter your whole outlook on the essence of what makes us who we are, and I have come to think of myself of someone whose life has been adversely affected by TBI. It has also made me re-assess the role of loved ones, families and strangers in how individuals experience and manage TBI.

To understand my motivations for undertaking this research I must think back to the day my world was irreparably altered and my future set on a new path. My dad suffered a TBI in 2003, when he was knocked off his push bike. The memories of the day I found out are still vivid. Before this time I had no idea that my strong, fiercely intelligent, social whirlwind of a dad could be changed so irreparably by an impact to his brain. Before this I was set on a career of sports journalism and I gave little thought to our mental lives or how our brains function to co-ordinate and sustain this. As my mum and dad had split up when I was small my dad lived in Surrey so the practical difficulties this posed in being there for him throughout his time in hospital were substantial. The whole experience of understanding what had happened and what might happen was very frightening and confusing to a then fairly self-interested 18 year old. Across the year my dad began to recover medically from his injury but new challenges were always present and the psychological and cognitive impact was great. Unfortunately my dad then died from cancer a year later and so my difficult direct experience into the

personal impact of brain injury ended, though the memories did not leave me, nor did the desire to support those with brain injury.

I went on to work in a voluntary capacity in privately funded care homes for those undergoing rehabilitation after TBI. I was at this point naïve and unconfident to how I could make any form of impact on family members and mainly stuck to one to one work with people with brain injury. Then, once going to university to study Psychology other areas of my life became to be more important and I temporarily forgot about the professional, though not the personal side of brain injury. Once graduating from university I went on to have Assistant Psychology experience in the areas of adult mental health, dementia, psychosis, looked after children and stroke. Throughout this I began to learn that across a wide range of conditions family members have needs and are crucial to the process of therapeutic intervention.

When I then got onto the Doctorate in Clinical Psychology (DClin.) course the opportunity to use my research project to investigate the area of TBI was never in question as I felt more comfortable with the experiences I'd had and wanted to use them positively. Before this research I did not have any real idea how other family members might specifically have experienced the process of a TBI as I had not really read any of the literature around family members and brain injury. At first I was not even sure this was an area that needed inquiry. However, after speaking to professionals in the field it became clear that the needs of family members are a very important topic and continue to not be fully addressed. I decided that I wanted to use a qualitative methodology as I was not aware of any formal models or theories about how family members go about 'sense-making' what TBI is and so felt I would be best exploring the area with an open mind. Grounded theory was used as I hoped it would enable me to integrate emerging themes together in a model which would hopefully pull together some of the processes that people go through when understanding TBI.

As it may be seen I have strong motivations, drives and beliefs about this area. The core aim of the methodology I have chosen is to remove myself from these pre-conceived ideas. I must try to discover the narratives of the people I interview in the manner in which they were meant by their

author. The constructivist epistemology I am coming from explicitly requires me to see humans as “observers, participants, and agents who actively generate and transform the patterns through which they construct the realities that fit them” (Reich, 2009). I need to remove myself enough to enable me to think about the ways that people create meaning of the world through constructs, which endeavour to make sense of what can be a chaotic world.

My initial ideas are that people will experience the process of TBI as negatively as I did. As we as a family received what I felt was very little support and almost no information from professionals, my initial thoughts might be that anything other than this experience is surprising. In my opinion there is very little in the media about brain injury, though Richard Hammond and Fabrice Muamba have changed this somewhat, and so I would presume that most people would be shocked and confused by the sudden occurrence of a TBI. The process of sense making I would personally think would be very faltering and built upon narratives collected from professionals and then filtered through processes such as the need to maintain hope.

I will need to examine my own preconceptions and ensure that the areas of people’s narratives that match my expectations have not been led by my questioning. It may be that I have expected certain responses, or over interpreted the responses in favour of my expectations. Through constant supervision and rigorous data checking I can double check that they are the participants’ experiences that I am picking up on. Line by line open coding will enable me to identify in a microscopic way what the different themes are which I may otherwise miss when in the process of carrying out an interview. Through the use of reflective memos and a journal I will aim to consider how new areas of inquiry could be understood within the existing literature and how it indicates a person is making sense of what they have experienced.

Appendix 2: Pilot interview one

Pilot interview 1:

Date: 01/04/2012

Participant: H (51 Years old, ex-wife of person who suffered TBI (P), Person who suffered TBI is deceased, Event occurred 9 years ago).

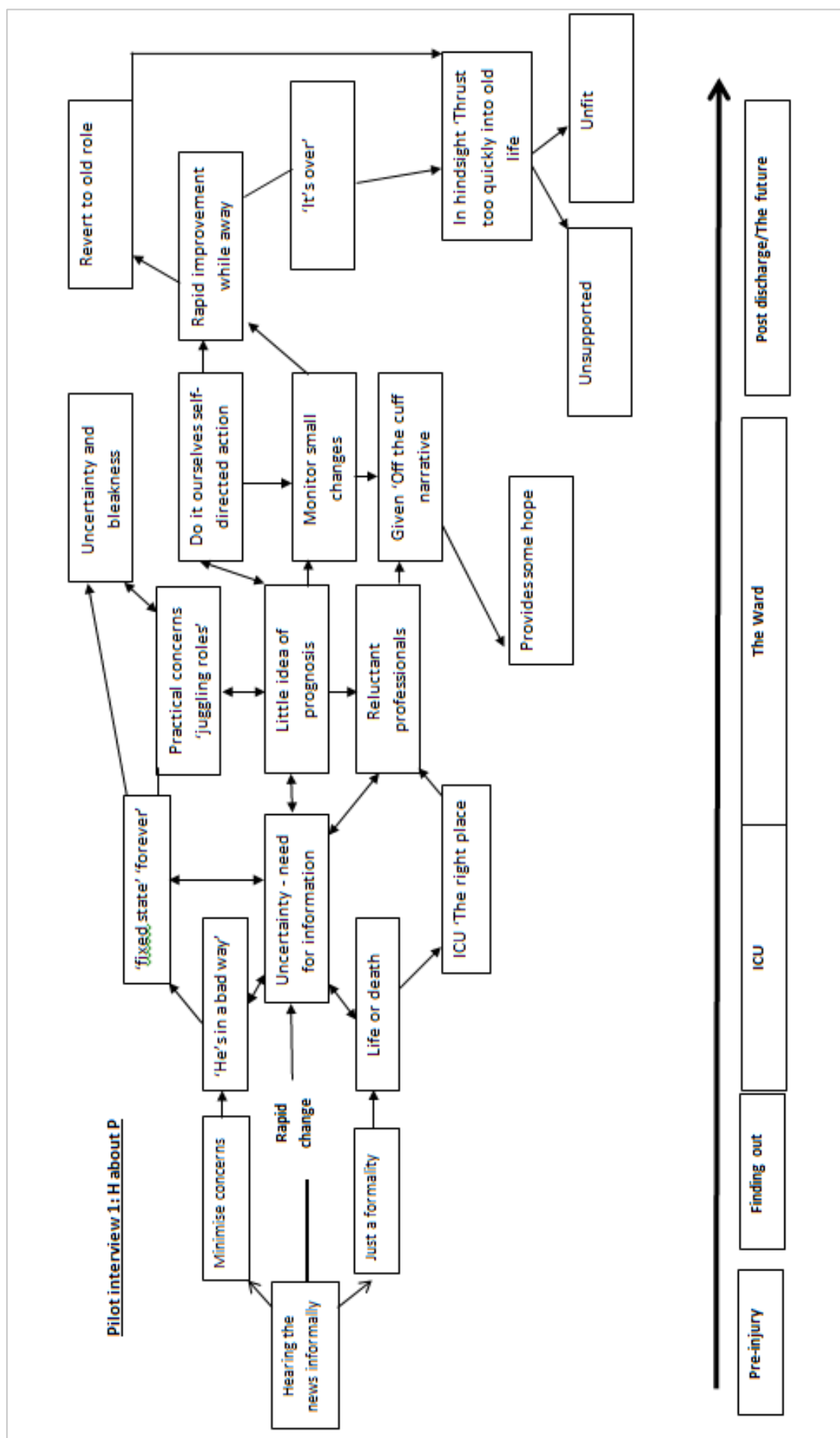
Narrative summary

H described the quick, informal delivery of news about an accident that had happened to her ex-husband. This information was relayed via telephone by a friend as though the 'worst were over' and there was a sense of minimal concern. Hospitalisation appeared to be just a formality and action was limited.

There was then a very rapid turnaround in thinking, as the reality of the situation became clear and it emerged through other family members that her ex-husband was 'in a bad way'. The narrative suddenly became one of 'life or death' concerns and the rapid realisation that a catastrophic event had occurred. There was a quickened need to gather information and the language regarding the future is full of words like permanent change, 'forever' and 'will never be the same again'. There was a conveyed sense that the medical environment P was in was the right place to be but also that while the medical situation was controlled, professionals were reluctant to divulge information about prognosis. Family members felt they needed to keep out of the way and there was little they could do to help. This led to much uncertainty and heightened practical concerns over how to juggle the split role of normal life vs. 'needing to be there'.

There was then a change in environment as P showed positive medical recovery and was moved to a ward. The narrative became one of reluctant acceptance that professionals had a lack of desire to give information. H appeared to say that family members had to become self-directed and begin to communicate between visitors of P, monitoring and recording for signs of improvement. The ward appeared to be a place where H felt that inquisitive, self-directed learning was important. One professional appeared to offer a change to this narrative offering an 'off the cuff' story which inspired hope and began to change the idea of a 'permanent, forever' future. This process was repeated with small improvements bringing about hope but lack of prognosis retaining an underlying feeling of uncertainty and 'bleakness'. There was a 'need' expressed for some idea of variation in prognosis to be offered.

The narrative ends as quickly as it started; rapid progress occurred whilst H was not there and she learnt about it through 'here say'. There was sense that it was all over and that old roles could be resumed. The final thoughts appear to be very much in 'hindsight' over how, despite thinking the crisis was over there was a lack of information and understanding about the lifelong impact. The thoughts reflect concerns about how P was 'thrust back into normal life' and was 'unfit' and unsupported to return to his old role as a responsible parent and had reduced capacity.



Hypotheses

- It appears that there was great importance placed on potential prognosis. H spent some time saying how statistics of recovery rates and concrete information would have helped. Even if a definite outcome could not be suggested the uncertainty around prognosis appeared to be very problematic in terms of roles and practical concerns. It might be that other people are given a clearer prognosis which helps reduce this uncertainty.
- As the brain injury being talked about was some time ago it felt like there was a lot of reflection that had taken place which 'tidied the narrative up'. Language was quite repetitive and used lots of clichés i.e. 'touch and go'. There was definite use of hindsight to help include information learnt since the injury. People experiencing the brain injury in the here and now might not have the same ability to consider the events in this manner. They might become more 'preoccupied' with certain events or things that have been said to them.

Aims:

- In line with the aims of looking at knowledge development aim to ask more targeted questions about what was learnt at each stage.
- Ask more about the self-directed actions that took place as the second pilot will include a second family member of P's.
- I stopped when H was talking about the idea of it being a 'fixed state and forever', I may have done this unconsciously as it is a painful personal topic however it was very telling and the narrative jarred at this point. Aim to try and ask more questions around where these ideas came from if this point comes up again.
- The narrative speeds up at the start, then there was a slow period of exploring what H felt like and what was going on at the time P was in hospital. The end of the narrative cuts off however as H had little involvement. The second pilot interview might allow for slower questioning around this period.

Appendix 3: Poster for recruitment

Salford Royal **NHS**
NHS Foundation Trust

Trafford **NHS**
Primary Care Trust



**Are you the family member
or partner of someone who
has experienced a traumatic
brain injury?**



**Would you like to talk about your
experiences?**



**Would you like to find out more
about a research study being
carried out in this area?**



**Please read the information
sheet to find out more**



Appendix 4: Participant information sheet



Information sheet for participants

Name of study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson – Trainee Clinical Psychologist

Overview of study

This study is interested in the area of traumatic brain injury (TBI). Specifically the study will involve talking to the family members of people who have suffered a TBI. A TBI is an injury to the brain that has occurred due to an external cause, such as a bang to the head. The study aims to look at family members' understanding of what a TBI is, how they came to this understanding and what their expectations for their own and their relative's future are. The way this will be studied is by interviewing the family members of people who have suffered a TBI. The research will involve family members (Blood relatives and those who play a significant role in the person's life) talking about their experiences. Family members must live in the Greater Manchester area and must take an active role in the person with the TBIs life i.e. Visit/visited them in hospital/inpatient settings/see them at home on a weekly basis. Participants cannot take part if they are under 18, living outside of Greater Manchester or do not speak English as a first language.

Why conduct this research?

This study aims to investigate how family members navigate the difficult process of being faced with the sudden and often shocking occurrence of a TBI. It is hoped that this study will add to existing research around what family members need to feel supported. It is also hoped it will help professionals to work more effectively with people with TBI and their family members.

Important note about your decision to take part in the study.

If you have been approached in clinic to participate you should not feel under any obligation to participate because a family member is being treated at the clinic. If you decide not to participate, this will not affect the care of your family member.

Further information if you are interested in taking part

What method is being used?

The method being used is called Grounded Theory. This method places emphasis on the participants guiding the researcher in what is important to them. Therefore, interviews will follow a flexible (semi-structured) schedule. Grounded Theory also requires the researcher to talk to as many

different people as possible to get lots of different perspectives. It will be important for the researcher to speak to people of different genders, different family relations and people whose family relation experienced the injury at different time periods.

What order will things happen in the study?

Those interested in taking part will be asked to fill in some brief demographic information on a paper form (Gender/Age range/Relationship to the person with the TBI/Approximation of the date the TBI took place). This will help the researcher to make sure they can speak to as many different people as possible. If a person expresses an interest, the researcher will contact that person within a week to speak with them about the study and make arrangements to meet to conduct the interview. If the researcher has already spoke to several people with similar demographic information it may be that their information is kept on file until the researcher decides whether more interviews need to take place.

Those taking part in the study would then be required to meet with the researcher for approximately 1 hour. This interview can take place at home or in the hospital dependent on preference. This interview will be audio recorded and these recordings will be typed up into written transcripts. It is recognised talking about an emotional subject such as TBI may be an upsetting experience. All participants will be treated with empathy and respect when being interviewed and interviews will stop immediately if the participant wishes it to. The researcher will then take time to listen to the participant and endeavour to point them in the direction of any support needed. The Clinical Psychologists associated with this research will be willing to meet with participants to talk through any distress or concerns.

How will your information be kept and used?

The information sheet and any audio recordings will be given code numbers so nobody but the researcher and Clinical Psychologist in this service will know participants identities. All data shall be kept safe and destroyed 2 years after the research has ended. Anonymised quotes may be typed up into the final draft of the research.

What happens if you have more questions?

After participants have carried out the interview they may contact the researcher at any point to ask any questions which they may have. All participants have the right to withdraw from the interview at any point and this will in no way affect any treatment participants or their family members receive.

What happens once the study is over?

Once all of the interviews have been analysed the researcher will contact participants for a final phone call to feed back the findings and ask for the opinions of the participants. This is to ensure that any theories the researcher has are felt to be grounded in the interviews they gave. The participants will be welcome to a copy of the final research report.

I want to take part

If you wish to take part please complete the Participant consent form and the demographic information sheet. You will then be contacted within a week of the researcher receiving your information.

Contact details

If you have any questions please contact the researcher Hannah Nelson at:

Hannah.nelson@liv.ac.uk

Telephone:

Or the research supervisors who will be helping recruit participants Dr Stephen Mullin at:

Salford Neuropsychology Department: 0161 206 5588

Appendix 5: Demographic information sheet



Demographic information sheet

Name of the study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson – Trainee Clinical Psychologist

Date:/...../.....

Information about you

Name:.....

Age:..... **Gender:**

Address:

.....

.....

Postcode:

Telephone number: **Best time to call:**

Information about the family member who has suffered the Traumatic Brain Injury (TBI)

Relationship to family member with TBI:.....

Approximate date accident occurred:.....**Month****Year**

Where is your family member now? (Please circle)

Home **Hospital** **Rehab unit (NHS)** **Rehab Unit (Private)**

Other

Thank you for taking the time to complete this information sheet. The researcher will be in touch with you within a week to discuss the next step.

Appendix 6: Consent form for participants



Consent form for participants



Name of the study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson

Supervisors: Dr Gemma Wall – Clinical Neuropsychologist Dr Stephen Mullin – Clinical Neuropsychologist
Dr Jim Williams – Clinical Psychologist/Clinical Director

Please read the following statements and initial the boxes if you agree:

I believe I meet the criteria to take part in the study. I am over 18, live in the Greater Manchester area and have a partner/family member who has suffered a TBI:

☐

I agree that I have read the patient information sheet and had the opportunity to ask any questions about the study:

☐

I agree to being contacted to take part in a semi-structured interview

☐

I agree that, after my interview and demographic information sheet are coded to ensure confidentiality, they will be stored securely for up to 2 years after the study. After this point they will be destroyed. I agree that anonymised quotes from my interview may be included in the final write up of the study:

☐

I agree that I will be contacted by phone to feedback the conclusions that have been drawn from the interviews in order to offer my opinion.

☐

I am aware I can withdraw from the study at any time and this will not affect me or my family member in any way.

☐

Name:..... Signature:.....

Appendix 7: Interview schedule 1



Interview schedule 1: Semi –structured schedule for initial interviews

Name of the study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson

Supervisors: Dr Gemma Wall – Clinical Neuropsychologist Dr Stephen Mullin – Clinical Neuropsychologist
Dr Jim Williams – Clinical Psychologist/Clinical Director

Introduction

Hello my name is Hannah Nelson and I will be carrying out the interview today. By now you will have read the information sheet and signed the consent form. If we can just look at each point on the consent form and check whether you have any questions?

Read through consent form.

Just to re-cap I am interested in looking at Traumatic Brain Injury. I am researching the process you and others are going through in trying to understand what a traumatic brain injury is. Also I am interested in how you are thinking in relation to your expectations for the future for yourself and your family member

The interview will last approximately an hour, unless you feel you have more to tell me and are happy to continue. If at any time you want to stop: for a break; because you do not wish to continue; or you do not wish the recording to continue; please signal to me or tell me you wish to stop. If I can see you are becoming upset in any way I will ask if you would like a moment to collect yourself or whether you would like to stop and we will take time to ensure you feel ok.

You have the right to stop the interview at any point and your recording will not be used if this is your wish. This will in no way affect any part of your family member's or your future treatment and your wish will be treated with the utmost respect.

Is that ok?

Do you have any questions?

Thank you, we will now begin. I will introduce you on the recording by saying your code number.

Semi-structured interview – To be used as a guide

Questions around the injury and understanding of what happened

- 1) Can you tell me about the events leading up to your family member's injury?
- 2) What happened next?
- 3) Please could you tell me about your thoughts and feelings when you heard this news?
- 4) What did you think had happened?
- 5) What were the questions on your mind in those early stages?
- 6) Did you ever hear the words Traumatic Brain Injury mentioned or anything similar?
- 7) What if anything did you know about Traumatic Brain Injury before (insert name) got injured?
- 8) What have you learned since?
- 9) How did you learn that?

Questions around expectations

- 10) What hopes or fears did you have for your family member?
- 11) Were these hopes and fears addressed? How? / by whom? / when?
- 12) Did anyone give you any information about what to expect in terms of prognosis or recovery?
- 13) If so, how did that information affect you?
- 14) Looking back, do you think the information was accurate?
- 15) Did you find out about traumatic brain injury through any other sources?
- 16) Who or what has been most helpful to you during this time?

- 17) At the current time, do you think you have enough understanding of what has happened and is likely to happen?
- 18) If so, at what point did you feel this happened.
- 19) Has what you hope for, fear and understand changed since the early days If so, how?
- 20) How has the injury affected you day to day?
- 21) How has it affected your family member (insert name) day to day
- 22) What do you think will happen in the next few weeks?
- 23) What do you think will happen in the next six months?
- 24) What do you think the future will look like for you and your family member?
- 25) Is there anything else you think I should know to understand your experience better?
- 26) Is there anything you would like to ask me?

Potential prompts – To be used throughout

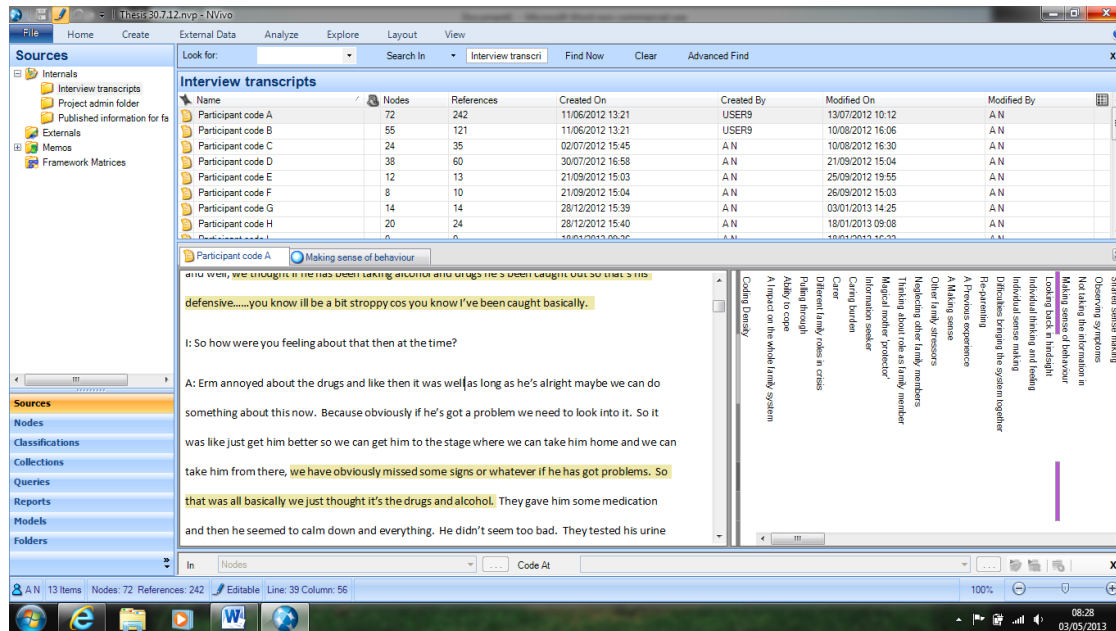
- Can you expand upon that?
- You said can you tell me a little more about that?
- Could you describe further?
- You saidcan you tell me a little more

Ideas for questions around a 'life change' (p32) taken from:

Charmaz (2010) Constructing Grounded Theory: A Practical Guide through Qualitative analysis. Sage.

Appendix 8: Open coding in NVIVO-9

This screenshot shows the Coding stripes for 'Making sense of behaviour' alongside example references from participants A and B.



<Internals\\Interview transcripts\\Participant code A> - § 4 references coded [1.18% Coverage]

Reference 1 - 0.30% Coverage

We thought if he has been taking alcohol and drugs he's been caught out so that's his defensive.....you know ill be a bit stropopy cos you know I've been caught basically.

Reference 2 - 0.26% Coverage

We have obviously missed some signs or whatever if he has got problems. So that was all basically we just thought it's the drugs and alcohol.

Reference 3 - 0.30% Coverage

Well he's been up all night and he's been drinking and he still had a headache and we thought alcohol again all points to this because that's what we have been told.

Reference 4 - 0.33% Coverage

It was just like what..why's he doing that? Whys his body..you know. Didn't know anything about fits. I mean I know people...roughly about people have epilepsy and things like that.

<Internals\\Interview transcripts\\Participant code B> - § 3 references coded [3.21% Coverage]

Reference 1 - 0.62% Coverage

Some of the things you could see where he was coming from. I don't know where Jesus came out, because we aren't a religious family apart from going to a church school at infant school don't know where that came from but...yeh I could, he remembered that he was a carpenter for a job.

Reference 2 - 1.47% Coverage

B: Yeh and he can remember he has a van at work so that sort of, I could see where he was coming from it was just that little link I couldn't understand. Then the next day he said 'errm I'm going to get a boat mum', so I said 'oh right, what you going to do with the boat?', 'I am going to fix it up'. So I thought 'oh right, that's a good good hobby', 'I'm going to put the boat in your garage', I thought 'oh well he's remembered that I've got a garage, so I said 'alright'. He said 'because when the waters comes you know we'll have to get everyone on the boat, we can start because you've got two dogs already haven't you?' (Laughs) Now he's Noah! (Laughs). Right ok then..

Reference 3 - 1.12% Coverage

B: No I just took it for what it was really, thought it was, he was getting certain elements right in his head but then obviously mixing up certain things. I spoke to one of the doctors later on and erm I said he seems to be not getting as confused now and he thinks..he sort of..I explained to my son, your brains got lots of wires and it looks like all the wires are still there but they are just connecting to the wrong ones. Half way through a sentence he's connecting to another wire and going off on a tangent.

The open coding initially created 118 nodes from the first four transcripts A-D. Participant A had 200+ nodes references, participant B 133 and thereafter coding took place for new information or references which were felt encapsulated the phenomenon better.

NVivo 10.0.0.0 - NVivo

File Home Create External Data Analyze Explore Layout View

Look for: Search In Nodes Find Now Clear Advanced Find

Nodes

Nodes
Casebook
Thematic framework
Relationships
Node Matrices

Sources

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
A lack of information	1	1	02/07/2012 16:05	A N	26/07/2012 16:48	A N
Accepting others emphasis on drugs and the drink.	2	11	11/06/2012 13:33	USER9	07/07/2012 17:00	A N
Accepting problem and thinking of resolution	1	1	02/07/2012 15:49	A N	26/07/2012 16:48	A N
Adjusting to ICU	1	1	12/06/2012 14:38	USER9	26/07/2012 16:48	A N
Asking advice of friends	1	1	03/07/2012 15:43	A N	26/07/2012 16:48	A N
Awareness of rights	1	1	02/07/2012 16:19	A N	26/07/2012 16:48	A N
Begging for an ambulance	1	2	07/07/2012 16:55	A N	26/07/2012 16:48	A N
Being directed by professionals	2	5	11/06/2012 13:40	USER9	03/07/2012 13:33	A N
Being with each other	1	1	02/07/2012 15:58	A N	26/07/2012 16:48	A N
Better much better	1	1	02/07/2012 16:38	A N	26/07/2012 16:48	A N
Can't focus on anyone but son	1	1	03/07/2012 13:34	A N	26/07/2012 16:48	A N
Caring burden	1	1	02/07/2012 16:27	A N	26/07/2012 16:48	A N
Caring role as mother	1	4	03/07/2012 14:01	A N	26/07/2012 16:48	A N
Comparing pre injury to post injury	1	1	03/07/2012 15:38	A N	26/07/2012 16:48	A N
Concerns about practical issues	1	1	02/07/2012 16:25	A N	26/07/2012 16:48	A N
Confusion about everything	1	2	12/06/2012 15:27	USER9	26/07/2012 16:48	A N
Conscious of mood changes	1	1	03/07/2012 15:39	A N	26/07/2012 16:48	A N
Contemplating life or death	3	10	12/06/2012 14:05	USER9	30/07/2012 17:07	A N
Crisis point	2	4	12/06/2012 14:11	USER9	26/07/2012 16:48	A N
Crying out for help	1	1	02/07/2012 16:35	A N	26/07/2012 16:48	A N
Delivery of news	2	2	11/06/2012 14:09	USER9	26/07/2012 16:48	A N
Desire to seek guidance	1	1	03/07/2012 15:29	A N	26/07/2012 16:48	A N
Deteriorating condition linked to inattentive staff	1	3	03/07/2012 13:57	A N	26/07/2012 16:48	A N
Didn't mean anything what so ever	1	2	11/06/2012 14:00	USER9	26/07/2012 16:48	A N
Dilemma about info on prognosis	3	4	02/07/2012 16:04	A N	30/07/2012 17:25	A N
Disagreeing about circumstances of the injury	1	1	07/07/2012 16:49	A N	26/07/2012 16:48	A N
Disagreeing with rehab centre opinion	1	1	02/07/2012 16:24	A N	26/07/2012 16:48	A N
Distractions helping	1	1	03/07/2012 13:28	A N	26/07/2012 16:48	A N
Do you think that has anything to do with the bump on his head	1	2	11/06/2012 14:07	USER9	26/07/2012 16:48	A N
Explaining range of outcomes	2	2	03/07/2012 13:07	A N	30/07/2012 17:24	A N

A N 129 items

08:34 03/05/2013

Appendix 9: Example of narrative and figural summary

Participant interview 4: Participant D

Date: 2nd June 2012

Participant: T (47 year old partner of C, C suffered a TBI in an attack in May 2012, at the time of interview C was in hospital but due to be discharged home).

Narrative summary

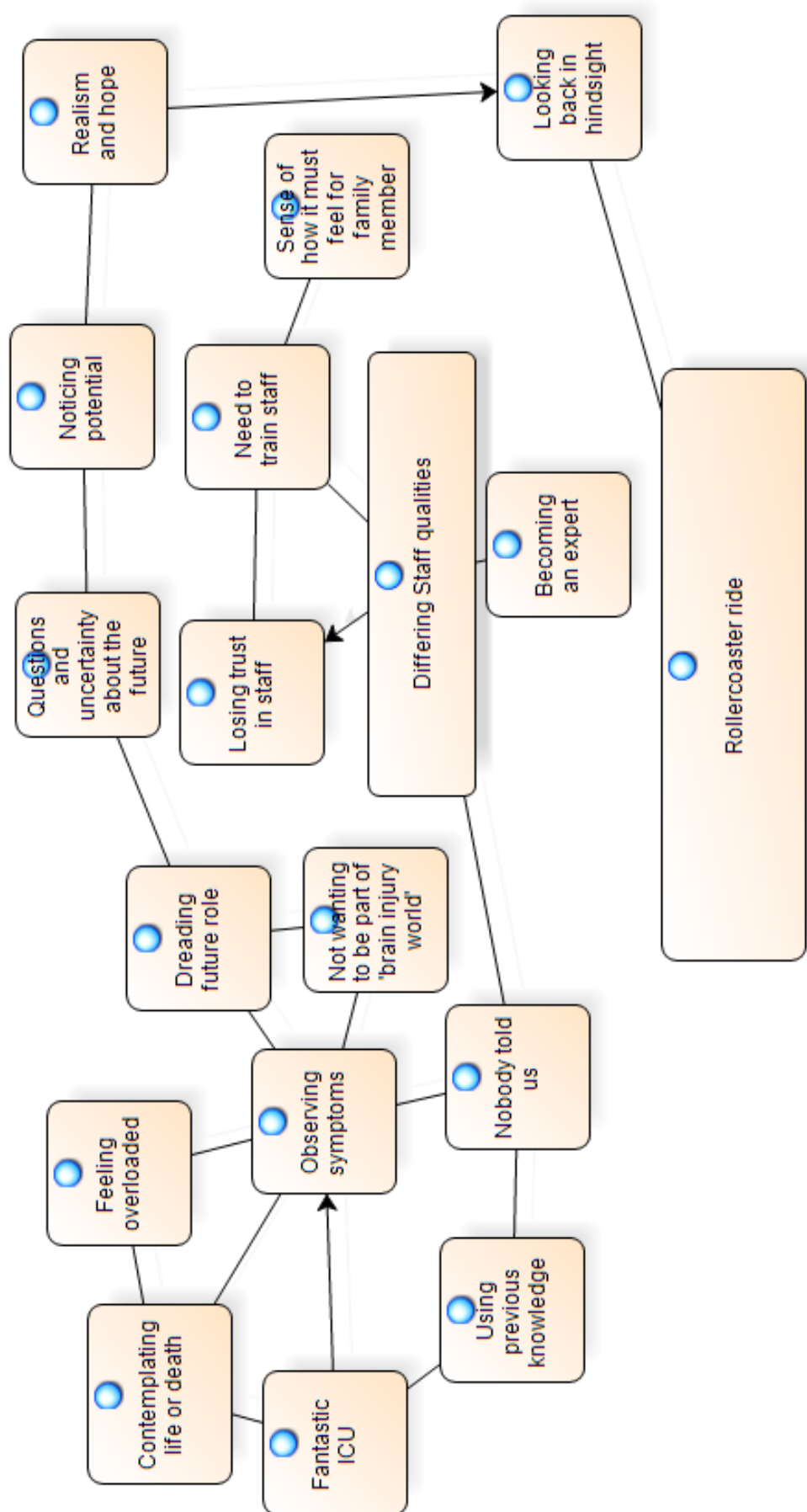
The narrative begins with a quick summary of what happened when C was attacked. The medical facts of the accident are relayed in a straightforward manner. It becomes clear that T has some awareness of the terminology surrounding brain injury due to her job role as an employment advisor. The first contact T has with the hospital is positive and ICU is felt to be a fantastic environment. The sole initial concern is life or death and T is told that the injury is very severe. It is felt that the long term outcomes are too much to consider at this point. There is a sense of being overwhelmed and unable to consider the future. The key difference noted on moving from ICU is a decrease from the resource intensive environment to one which is less clear in role. Practical concerns are beginning to kick in at an early stage in terms of financial resources and travelling.

There is an initial sense of elation at C's medical and physical progress but this 'up' is followed by the beginning of a very long low and a sense of bewilderment and dread. Behavioural symptoms begin to be described and the increasingly alarming nature of the behavioural problems leaves T feeling terrified about a future consisting of caring for C while he is this way. There is a feeling that this might be a permanent future. This period of time is finally revealed to T, by a leaflet given to her, as C being in post-traumatic amnesia (PTA). The leaflet also gives relief as it suggests to T that this is a temporary condition and will pass. It is felt in hindsight that the leaflet could have saved a lot of worry if given earlier on.

Staff members at this time are referred to as variable and inconsistent and this unfortunately leads to a feeling of losing trust. Good positive qualities in staff members relate to them being a calming influence and being able to carry out simple fun tasks with C to pass time. Less positive qualities are staff members seeing the job as a burden. The theme of some staff members not being totally receptive to C continues and there is frustration from T that this is the case. T feels she needs to take a more assertive role in advocating for C. T feels her knowledge about 'who' C is could have been better utilised. The future is still unclear and there is recognition that it is hard to give a clear prognosis. The here and now is more important at the moment and a sense of hope and progression is important.

The transition to the next ward is not clear as T is not informed of the move. What is clear to T is that she notices a marked and rapid improvement when C moves to the rehabilitation ward. T is very aware of what 'rehabilitation' is and feels that it could have started at a much earlier stage even if it were just in smaller ways. T feels strongly that staff members could negate the need for lengthy rehabilitation if they were trained better. T still feels her knowledge of C could be put to better use as C is often confused by some of the tasks he is given. The pressure of visiting hospital is still present and there is a feeling of dread entering the hospital each time.

Discharge is viewed positively due to the hopeful attitude of the staff on the rehabilitation ward. This stage of 'recovery' also fits well with T's job role so she feels realistic about the challenges which lie ahead. There is a 'traumatised' feeling about the whole experience though and a sense that it has been a rollercoaster ride.



Appendix 10: Operational memo for axial coding

The operational memo below helped to consider what the key points were in the participant's narratives so far. This then contributed to an initial attempt at drawing these narratives together in a model that represented all participants. This was a helpful exercise as it indicated what information was missing and also highlighted that the model as yet did not have enough dynamic elements the 'if this then that' links.

Memo: Operational memo

Topic: Moving on to the axial phase of coding

Date: 18/10/2012

Moving onto the process of axial coding the key task is to think about the relationships between the themes. There needs to be more emphasis on the model being dynamic and not static. There is a focus on relationships and creating 'If I have X I have Y'.

Exercise

Briefly going through each participant's interview and thinking of 6-7 statements that summarise them.

Participant A

- Punctuating moments of feeling overwhelmed and experiencing crisis
- Needing some idea of what the next stage is – Can I be hopeful?
- Feeling that some professionals do not understand 'they have forgot more than I'll know'
- Needing to take initiative and advocate
- Feeling like it is a long and lonely journey
- Anger at what could have been done better

Participant B

- Son being totally central and the injury all consuming
- Feeling confused that nothing is being done at times
- Having a dilemma about wanting to know about future but appreciating this is not possible
- Needing reassurance on correct route
- Feeling that hope at future due to more positive outcome

Participant C

- Feeling let down and angry
- Feeling nobody cares and social network has disappeared
- Feeling that the outcomes of the injury are perhaps more serious than professionals believe
- Threatening and fighting for support
- Feeling of horror about the whole process – not contained
- Spirituality as one positive support factor

Participant D

- Feeling strongly in hindsight that things could have been better
- Staff members felt to be very varying in terms of skills

- Experience matching stage makes D feel more confident
- Considering future role as a carer 'not' partner
- Needing to see potential and hope
- Behaviours of relative being scary and unexplained

Participant E

- Role as a father totally key and the expectations of needing to care crucial
- Family and friends pulling together hugely important
- Strong emphasis on key professionals making the difference
- Hope as crucial to wellbeing
- Post hospital as being hugely disorganised and no consistency
- Trust in professionals as important

Participant F

- Light-hearted view of the whole process
- Drive to learn and know about what's happened
- Comparison with previous life experiences
- It could have been worse
- Self-reliance and own sense making

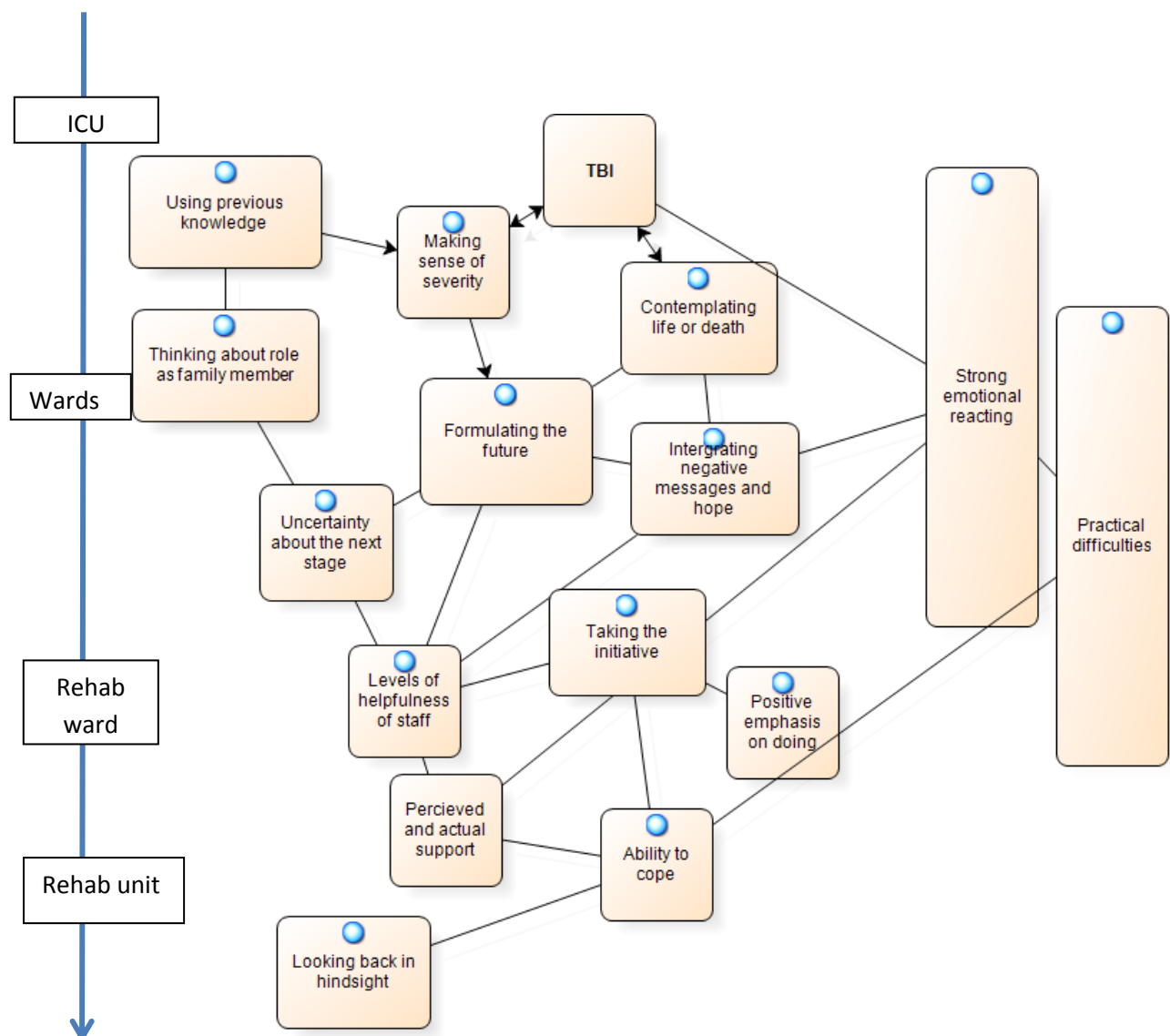
Appendix 11: Model after first six interviews

The model and the consideration of how the concepts fit with the data helped inform a set of hypotheses that helped to develop a second interview schedule.

Memo: Coding memo

Topic: Emerging themes from first six interviews

Date: 26/09/2012



Appendix 12: Operational memo: Hypotheses pre axial coding

Memo: Operational memo

Topic: Moving on to the axial phase of coding

Date: 10/10/2012

Reminder of research questions

- 1) What did family members know about TBI prior to the traumatic injury?
- 2) How did family members experience the traumatic event and the process of hospitalization?
- 3) Where was or is information acquired from and how is it being interpreted?
- 4) How has information been used to construct an understanding of recovery?

Hypothesis

Single hypotheses

- If people are asked to describe traumatic brain injury they can often come up with the ‘facts’ of what it is a possibly medical knowledge, however this does not appear to help them adequately through the experience. What has happened is a hugely personal experience. The words used to describe what brain injury are, are more descriptive and focus on the ‘journey’ of how it is experienced. The experience appears to be like entering a dark path which is only illuminated a bit at a time. Medical knowledge in itself does not appear to help understanding.
- Knowing that there is a plan and a structure to what is happening is helpful in itself. This is very distinct to knowing what the prognosis is. Family members appear to be aware that they cannot be told exactly what will happen.
- Life or death thinking is actually quite similar between everyone and the only real differences between people are how soon into this process they begin thinking about the future and how much they want to know.

Relational hypotheses

- People will attempt to use any current experience and knowledge to understand what it happening. However in most cases the experience of brain injury appears to take them by surprise as what they thought they might have understood about the medical side of the event does not prepare them for the on-going emotional impact. Experience varies between the participants and when thinking about it further using a constant comparison method these could be described as three main areas:
 - Lived experience
 - Lifestyle - This might be an area worth exploring as it might encompass social support.
 - Medical knowledge
 - Brain injury specific knowledge

- Skills – this might be practical skills but it might also link with initiative in terms of some people feeling they are able to ask for help and advocate on the family members behalf?

Previous experience might have relationships to feelings of efficacy and positivity about ability to cope. It might also link in with how people negotiate the journey of brain injury; participant F had a mixture of 4 'previous experience themes and so might have felt she had a better set of knowledge and skills to handle what was being thrown at her.

- There is definitely a difference between roles and this appears to be impacted upon by previous relationship as if the parent or partner was very close to the person there appears to be a difference to if they weren't close. There are some quite clear roles actually emerging which have to be negotiated over time and return to 'how things were' whilst still having this 'hospital role'.

- **Hospital roles**

- 'Magical mother' or 'protector' – The magical mother theme appears to be from the idea that two mothers felt such a strong bond to their sons that they felt they needed to be in the hospital to keep them alive. The role of mother for these two people seems to be enhanced and they look after their children as though back in childhood feeding them and nurturing them i.e. applying cream and cutting nails. This is similar to a protector role of the father which emerges which indicates a need to look after and protect the son. This role also seems to encompass a 'advocate' role whereby people feel they need to push for the person's rights.
- 'Restorer' – There is a sense that a person needs to be restored to 'how they were' and that the family member is a protector of the identity of the family member and needs to communicate this to staff members.
- Information seeker – Some people actively seek out information from other sources such as the internet.
- 'Re-parenter' – Some people see this role as a return to parenting a much younger child and find this difficult. One person who did not have a close relationship to their child at the time appears to take on this role as opposed to the 'magical mother' role.
- Child-parent' - Partners appear to find the caring of the person close to them more difficult as they have previously enjoyed an intimate relationship and suddenly find themselves in a more child-parent relationship.

Post hospital

- 'Flying the nest again' - For parents they seem to find it difficult to balance the change from being a protective parental figure to starting to relinquish dependence and let the person get back to being independent.

I am not sure about these roles as yet and need to explore more from the partner's point of view. Does a person's role relate to what personal skills they think they as the people I have spoken to are all more 'dominant' characters and so might take more active roles and there might be people who are more passive? An example of a more passive role might be someone who helps organise practical things or someone who is quite reserved when it comes to engaging with hospital staff but who emotionally can provide a 'port in a storm'. This area of roles might relate to social support.

- **Initiative might be quite strongly correlated to the role that is taken on.**

Some people particularly the three mothers felt that if it hadn't been for their care their relative would not have recovered as well as they think he did. Initiative might be on a spectrum

- Social support is crucial to a person feeling they have their own team of people 'onside' if there is inconsistencies with staff this is helpful. People seem to seek an external source of support and when none is forthcoming spirituality can fill this role? A person with a large

social circle will possibly feel less pressure on themselves to try and fulfil all the roles that are needed.

- **How information is interpreted:** The most important thing is that everybody wants to remain informed about what is happening in the moment, some people do not want to know every nuanced detail and seek explanations for each and every incident that occurs. However all people seem to want to know literally what is being done at this moment. Some people just want to take it step by step. However there is a lot of 'behind the scenes' thinking about the future specifically about how the person might be affected and how they might change from their pre-injury state. The differences between the people might be explained by how much investment they have in 'hope' and not wanting to seek any medical confirmation of the fact that there might be some significant changes. In this instance the literature talks about 'denial' and this might be a factor for some people wanting to stay positive and in the moment.
- The area of information interpretation might link in with adjustment post injury however as it often comes as an unwelcome shock when people get their family member home and they are not as 'well' as they were. People who compare pre-injury to post-injury and find a negative comparison appear to be angrier and feel support is lacking. Those who construct changes as positive appear to feel more positive about the future.
- Everybody describes the hospital process as really emotional and overwhelming. The use of a roller-coaster metaphor appears to be used on several occasions and 'peaks and troughs' in other instances. People obviously react completely differently and it is hard to pick out a pattern from the interviews. One very obvious thing is C perceived she had little social support and obviously felt more lonely and isolated. Social support and good professional support particularly described as being a Psychologist who gave quite intensive support appeared to mediate the emotional impact. Care appears to be patchy and it is only when a 'competent professional' takes on the role of lynch pin that the family appears supported. Narrative C did not progress through the same wards as J did and so missed out on the Psychologist who fulfilled this role.
- People develop knowledge across the process of the injury however there may be a sense that missing 'competencies' developed early on will still be present at the end of the hospital process and then will be exacerbated should they not be managed. For example a person with low social support and a low number of skills will find going home very difficult due to the on-going low social support and lack of knowledge about how to manage the person. Coming into contact with a professional who can identify and manage some of these needs will help.

Appendix 13: Operational memo: Imaginary radio interview

Memo: Operational memo

Topic: Moving on to the axial phase of coding – Radio Interview: Imaginary 2 minute radio presentation summarising research so far.

Date: 22/10/2012

My research has begun by interviewing 6 family members with a TBI. The emerging areas can be divided into structural themes which appear to resonate with all family members and then some emerging themes within this framework which appear to vary across family members.

Firstly when considering the development of understanding for family members it appears that this is described within a narrative of a journey that has been progressed through. There is the initial shock of the accident or injury where thoughts appear to be disorganised and there is a reliance on professional direction and advice. Life and death at this point are all consuming for family members and there are degrees of how well people emotionally cope with this. It is clear, apart from in one case (who wasn't) that if you are closely related to the person they become the total centre of thinking. Interestingly it is often to the detriment of other family roles such as being a wife. Family members in this time find it hard to retrospectively think how knowledge was developing as most had no experience and so felt quite blind to what was unfolding. Interestingly these accounts appear to remain untainted by more recent thought as there is almost a 'haunted' quality to how they are told as if the emotional memory is still very alive.

Another theme present for all was the idea of the journey through the TBI progressing in stages. As the stages advance individuals appear to become more aware of their developing knowledge and what they see as things that aren't 'right'. Initiative becomes more important as stages progress with people feeling that as knowledge is not being offered through the 'official' channels so they must seek it elsewhere.

There are some early differences in this sample. It appears that family member dynamics pre-injury can have an effect on how the person constructs their understanding of TBI. Difficult family relationships pre-injury might become more complex whereas 'close' family units might gather together while in hospital but then feel the effects of the changes on family life post-discharge. There is also something emerging in how the situation is appraised in various ways. If a person feels hopeful this can lead to feelings of efficacy and an action or 'doing' focus. If professionals do not support this there can be friction. Personal appraisals of self and how the person expected to cope are also an emerging area. Most people picked positive personal and interpersonal qualities in themselves that they felt had been undermined by the TBI experience.

Another current thought after these interviews is wondering whether people use previous skills, knowledge and experience in their sense making. Most people referred to some previous experience that didn't quite match their expectations of what had happened. However they did appear to be trying to use this to make sense of how to manage this new experience. One participant who had, had quite an eventful life appeared to be quite relaxed about living with someone with TBI. However she hadn't been involved with this person's hospital journey. Perhaps there is something in being emotionally involved in the process that is actively quite traumatizing and leaves an imprint on the person. Finally another key area being noted is the perception of competency of staff members. Staff

are felt to be at different levels of competency in terms of aiding the process of understanding. There appears to be the 'model professional' and then those who were mainly felt to be actively discouraging of hope who were viewed very negatively.

So that's where the research is at the next stage will be to think about how these themes might vary from person to person and start to link together.

Appendix 14: Interview schedule 2



Interview schedule 2: Semi –structured schedule for initial interviews

Name of the study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson

Supervisors: Dr Gemma Wall – Clinical Neuropsychologist Dr Stephen Mullin – Clinical Neuropsychologist
Dr Jim Williams – Clinical Psychologist/Clinical Director

Introduction

Hello my name is Hannah Nelson and I will be carrying out the interview today. By now you will have read the information sheet and signed the consent form. If we can just look at each point on the consent form and check whether you have any questions?

Read through consent form.

Just to re-cap I am interested in looking at Traumatic Brain Injury. I am researching the process you and others are going through in trying to understand what a traumatic brain injury is. Also I am interested in how you are thinking in relation to your expectations for the future for yourself and your family member

The interview will last approximately an hour, unless you feel you have more to tell me and are happy to continue. If at any time you want to stop: for a break; because you do not wish to continue; or you do not wish the recording to continue; please signal to me or tell me you wish to stop. If I can see you are becoming upset in any way I will ask if you would like a moment to collect yourself or whether you would like to stop and we will take time to ensure you feel ok.

You have the right to stop the interview at any point and your recording will not be used if this is your wish. This will in no way affect any part of your family member's or your future treatment and your wish will be treated with the utmost respect.

Is that ok?

Do you have any questions?

Thank you, we will now begin. I will introduce you on the recording by saying your code number.

Semi-structured interview – To be used as a guide

- 1) How do you normally cope in a crisis? Did this feel different?
- 2) Are you the kind of person who needs to know every detail of what's happening? How did you manage the fact that you couldn't?
- 3) What kind of relationship did you have to x before the accident? Has this changed? Did you think about this in hospital?
- 4) What skills, knowledge or experience did you feel you had which helped you cope?
- 5) What skills, knowledge or experience did other family members have?
- 6) Do you think other family members had different roles?
- 7) If, hypothetically, the injury had happened to another family member do you think your role would have been different?
- 8) How did your previous relationship in relation to the person change? What was the new role that you took on?
- 9) Apart from hospital staff what support did you draw upon? Did you find other people helpful? What help did they provide?
- 10) Would you say you are an optimistic person? How did this help or hinder you if so?
- 11) Did professionals tell you anything positive that stuck in your mind?
- 12) Did professionals tell you anything negative that stuck in your mind?
- 13) Do you feel there was a role for denial in any information you were told?
- 14) How 'well' do you think x has recovered?
- 15) When x was discharged what did you think would happen next? Did this happen?
- 16) What was your role when x left hospital?

Potential prompts – To be used throughout

- Can you expand upon that?
- You said can you tell me a little more about that?
- Could you describe further?
- You saidcan you tell me a little more

Appendix 15: Axial coding NVIVO-9

Axial coding aims to develop links at the conceptual level. It aims to link categories at the level of properties and dimensions. The screenshot illustrates concepts beginning to link together at the level of properties and dimensions. The nodes here are being pruned and organised to create more distinct concepts. The narrative and figural summaries were used to consider a mod

Nodes							
Name	Sources	References	Created On	Created By	Modified On	Modified By	
⊕ A Making sense	0	0	13/07/2012 11:34	A N	04/01/2013 09:50	A N	
⊕ A Other systems that help or impact	0	0	28/12/2012 16:05	A N	28/12/2012 16:05	A N	
⊕ A personal rollercoaster ride	4	4	09/08/2012 17:05	A N	18/01/2013 09:13	A N	
⊕ A Taking the initiative	2	14	12/06/2012 15:19	USER9	28/12/2012 16:00	A N	
⊕ Advocating needs of family member	4	6	13/07/2012 11:16	A N	10/08/2012 15:45	A N	
⊕ Becoming an expert	3	4	13/07/2012 11:09	A N	03/01/2013 14:24	A N	
⊕ Co-incidental knowledge development	1	3	12/06/2012 15:22	USER9	02/07/2012 16:09	A N	
⊕ Finding and reading sources	4	9	12/06/2012 14:52	USER9	26/09/2012 14:53	A N	
⊕ Negatives of taking initiative	1	3	02/07/2012 16:26	A N	24/09/2012 12:53	A N	
⊕ Self taught knowledge	3	5	12/06/2012 15:24	USER9	25/09/2012 16:17	A N	
⊕ Trying things out	1	1	02/07/2012 16:08	A N	24/09/2012 11:37	A N	
⊕ Using previous knowledge	6	10	13/07/2012 11:08	A N	25/09/2012 16:17	A N	
⊕ A Temporal stages	1	2	07/08/2012 16:47	A N	18/01/2013 16:10	A N	
⊕ A The injured family member	2	2	03/07/2012 13:34	A N	03/01/2013 14:07	A N	
⊕ Being directed by professionals	3	6	11/06/2012 13:40	USER9	24/09/2012 12:53	A N	
⊕ Being prepared	1	1	03/01/2013 14:01	A N	03/01/2013 14:01	A N	
⊕ Confusion about everything	1	2	12/06/2012 15:27	USER9	24/09/2012 12:53	A N	
⊕ Crying out for help	3	3	02/07/2012 16:35	A N	26/09/2012 15:26	A N	
⊕ Danger of offering diagnostic information	3	12	11/06/2012 13:33	USER9	04/01/2013 10:43	A N	
⊕ Feeling guilty	1	2	02/07/2012 16:52	A N	26/09/2012 15:26	A N	
⊕ Feeling involved and informed (ICU)	5	8	03/07/2012 12:48	A N	03/01/2013 14:22	A N	

The screenshot shows the NVivo 9 software interface. The main window displays a list of nodes under the 'Nodes' tab. The nodes are organized into a hierarchical structure, with some nodes expanded to show sub-nodes. The table below represents the data shown in the screenshot.

Name	Sources	References	Created On	Created By	Modified On	Modified By
⊕ A personal rollercoaster ride	4	4	09/08/2012 17:05	A N	04/04/2013 10:57	A N
⊕ A Relationship to person	1	1	28/12/2012 15:56	A N	04/04/2013 11:25	A N
⊕ A Staff members	1	1	20/06/2012 20:35	A N	04/04/2013 10:57	A N
⊕ At injury point	0	0	28/03/2013 11:19	A N	04/04/2013 10:57	A N
⊕ Contributing factors	0	0	28/03/2013 14:46	A N	04/04/2013 10:57	A N
⊕ Early strategies for sense making	0	0	20/03/2013 16:05	A N	04/04/2013 10:57	A N
⊕ A Hope	9	17	04/01/2013 10:07	A N	04/04/2013 10:53	A N
⊕ A Taking the initiative	2	14	12/06/2012 15:19	USER9	28/03/2013 14:54	A N
⊕ Asking questions	3	4	11/06/2012 14:07	USER9	28/03/2013 11:58	A N
⊕ Contemplating life or death	3	10	12/06/2012 14:05	USER9	24/09/2012 12:53	A N
⊕ Listening to staff members	1	1	28/03/2013 14:23	A N	28/03/2013 14:57	A N
⊕ Looked like there was nothing wrong	1	2	03/07/2012 12:45	A N	26/09/2012 15:26	A N
⊕ Observing symptoms	7	24	11/06/2012 13:32	USER9	04/04/2013 11:42	A N
⊕ Spirituality	2	3	10/08/2012 16:06	A N	03/01/2013 14:18	A N
⊕ Strong emotional reacting	3	10	12/06/2012 12:20	USER9	03/01/2013 14:08	A N
⊕ Taking it day by day	3	8	03/07/2012 12:51	A N	28/03/2013 12:00	A N
⊕ Interpretations	0	0	28/03/2013 11:38	A N	04/04/2013 10:57	A N
⊕ Later strategies for sense making	0	0	20/03/2013 16:10	A N	04/04/2013 10:57	A N
⊕ Looking back in hindsight	7	12	11/06/2012 13:55	USER9	12/04/2013 09:22	A N
⊕ Nobody told us or guided us	8	49	02/07/2012 16:42	A N	04/04/2013 10:57	A N
⊕ Outcomes	0	0	20/03/2013 16:10	A N	04/04/2013 10:57	A N
⊕ Prior to the TBI	0	0	28/03/2013 11:12	A N	04/04/2013 10:57	A N

Appendix 16: Operational memo: Hypotheses pre selective coding

Memo: Operational memo

Topic: Hypotheses

Date: 18/02/2013

Reminder of research questions

- 1) What did family members know about TBI prior to the traumatic injury?
- 2) How did family members experience the traumatic event and the process of hospitalization?
- 3) Where was or is information acquired from and how is it being interpreted?
- 4) How has information been used to construct an understanding of recovery?

I will now describe the hypotheses that have emerged through open and axial coding of the 12 transcripts.

General hypotheses

- Constructing an understanding is a means to the ultimate end of the person with TBI ‘getting better’. Probably because of this a premium is placed on learning through doing and seeing progress.
- Information as mentioned in research question 3/4 does not accurately describe the processes involved in what is a sense making process. Concepts such as hope are interlinked with these processes in the family member conceptualising recovery.

Processes

- Initially there is very little experience that a person can draw upon to understand what is happening so basic knowledge such as that acquired from TV programs is used alongside needing to ask lots of questions. Observing signs and symptoms is a skill that starts to emerge as well and people at the early stages often describe in detail what is happening.
- Experiential knowledge development is the most important process of acquiring knowledge. Three concepts that are particularly relevant here the use of observation, taking information from professionals and initiative. Observation is used as a method of gathering information that the family member can compare with other sources of information. Professionals are felt to be more or less helpful in terms of providing knowledge. It doesn’t have to be always positive information however the manner of delivery of information is important. Initiative is always described by participants at some point as a logical step to take.
- More initiative is taken as time goes on this is due to a need for progress, possibly interlinked with the need for hope. As more initiative is taken an ‘expertise’ is developed. Professionals are considered to be more or less attuned with this process.
- Given the potential importance of these processes those family members who are not as closely involved with the hospital process or with the person with the TBI will be reliant on those who are to construct an understanding. This may entail them taking up other roles to support the other family members.
- Internal belief systems such as being spiritual and praying for recovery or hope and optimism are complex and deeply ingrained in any sense making. There is a need to have a positive feeling for the future and the concept of disavowment from the cancer literature may accurately convey how family members cope with any threats to this mind set.
- Disavowment is the family turning away from facts by transforming or reconstructing aspects of the threatening situation, i.e. they play with reality by creating “cover stories”. That is they

are aware of the real life difficulties of the situation but need to actively transform its personal meaning to make it easier to cope with.

Contributing factors

- While not the main focus of this research it is obvious that emotions have an impact on the sense making process. Anger, confusion, anxiety, sadness are all important factors in how a person can make sense of what is happening. Cognitive theory around how thoughts can impact on emotions and behaviours and vice versa and how both can be amenable to change make sense in the context of this area.
- The role changes a person goes through also have an impact on how available and willing they are to take part in the process of recovery. Three important characteristics that have emerged through the analysis are comfort, responsibility degree to which expectations have been altered. It might be hypothesised that if someone feels more responsible for the wellbeing of a family member they will be more highly motivated to play a large part of the recovery process i.e. A father or mother. Additionally how comfortable the family member is with playing a role such as caring may impact. So someone may have a high degree of responsibility for the person but not feel very comfortable in the role they need to play. This might be most difficult if the expectations of the relationship have been substantially altered so a wife and husband whereby the husband was the 'breadwinner' and caring figure who then gets injured.
- As previously mentioned initiative appears to be very helpful for people to feel like they are moving forward but it may not always be possible due to geographic location. Someone may live far away from the hospital the person is in and find this difficult. It may be that the person is close by but the family member does not feel confident in taking initiative so ends up feeling distanced in this way.

Consequences

- An emerging what could be seen as 'expertise by experience' emerges as the person with the TBI is recovering. Different people may have different levels of expertise dependent on how much contact they had with the person which will have been influenced by factors such as geographic location, confidence and degree of comfort in taking action. Particular role they played in the process will have been important.
- A shared family narrative and way of thinking has been seen in some of the transcripts. Often this is shared with the person with the TBI. It appears that the more that is shared the more cohesive narrative there is around the person.
- Additionally many people have a 'shadow' area that has not been shared with the family or person with TBI and this can continue to be a problem in terms of it being a constant block on progress.
- Progress is an obvious and important consequence and is often talked about in detail. When thinking about how it relates to the re-shaping of the family there is an emphasis on small but crucial steps such as learning to shave again or eat a kebab as that is what the person would have previously enjoyed. This links back to goals and observable methods of progress being crucial.

Appendix 17: Interview schedule 3



Interview schedule 3: Semi –structured schedule for initial interviews

Name of the study: A Grounded Theory study investigating how family members come to understand Traumatic Brain Injury and how this influences their expectations for recovery

Name of researcher: Hannah Nelson

Supervisors: Dr Gemma Wall – Clinical Neuropsychologist Dr Stephen Mullin – Clinical Neuropsychologist
Dr Jim Williams – Clinical Psychologist/Clinical Director

Introduction

Hello my name is Hannah Nelson and I will be carrying out the interview today. By now you will have read the information sheet and signed the consent form. If we can just look at each point on the consent form and check whether you have any questions?

Read through consent form.

Just to re-cap I am interested in looking at Traumatic Brain Injury. I am researching the process you and others are going through in trying to understand what a traumatic brain injury is. Also I am interested in how you are thinking in relation to your expectations for the future for yourself and your family member

The interview will last approximately an hour, unless you feel you have more to tell me and are happy to continue. If at any time you want to stop: for a break; because you do not wish to continue; or you do not wish the recording to continue; please signal to me or tell me you wish to stop. If I can see you are becoming upset in any way I will ask if you would like a moment to collect yourself or whether you would like to stop and we will take time to ensure you feel ok.

You have the right to stop the interview at any point and your recording will not be used if this is your wish. This will in no way affect any part of your family member's or your future treatment and your wish will be treated with the utmost respect.

Is that ok?

Do you have any questions?

Thank you, we will now begin. I will introduce you on the recording by saying your code number.

Semi-structured interview 3 – To be used as a guide

Theme: Observation

When you observed something happen with your family member what was it important then to do? Why?

What helped you do this?

Can you think of a time when others observed something? how was it fed back to you if it was? What action did you take if any?

Were there times when you weren't with your family member? How did this feel not being able to see them? What were you thinking at these times?

Theme: Professionals

Can you think of a time when you were told something by a professional that didn't match with what you were feeling or seeing? What did you do? How did it feel? What happened next?

Can you think of a professional who had an impact on how you understood what was happening? What did they do? What didn't they do?

When professionals were no longer involved who was most involved? Why was this?

How often did your family communicate about progress? Are there any particular incidents you remember being told about?

Theme initiative:

What does the concept initiative mean to you?

Can you think of times where you felt you needed to act on initiative?

Can you think of a time when you made your own 'intervention' for a family member? Why did you do this?

How comfortable did you feel doing this?

What guided you?

Theme: Comfort and responsibility

Given your relationship with your family member how responsible for that person's recovery did you feel? Did this change?

How comfortable did you feel when they were in hospital with the things you needed to do? Did this change? If so what made it change?

How much of a change was there in terms of your relationship with the person pre and post injury? Was this surprising? How did you make sense of what had changed?

Theme: Hope and use of other frames of thinking

When someone told you something negative was your reaction to go with what they had said? Did you think anything else? Did you discuss this with family members?

How did you know what was going to happen next in the process of recovery? How did this feel?

Did you feel confident in your abilities to cope with the situation? What influenced this?

There is a concept I am interested in called disavowment it means that at times the 'family turns away from facts by transforming or reconstructing aspects of the threatening situation, i.e. they play with reality by creating "cover stories". That is they are aware of the real life difficulties of the situation but need to actively transform its personal meaning to make it easier to cope with'. What do you immediately think when you hear that?

Theme: Expertise

If you were to rate your understanding of TBI at the start what number out of 10 would you have given yourself? If you could rate yourself again now what would it be? Why do you think this is? What helped change this number?

Would you say different family members would rate themselves differently? Why might this be? Can you think of an example?

Theme: Developing narrative

Would you say your understanding of what happened and how you felt about it is something the rest of your family would know about?

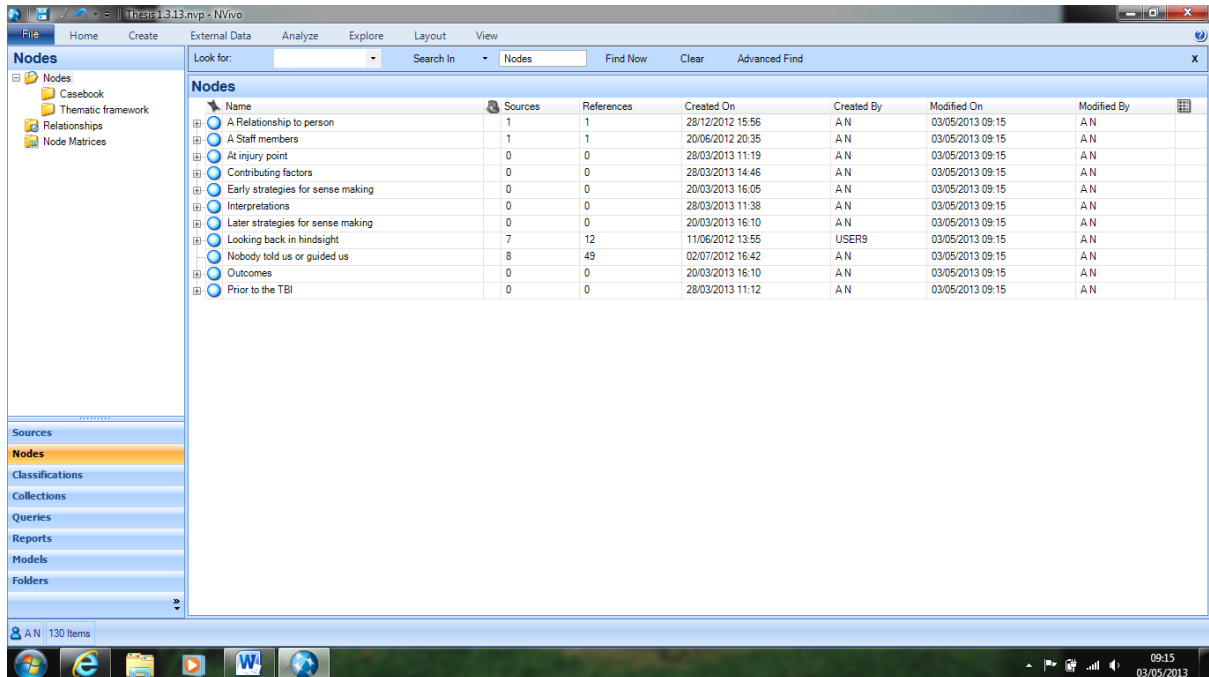
Would you say there is a common story in the family about what happened? Have key incidents ended up being discussed more often?

Potential prompts – To be used throughout

- Can you expand upon that?
- You said can you tell me a little more about that?
- Could you describe further?
- You saidcan you tell me a little more

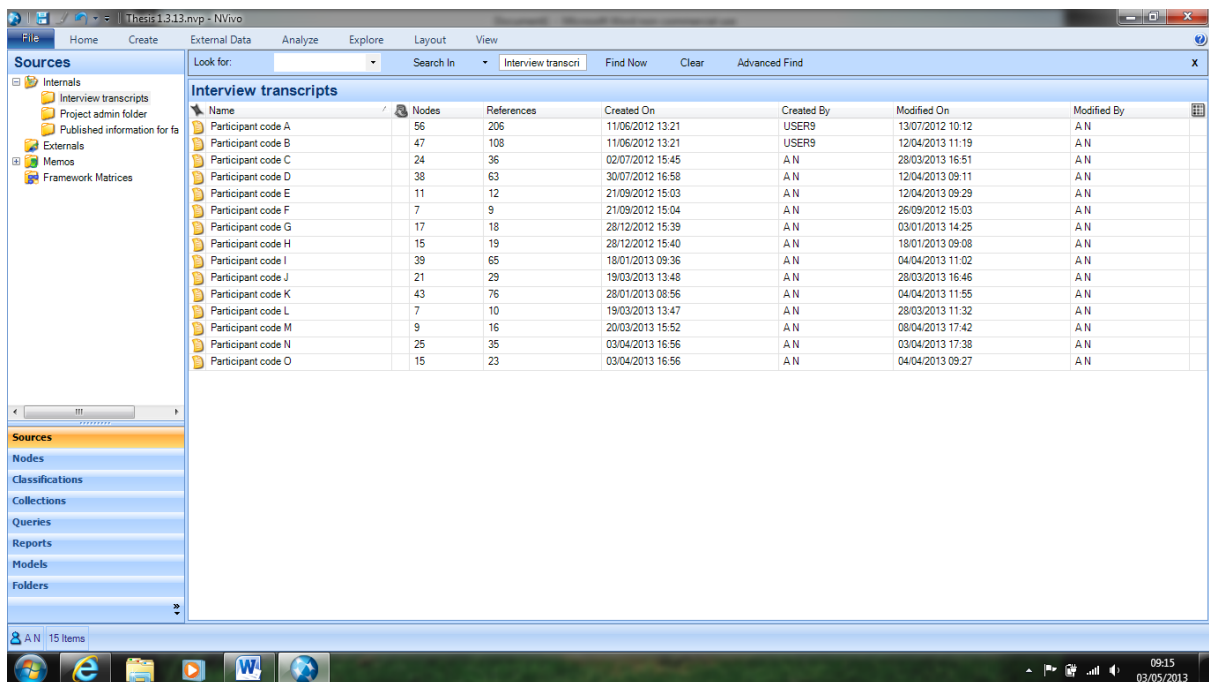
Appendix 18: Selective coding NVIVO-9

Selective coding



Name	Sources	References	Created On	Created By	Modified On	Modified By
A Relationship to person	1	1	28/12/2012 15:56	A N	03/05/2013 09:15	A N
A Staff members	1	1	20/06/2012 20:35	A N	03/05/2013 09:15	A N
At injury point	0	0	28/03/2013 11:19	A N	03/05/2013 09:15	A N
Contributing factors	0	0	28/03/2013 14:46	A N	03/05/2013 09:15	A N
Early strategies for sense making	0	0	20/03/2013 16:05	A N	03/05/2013 09:15	A N
Interpretations	0	0	28/03/2013 11:38	A N	03/05/2013 09:15	A N
Later strategies for sense making	0	0	20/03/2013 16:10	A N	03/05/2013 09:15	A N
Looking back in hindsight	7	12	11/06/2012 13:55	USER9	03/05/2013 09:15	A N
Nobody told us or guided us	8	49	02/07/2012 16:42	A N	03/05/2013 09:15	A N
Outcomes	0	0	20/03/2013 16:10	A N	03/05/2013 09:15	A N
Prior to the TBI	0	0	28/03/2013 11:12	A N	03/05/2013 09:15	A N

The NVIVO-9 screenshot below indicates the number of nodes and references for each participant at the end of the selective coding process.



Name	Nodes	References	Created On	Created By	Modified On	Modified By
Participant code A	56	206	11/06/2012 13:21	USER9	13/07/2012 10:12	A N
Participant code B	47	108	11/06/2012 13:21	USER9	12/04/2013 11:19	A N
Participant code C	24	36	02/07/2012 15:45	A N	28/03/2013 16:51	A N
Participant code D	38	63	30/07/2012 16:58	A N	12/04/2013 09:11	A N
Participant code E	11	12	21/09/2012 15:03	A N	12/04/2013 09:29	A N
Participant code F	7	9	21/09/2012 15:04	A N	26/09/2012 15:03	A N
Participant code G	17	18	28/12/2012 15:39	A N	03/01/2013 14:25	A N
Participant code H	15	19	28/12/2012 15:40	A N	18/01/2013 09:08	A N
Participant code I	39	65	18/01/2013 09:36	A N	04/04/2013 11:02	A N
Participant code J	21	29	19/03/2013 13:48	A N	28/03/2013 16:46	A N
Participant code K	43	76	28/01/2013 08:56	A N	04/04/2013 11:55	A N
Participant code L	7	10	19/03/2013 13:47	A N	28/03/2013 11:32	A N
Participant code M	9	16	20/03/2013 15:52	A N	08/04/2013 17:42	A N
Participant code N	25	35	03/04/2013 16:56	A N	03/04/2013 17:38	A N
Participant code O	15	23	03/04/2013 16:56	A N	04/04/2013 09:27	A N

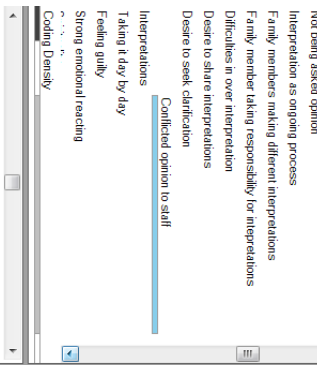
The screenshot below indicates an example from the selective coding phase. Here text has been coded which fits with the emerging theory and brings together a number of concepts. Here the concepts of observation, progress and conflicted opinion with staff are discussed by participant O.

Which I think just was more frustrating than anything else.

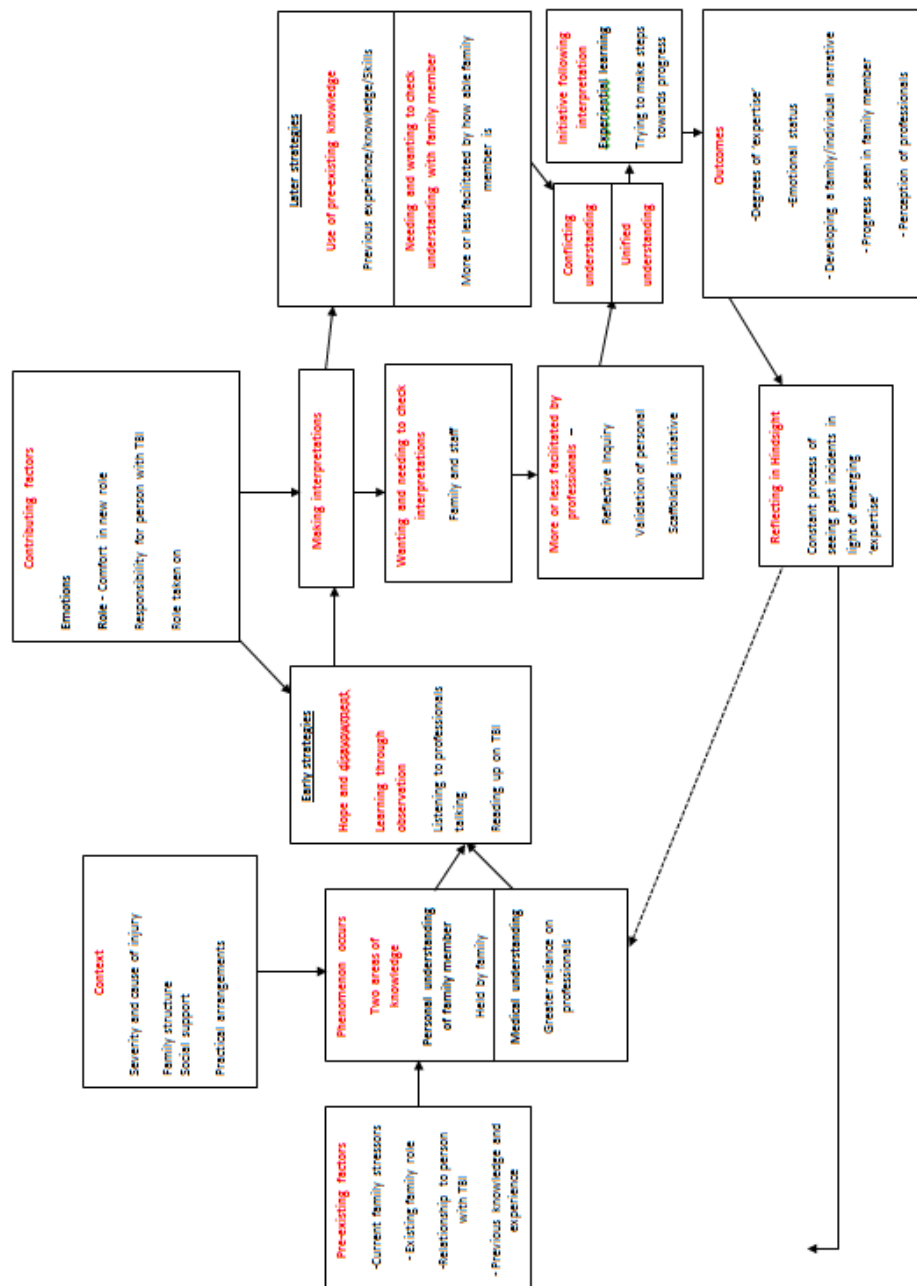
I: And going back to the idea of observation, was that one of the major ways you could tell that what they were offering wasn't matching your family member?

A: Yeah I mean obviously, but we spent a lot of time erm doing, the interesting thing was, because he was, erm, obviously able to vocalise concerns and things, even when he was saying that he was fine with certain things and it wasn't a problem, they'd kind of persist or they would, sort of, treat him as if he wasn't and I think that just frustrated him more and then, you know, made him not want to be helped by them and then in some ways obviously it would have been, there were some areas, on some level they probably could have helped you know on an appropriate level of er, kind of help. But, cos we would see the kind of things that he wanted to do and was capable of we could provide a kind of, er, just a higher level I guess of interaction. Not, I don't think it's really, kind of, any kind of considered you know way of progressing it was just a level of interaction that was more suitable.

I: So you weren't really acting on any strong understanding, necessarily, of brain



Appendix 19: Provisional model mid selective coding



Appendix 20: Final story line memo

Memo: Theoretical memo

Topic: Story line memo

Date: 8th April 2013

Reminder of research questions

- 1) What did family members know about Traumatic Brain Injury (TBI) prior to the traumatic injury?
- 2) How did family members experience the traumatic event and the process of hospitalization?
- 3) Where was or is information acquired from and how is it being interpreted?
- 4) How has information been used to construct an understanding of recovery?

Story line

At the time of injury most family members say they have no experience or knowledge of Traumatic Brain Injury (TBI), however they have some basic knowledge of medical vocabulary (Coma, resuscitation etc.). Those who do have knowledge of TBI, for example through work, appear to feel they start from a similar point to those who know nothing. This is because the sensemaking process is about understanding how TBI relates personally to what has happened and will happen to their family member. Generic facts are not as helpful as personally applied understanding. From the beginning there are several general factors which should be considered as exerting an impact on the sensemaking process but that are not easy to predict. Emotional fluctuations, practical difficulties and other stressors can make the process of sensemaking even more difficult.

It becomes clear early on that there is a distinction between feeling involved and informed by professionals and feeling that nothing is being explained properly. Most people feel positive about the information being delivered in intensive care (ICU). They describe feeling they start to become 'expert' at monitoring the machines and considering what they mean for their family member. The families all have a similar view of the situation which is to get through the life and death crisis and there is a rough understanding of the next stage i.e. the person 'waking up'. However after ICU these families often start to report feeling they are not told enough. Additionally some families feel from the start they are 'not told anything'. This leads to an increased reliance on other ways to take in information. Observation of the ward, injured family member and staff members is complemented by reading sources and asking questions. Additionally hoping for progress and thinking spiritually are selected as 'mind sets'. Those who feel involved and informed also observe and search out sources to read but feel less reliant on this.

After the person with the brain injury is out of danger there are a number of strategies which become more important. Observation is still the key way that most people seem to be building an understanding of what is happening. Additionally people appear to realise that previous experiences can be helpfully applied in the brain injury setting, for example, parenting experience to help the family member re-learn skills like reading. The person with the brain injury can also often start to communicate important information about how they feel and what would be helpful. After the initial stages there is also a shift to focusing on the future. Family members try and make sense of how their role in relation to the person has changed and will change. The future is envisioned in terms of how it

might look practically. Observation is also important here as people compare their family member pre and post injury, in ways that professionals can't, to consider how things might have changed. Family members described feeling different thoughts when thinking about the future and the two characteristics appeared to be how confident they felt with the changes in their role and how responsible they felt for their continued involvement. Those who feel they can manage the change in role and feel responsible for the person are motivated to use what they are learning to improve the situation for the person. A form of experiential learning takes place where family members 'try things out', for example giving the person a ball to squeeze to improve strength. Those who feel less confident might sit by the bedside interpreting incoming information but feeling more reliant on staff members to point out what are seeing and what they can do. Those who do not feel responsible for the person and so are less involved (Friends or distant family members) will rely more on other family members' interpretations to guide their understanding.

The desire to check interpretations is due to the still limited understanding of what the next stage is and what is being observed. Staff members are either felt to be helpful at listening to interpretations and providing information or not. Staff members who are not perceived to be helpful don't do a number of key tasks. They are perceived as not guiding initiative or are not seen to be 'doing' practical tasks themselves, for example not engaging the person. They are perceived as offering generic TBI information not personally tailored information. They are deemed to have an unsupportive bedside manner. Finally they are felt to not facilitate hope and a sense of progress. This then leads to a conflicted understanding. Within families there can also be different understandings of what is occurring for the person with the TBI and how best to respond to this. Conflicted understandings appear to lead to a number of outcomes. These are; not feeling as confident in the developing 'expertise'; an Individual or conflicting narrative of what is happening emerging; Unclear/different view of steps to progress and negative or differing perceptions of professionals competency.

The opposite can occur when professionals are felt to be helpful at listening to families' concerns. Similarly family members can share their interpretations. This leads to a more unified understanding. There is now a greater confidence the knowledge or 'expertise' that is being formed; there is a positive or shared view of steps to progress; a joint understanding of the next step and a positive perception of professionals' competency.

The process that has been described occurs over and over throughout the life time of the person with the TBI. Years after discharge from hospital the interpretations within families take precedence over interpretations with professionals. Family members' interpretations will have differed depending on what previous stages they have come through. For example if a family member felt that they were very confident in taking initiative and another didn't the former may feel they have a better understanding of what is helpful for the person. Expertise development years after the injury is increased however observation, reading, previous experience and talking to the person with the TBI are all still important strategies. Finally, given the fact that family members were interviewed at different stages throughout the injury continuum it emerged that a common process was reflecting on previous events in hindsight and using emerging 'expertise' to ground previously confusing or hard to understand comments, sights or actions.

