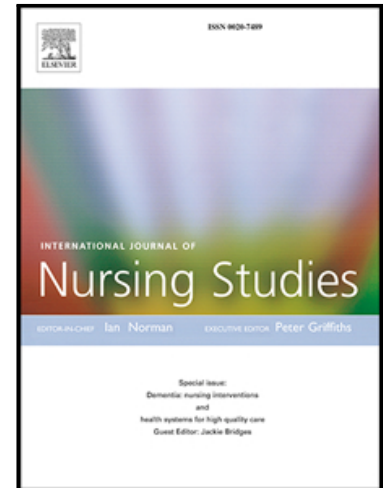


## Journal Pre-proof

The experience of families following Traumatic Brain Injury in adult populations: A meta-synthesis of narrative structures.

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PII: S0020-7489(21)00190-5  
DOI: <https://doi.org/10.1016/j.ijnurstu.2021.104043>  
Reference: NS 104043

To appear in: *International Journal of Nursing Studies*

Received date: 1 December 2020  
Revised date: 10 July 2021  
Accepted date: 15 July 2021

Please cite this article as: Charlotte Jane Whiffin RN, BA (Hons), PhD, Senior lecturer , Fergus Gracey BSc, MSc, ClinPsyD, PG Dip, PhD, Associate Professor , Caroline Ellis-Hill BSc(Hons), MSc, SROT, PhD, Senior Lecturer, The experience of families following Traumatic Brain Injury in adult populations: A meta-synthesis of narrative structures., *International Journal of Nursing Studies* (2021), doi: <https://doi.org/10.1016/j.ijnurstu.2021.104043>

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**Title:** The experience of families following Traumatic Brain Injury in adult populations: A meta-synthesis of narrative structures.

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## Abstract

**Background:** Traumatic brain injury has a significant effect on uninjured family members. Typically, this has been examined with a focus on psychopathological outcomes including stress, depression and anxiety. However, in recent years there has been increasing interest in the subjective experiences of families post-injury leading to a plethora of qualitative studies. Therefore, an in-depth examination and synthesis of this literature is now relevant and timely.

**Objective:** To examine the subjective experiences of families following traumatic brain injury in adult populations in the sub/post-acute period through the synthesis of original qualitative research.

**Design:** This paper presents a meta-

**Data Sources:** @K

data about the subjective experiences of family members of adults with traumatic brain injury and had been published in a peer reviewed journal. Studies with mixed brain injury samples, child or adolescent traumatic brain injury or disorders of consciousness were excluded. Hand searching and citation searches were also completed.

**Review methods:** Two reviewers screened titles, abstracts and full text and reached consensus through critical discussion. Thirty papers were finally agreed for inclusion in this review. Each study was then assessed for relevance, resonance and rigour using the Critical Appraisal Skills Programme (CASP) tool. Line by line coding of the findings in each paper was conducted as the basis for a thematic analysis and synthesis.

**Results:** Descriptive themes were identified followed later by analytical themes. This final stage was informed by a narrative lens and from these, eight narrative functions belonging to four dimensions were identified from the subjective experiences of families post-traumatic brain injury. Specifically, these were: (1) Displacing and Anchoring; (2) Rupturing and Stabilising; (3) Isolating and Connecting; (4) Harming and Healing.

**Conclusions:** The interpretation of the narrative functions revealed the substantial existential work involved in negotiating lives, maintaining family system equilibrium and moving forward. As such, family members have their own unique narrative needs. Despite contemporary service models built around the injured person, service providers are well placed to support families in this everyday narrative work through actively attending to narrative structures and understanding the implications of these for family experience.

The study protocol was registered with PROSPERO (International prospective register of systematic reviews) in July 2018 (Registration number: CRD42018085824).

**What is already known about the topic?**

Traumatic brain injury has a significant effect on uninjured family members traditionally examined through measures of stress, depression, anxiety and reduced quality of life. More recently there is increasing interest in the subjective experiences of families and the importance of family context post-injury. Given the increasing number of qualitative publications a meta-synthesis of family subjective experiences post-TBI is relevant and timely.

**What this paper adds**

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negotiate their lives following traumatic brain injury. This synthesis provides insight into how families make sense of their own lives post-injury and revealed their unique narrative needs which extend beyond those of the injured person. This synthesis challenges contemporary service models, built around the needs of the injured person, and asks service providers to engage in narratives in a way that may help family members come to understand and make sense of what they have been through.

**Key words**

Head injury  
Traumatic brain injury  
Family  
Qualitative  
Meta-synthesis  
Narrative

**140 character tweetable summary**

This synthesis showed the immense and invisible work required for family members to maintain family system equilibrium and negotiate their lives post-TBI.

## 1. Background

Traumatic Brain Injury (TBI) is a global health concern (World Health Organisation, 2017) affecting millions of people each year and is considered the leading cause of disability for those under the age of 40 years (Teasdale, 1995, Seeley et al., 2006, Fleminger and Ponsford, 2005). Traumatic Brain Injury has a significant effect on family relationships, lifestyles and quality of life (Verhaeghe et al., 2005). Uninjured family members have been identified as at-risk of developing depression, stress and anxiety (Perlesz et al., 2000, Riley et al., 2019, Riley, 2007, Rivera et al., 2008, Harris et al., 2001). It is not the physical demands of caring that causes the greatest burden but trying to live with changes in personality, behaviour and cognition (Blake, 2008, Connolly and O'Dowd, 2001, Jackson et al., 2009, Perlesz et al., 2000, Ponsford et al., 2003, Wells et al., 2005, Harris et al., 2001). Poor family functioning has been associated with emotional distress such as anxiety, depression and increased strain (Anderson et al., 2002, Gan et al., 2006, Ponsford et al., 2003, Ponsford and Schonberger, 2010, Sander et al., 2002).

Family experiences have been examined (Couchman et al., 2014, Jumisko et al., 2007, Whiffin et al., 2015, Whiffin et al., 2019, Yeates et al., 2007) showing how subjective changes experienced by family members are important in understanding recovery and rehabilitation for the whole family. This is from the initial impact of the injury often for many years afterwards when formal support opportunities may have diminished. Despite two literature reviews calling for a more in-depth understanding of the process and patterns of family adaptation following TBI (Verhaeghe et al., 2005, Perlesz et al., 1999) there have been no meta-syntheses to enhance our understanding of these complex processes following TBI in adult populations and especially how they evolve over the sub-acute / post-acute period. Subsequently, a meta-synthesis was used to address the following aim: *to increase understanding of the subjective experiences of families following TBI in adult populations in the sub/post-acute period.*

## 2. Methods

The study protocol was registered with PROSPERO (International prospective register of systematic reviews) in July 2018 (Registration number: CRD42018085824).

### 2.1 Synthesis Methodology

The synthesis was informed by Thomas and Harden (2008) rooted in a critical realist philosophy (Tong et al., 2012). We applied a narrative lens to the synthesis process (Webster and Mertova, 2007), building on the theoretical developments of the authors (Whiffin et al., 2015, Whiffin et al., 2019). This synthesis was a careful exercise that analysed each study in detail while also preserving its integrity (Sandelowski et al., 1997).

### 2.2 Search strategies and paper identification

Search terms for pre-  
The initial search strategy was developed for MEDLINE (see Table One) and adapted for The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complementary Medicine Database (AMED), PubMed and PsychINFO. A final search was conducted in July 2019. All searches were conducted from database inception with the following limits: English language and peer-reviewed research. Complementary searching included a search of reference lists of included studies and hand searching of *Brain Injury, Neuropsychological Rehabilitation* and *Journal of Head Trauma Rehabilitation*. ResearchGate and Google Scholar were also searched.

[Insert Table 1]

## 2.4 Eligibility Criteria

### 2.4.1 Inclusion

Inclusion criteria were set to ensure papers included in the synthesis were peer reviewed, primary research using qualitative methods and reported raw data that could be analysed. Mixed methods studies were included if the study published qualitative data. The aim of the paper had to examine the family experience of traumatic brain injury in adult populations and include family members in the sample. Adulthood was originally defined as 18 years or above; however, studies frequently included older adolescents who were 16 years or above. Therefore 16 years of age was used as an indicator of adult injury and used for inclusion. One study, however, had 2/13 participants who were aged 13 and were therefore below this threshold (Fumiyo et al 2009). After discussion a consensus was reached to include this paper given the relevance of the wider sample who were above the threshold for inclusion.

#### *Inclusion criteria*

Qualitative research  
 Direct quotes  
 Published in a peer reviewed journal  
 Family member of a person with TBI  
 Family related aim/question  
 Age of injured person at data collection 16 or above

### 2.4.2 Exclusion

Exclusion criteria were agreed to remove all studies using mixed acquired brain injury populations and where the outcome was unknown or where return home was unlikely such as disorders of consciousness and those still in critical care/intensive care. Studies of military personnel were also excluded because of the potential presence of PTSD and prior experience of family reintegration post-deployment. We aimed to exclude all paediatric injury; however, age at injury and age at data collection were not consistently reported. If on review the study was clearly investigating paediatric injury the study was excluded. Studies that reported on interventions without insight into the family experience were excluded as were any studies that focused solely on the individual with injury, i.e. recovery, return to work or social participation.

#### *Exclusion criteria*

Age of the injured person at data collection under 18 years  
 Family members of persons with more general brain injuries, disorders of consciousness, those still in critical care/intensive care or military personnel post-combat  
 Secondary research  
 Focus of the study was on an intervention, or more specifically on the individual with injury, i.e. recovery, return to work, social participation

## 2.3 Search Outcome

From the database searches conducted in July 2019 1783 papers were identified for review and 16 papers were identified from the complementary searches. A total of 1799 were then independently screened by CW and FG first by title and abstract and then by full text against the eligibility criteria. Consensus for eligibility was reached through critical discussion between CW and FG leading to the final selection of thirty papers (see Figure One).

[Insert Figure 1]

## 2.4 Quality Assessment

Methods for quality assessment of papers included in a meta-synthesis remains contested (Garside, 2014). Some argue structured critical appraisal has little value (Dixon-Woods, 2004) others consider it essential (Carroll et al., 2013). The Cochrane collaboration recommend the Critical Appraisal Skills Programme (CASP) (Noyes et al., 2019) others prefer broader criteria relating to acceptability of methods, epistemology, the use of theory, and relevance to the review question (Popay, 2005, Murphy et al., 1998, Salter et al., 2008). In this meta-synthesis we developed a combined approach centring on three criteria: relevance, resonance and rigour. Relevance was evaluated based on the primary research question and the participants in the study. Resonance was judged based on the content, style, scope and communicative power of the study findings. Rigour was appraised through the use of the CASP tool and formal scoring system reported by Duggleby et al. (2010). In this scoring system eight of the ten questions are given a score of one (weak: little to no justification on a specific point), two (moderate: authors do not fully elaborate) or three (strong: extensive justification and explanation). No paper was excluded based on this discussion. To reflect the outcome of these critical discussions around relevance, resonance and rigour each paper was

*Core, Central or Peripheral* u u

[Insert Table 2]

## 2.5 Thematic synthesis

Data extraction was completed by CW and checked by FG (Table Three). Then, we returned to the

### 2.5.1 Stages one and two: coding text and developing descriptive themes

CW read the findings of each paper several times, and made entries in a reflective diary. Semantic and latent codes were applied to papers line by line using NVivo Software. Papers categorised as # papers and further codes identified. Finally, peripheral papers were coded where very few new codes were required; a point indicative of saturation. Codes were continually expanded and contracted to develop higher order descriptive themes.

### 2.5.2 Stage three: generating analytical themes

The generation of analytical themes was an inductive process. Descriptive themes were discussed between first and second authors and possible interpretations explored. It was essential that we understood our own philosophical positions and our narrative lens significantly influenced these discussions. These narrative structures prioritise sequence and consequence (Riessman and Quinney, 2005). This temporality helps to make sense of life before, life now and life after critical life events. Following this analytical process, the themes identified were positioned as dimensions. This narrative interpretation was then critically explored with the third author (CEH) as a sense-check of meaningful interpretation. Prior to publication the search was re-run applying the same criteria for selection to identify any new publications in the field pertinent to the metasynthesis. In June 2021 five additional papers were identified (Chhuom and Thompson, 2021, Stenberg et al., 2020, Kreitzer et al., 2020, Grayson et al., 2021, O'Keeffe et al., 2020). Data were extracted, a CASP appraisal completed and each paper categorised as core, (n=2, O'Keeffe et al. (2020), Stenberg et al. (2020)), central (n=1, Grayson et al. (2021)) and peripheral (n=2, Chhuom and Thompson (2021), Kreitzer et al. (2020)). While these studies may have offered further insight into the family experience of TBI they broadly supported the findings of the original synthesis and are not reported in this synthesis.

## 2.6 Trustworthiness

There are four domains associated with trustworthiness in qualitative research: credibility, dependability, transferability and confirmability (Lincoln and Guba, 1985). To achieve credibility

traditional methods such as member checking, prolonged engagements and persistent observation are not possible in a meta-synthesis. However, we did use a large sample, we engaged in an immersive analysis aided by critical reflexivity, used peer debriefing and explored interpretation with a third author. Dependability was ensured through procedural rigour by developing a robust, repeatable and transparent approach to systematic searching, appraisal and analysis. Transferability of the findings is made possible through the thick description and rich detailed quotes presented. These are accompanied with contextual information about which family member provided each quote. Lastly confirmability is achieved when findings are clearly derived from the data and when credibility, transferability and dependability are all achieved (Lincoln and Guba, 1985.). In this [Webster and Mertova, 2007](#)) aided by the detailed analysis and transparent reporting of all theoretical, methodological, and analytical choices ([Nowell et al., 2017](#)).

### 3. Results

#### 3.1 Characteristics of included studies

Only three papers pre-dated 2000, there were 10 between 2000 and 2009 and 17 between 2010 and 2019. Papers originated from the US (n=13), UK (n=6), Australia (n=4), Canada (n=3), Sweden (n=2), Japan (n=1) and South Africa (n=1). Methodologically, papers used generic qualitative designs (n=7), grounded theory (n=6), interpretative phenomenology (n=3), Interpretive Phenomenological Analysis (IPA) (n=2), narrative (n=3), descriptive phenomenology (n=3), surveys/questionnaires (n=2) participatory (n=2), descriptive interpretive (n=1) and mixed method (n=1). As would be expected most studies used individual interviews (n=23) or focus groups (n=3). However, three studies used a qualitative analysis on open questions in a survey and one used existing narratives in the public domain.

Uninjured participants were mostly female (n=633) versus male (n=212) who described experiences of injured people who were mostly male (n=542) versus female (n=139). Participants in the studies were either mixed groups of carers or close relatives and friends (n=10). Studies with specific family members included spouses/romantic partners (n=6), wives and female partners (n=3), mothers (n=6), mothers and fathers (n=2), siblings (n=2) or adult children (n=1). The severity of injury was commonly unreported in studies (n=10). Those that did report injury severity were either mixed mild severe (n=3) or moderate severe (n=8); or severe (n=9). Length of time since injury across all papers ranged from one month to 27 years. Following appraisal, 17 papers were categorised as *core*, seven as *central* and six as *peripheral* (please note, several papers report on the same participants therefore characteristics should be interpreted with caution).

[Insert table 3]

#### 3.2 Themes and subthemes drawn from analysis

In this meta-synthesis the family experience of TBI in adult populations was seen to fall within four dimensions each containing two narrative functions which were inter-related. The final dimension captured broad notions of harming and healing within which the other narrative structures fell.

- (1) Displacing and Anchoring
- (2) Rupturing and Stabilising
- (3) Isolating and Connecting
- (4) Harming and Healing

Narrative functions were often co-existing, vacillating positions, rather than static evaluations, presenting a rich and complex interpretation. In this synthesis attention was paid to stories that are not shared as commonly as well as those that are more dominant. This allowed us to explore both thin narratives which can be limited in possibilities and thick narratives which are more complex,



nuanced and open to wider possibilities. Each dimension, and the associated narrative functions, are discussed below.

### 3.2.1 *Displacing and Anchoring narratives: Evaluation of change*

Anchoring and displacing narratives were located across all timepoints, across relationships, and moved fluidly from displacing to anchoring and back again. They were used by the family to evaluate change and the impact of TBI on their lives. Experiences that displaced family members often initiated an anchoring response, where family members actively worked to stabilise themselves and their family.

#### *Displacing*

These represented negative change and a loss of hope for the future. (Ugry Godwin et al., 2014, p.402)

... happiness with the present and the future.

Displacing narratives were sometimes triggered by healthcare professionals as family members who were forced to consider change, tempering their hope for a better future.

Displacing included explicit reference to unwelcome change whereby the injured person, themselves or their relationship was different. Often the injured person was referred to as a new person.

Difference was judged by many criteria including changes in: trust, emotional recognition, expression, control, appreciation, reciprocity, tenderness, cognition, appearance, ability, interpersonal skills, initiation, conversation, depression, tenderness and initiative. Change which could not be absorbed displaced the person from themselves, their injured relative, wider family and social network.

[Wife] ... @ ... @ ... (Bodley-Scott and Riley, 2015, p.212)

Loss of special traits, unique to the person such as humour, drive or special mannerisms and the presence of unwelcome traits such as anger were especially displacing.

Evaluation of recovery was temporal and fluid, comparisons were made to the past and future. Goals were adjusted, re-shaped, scaled up and scaled down. Family members wanted to share how the experience had changed them and their future possibly displacing their own present and future selves.

# ... @ ... @ ... @ ... @ ...  
*rationalize sometimes that I do what I do and act as I act, just to make it through life. Yes, I consider myself a survivor as well as my wife, because that is what I feel I have needed to do to make it in this n* ... (Godwin et al., 2014, p.404)

[Mother] ... @ ...  
*future...everything how we were looking forward to.. .life...on.. .you know.. .as life was going to be a completely different world to what it is now.. .and we just had to kind of like.. .all of a*

(Whiffin et al., 2015, p.855)

#### *Anchoring*

These narratives had dimensions of hope, stability and continuity. They were present in early stories of survival and recovery, anchoring the person in the present and securing their future. These were intensely positive moments as family members searched for signs of return to normal.

[Family member] ... @ ... V ... @ ...  
*put ... V ... -and she threw the facecloth. She was mad. But she knew I was there because she looked at me and it was not an empty look* ... (Keenan and Joseph, 2010, p.30)

























































<a href="#">Townsend and Norman (2018)</a> UK	How is TBI experienced by family members and friends, interconnections and consequences for the person with TBI	Interpretive Phenomenological Analysis	One semi-structured interview	9 uninjured family members, 2 friends (n=11)	9 female, 2 male	1 mother, 2 sisters, 1 brother, 2 daughters, 1 niece, 1 husband, 1 grandmother, 2 friends	no severity data	8 male, 3 female	Age at injury 14-52; Age at data collection 22-69	2-20 years	Interpretive Phenomenological Analysis (Smith & Osborn 2008)	Continuity and discontinuity: making sense of post-injury identity; Damage, loss and grief; Roles and responsibility: behaviour towards the TBI survivor; Coping and not coping	21	Core
<a href="#">Whiffin et al. (2015)</a> UK	Narrative of non-injured family members first year after head injury.	Longitudinal narrative case study	3 x unstructured in-depth interviews 1,3,12 months post injury	Uninjured family members from three families (n=9)	6 female, 3 male	2 spouses, 4 parents, 1 adult child, 2 siblings	Severe	1 male, 2 female	Age at injury and age at data collection not stated in this paper but reported in Whiffin 2017 as 19-58 (prospective study)	1-12 months	in-depth narrative analysis (Riessman 2008)	Five interwoven narratives: trauma, recovery, autobiographical, suffering and family. The narrative approach emphasized that the year post-head injury was a turbulent time for families, who were active agents in the process of change.	23	Core
<a href="#">Whiffin et al. (2019)</a> UK	Narrative structures of uninjured family members understand change	Longitudinal narrative case study	3 x unstructured in-depth interviews, 1,3,12 months post injury	Uninjured family members from three families (n=9)	6 female, 3 male	2 spouses, 4 parents, 1 adult child, 2 siblings	Severe	1 male, 2 female	Age at injury 19-58; Age at data collection 19-58	1-12 months	in-depth narrative analysis (Riessman 2008)	Biographical attendance; biographical disruption; biographical continuity; biographical reconstruction.	22	Core
<a href="#">Wongvatunyu and Porter (2005)</a> USA	Experience of mothers of young adults with TBI at least 6 months previously.	Descriptive phenomenology	Three interviews using open ended questions over two months	Uninjured Mothers (n=7)	7 female	Mothers	Moderate / Severe	5 male, 2 female	Age at injury 16-26; Age at data collection 20-36	8 months - 20 years	Descriptive analysis and intersubjective dialogue (Porter, 1998)	reconnecting my child's brain; considering my child's safety; making our lives as normal as possible; dealing with our biggest problem; advocating for my child.	19	Central
<a href="#">Wongvatunyu and Porter (2008a)</a> USA	Perceived changes in family life six months or more young	Descriptive phenomenology	Three in-depth interviews using open questions	Uninjured Mothers (n=7)	7 female	Mothers	Moderate / Severe	5 male, 2 female	Age at injury 16-26; Age at data collection 20-36	8 months - 20 years	Intersubjective Dialogue (Porter, 1995)	Getting attention from each other for different reasons now; getting along with each other since the injury; facing new financial	20	Core

	adult child TBI.											hurdles: going our separate ways down this new path; Splitting the family apart against our will.		
<u>Wongvatuny and Porter (2008b)</u> USA	Personal social context of experience of mothers young adult survivors moderate / severe TBI	Phenomenological method for describing life world	Three in-depth interviews using open questions over two months	Uninjured Mothers (n=7)	7 female	Mothers	Moderate / Severe	5 male, 2 female	Age at injury not stated in this paper, but reported in <u>Wongvatuny and Porter (2008a)</u> as 16-26; Age at data collection 20-36	8 months - 20 years	Phenomenological method for describing life-world	Having a child who survived a TBI as a young adult, perceiving that life has really changed, having sufficient support/feeling bereft of any help, believing that my child is still able, and believing that I can help my child	21	Core