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-synthesis using Thomas and Harden's framework of 'thematic synthesis' rooted in a critical realist philosophy.

Data sources: In July 2019 five electronic databases, were searched for the terms 'traumatic brain injury', 'family' and 'qualitative'. Studies were included if the primary research reported qualitative 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).

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

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What is already known

- 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

- This synthesis revealed the immense and invisible existential 'work' required for families to 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.

1. Introduction

Traumatic Brain Injury (TBI) is a global health concern (World Health Organisation, 2021) 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

This study adopted the 'thematic synthesis' framework of 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-planned searches combined 'Traumatic Brain Injury', 'Family' and 'Qualitative'. The initial search strategy was developed for MEDLINE (see Table 1) 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.* Research Gate and Google Scholar were also searched.

2.3. Eligibility criteria

2.3.1. 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

2.3.2. 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

Table 1
Medline search strategy.

S1	AB "Head Injur*" OR TI "Head Injur*"	22,951
S2	AB "Traumatic Brain Injur*" OR TI "Traumatic Brain Injur*"	32,876
S3	AB "Brain Injur*" OR TI "Brain Injur*"	60,211
S4	(MM "Brain Injuries") OR (MM "Head Injuries, Closed") OR (MM "Craniocerebral Trauma") OR (MM "Head Injuries, Penetrating")	58,952
S5	S1 OR S2 OR S3 OR S4	101,635
S6	AB Famil* OR TI Famil*	1001,154
S7	AB Parent* OR TI Parent*	384,312
S8	AB Spous* OR TI Spous*	17,580
S9	AB Sibling$ OR TI Sibling$	47,720
S10	AB Mother$ OR TI Mother$	198,797
S11	AB Father$ OR TI Father$	37,611
S12	AB (Carer$ OR Caregiver$ OR Relative$) OR TI (Carer$ OR Caregiver$ OR Relative$)	905,514
S13	(MM "Family") OR (MM "Adult Children") OR (MM "Family Relations") OR (MM "Parents") OR (MM "Siblings") OR (MM "Spouses") OR (MM "Fathers") OR (MM "Mothers")	106,309
S14	(MM "Caregivers")	22,720
S15	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	2292,079
S16	AB qualitative OR TI qualitative	204,125
S17	AB ("case stud*" OR Case-stud*) OR TI ("case stud*" OR Case-stud*)	91,783
S18	AB "grounded theory" OR TI "grounded theory"	10,513
S19	AB (phenomenology or phenomenological or lived experience) OR TI (phenomenology or phenomenological or lived experience)	26,370
S20	AB "discourse analysis" OR TI "discourse analysis"	1556
S21	AB ethnography OR TI ethnography	2355
S22	AB narrative OR TI narrative	34,366
S23	AB "content analysis" OR TI "content analysis"	24,414
S24	AB "thematic analysis" OR TI "thematic analysis"	15,178
S25	AB "Focus group*" OR TI "Focus group*"	41,384
S26	AB "constant comparison" OR TI "constant comparison"	1383
S27	AB interpretive OR TI interpretive	6901
S28	AB hermeneutic* OR TI hermeneutic$	3333
S29	(MM "Qualitative Research") OR (MM "Hermeneutics") OR (MM "Grounded Theory")	2805
S30	S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29	379,915
S31	S5 AND S15 AND S30	536
S32	(S5 AND S15 AND S30) NOT AB shaken baby syndrome NOT AB (pediatric or peadiatric) English Language	507

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

2.4. 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 Fig. 1).

2.5. 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 classified as 'Core, Central or Peripheral' (Table 2).

2.6. Thematic synthesis

Data extraction was completed by CW and checked by FG (Table 3). Then, we returned to the section headed 'findings' or 'results' to commence the analysis and thematic synthesis.
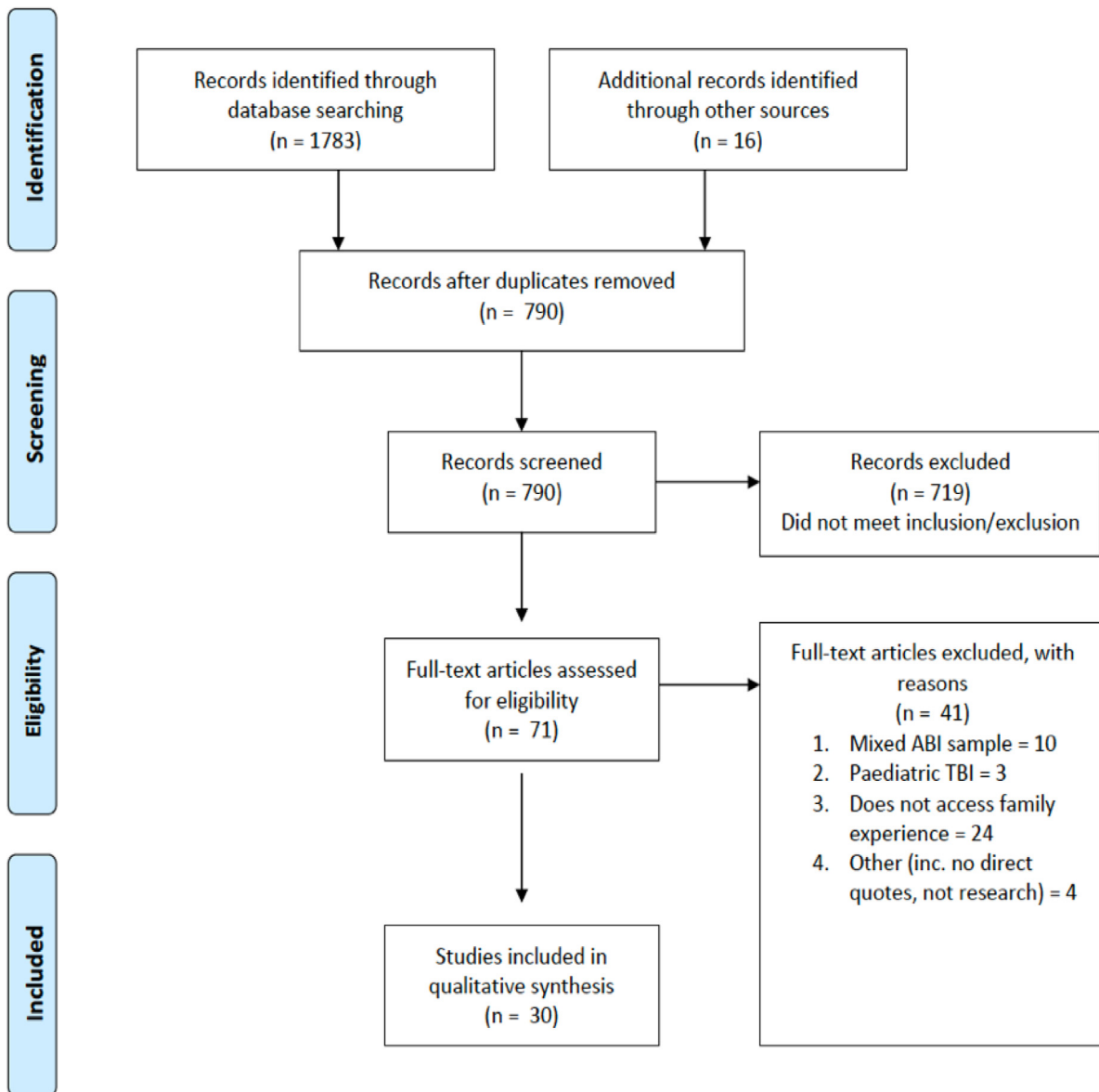
Fig. 1. PRISMA flow diagram.

Table 2
Classification of papers as core, central, peripheral.

Core	Relevance – Research question explicitly aligned to the review question
	Resonance – Findings are rich, complex and evocative and make a meaningful and insightful contribution to advancing the evidence base
	Rigour – methodologically congruent and appropriately applies qualitative methods
Central	As above but may fail to meet one or more of the criteria in its fullest sense.
Peripheral	Relevance – Research findings relevant but research question not completely aligned to the meta-synthesis question
	Resonance – Findings superficial, thin or expected, do not advance the evidence base in a meaningful way
	Rigour – There may be questions about the methodological congruence of the study and if methods were appropriately applied

2.6.1. 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 'core' were coded first to establish a coding book. Codes were then applied to 'central' 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.

2.6.2. 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 dimen-

Table 3
Data Extraction.

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Acorn and Roberts (1992) CAN	Determine needs of family and assess availability, use and helpfulness of support groups in meeting needs.	Questionnaire	Open ended responses within a question-naire	Uninjured wives caring for a husband (n = 12)	12 Female	Wives	Not stated	12 male	Age at injury not given. Age at data collection: 6, were 46 and over; 4, were 36–45; 2, were 26–35)	1–17 years	latent content analysis	Role change, emotional impact of the injury, the concept of hope and the need for support.	13	Peripheral
Bodley-Scott and Riley (2015) UK	Explore social, behavioural and emotional changes experienced by partners of persons with TBI. Explore emotional and relationship impact	Interpretive Phenomenological Analysis	Two flexible interviews one-three weeks apart	Uninjured cohabiting partners (n = 5)	5 female	Partners	Moderate/ Severe	5 male	Age at injury: 24–39.5 years. Age at data collection: 29 −42	9 months - 7 years	Interpretive Phenomenological Analysis (Smith et al. 2009)	Emotional Impact (Direct emotional impact; Identity change; Managing the changes) Impact on the relationship (Feeling Love; Receiving Love)	23	Core
Carson (1993) USA	Describe parent's experience following a brain-injured child's return home	Grounded Theory	Interviews and follow-up interviews with three (3 instruments also used to collect quantitative data)	Parents and brain injured off spring from 20 families (total n=not given)	Gender not reported	Parents	moderate/ Severe	41% female (n = not given)	Age at injury not given: Age at data collection 17 - 35	8–70 months	Constant Comparison	Theory: Investing in the comeback - describe the parent's work after brain-injured son or daughter returns to the home setting. Three phases: centring on; fostering independence; seeking stability	15	Central
Degeneffe and Olney (2008) USA	Comprehensive and contextual understanding of sibling future concerns	Grounded Theory	Postal survey open question	Uninjured adult siblings (n = 280)	Reported as 201 female; 78 male	Siblings	No severity data	186 male; 93 female	Age at injury not reported: Age at data collection: Mean 36.73	1–47 years	Constant Comparison (Denzin & Lincoln 1994)	Recovery; future caregiver; independence; professional care; relationships and family; safety; advocacy; substance abuse	17	Peripheral

(Continued on next page)

Table 3 (Continued).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Degeneffe and Olney (2010) USA	How the lives of adult siblings of persons with TBI, are different since the injury	Survey	Five open ended questions	Uninjured adult siblings from 201 families (n = 272)	195 female; 76 male (one participant did not report gender)	Siblings	No severity data	179 male (female n=not given)	Not stated but average age of uninjured sibling 25.2 years old when sibling was injured. Mean age difference 4.9 years.	at least 6 months	Constant Comparison (Denzin & Lincoln 1994)	Family (Family impact of the TBI, closeness and growing up); Caring (Caring for and caring about the family member with TBI); Making sense of the experience (personal development; grieving; existential change; psychological distress; guilt)	19	Core
Engström and Söderberg (2011) Sweden	Transitions as experienced by the close relatives of people with TBI	Descriptive Interpretive method	One semi-structured interview	5 close relatives	5 female	1 sister, 1 wife, 3 mothers	No severity data	4 Male, 1 female	Age at injury not given; age at data collection 36–76	10–26 years	Interpretive descriptive analysis (Thorne, Kirkham & Mac Donald-Emes 1997)	Transitions: Starting point; pattern of Daily life; Transitions in Relationships (all family relationships had changed); Social Life	18	Peripheral
Fumiyo et al. (2009) Japan	Psychosocial process followed by mothers caring for young sons with TBI within 5 years of injury	Qualitative, descriptive, inductive	One semi-structured interview	13 mothers	13 female	Mothers	no severity data	13 male	Age at injury: approximately 13–29 (2 were 13, 1 was 17, 1 was 16): Age at data collection 15–30	11 months - 3 years and 5 months	Modified grounded theory (Kinoshita, 2003)	Five stages" Avoidance; Closed; Support seeking; withdrawal; reconstruction	20	Peripheral
Gill et al. (2011) USA	Lived experiences of couples regarding TBI and intimate relationships	Open grounded theory	One individual open ended in-depth semi-structured interview	18 couples, injured person and intimate partner (n = 36)	13 female; 5 male	Partners	No severity data	12 male, 6 female	Age at injury not given. Age at data collection: 21–59;	0.55–25 years	Grounded theory analysis (Patton 2001, Jeon 2004)	Barriers to intimate relationships; Factors related to relationship strength	21	Core
Godwin et al. (2014) USA	Framework for conceptualizing and assessing couples after TBI	Grounded Theory	Existing personal narratives written by survivors of TBI and/or their romantic partners and clinician-authored literature.	Consumer authored documents (29 blogs, 5 reported narratives, 6 memoirs) 35 by injured/uninjured 5 clinician authored (n = 40)	Not reported	Partners	No severity data	Not reported	Age at data collection: Not specified. Age at injury not specified. but old enough to have a romantic partner	Not specified	Constant Comparison (Corbin & Strauss)	Five primary themes: Ambiguous Losses, Identity Reformations, Tenuous Stability, Non Omnes Moriar and The New Us. Two grounded theories: Relational Coring and Relational Recycling.	20	Core

Table 3 (*Continued*).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Gosling and Oddy (1999) UK	Sexual relationships following head injury view non-injured spouse	Mixed Methods	One semi-structured interview	Uninjured partners in heterosexual relationships for at least 3 years prior to injury (n = 18)	18 female	Partners	Severe	18 male	Age at injury not reported: Age at data collection: Mean 42.1	1–7 years	Grouped into categories then examined for shared themes (Henwood & Pidgeon (1995) Grounded theory	Role change; Partners' perceptions of patients' feelings; Relationship changes; positive aspects of the relationship; The future; Other concerns	14	Peripheral
Hammond et al. (2011) USA	Experiences spouses residing with individuals living with TBI	Qualitative	Focus groups (two groups)	Uninjured spouses (n = 10)	5 female,5 male	Spouses	mild-severe	Not reported	Age at injury not reported; Age at data collection not reported but old enough to be married	6–12 years	Constructivist approach to grounded theory (Charmaz, 2000; Glaser & Struss, 1967; Strauss & Corbin, 1990)	Staying married; temporality; spatiality; trust; communication' emotional attachment; caregiver responsibilities; financial responsibilities; reactions to added responsibilities. (Fondness/affection; glorifying the struggle; marital disappointment/disillusionment; negativity toward spouse; We-ness versus separateness; Chaotic relationships; Volatility of the relationship; Gender role stereotypes)	22	Core
Hammond et al. (2012) USA	Experience of irritability in family system perspective people with TBI and spouses	Participatory Research	Focus groups (5 different groups met 10 times each)	10 Uninjured, 16 injured persons (n = 26) subset of larger study including 2 parents, 13 healthcare professionals, 8 facilitators/observers/ researchers (n = 44, Some participants represented more than one role)	7 female, 3 male	Spouses	mild-severe	12 male, 4 female	Age at injury not reported: Age at data collection: 18–66	2–16 years	Constructivist approach to grounded theory (Charmaz, 2000; Glaser & Struss, 1967; Strauss & Corbin, 1990)	Irritability breeds further irritability; spousal reactions can trigger irritability amongst persons with TBI; Difficulties making emotional connections may incite irritability and negative spousal interactions; communication breakdowns may exist that provoke irritability; Expectations of others (real or perceived and spoke or unspoken) may contribute to irritable behaviours.	22	Core

Table 3 (*Continued*).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
D. Harris and Stuart (2006) South Africa	Experience adolescents brain injured parent, framework of existential-phenomenological methodology.	Existential Phenomenology	One non-structured/semi structured Interview	Uninjured children (17–19) living with and able to remember their father pre-injury (n = 4)	2 female, 2 male	Children	Severe	4 male	Age at injury not stated; age at data collection not stated (old enough to have adolescent children)	1.5–7 years	Phenomenological Analysis (Byrne, 2001; Kleiman, 2004)	Shock & fright; Coping and adaptation; Religion; Positive meaning-making; Lack of information provided; Worry and anxiety about family and parentification; loneliness and isolation of themselves and the family; Changes in family relationships; Changes in self; The role of culture and ethnicity.	17	Peripheral
Jumisko et al. (2007) Sweden	Close relatives' experiences living with person with moderate or severe TBI.	Phenomenological hermeneutic method	One qualitative research interview	8 uninjured close relatives, 12 injured persons (n = 20)	7 female, 1 male	2 mothers, 1 father, 2 partners, 2 siblings and 1 daughter	Moderate/ Severe	10 male, 2 female	Age at injury not stated; Age at data collection 23–50	4–13 years	Phenomenological hermeneutic interpretation (Ricoeur 1976).	Trying not to lose one's foothold. Subthemes: Getting into the unknown; Becoming acquainted with the changed person; Being constantly available; Missing someone with whom to share the burden; Struggling to be met with dignity; Seeing a light in the darkness	21	Core
Kao and Stuifbergen (2004) USA	Experience of relationship young adult TBI survivors and their mothers.	Phenomenology (Van Mannen 1990)	One individual semi-structured Interview	12 Mother-adult child pairs (n = 24)	12 female	Mothers	Severe	9 male, 3 female	Age at injury not stated: Age at data collection 18–25	2–11 years	Phenomenological analysis (Colaizzi 1978)	The sense of abnormality; The period of uncertainty; Mother-Child relationship Themes (Dependence and autonomy; Marital menace; Maintain harmony); The interaction between TBI and Family relationship	22	Central

Table 3 (Continued).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Keenan and Joseph (2010) CAN	Needs of individual family members severe TBI do needs change over time.	Qualitative	Two semi-structured interviews, 1st within 4 days of transfer out of ICU, 2nd within one week of discharge	Uninjured family members (Interview_1 $n = 25$; Interview_2: $n = 19$	21 female, 4 male (interview 1); 15 female, 4 male (interview 2)	9 mothers, 3 fathers, 5 wives, 4 sisters, 3 girlfriends, 1 brother (interview 1); 5 mothers, 3 fathers, 4 wives, 3 sisters, 3 girlfriends, 1 brother (interview 2)	Severe	14 male, 1 female	Age at injury 17–58; Age at data collection 17–58	Not stated but interviews completed within 4 days of transfer from ICU	Thematic Analysis (Braun & Clarke)	Trajectory of family experience: getting the news; uncertainty about the prognosis; making sense of the news and moving on. Needs of family members: involvement in care; looking for progress; managing life and holding on to hope. How family members lived the experience was influenced by: support; information; professional support and community support	21	Core
Knox et al. (2015) Australia	Perspective spouses severe TBI and initial model, support partners with decision-making	constructivist grounded theory	Two in-depth interviews	Uninjured cohabiting spouses (three heterosexual, one same sex) relationship length at least four years. Three couples commenced relationship after TBI was sustained ($n = 4$)	1 female, 3 male	Spouses	Severe	2 male, 2 female	Age at injury 29–38; Age at data collection 42–47	8 - 19 years	Constant Comparison	Features of the spousal relationship in decision making: Understanding the functional implications of the brain injury on their partner; Seeing the person in a positive light; being committed to the relationship; Finding a way to communicate; Learning from experience. The process of decision making: Stage 1. Remaining vigilant to decision-making opportunities; Stage 2. Recognising and initiating a decision point; Stage 3. Evaluating involvement; Taking action; Stage 4. Living with the outcome; Stage 5. Reflecting on the process.	20	Central

Table 3 (Continued).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Knox et al. (2016) Australia	Shared meaning adults with TBI and parents decisions about life	constructivist grounded theory	Two-three unstruc-tured interviews (broad topic guide) 18 in total	4 uninjured parent and 4 Injured adult children dyads (n = 8)	3 female; 1 male	3 mothers, 1 father	Severe	3 male, 1 female	Age at injury not stated; Age at data collection 27–47;	7–17 years	Charmaz 2006, Corbin & Strauss 2008	A guiding construct of reimagining the future: (1) making decisions with parental support, and (2) reducing parental involvement	23	Core
Kratz et al. (2017) USA	Parent and partner moderate or severe TBI describe their quality of life	Qualitative	Focus groups (nine separate groups)	Uninjured caregivers (n = 52)	40 female, 12 male	31 parents (8 fathers, 23 mothers); 21 partners (4 husbands, 17 wives)	Moderate/ Severe	Not reported	Age at injury not given; age at data collection 23–75	at least 1 year (less than 28 months = 3; 18 months to 3 years = 10; over 3 years = 39)	thematic content analysis (Braun & Clarke)	(1) Caregiver Role Demands, reflecting how new responsibilities post-TBI affect the caregiver; and (2) Changes in the Person with TBI, reflecting how changes in the person with TBI affect the caregiver	20	Core
Layman et al. (2005) USA	'Insider' perspectives of older couples impacted by TBI,	Participatory Action Research	One individual semi-structured interview	7 uninjured partners, 8 injured persons, 6 control individuals (n = 21)	2 female, 5 male	7 Partners	Mild-severe	3 male, 5 female	Age at injury not given; age at data collection 62 - 84	3–21 years	Qualitative content analysis (Downe-Wamboldt 1992)	Relatedness (interpersonal communication, dependence, role changes, sexual intimacy and inter-personal support); Relationship persistence (critical incidents, reasons given for staying in the relationship and references to love)	18	Core
Lefebvre et al. (2008) CAN	'Victims' long-term social integration (10 years post-trauma) contribution services received TBI victims and family caregivers.	Qualitative study design	One individual semi-structured interviews	21 uninjured caregivers, 22 injured persons (n = 43)	12 female, 9 male	6 father or mother, 2 child, 1 sibling, 4 spouse, 4 common-law spouse, 2 friends, 1 ex-spouse	Moderate/ Severe	15 male, 7 female	Age at injury not given: Mean age at data collection 42.4 (30–39 45.5%; 40–49 36.4% 50–59 9%; 60 and over 9%)	Mean 12.8 years	Thematic Content Analysis (Paterson et al.)	Support from relative is key to social integration. Support role is exacting, making daily life difficult. Specific family caregiver impacts: balancing work and caregiving; profound impact on family relationships some positives but usually negative; 'enormous amount of energy required' also time, effort, 'years of daily interventions', 'need to believe in the process'; stress, financial burden, dependence of injured person, worry, family break up, lack of re-sources/services.	17	Central

Table 3 (Continued).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Mäkelä (2017) UK	Personal and intersubjective understandings identity, within family and neurorehabilitation clinicians	Narrative case study	Dyadic narrative interview	uninjured mother and Injured adult child dyad (n = 2)	1 female	Mother	No severity data	1 male	Age at injury not stated; age at interview 19.	several months prior to interview	inductive and holistic	Personal and intersubjective understanding of identity loss. Conflicting family interactions and normative neurorehabilitation clinicians. Mother describes not living the life she had anticipated. Recovery takes place within the system of the whole family. Family interactions: portrays the work that she undertook along with other family members; maintaining 'mother identity'; negotiating balance between support and control.	16	Central
Nalder et al. (2012) Australia	Experiences of family caregivers transition hospital to home, first six months	Qualitative interpretivist paradigm (part of a larger mixed methods study)	One semi-Structured Interview (4 face to face 6 telephone)	Uninured family caregivers (n = 10)	10 female	6 spouses, 3 parent, 1 ex-partner	No severity data	10 male	Age at injury not stated; Age at data collection 18–55	7–12 months after re-entering community	Thematic framework approach (Ritchie and Lewis, 2003)	Wanting to Move Past the Injury; the weight of care responsibility; Wanting Normality for the Individual with TBI	21	Core
Tam et al. (2015) Australia	Experience of family caregivers challenging behaviours and strategies used	Qualitative study design	One semi-structured interview (3 open questions)	Uninjured family caregivers (n = 6)	6 female	4 mothers, 1 wife, 1 sister	Severe	5 male, 1 female	Age at injury 7–34; Age at data collection 28–43	9–23 years	Thematic Analysis (Braun & Clarke)	Families' reflections on the changes they find challenging; Impact of challenging behaviours on participation; Family experience; Family strategies	16	Central
Townshend and Norman (2018) UK	How is TBI experienced family members and friends, interconnections and consequences person 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

Table 3 (Continued).

Author, Year, Country	Research aim	Methodology/ Research design	Qualitative data collection	Study participants (n=)	sex of uninjured participants	Relationship to injured person	TBI severity	Gender of injured person	Age of injured person at injury; Age at data collection	Time since injury	Data analysis	Findings	CASP Score	Relevance to synthesis
Whiffin et al. (2015) UK	Narratives 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
Whiffin et al. (2019) UK	Narrative structures uninjured family membes 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. "narrative misalignment"	22	Core
Wongvatunyu and Porter (2005) USA	Experience of mothers of young adults 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 inter-subjective 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
Wongvatunyu and Porter (2008a) USA	Perceived changes mothers in family life six months or more young adult child TBI.	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 hurdles; going our separate ways down this new path; Splitting the family apart against our will.	20	Core
Wongvatunyu and Porter (2008b) USA	Ppersonal–social context o 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 Wongvatunyu and Porter (2008a) as 16–26; Age at data collection 20–36	8 months - 20 years	Porter's (1995) 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

sions. 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). For each of these new papers we extracted and tabulated the data and, following critical appraisal, categorised each paper 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 and 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.

2.7. 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 regard, we ensured that our findings were 'well-grounded' and 'supportable' (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).

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, instability, fracture and 'loss of You, Me, Us' (Godwin et al., 2014, p.402). Shattering of temporality was important in these narratives, an aching desire to 'go back' represented an overwhelming sense of unhappiness 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] – *"I lost my husband the day he had the accident because [partner] is not my husband; he's just somebody I have to care for now"* (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.

[Caregiver] *"I've changed, and even to this day, I find myself not liking who I've become. I 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 new life"* (Godwin et al., 2014, p.404)

[Mother] *".. .I said yeah because.. .it's completely changed.. .everything.. .how it was.. .your future…everything how we were looking forward to.. .life…on.. .you know.. .as life was going to be a completely different world to what it is now.. .and we just had to kind of like.. .all of a sudden go.. .it's like a bump [slaps hands]… stop.. .and then it's like…this pond of ripples"* (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] *"she was pulling at her tubes and I told her "No, take my face cloth" and I put it in her hand and she said, "No" – that's the very first word she said-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 – it was very lively"* (Keenan and Joseph, 2010, p.30)

Anchoring narratives appeared to absorb change in a way that enabled stability and continuity despite change. Anchoring narratives were also told to help family members create a positive representation of the future.

[Wife] *"Still I believe my husband—the gentle human being I married—exists in the body of this stranger and in some rare moments, he shows himself just for a few seconds to give us a hug & say he loves us … This makes it all better so we love him back and go on"* (Godwin et al., 2014, p.407)

Vigilant monitoring of special traits took place and when these traits were anchored in the present, change was absorbed as the 'essence' of the person was preserved.

[Mother] *"He's still my baby. He still has the same thoughts and the same wants. He still jokes, and he still kids around […] As long as he's still the same sweet person he was before, the physical part doesn't bother me"* (Wongvatunyu and Porter, 2008, p.1065)

Family members actively worked to develop these anchoring narratives.

[Mother] *"I couldn't accept that. I knew in the back of my mind that it was true. But I felt like if I truly accepted that, I would treat her differently, and she wouldn't get any better."* (Wongvatunyu and Porter, 2008, p.1065)

Family members were also actively involved in anchoring their own sense of self;

[Wife] *I want to play golf again. I want to go back to the way things were* (Fumiyo et al., 2009, p.284)

3.2.2. Rupturing and stabilising narratives: balancing family life

These narratives were told about everyday family life and the equilibrium of this system. Rupturing narratives included difficulties in the family; stabilising narratives included the work involved in a reducing conflict, bringing harmony and sustaining or redefining relationships. Stabilising narratives took time, effort and patience, and when these ran out, they could transform into rupturing narratives. Necessary changes in roles could also bring about ruptures in family life. These narratives coexisted and moved fluidly between helpful and unhelpful functions.

Rupturing

Rupturing narratives described the bickering, fights, distress, agitation, physical and verbal aggression, irritability and selfishness which families had to learn to manage. Family members felt they were treading on eggshells, had a heightened sense of vigilance and were desperate to avoid confrontation. Partners were seen to be hurt more than parents, but the impact was acutely felt by all.

[Sibling] *"he is difficult to be around. Often he says things that are very hurtful and without thought to create 'bad feelings' within the family"*(Degeneffe and Olney, 2010, p1421)

Anger had a strong presence both internally within the family system, and expressed towards those externally including friends, community members and care services. Present alongside it were other emotions such as blame and guilt, frustration and anxiety. In highly charged situations behaviours were mirrored, '[I] snap right back' (Hammond et al., 2012 p.1290), and family members found themselves ashamed and confused.

The consequences of role re-assignment shifted the balance of the family system and could further destabilise it. Undertaking the role of a carer was one such shift within the family system that was given significant attention.

[Wife] *"I was never a parent before with him. Now I feel like a parent. And that creates tension, because he doesn't like it"* (Kratz et al., 2017, p.29)

For some, the cumulative effect of the rupturing narrative made it impossible for families to stay together.

Stabilising

There was a great deal of work to be done to bring stability to the family as members fought 'not to lose their foothold' (Jumisko et al., 2007). Family members needed to work towards a new rhythm and actively reassigned roles and responsibilities within the family. The return of equilibrium to a system in turmoil took a great deal of effort and was described as a journey.

[Wife]*"It's like living with another person in your marriage. Only the name of that person is TBI. And you kind of have to figure out how you're going to live—how the three of you are going to live together"* (Kratz et al., 2017, p.27)

New responsibilities ranged from being a personal assistant, chauffeur, nurse, medic, advocate, gardener, domestic, therapist, guardian, family mediator, teacher, friend, parent and carer.

[Wife] *You know, you do everything. I mean EVERYTHING with the big "E"* (Kratz et al., 2017, p.24)

Family members were actively involved in evaluating and minimising risk. Harm came in many forms, physical, sexual, emotional, financial and family members had to steer a course through the many threats they faced. Active strategies to reduce risk included helping to maintain relationships, committing to not arguing, modifying the environment, allowing more time to communicate, reducing distractions and sensory overload and managing fatigue. Family members also reported the importance of time apart.

Keeping the family together was described through enduring love, a fear of social repercussions or a 'principled stance against separation' (Layman et al., 2005). Other reasons to maintain the family equilibrium were less romantic citing social or financial constraints.

3.2.3. Isolating and connecting narratives: the space between

These narratives were told about 'the space between'. This metaphorical and physical space between family members and those both internal and external to the family served to either bring people together or push them away. Connecting narratives explained how and why family members felt closer. Isolating narratives emphasised the growing chasm between their lives.

Isolating

In isolating narratives, the acute sense of loneliness and isolation was palpable. Losing a partner in which to confide, losing a close sibling relationship, losing the support of a social network, dealing with hidden disabilities and not being understood served to compound these feelings. Spouses described being married but living alone.

[Wife] *"the one person in the word that you have always turned to for support and to give you what you needed, to hug you and say it's going to be alright – is not able to give you that anymore. So there's a sense of aloneness that starts to manifest itself in everything that you do"* (Hammond et al., 2012, p.1290)

Sex with someone who seemed different felt unsettling and one woman felt close to being raped. Lack of sex and physical affection caused isolation in marriages. However, the loss of intimacy, companionship, reciprocity and tenderness between spouses was felt most acutely.

[Female partner] *"In the early days, I don't think I'd have said I loved him. I think to be honest I think I really felt sorry for him. There wasn't really much love there"* (Bodley-Scott and Riley, 2015, p.212)

Immersion and unquestionable commitment were all consuming and in moving closer, both spatially and emotionally, to one family member meant there was a consequence for other family members which created more distance. Family members felt isolated from themselves and their relationship, not living the life they expected or being able to retain important relationship traits.

[Female partner] *"Doing things as a family had been a central part of Lisa's life* before *the injury, and she was saddened by her partner's reluctance to join in anymore […] It's like that spontaneity, that's all gone. That's just – that's not there anymore. And I really miss that"* (Bodley-Scott and Riley, 2015, p.210)

Outsiders to brain injury were seen as unable to understand or comprehend. Even the injured person was thought to be unable to fully comprehend the experiences of the uninjured members. These encounters only served to isolate them further from their family and social network.

[Adult daughter] *"…So I think that was quite horrible for Suzanne and then these changes in temper and mood and short fuses that she's told me about… if no one else witnesses it or…no one else sees it …that must be pretty tough …"*(Whiffin et al., 2019, p.1282)

Even professionals were seen as lacking insight and understanding which also left family members feeling like they were on their own.

[Close relative] *"[T]hey don't listen to us who are close to her and know what she needs . . . they must investigate here and there to see if she needs that help which she is entitled to . . . you must push and shove in order to get this help . . . it's really wrong and . . . outrageous . . . that they don't listen"* (Jumisko et al., 2007, p.361)

Being isolated from healthcare professionals meant they struggled to get the help and support they needed compounding their sense of isolation.

Connecting

Connecting narratives included commitment, family members suffered together and saw their well-being as inextricably linked. Commitment transcended injury and family members spoke of their love and appreciation for each other, helping them to feel closer. Where appreciation was present in the relationship and family members explored shared interests, they felt closer.

Acts of care, expressing the importance of their role in the recovery and positioning themselves as experts, were connecting.

[Sibling] *"under no circumstances would I not do everything I possibly could to make sure that my brother has every advantage and opportunity possible to get well and get his life back"* (Degeneffe and Olney, 2010, p.1422)

Family members were 'invested in the comeback' Carson, 1993 and through this investment shared the pride associated with recovery when it came.

[Mother] *"He just needs someone to show him how to do it. That was one of those Kodak moments, like, "Mom has tears in her eyes." So proud of my boy, throwing that ball"* (Wongvatunyu and Porter, 2008, p.1069)

After this acute need to pull inward to feel connected, family members were then positioning themselves so they could step back. Family members explored the balance between agency, autonomy and advocacy and felt torn. They asked themselves if they were they ready to let go.

[Parent] "its *really important to me to care about him and love him and be interested in what he's doing, but I need to let him make his own decisions"* (Carson, 1993, p.170)

It was also important for family members to feel connected to their own sense of self after injury. In this regard, family members talked about ways they used to feel like themselves again, to keep their own sanity, to feel like something beyond a carer and to try and make their life meaningful again.

[Mother] "*You got to have something to make you feel at least happy a little bit of the day and to laugh and revive your own* soul, *because you just get so exhausted and so overwhelmed with all the time in the hospital. And they are not happy places"* (Wongvatunyu and Porter, 2008, p.1070)

These supportive communities within and beyond the family who had empathy and insight underpinned their ability to move forward and begin to heal post TBI.

3.2.4. Harming and healing narratives: a temporary position for viewing life

Harming narratives reflected the darkness that families lived with in their lives. The inability to process their experiences in a meaningful way often meant family members were left without hope, a sense of deep sadness, and an inability to start life again. They were founded on displacing, rupturing and isolating narratives. In contrast, healing narratives were told about the 'light', the move toward meaning, sense making, hope, personal growth from tragedy and moving forward. These were fed by anchoring, stabilising and connecting narratives. Reflections changed fluidly over time between harmful and healing narratives.

Harming

First there was trauma, felt in all is rawness. Fear and helplessness left family members numb.

[Family member] *"I never experienced that physical feeling that I had and it stays with you"* (Keenan and Joseph, 2010, p.27)

Family members struggled to take it all in, to make sense of it and looked for answers no one had. The future was ambiguous,

strange and unfamiliar, as family members struggled to move past the injury and its effects.

[Caregiver] *"I have lost much of my hope in the future .. . Like [my husband] has said, "I wouldn't wish this on my worst enemy"* Godwin et al. *(2014, p.404)*

Day to day life became a habit, a ritual, something to move through without reflection, as the pain of looking forward, and back, was too great. Family members lost their hope for the future or a return to normality. Family members lost themselves and relationships were damaged.

[Wife] *"I'm just sort of…surviving…but I'm not…I don't feel I can be happy hundred per cent as I was before.. .[.. .]…but as a family… [exhale].. .yeah we feel…what's the word.. .harmed I suppose, it's scarred…mmm"* (Whiffin et al., 2015, *p.584*)

Fears for the future weighed heavily.

[Sibling] *"I fear he well never enjoy the normal pleasures in his life like working, providing for yourself, relationships with the opposite sex, marriage, sex, having children. I fear he will never be financially* independent. *I fear for his lifelong happiness"* (Degeneffe and Olney, 2008, *p.244*)

Family members felt that they could not allow themselves to collapse but living around new behaviours left family members at their 'wits end' (Tam et al., 2015).

[Family caregiver) *"Everything is just harder. Things get missed. Things don't get done any more. It's tiring; I'm tired. My body … you know I don't get to do exercise. I don't get to eat right any more hardly. I'm always sad; I am always on the verge of tears …"* (Nalder et al., 2012, *p.114*)

Lack of self-care was common as family member's' lives had been put on hold. Feeling trapped or tied, like there was no escape, limited their life and their enjoyment. Years of sacrifice left some feeling resentful and bitter.

Family members felt emotionally overwhelmed and were trying to process complex and unresolved grief which could not be easily shared with the injured person family or social networks. The trauma remained vivid and brought about intense emotional reactions for some even years after.

Healing

In contrast, healing narratives were told about sense making and how family members tried to move forward, to take something positive from living in the context of TBI and find meaning. Although the future was different from that anticipated it was now revised within the context of TBI and looking forward became less painful. The future could now be viewed with optimism and opportunity.

[Caregiver] *"Together, we rediscover something in ourselves that has been missing for a very long time:* playfulness*. I thought it had disappeared forever. Its return feels like the first glimpse of the sun's rays after a long stretch of stormy weather"* (Godwin et al., 2014, *p.408*)

Family members reported the need to feel hopeful and held on to hope. Maintaining a positive outlook was part of this, they valued words of encouragement and asked for hope not to be destroyed.

[Partner] *"There is hope! – and there are tremendous rewards for those who hang in there"* (Acorn and Roberts, 1992, *p.327*)

Family members talked specifically about their increased confidence, empathy, tolerance, maturity, determination, self-awareness, appreciation of others, psychological / personal resilience, patience, the strength of family bonds and a desire to help others. In these stories TBI was a significant event and treated as a learning experience where family members gained new and enlightened perspectives on, and a greater respect for, life.

[Sibling] *"Looking back, I do not care very much for the person I was before all of this. I was much less sensitive or understanding. I have had to establish my life all over again, as it all seemed to 'crash' along with my twin brother's accident. Since I have been so close to him, it seems that much of the recovery process applies to* me *as well as to him. I have developed more confidence about facing the 'unknown' future* (Degeneffe and Olney, 2010, *p.1423*)

Family members were faced with the fragility of life and the realisation that life is short. Drawing some positive meaning from such trauma was a way of moving forward and realising personal resilience and inner strength. They placed value in things others took for granted and talked about a deep sense of love and connection.

[Partner] *"It's been the greatest challenge of my life and it's taken almost everything I had to give, but it's been worth it. The bond between us is made of steel and will never break"* (Acorn and Roberts, 1992, *p.326*)

For some, meaning was drawn from those who reported positive change in the injured person. The injured person, when they were less opinionated, judgemental, argumentative, was welcomed within the family. Improved relationships, including sexual relationships, were also reported.

Family members felt they were learning about life and talked about their own shifts in identity seeing TBI as a transformative, life altering, process where they shed their old selves, let go of parts, retained parts and developed new parts of themselves. There was a sense that while family members would not wish for the injury to have happened, this existential change was only possible with it and they would not be the same people without it. Love had grown deeper, bonds were stronger, things that were not important before became important now. Families saw themselves as the lucky ones.

The ability to extract meaning in this way helped families to heal. Grief was seen as a path to healing, a process to go through to enable them to move forward.

[Caregiver] *"Once I allowed myself the steps of mourning, I became better able to let go and face each day with a* sense *of purpose. I am not muddled down with the sadness of the loss of that part of his personality. I have read where people need to mourn for the loss of part of a loved one. Maybe I am the only one, but I do believe it was a healing of a sorts. [Now] we laugh together, talk about growing up together, reshare all the incredible adventure we have had together … Perhaps someone else will see the need to mourn for that which has been lost … for finding who we are now"* (Godwin et al., 2014, p.408)

Healing narratives were deeply embedded within the injured person's recovery, so as they recovered so did the uninjured members. Where that recovery wasn't possible, family members had to find a way to heal themselves.

4. Discussion

4.1. Main findings and theoretical significance

During the process of analysis and synthesis of 30 primary research papers eight narrative functions, belonging to four dimensions were identified. Specifically, these were: (1) Displacing and anchoring; (2) Rupturing and Stabilising; (3) Isolating and Connecting; (4) Harming and Healing. These storied human experiences revealed the processes and patterns of families who were

navigating their lives in the context of TBI. Our synthesis maps the empirical evidence pertaining to families affected by head injury and highlights what is invisible within this discourse, which in our interpretation is the existential 'work' required by family members to respond to the challenge to self, family and everyday life at a deep and significant level. In addition, this synthesis clearly highlights the incredible positive potential achieved by some family members, often neglected by a pathologizing approach to research and service provision. We now turn to situate these findings within the context of the current evidence base, and reflect on the extent to which established thinking and traditional views are challenged. From this position we offer some practice recommendations relevant to all service providers working in this field.

Changes in identity, personality and self-concept for the injured person are well-documented post brain injury from the perspectives of the injured person themselves and as an evaluation of these changes by their relatives (Yeates et al., 2008; Norup and Mortensen, 2015; Weddell and Leggett, 2006; Tyerman and Humphrey, 1984). This synthesis examined the subjective experience of change by family members and suggests the evaluation of change is complex, contextual and relates to changes in the injured person, the family member themselves and the relationships within this family system. As Yeates et al. (2007) suggested, it is essential to attend to the family context not just the individual, and service providers should find ways of engaging with the personal and social meanings being used by family members to provide individualised support.

The narrative function of 'rupturing' captured the sense of the injured person being 'there and not there', an idea that has been linked to the literature on ambiguous loss. This has become a common term in the brain injury community to explain the grief caused by non-physical loss (Kean, 2010; Landau and Hissett, 2008; Giovannetti et al., 2015). This synthesis offers a deeper understanding of this concept exposing the multiple narratives that co-exist around loss, grief, isolation, and that these have both temporal and temporary features. In conducting this synthesis, we have not only aggregated the additional nuances discovered in prior qualitative research, but also present this in a narrative framework. As such adjustment is identified as a process rather than a definitive outcome. The results of the synthesis indicate this process is complex and fluid, not one with clear linear stages and end point, much like Verhaeghe (2005), who described living in the context of TBI as an ongoing process. However, in contrast to Verhaeghe et al. (2005) we do not suggest this is a 'never-ending cycle' (p.1007) instead we offer a more hopeful interpretation that suggests family members are engaged in a constant process of negotiating and evaluating their position within personal, relationship, family and wider narratives, with potential for 'healing narratives' of hope and new meaning.

The narrative structures presented here offer a deeper appreciation of the multiple aspects of tension and equilibrium that might be being negotiated in a family system at any given time, consistent with the comment that 'TBI constitutes a major violation of (and challenge to) family homeostasis' (Verhaeghe et al., 2005). The negotiation of role and relationships within the system fosters both new connections and new isolation and were similarly identified in a meta-synthesis of parental experiences of childhood ABI (Tyerman et al., 2017). These findings illustrate the constant on-going existential challenges facing family members and what this feels like. While our usual lives are quite stable and 'safe' TBI disrupts this sense of coherence and ability to move forward in a relatively predictable manner. Family members find themselves not knowing where life is going and the familiar life rhythm is no longer predictable. Therefore, there can be a significant amount of work required to bring stability to this system to enable the fam-

ily to move forward. Often these steps forward are fragile and can be pushed back by negative experiences such as unintended lack of appreciation of the challenges faced by families from service providers or wider societal interactions.

In addition, family members need to sustain their own sense of self for mental and physical wellbeing. However, evidence-based practice and service models, built around the needs of the injured person are not adequately positioned to recognise and address the needs of uninjured members in their own right.

4.2. Clinical implications

This synthesis has shown that family members have their own unique journeys, needs and perspectives which are not simply in response to the injured person. Using a narrative approach has helped us to see the full complexity of their experiences, their individual and family contexts and the challenge of managing these to bring balance to their lives. Being sensitive to, and engaging in, narrative stories may be one way of opening dialogue between service providers and family members that values and validates their experiences. Working with family members to understand their own story may help them to make sense of what they have been through (Stejskal, 2012). McAdams (1993) explained that narrative order is essential in creating a sense of meaning and direction. In a scoping review D'Cruz et al., 2019 affirmed the usefulness of narrative approaches to support the development of a strengths-based identity for those with TBI. While there is some limited discussion of the use of narrative therapy with families post-ABI (Butera-Prinzi et al., 2014) and TBI couple counselling (Hawkins et al., 2018) it is not yet clear how a range of narrative approaches may be helpful for uninjured family members. Nor is it clear what specific conditions or circumstances best enable families to do the work of transition that they are engaged in. However, this synthesis suggests family members may benefit from approaches that help them move from narratives of displacing, isolating, rupturing and harming toward developing thicker and richer narratives that contain anchoring, connecting, stabilising and healing functions. Narrative approaches offer families the chance to tell their story and to have this witnessed and validated (Butera-Prinzi et al., 2014). We argue that there are significant opportunities for service providers to support families to do this.

One way that service providers can engage in narratives, without crossing into narrative therapy, is to incorporate The Life Thread Model (Ellis-Hill et al., 2008) into conversation and interactions with family. The Life Thread Model is used as a metaphor for the stories, or strands, that we create and recreate about ourselves and our lives. In Fig. 2 we overlay the eight narrative functions onto the Life Thread model to advance our understanding of how stories are used to understand and make sense of experience post-TBI. We offer this to service providers as a practical way that they can begin to discuss the wider impacts of TBI with family members.

By listening to narratives in a non-judgemental way and aiming to appreciate and get some insights into the person's lifeworld, what their life *feels like* not just what it looks like from the outside, it is possible to open up new ways of working and tap into the human needs of the person (Galvin and Todres, 2013). There is a recognition that at a deep human level 'what matters' in life has been deeply affected. Todres et al. (2009) carried out a phenomenological analysis of what makes us feel more or less human and identified eight dimensions. These are all facets of the same phenomenon (feeling human) and offer different ways that we can enhance the life of others. By considering some of the dimensions, it can be seen that by hearing, sharing and acting upon narratives we can develop more humanising practices in many different ways.
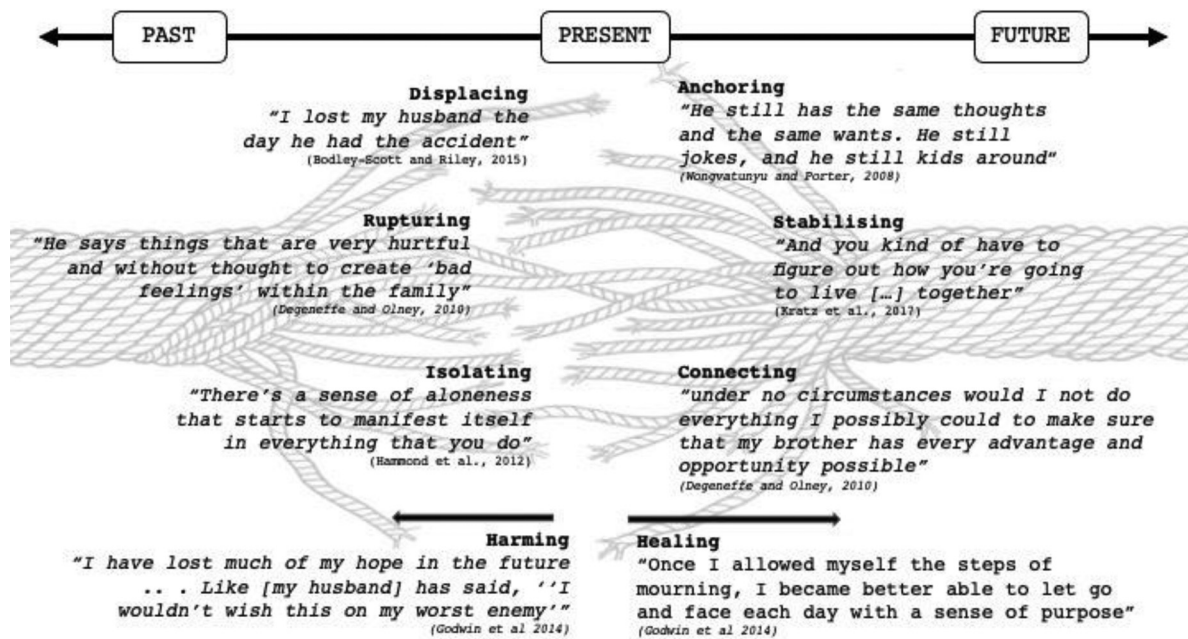
Fig. 2. Advancing the Life Thread Model (adapted from Ellis-Hill 2008, reprinted with permision).

We are considering a person's 'insiderness', what life feels like for them; we are recognising their uniqueness, helping them to make sense of their own situation, helping them to develop their personal journey, through a sense of recognition and togetherness. All of these aspects can contribute to a sense of agency, energy and the ability to move through life in a more positive way. Undoubtedly there is the need for formal therapy for targeting problems, but all service users can listen to, share and validate narratives helping family members create meaning and move forward in their lives.

4.3. Implications for future research

We recommend more research on family systems further examining the complexity and importance of family contexts to the post-injury experience, and exploring the conditions that maximise development of healing narratives. Further studies are also encouraged in underrepresented populations such as fathers, adult children and siblings. We were unable to extract data on same sex relationships and people from differing ethnic backgrounds and recommend research that considers these underrepresented groups to ensure we are developing evidence and services that are inclusive and contextually sensitive (Newby et al., 2020; Burnham, 2012). Finally, the use of narrative approaches with uninjured family members is an emerging area and further evaluation work is needed.

4.4. Limitations

This synthesis was limited by restricting inclusion to papers with only TBI populations, those for which the injured person was able to return home and those who were not from within the military. Our findings must also be viewed within the context of the evidence base which was predominantly female family members affected by the injury of a male relative. This narrow focus has meant that study findings from the wider community of brain injury survivors were excluded. In addition, using a critical realist paradigm ignored the methodological/theoretical differences between qualitative studies which dilutes the importance of methodology in favour of a pragmatic approach.

5. Conclusions

This meta-synthesis examined the subjective experiences of families following TBI. A unique approach applied a narrative lens during synthesis facilitating development of rich and complex interpretations of existing qualitative data. This synthesis paid attention to multiple co-existing stories and how the past, present and future was made sense of in the context of TBI. The substantive, and new, interpretations in this meta-synthesis revealed the substantial work involved in maintaining family system equilibrium through the eight narrative functions which existed within four broad dimensions. These findings advance the evidence base by providing insight into how families make sense of their lives within the context of TBI and provide the basis for a more humanising approach to support families post-TBI.

CRediT authorship contribution statement

Charlotte Jane Whiffin: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Project administration. **Fergus Gracey:** Methodology, Formal analysis, Investigation, Writing – original draft. **Caroline Ellis-Hill:** Investigation, Writing – original draft.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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