Qualitative Investigations into the Experiences of Family Members Affected by Childhood Acquired Brain Injury

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It should also be acknowledged that some material throughout this thesis has utilised my ClinPsyD Thesis Proposal.

Abstract

This thesis aimed to explore the lived experiences of families following child brain injury. For the systematic review, family experiences following child traumatic brain injury (C-TBI) were explored using 12 qualitative studies involving different family members. Results detailed three overarching themes: ‘Grateful for the Good’, ‘The Weight of it All’, and ‘Just Not Good Enough’. Within these findings, gender, culture, and family role highlighted how experiences can alter dependant on these contextual differences. The empirical paper investigated parents’ narratives following child acquired brain injury (C-ABI) using a creative method of wool and stones. Three core narratives were developed: 1) Suffering and Sacrifice: Throwing Stones 2) Relational Rupture and Harmony: The Forgotten Rock 3) Positive Discovery: The Shinier Stone. While sharing their stories, parents’ use of materials fluctuated. Some used materials to express emotions and represent family structures and personalities, whilst others either absent-mindedly engaged with materials, or interacted with them very little. The work of the thesis contributes to advancing understanding of family’s experiences post child brain injury, with novel insights into the use of creative materials alongside stories. The findings could inform development of novel qualitative methods or opportunities for family support however, further research is needed.

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Chapter 1. Introduction to the Thesis

An acquired brain injury (ABI) can occur, post-birth, for many reasons such as trauma to the brain from falls, accidents, or assault, as well as meningitis or stroke (Hawley et al., 2013). In England, approximately 30,000 children are admitted to hospital following a head injury every year, which can lead to a traumatic brain injury (TBI) (NHS Digital., 2015). Of these injuries, 15-20% are considered between moderate and severe in severity (Hawley et al., 2013).

ABI can result in physical, emotional, cognitive, social, and psychiatric challenges varying in intensity and complexity (Anderson et al., 2012; Beauchamp & Anderson, 2013), impacting not only the individual with the injury, but those around them too (Bowen et al., 2009). Physical problems such as mobility, sleep, fatigue, and balance following injury can occur, causing a child, and their families, significant concern. A child's ability to make and maintain friends can be reduced when faced with emotional and cognitive difficulties, thus, having an overall impact on their social skills (Anderson et al.; Yeates et al., 2004). These social abilities were further impacted when families experience poorer social adjustment and significant impact to family functioning (Anderson et al.). As well as social difficulties, conflict and challenge can occur within the family home where a child's mental health may be impacted following injury, resulting in increased risk of attention deficit hyperactivity disorder, personality change, depression, anxiety, and behavioural challenges (Schachar et al., 2015). Linking to increased prevalence of ADHD, a child's attention, and emotional control abilities, as well as other executive functioning such as memory are likely to be affected (Keenan et al., 2018). Such difficulties can vary depending on the injury type, severity, personal characteristics, and the home environment, with difficulties impacting on academic achievement later down the line (Keenan et al.).

Family Impact

Parents are key to a child’s brain injury journey which can consist of taking on many difficult roles and responsibilities. These challenges can result in stress, financial difficulties, and strain in relationships (Stancin et al., 2008; Jordan & Linden, 2013). For some, intimate relationships became more distant and insecure following their child having a brain injury, whereas, for others, these connections became closer, with more time and acceptance for one another (Tyerman et al., 2017). Parents can experience a grieving process following the loss of what their child previously was and can experience a lack of support from many aspects of care in the child’s recovery (Roscigno & Swanson, 2011; Jordan & Linden). In addition to reduction in support, parents report less engagement in social activities, thus, having less peer support throughout such a distressing period of their lives (Benn & McColl, 2004).

Parents are not the only family members impacted by child brain injury. Siblings can be important for child development as they are central to a family system, acting as companions, alliances, or competition (McHale et al., 2012). Closeness in siblings can result in better wellbeing, whereas following brain injury, the quality and time spent between parents and other children may lead to sibling rivalry (Brown et al., 2013). When gaining understanding into the impact of siblings following child brain injury, a systematic review revealed that siblings can report more mood and distress symptoms compared to controls and poorer psychosocial functioning was found when behavioural and social problems occurred in the injured child (Ownsworth & Karlsson, 2022).

Positive Adaptation

Due to the notion that the wellbeing of parents directly influences the overall functioning of the family, impacting on how a child might adapt following brain injury (Labrell et al., 2018), it is important to consider the positive outlooks some may hold following child brain injury. Research predominantly focuses on the adverse outcomes of traumatic life experiences, overlooking a crucial element of posttraumatic growth recognised as a valuable paradigm for understanding the positive aspects of addressing an individual's psychological and social care needs (Picoraro et al., 2014). Posttraumatic growth refers to positive psychological changes following a traumatic life-altering experience, encompassing themes such as heightened life appreciation, improved interpersonal relationships, increased personal strength, awareness of new life possibilities, and development in spirituality and religion (Picoraro et al.). The concept of posttraumatic growth enables a shift in focus towards the present moment, steering away from dwelling on past events resulting in a fuller and more meaningful life, although not a return to normal (Calhoun & Tedeschi, 2012). Whilst research outlines factors such as stress and responsibility as negative consequences for parents following child brain injury, research is somewhat limited in exploring the potential adjustments and sense-making following such experiences (Roscigno & Swanson, 2011).

Creativity in ABI Research

Learning from people’s stories following a traumatic event can be elicited from a range of different qualitative methods such as interviews and focus groups. Expression through verbal means alone may be challenging for some people, restricting the elicitation of narratives. Creative arts such as art, music and drama, use non-verbal therapeutic techniques which have supported engagement, enhanced focus and reduce anxiety and low mood (Hunter, 2019; Le Navenec & Bridges, 2005). When people engage in songwriting, they can experience a development of a new sense of self which can also elicit memories as well as address functional recovery goals (Pfeiffer & Sabe, 2015; Tamplin et al., 2016; Jacobsen et al., 2015). A study exploring the use of music therapy highlighted how 5 individuals shared their experiences of brain injury through song, narrating about personal relationships which helped them to adjust to their new ways of living and plans going forward (Roddy et al., 2020). This study, however, was based on a 6-week intervention and a small sample size, thus, drawing meaningful or significant change is somewhat a challenge. It is also based on only male adults with ABI. Baker et al. (2005) carried out a study exploring shared stories through song writing for people with brain injury outlined that both males and females shared lyrics which expressed some positive feelings such as happiness, but predominantly negative ones such as loneliness, isolation, and anger, with reflections on what makes them feel this way. Such self-expression could arguable be considered a strategy which helps people cope, reflect, and accept on things out of their control. This study included participants with TBI of both child and adult ages, and therefore, suggesting that expression can be useful for a range of ages. Studies including child injury is limited.

As well as music, drawing has been found to help people express themselves. A drawing-based group was carried out with adults with brain injury and throughout the process of the group intervention, signs of progression were found such as increased abilities in sharing experiences, increased verbalisation and social inclusion and self-discovery (Briks et al., 2020). Additionally, people became less anxious about being involved and some were able to work through some of their difficulties such as loss and identity (Briks et al.). These findings, however, were based on an adult population only.

Another creative, art-based approach to share stories of brain injury is using drama. Colantonio et al. (2008) carried out research based on a theatre piece named ‘After the Crash’ in which people with brain injury, their families and theatre staff produced an educational performance for healthcare workers sharing their lived experiences. Feedback from staff suggested that the emotional impact of the piece would be memorable, compared to just reading a story, and help gain a deeper insight into experiences (Colantonio et al.). These studies support one another in the idea that the use of creative methods can help people to share their individual experiences following brain injury, that verbal expression alone may not be able to achieve. The creative methods are common to people, however, there is scope to consider more novel approaches in supporting people to express themselves in qualitative research.

Activities such as using creative materials of threads, or wool and stones, is more novel in design, thus, adding further elements of creativity and exploration of narratives. The use of threads in narratives can represent a many emotions and experiences which can also be interpreted in a variety of ways. Ellis-Hill et al. (2008) created the Life Thread Model which was originally explored with stroke survivors and their families. The model describes a metaphor for the narratives people may make, or re-make, for themselves and how their life has been psychologically and socially following disability after birth. Whiffin et al. (2021) applied the Life Thread Model when conducting a synthesis of qualitative literature about the impact of TBI on family experiences. Following this, research has been carried out into the use of physical materials as a creative process to support family members to express their narratives of adaptation to life post injury (Ellis-Hill et al., 2019). Similar creative research methods including the use of wool and stones has been carried out in a participatory project to understand experiences of stroke within an inpatient setting (Galvin et al., 2020). Within these studies, the materials were used as a qualitative research method to help elicit experiences with more richness, not solely as a tool for adaptation. However, the expression and reflection on experiences within this process supported adaptation (Galvin et al.; Ellis-Hill et al, 2019). Therefore, there is scope for exploring creative qualitative research methods such as wool and stones as a tool for supporting parents adaptation post child acquired brain injury (C-ABI). Furthermore, current research using creative methods to generate the sharing of stories has predominantly been carried out within group settings, within health problems related to adults, thus the exploration of creative materials being used to elicit narratives linked to child brain injury, on a 1:1 basis is a gap in research.

Current Research

The first piece of work presented is a systematic review exploring family experiences following child brain injury using qualitative accounts. This is followed by an empirical paper focusing on the narratives shared by parents following child brain injury with the use of creative materials. Finally, a discussion and critical review will be outlined to consolidate the thesis findings and suggest future implications regarding theory, practise, and future research.

The main empirical study reported here is the first part of a wider collaborative study. The second part conducted by another ClinPsyD trainee (DS) explores the potential for the elicitation of narratives derived by the ‘wool and stones’ to be used clinically.

Chapter 2: Systematic Review and Empirical Paper, prepared for submission to Neuropsychological Rehabilitation

The research here is original work which was carried out under the supervision of Dr Fergus Gracey (Primary Supervisor), Dr Kiki Mastroyannopoulos (Secondary Supervisor) and Dr Charlotte Whiffin (Field Supervisor). I am the lead author and this paper is prepared for journal submission.

Family Members' Experiences of Child Brain Injury: A Meta Synthesis of the Qualitative Literature

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Abstract

Aims: The aims of this review were to synthesis qualitative literature which explored whole family experiences following child traumatic brain injury (C-TBI). The primary question was: What are the experiences of family members following childhood TBI? The secondary question was: What do family members report to be helpful in their experiences following childhood TBI?

Method: Electronic searches for papers were completed in October 2023 using PsychInfo, Medline OVID, CINAHL and Web of Science databases. Eligible studies were qualitative research of the experiences of any family member of a child who sustained a TBI up to the age of 20. All studies were quality rated using the CASP tool and given a category of either 'core', 'central' or 'peripheral' depending on their contribution to analysis. Data extraction was completed by the primary author and all included papers were checked against criteria by a second reviewer (DS). Data was analysed using thematic synthesis.

Results: Twelve studies met the inclusion criteria. Three main themes were derived from the synthesis summarising family experiences: 1) 'Grateful for the Good, 2) 'The Weight of it All', 3) 'Just Not Good Enough'. Family members found support from family, friends, religion and the community to be helpful. Contextual differences of gender, role in the family and culture altered experiences for some.

Discussion: Following a child's TBI, families can suffer from challenges adapting to life post C-TBI and the lack of knowledge provided by others. Mothers tend to prioritise others needs before their own, fathers may supress their emotions, and siblings often feel neglected. Support from members of the community, healthcare professionals and religion can provide comfort for some families, whilst others' refrain from seeking help due to cultural beliefs. Clinical implications and future research considerations are further discussed.

Registration: The protocol for the review was registered on PROSPERO (reference: CRD42023470678).

Introduction

Traumatic Brain Injury and Family Impact

Children make up 30% of attendees within accident and emergency departments because of head injury which can have significant, lasting, consequences (Neurological Alliance, 2016). Traumatic Brain Injury (TBI) is defined as an external force which alters brain functioning and pathology (Menon et al., 2010). The impact to brain function can result in cognitive, physical, and emotional difficulties which can cause challenges to social functioning, schoolwork, and later success (DePompei & Blosser, 2019)

Parents and parenting style can impact on a range of outcomes for a child with TBI. Research outlines that parents play a key role in the recovery and adjustment of their child which can have long lasting consequences of loss of control, increased distress, and guilt for not protecting their child (Brown et al., 2013). The psychological and physical health consequences of these experiences can cause parents to have increased levels of burden and less social connections (Brown et al.). This study used a sample of ten family members, providing rich data to encapsulate experiences. Parents' mental health difficulties following C-TBI could result in subsequent breakdown of relationships and financial problems for parents. Research suggests that although relationship problems can occur between parents around roles of caring and behavioural challenges (Brown et al.; Norberg & Steneby, 2009), research into divorce or separation for parents following child brain injury is limited. Furthermore, employment and finances can become an increasing concern for families. Aitken et al. (2009) described that a child's reduced functioning and ongoing needs require attendance to multiple clinical appointments which costs time and money leading to challenges in meeting employment expectations. As such, parents can experience significant financial burden and worry. This study, however, was quantitative in design, thus, lacking detailed insights into the individualised experiences.

Parents and other family members can experience a wide range of emotional consequences. Kirk et al. (2014) outlined that, similar to trauma responses, parents can experience ongoing emotional challenges after witnessing their child's accident which caused a TBI. Parents also struggle with feelings of guilt, isolation, and fear, resulting in adjustment to having a different child (Kirk et al.). A limitation of this study was that parents were all treated and recruited from one setting, thus, consideration into emotional needs being met in other services is needed.

C-TBI does not just impact parents, but the whole family unit. The experience of a brother or sister having a brain injury can have considerable consequences for a sibling (Gill & Wells, 2000) One of the longest relationships experienced across the lifespan is that of a sibling (Whiteman et al., 2011), thus, the role in which they play and the impact they experience is important in understanding the journey of child brain injury. It is also important to consider how siblings play an important role in the overall wellbeing and functioning of the family unit, thus, changes in behaviour could affect this. For siblings of a child with severe brain injury, the risk of psychological problems can be higher than those without (Sambuco et al., 2008). The injured child can have reduced functioning correlated with their siblings' own experiences of depression and behavioural problems following the injury, highlighting the circular impact of how each children's difficulties can impact one another (Sambuco et al.). Although the review was aimed at C-TBI, the sample also included multiple traumas and ABI. Research into sibling experiences following TBI is limited, thus, literature into ABI was explored. Tyerman et al. (2019) conducted qualitative research into five siblings accounts of their relationship with their injured brother or sister through an ABI. Themes emerged around 'coping with the nightmare', in which some siblings had been witness to the injury, with some referencing the experiences as near to death (Tyerman et al.). Another theme detailed feeling physically and emotionally disconnected from family relationships, mainly their parents and siblings (Tyerman et al.). This research was conducted in the UK only, thus, understanding experiences across countries, as well as cultures and service contexts would strengthen findings. Hickey et al. (2022) conducted a study in Australia where both parents and siblings were interviewed about their experiences following C-ABI. Themes emerged around negative changes to sibling interactions and an increase in parental expectations for the non-injured sibling (Hickey et al.). The qualitative data in this study, however, was conducted through open ended questions within a survey carried out in the home, thus, the external influences on how the sibling responded should be considered. Exploring siblings' experiences of when their sister or brothers' injury occurred between the ages of four and 24, Bursnall et al. (2018) found siblings to describe a sense of loss of balance, vulnerability from their parents being more absent and feeling a loss of belonging resulting in jealously, annoyance and guilt. These siblings also shared the process of gaining more responsibility, somewhat becoming a surrogate parent and the conscientiousness this brings (Bursnall et al.). This paper highlighted that, similar to parents, siblings also require information to understand and reduce confusion following child brain injury. These papers being based on ABI populations highlights the limited research into experiences of TBI alone.

The impact of child brain injury goes beyond parents and siblings, effecting other family members. Research into other family members' experiences, such as grandparents is limited. Sadruddin et al. (2019) carried out a review on the influence of grandparents on the health and development of a child, and, although not directly linked to brain injury, many studies within this review highlighted the impact of grandparents. Grandparents can have a lot of contact, provide care, and contribute financially for their grandchild (Sadruddin et al.). As such, grandparents can have an overall impact on a child's development and lifestyle. The limitation in research also extends to other potential caregivers such as uncles and aunties. As such, other family members should be considered when wanting to understand the experience of a child brain injury in a holistic way.

Amongst families' experiences, different obstacles can occur dependant on the stage of injury and setting of care. Within acute care settings, the focus for families can centre around seeking information from healthcare staff about their child's state, watchful waiting and beginning to make decisions about ongoing care. During this stage, staff can be heavily involved in the families' daily experiences, which reduces when the child becomes more stable (Reuter-Rice et al., 2017). The transition from hospital to home following injury was explored during a review which outlined that some parents can experience both positive feelings of excitement, and negative feelings of fear and doubt in their ability to cope with being at home with their injured child (Robson et al., 2005). The experience of being in hospital acted as a protective barrier and once families returned home, worry extended to all aspect of community living (Robson et al.). Literature into whole family experiences in the community following child brain injury is somewhat limited.

Community Integration and Gaps

Reintegration into society, such as school transitions or social reconnection, following a brain injury can be a complex and challenging process for children (Farmer et al., 2011). These transitions can differ dependent on severity of injury and complexity of needs, with enhanced support being vital. For children with moderate to severe TBI, returning to school can be delayed for weeks or months, impacting their academic progress and their social position (Farmer et al.). Receiving social support can be a motivating factor for children returning to school, however, for some they can experience rejection from peers (Roscigno et al., 2011). A child experiencing social disconnect during school can impact on life at home, and subsequently result in parent's ongoing concerns. Roscigno et al.'s (2014) study discovered that parents can be concerned for their child's academic and social development and report a lack of understanding from teachers and limited adaptations made to meet their child's needs. These barriers can result in parents needing to advocate for their children during such integrations, adding to overall negative experiences following C-TBI. The synthesising of research into community reintegration and family experiences following child brain injury is limited.

Previous reviews are arguably limited in research methodological design in which search terms are restrictive and unclear (Tyerman et al., 2017), and themes are described as opposed to synthesised (Vallee et al., 2023). Although a review has been carried out on family experiences of C-TBI (Rashid et al., 2014), this review was heavily quantitative in design and searches were carried out over 10 years ago. Previous reviews also hold some biases in their samples as they focus on family members in isolation, such as parents. They also lack exploration into social and contextual factors that may lead to different experiences following child brain injury, with previous literature mainly focusing on convergent themes amongst their findings.

Therefore, the aims of this review were to build upon Tyerman et al.'s (2017) review for TBI, to explore whole family community experiences following child brain injury, whilst holding in mind contextual factors that may influence such experiences. The primary question of this review is: What are the experiences of family members following childhood TBI? The secondary question is: What do family members report to be helpful in their experiences following childhood TBI?

Methods

Protocol and Registration

This systematic review followed the guidance of Thomas and Harden (2008) in which qualitative data from a range of study types and contexts was synthesised. The review followed the Centre for Reviews and Dissemination (CRD)'s 2009 guidelines on systematic reviews in healthcare and remained in line with the Preferred Reporting Items for Systemic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021). A protocol for the review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) database, detailing the inclusion and exclusion criteria, as well as, the search terms, screening process, and the method (reference: CRD42023470678).

Eligibility Criteria

***Rationale**.* Search terms were identified from 2 previous reviews (Tyerman et al., 2017; Vallee et al., 2023) with additional terms identified to be inclusive of family members beyond just parents, and a wider range of study settings or context. A medica librarian supported this process.

***Inclusion**.* Peer-reviewed papers, written or translated in English which focused on children and adolescents who had sustained a traumatic brain injury up to the age of 20 were included. These papers were required to include experiences of the child brain injury from the perspective of any family member, and where experiences were based on community context. Studies could consist of any qualitative research design. Studies of mixed method design which included available qualitative data that related to the question were also eligible.

***Exclusion**.* Papers which included children either before, during or 6 months post birth at the time of injury were excluded from the study in order to capture adaptation and change to life. If any of the sample included children outside the 6 month – 20 years age range at the time of injury, the paper was excluded. Where the injury was related to a non-brain injury disease or illness, or mild concussion, papers were excluded, as well as experiences related to the death of a child. Where the sample consisted of participants with other unrelated illnesses, papers were excluded to ensure experiences were brain injury focused. Brain injuries that occurred due to a neurological, genetic condition were excluded along with quantitative research. Dissertations were not automatically excluded depending on the quality and relevance of the data to the question, and inclusion of data on under-represented groups.

Information Sources and Search Strategy

The available literature was identified by electronically searching four databases: Medline OVID, CINAHL, PsychInfo and Web of Science, and manual searching the reference lists of included studies. Title and abstract keyword searches were performed. MESH terms for the four headings outlined in Table 1 were also used within the search databases, except Web of Science that omits this functionality. To combine search terms effectively and to maximise search results, Boolean operators ‘and’ and ‘or’, and truncation symbols such as ‘*’ were used (See Table 1). No date restrictions were applied to the search.

Table 1:

Search Terms

Family~ Terms		Child~ Terms		Brain Injury~ Terms		Methodology Terms
Parent* OR Mother* OR Father* OR Mum OR Dad OR Caregiver* OR Family OR Families OR "Stepparents" OR sibling* OR sister* OR brother*	AND	Child* OR adoles* OR teen* OR paediatric OR pediatric OR youth OR young person OR young people OR young adult OR infant OR baby	AND	"Brain Damage" OR Meningitis OR Encephalitis OR "Brain Injury" OR Stroke OR "Arteriovenous Malformation" OR Aneurysm OR "Brain Haemorrhage" OR "Cerebral Haemorrhage" OR Asphyxiation OR Suffocation OR "Brain	AND	Qualitative OR "Grounded Theory" OR "Narrative Analysis" OR "Thematic Analysis" OR Experience OR "content analysis" OR ethnog* OR Phenomenolog* OR "Discourse Analysis" OR "Framework Analysis" OR "Conversational analysis" OR

	OR kid OR toddler	Tumo*" OR "Cerebral Tumo*" OR "Brain Neoplasm" OR Neurosurgery OR "Head Injur*" OR "cerebral vascular accident*"	"Qualitative Methods" OR "Focus Group" OR Interview*

~used for MESH terms, in addition to ‘qualitative’.

Selection Process and Quality Checks

The four databases were used to identify records that may meet inclusion criteria based on the search terms used. All results were retrieved and entered into Endnote, and then Rayyan, for duplicate removal. Title and abstract screening were then carried out by the lead researcher. Finally, full text articles were screened by the lead researcher.

A random sample of 15% (N=344) of the original papers were screened by a second reviewer (DS) using Rayyan. The percentage agreement with the first author (LD) was high, 98.8% (N= 340). Discrepancies between the first author (LD) and the second reviewer were overcome through consultation. The authors for this review met on a regular basis to discuss the screening process and to support decision making, ensuring consistency and transparency. The second reviewer also checked 100% of the 12 papers to determine inclusion accuracy.

Data Extraction Process

Using CRD’s guidelines on systematics reviews in healthcare, data was extracted to include study and participant characteristics and a summary of key themes found (CDR, 2009). Further detail including severity and type of child brain injury was included.

Assessment of Methodological Quality

Methodological quality of included papers was checked using the Critical Appraisal Skills Programme (CASP) qualitative research checklist (CASP, 2023). The checklist consists of ten questions which focus on the research aims, methods, research design, recruitment, data collection, reflexivity of the researcher, ethical considerations, data analysis, details of findings and their contributions to existing literature, and proposed clinical and research implications (CASP, 2023). Based on CASP guidance and the primary researcher's own perimeter, papers that scored at least a 7 out of 10 using the CASP rating were considered good, whereas less than was moderate to poor quality. The second reviewer (DS) conducted a quality check on 20% of the full CASP ratings.

The Cochrane Group recommend the use of the checklist as a framework to guide and inform findings and the synthesis of them (Long et al., 2020). Papers were also rated using a classification process to determine how close they were in relating to the research question. Papers received either a 'core', 'central' or 'peripheral' rating guided by previous work by Whiffin et al. (2021). For core papers, data was highly relevant to the review question and held good methodological quality. For central papers, the quality of methodology remained good, however, was less related to the research question than the core papers. For peripheral papers, the methodological quality and the relational closeness to the research question were weaker compared to the core and central papers. Thus, the papers rated as core held greater importance within the analytic process and were used to derive the initial coding framework. Four papers received a 'peripheral' rating and were predominantly used to provide contextual information in line with already occurring themes in the analysis. These methodological appraisals were shared and discussed with a senior member of the research team (FG).

Synthesis methods

The exploration of family members' community experiences of TBI was analysed through thematic synthesis. Combining and modifying meta-ethnography and grounded theory approaches, thematic synthesis aims to go beyond the initial stage of descriptive themes to interpret analytic themes, using a constant comparative method (Thomas and Harden, 2008). Due to the flexibility within this method, different epistemology positions can be applied during its use (D'Cruz et al., 2019). The method uses three stages which overlap to some extent; 1) using findings from included studies and coding them line by line, 2) sorting codes to construct descriptive themes which then 3) generate the development of analytical themes, going beyond the original findings of the primary studies (Thomas & Harden, 2008). Thomas and Harden (2008) discussed that when synthesising qualitative data there can be concern that context is lost or misinterpreted, thus, understanding of why experiences might not be transferred across studies is important in addressing this concern. A systematic review of qualitative literature can focus on the repeated aggregation of themes represented in different studies, however, weight of analysis can also focus on individualised experiences that differ from other studies, to represent marginalised groups or minimised voices (Duden, 2021). Also, in qualitative work, attention is paid to the richness and meaning, thus, power to meaning rich data may be regarded as high status in the analytical process. Furthermore, as recruitment into research is not always representative of society (Wallerstein et al., 2019), the researcher thought it important, within this review, to also give lens to a paper which provided more of a unique voice. This is also supported by the researcher's social constructivist (Amineh & Asl, 2015) standpoint in which people construct their own realities, whereby these realities may differ from the commonality of others. As such, within this systematic review, contextual differences may be represented by one or two papers only. Both approaches of recognising similarities as well as contextual difference for synthesisation of results contributes to a more holistic understanding of family's experiences following C-TBI. NVIVO qualitative analysis software was used to assist the coding process.

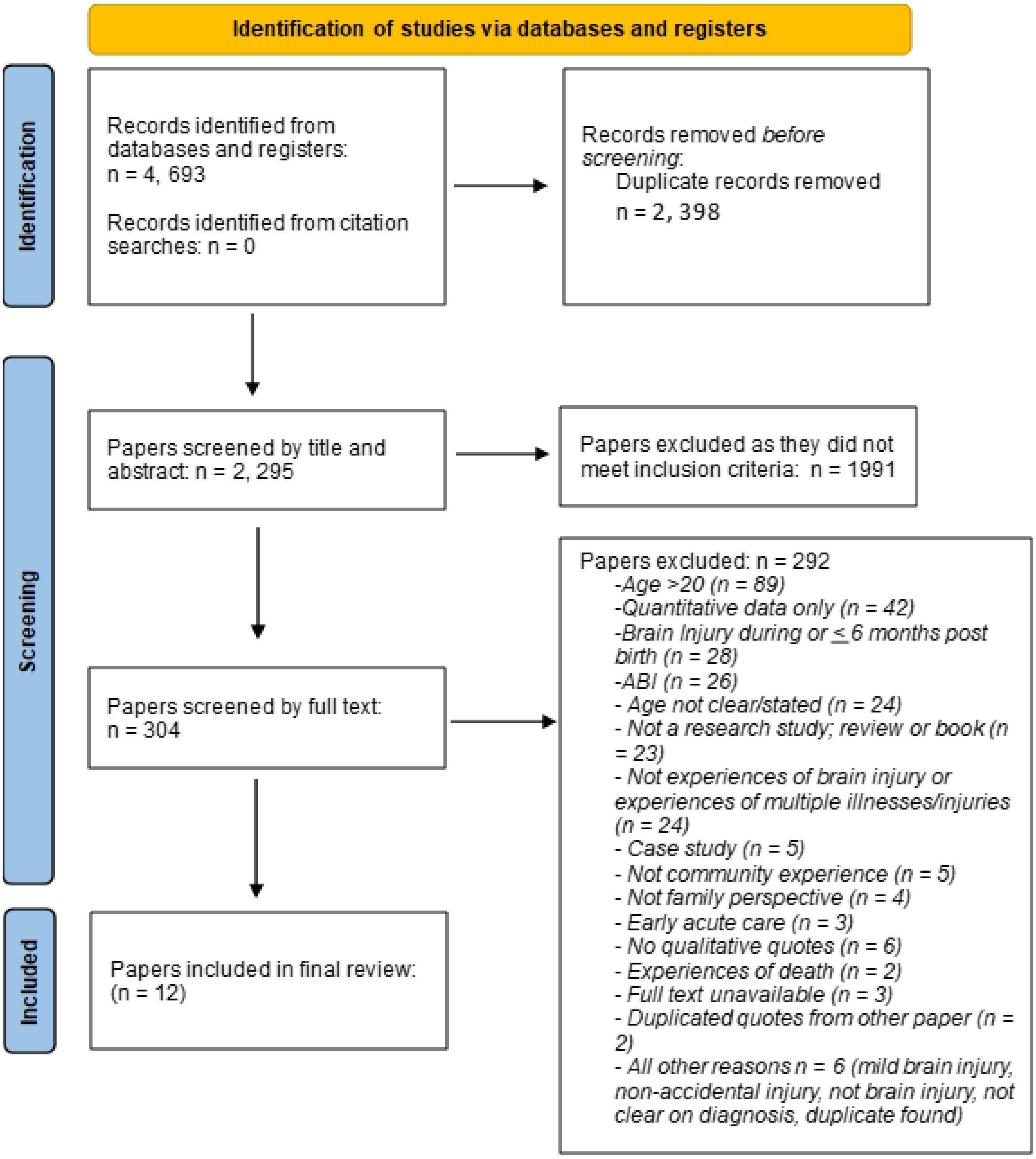
Results

Study Selection

Electronic searches using the four databases were conducted in October 2023 and generated a total of 4,693 results. Following the removal of duplicates, 2,295 studies remained and were screened by the primary author. Following screening by title and abstract, 304 articles remained and were screened at the full-text stage, resulting in further reductions. Out of the 304 papers, 292 were excluded. The main reasons for exclusion were: out of age range (n=89), quantitative data (n=42), brain injury prior, during or ≤6 months post birth (n=28), ABI (n=26), age not clear or stated (n=24), not a research study (n=23), not experiences of brain injury or just brain injury (n=23). The number of papers generated, removed, screened, and reviewed, and all exclusion reasons are outlined in the PRISMA flowchart below (Figure 1).

A total of 12 studies were subsequently included in the review. Manual searching of the reference list of these included studies did not generate any further papers to include. Upon review of articles which were thesis/dissertations within the search, although not peer reviewed, those that were deemed to add significant value to the research question were included. One paper added contextual difference from the perspective of parents from a non-white population, one was cited in other papers which drew researchers into its core value and importance and the other had more in-depth quotes compared to a peer reviewed paper of the same author with the same quotes in their findings, thus, was deemed to provide more richness for analysis.

Figure 1: PRISMA Flowchart



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Study Characteristics

Out of the 12 articles included for final synthesis, two used thematic analysis, one used content analysis with a phenomenological approach, one used a framework approach, four used grounded theory methodology, two used content analysis, one used descriptive phenomenological investigation and one used interpretative phenomenological analysis. All studies used interviews or focus groups for their methodology.

The total number of family member participants included in the papers was 171 which included 101 mothers, 33 fathers/stepfathers, 3 grandmothers and 1 uncle. 33 participants specific caregiving role was not specified. Two of the articles (Roscigno, 2009; Roscigno, 2015) consisted of the same 36 mothers and 8 fathers as participants, but with different data reported. No articles were from siblings' perspectives of C-TBI, thus, sibling experiences were gained through secondary knowledge from parental reports. For mechanisms of TBI, three studies did not report how participants got their TBI, and one study included all motor accidents. All other studies included mixed types of trauma, including motor accidents, sports or recreational related accidents, falls, a gunshot, a firearm, blunt force trauma, and non-accidental injury.

Citation of each included study, key characteristics and key findings are outlined in Table 2. An extended version of the table, including CASP and Core, Central and Peripheral ratings can be found in Appendix C.

Table 2:
Study Characteristics

Author(s) (and Date)	Focus of Study	Methods of Data Collection (all verbal expression only)	Analysis Used	Family member(s) included and total sample size of these	Mechanism of C-TBI (written verbatim)	Age (y) range at time of child's injury/ presumed age (based on study criteria)	Time since injury (m=months, y=years)	Categorisation of Core, Central, and Peripheral (CASP Rating)
Clark et al. (2008)	Family relationships and support and services	Semi-structured interviews	Interpretative phenomenological analysis	All mothers N=10	4 pedestrian road traffic accident, 3 road traffic accident, 2 falls, 1 sports injury	4-13	2y 1m-6y 11m	Core (7)
Brown et al. (2013)	Parenting a child with TBI	Focus Groups or individual telephone interviews	Thematic analysis, philosophical position: not reported	7 mothers, 2 fathers/ stepfathers, 1 Grandmother N=10	2 suspected but unconfirmed non-accidental injuries, 1 non-accidental injury, 3 motor vehicle accident, 1 sport, 1 fall	1.5-9	2y 6m-12y 6m	Core (7)
Smucker (1996)	Empowerment following child brain injury	Interviews	Grounded theory, philosophical position: symbolic interactionism	11 mothers, 6 fathers and, 1 uncle N=18	4 auto accident, 1 gun shot, 1 fall, 1 skiing accident, 1 sledging accident, 2 hit by car, 2 bike vs car	6-15	<1y – 3y	Core (9)

Roscigno (2009)	Social experiences following moderate to severe TBI	Interviews	Descriptive phenomenological investigation	34 mothers, 8 fathers; 5 couples interviewed together N=42 1 parent was a biological grandparent but gained parental custody, unknown if classified as mother or father for the study	18 motor vehicle accident, 6 car verses child, 4 recreational vehicle, 5 sports/recreational related accident, 3 blunt force trauma, 2 firearm	6-18	4-36m	Core (9)
Wilson (2009)	Sources of stress and coping strategies for African American caregivers of youth with TBI	Semi-structured interviews	Grounded theory, philosophical position: not reported	11 mothers, 4 fathers; 2 couples interviewed together N=15	All motor vehicle accidents	5-17	Not reported	Core (9)
Gauvin-Lepage and Lefebvre (2010)	Social inclusion with TBI	Semi-structured interviews	Content analysis	3 mothers and 1 father; 1 couple interviewed together N=4	1 skiing accident, 1 traffic accident also involving Mum, 1 bicycle accident	11-14	1-3y	Central (9)
Jones et al. (2010)	Day to day occupations of parents who care for childing in the home after severe TBI	Interviews	Constant comparative analysis used in grounded theory, philosophical position: not reported	4 mothers and 3 fathers N=7	Not reported	2-5	2-6y	Central (9)

Kirk et al. (2015)	Experiences of TBI and information and support needs	Semi-structured interviews	Framework approach	18 mothers, 9 fathers/stepfathers and 2 grandmothers N=29	11 road traffic accident, 5 fall, 3 off-road bicycle/motorcycle accident	3-16	6m-6years	Central (7)
Roscigno et al. (2015)	School reintegration needs	Semi-structured interviews	Content analysis following descriptive phenomenology	34 mothers, 8 fathers; 5 couples interviewed together N=42 1 parent was a biological grandparent but gained parental custody, unknown if classified as mother or father for the study	18 motor vehicle accident, 6 car verses child, 4 recreational vehicle, 5 sports/recreational related accident, 3 blunt force trauma, 2 firearm (extracted from 2009 paper as not reported in this paper)	6-18	4-36m	Central (8)
Chisholm and Bruce. (2001)	Parenting a child with TBI, perceptions of what resources are available and how those resources influenced experiences	Interviews	Content analysis	Caregivers, does not specify N=10	Not reported	5-15	Not reported	Peripheral (5)

Todis et al. (2018)	Hospital to school transition	Semi-structured interviews	Thematic analysis, philosophical position: not reported	Parents (does not specify mothers or fathers) n=23	Not reported	4-15	Not reported	Peripheral (6)
Rennie et al. (2020)	Social changes and challenges in rural areas for TBI	Interviews	Iterative approach based in grounded theory	All mothers N=3	1 fall off playground equipment, 3 car accident	8-16	2-7y	Peripheral (5)

Main Findings

Three overarching themes, with further descriptive subthemes, came from the synthesis: 1) ‘Grateful for the Good’, with subthemes of good support systems and holding onto the positives 2) ‘The Weight of it All’, with subthemes of the loss of self and health, the change to family dynamics and the fight of getting the right support. Within this theme, contextual differences of gender and culture were identified, resulting in further descriptive subthemes of ‘punishment’, ‘not reaching out’, and ‘being the man’. The third theme 3) ‘Just Not Good Enough’ had subthemes of the lack of information and understanding, lack of support, and negative responses. A further contextual difference of family role was identified, resulting in the descriptive subtheme of ‘being the sibling’.

Grateful for the Good

The theme of ‘Grateful for the Good’ focuses on what has gone well for families in their journey of child brain injury. This was categorised into two additional descriptive themes 1) ‘Good Support Systems’, and 2) ‘Holding onto the Positives’.

Good Support Systems.

When sharing their experiences, family members were able to reflect on what was helpful in their journey regarding support they received from others. This support predominantly stemmed from either friends, family, health care, education or religious groups.

Some participants felt that without their faith, they would not have been able to manage. Participants in a study conducted in America described feeling taken care of by God:

“I can honestly say the only thing that gets me from one day to the next is my faith. You know, figuring that God’s not going to give us anymore that we can handle and he’s taken care of us so far” (Smucker, 1996)

and understood by God:

“One of the best things that ever happened to me was I had a preacher that came and said, ‘It’s okay to be angry, because God knows you are. And it’s okay to be bitter, because God knows you are. And it’s okay to shout out and tell God how angry, because God knows you are’” (Smucker, 1996).

For participants of African heritage, the practise of prayer helped them to get through*:*

“We prayed so much in the hospital and got a couple pastors come by and pray with us... There was no way that we would survive without it” (Wilson, 2009).

Prayer was also used as pivotal to families’ beliefs that the child’s recovery was between them and God, as outlined by an uncle:

Never could believe I could do this. But with the help of the Lord, anybody can to anything... Put your mind to it, it could be done.” (Smucker, 1996).

Faith was not the only support avenue experienced by family members following C-TBI. For some, the need to be around others and share laughter was important*:*

"One thing we really missed was laughing…We'd call up friends and say, please come to dinner… Just come, we have to talk to somebody. We have to have something in our hearts besides fear." (Smucker, 1996)

and, for others, the closeness of friendships was key:

"(I have) some unbelievably brilliant pals, and that's made a big difference" (Clark et al., 2008).

Families were able to pull together during this traumatising time and the support of this felt uniting by one participant's description:

"You did all bond and . . . you kind of get through it and you're very supportive of each other. . .. I think family support has been really important. And not any one person in particular, but, from the whole thing really" (Clark et al., 2008).

Within support systems, the sense of community helped a lot of people through their journey. Some appreciated supportive and encouraging comments from peers to their child:

"People were coming up to her and telling her that it made them feel like whatever they had going on was nothing. They were like, 'You give me hope, you give me strength.'" (Rennie & Goforth, 2020).

Another participant appreciated supportive behaviour from peers following the experience of both friends being involved in the same accident*:*

"They went in (school) holding hands, I believe. I think her and the girl that was driving the car… These delicate girls were alive, and it was a healing for the whole community". (Rennie & Goforth, 2020)*.*

The sense of community also came from relating to others in a similar situation in an organised group format, adding to a sense of belonging:

"Being here [in the focus group] lets me see that there are other people [in a similar situation]" (Wilson, 2009).

In addition to the support of family, friends, peers and religions practises, some people found health care and school professionals helpful. For some, the experience of feeling heard and understood was paramount:

"Georgina (clinical psychologist) was the first person who listened, understood and said, 'Yes, I think you're right'." (Clark et al., 2008).

This was also experienced in the form of multi-agency working for one participant:

*"They all sat down, her [school nurse], the principal, the social worker, her teacher... They all sat down and they discussed with them [rehabilitation team], what happened, what kind of effect it will have on [her learning], different cautions ... that everybody would have to take when she came back to the school... They all came together as a community, and even the students, they had like a fund-raiser for her and everything, and it was nice… That school was like family." (*Roscigno et al., 2015).

For some, appreciation of information sharing was heightened when given in a straightforward and honest way:

“We had some (staff) that said, ‘Your child may be different. That’s okay, because you don’t know, you might like what’s different in her, and she may have had something that is going to be so much better now. And she will be different, and you may see things that you wish that were there, but there's going to be new things that you can help build up’ And that’s what I appreciated, that honesty is that ray of hope to hold onto. It was very helpful” (Smucker, 1996)*.*

Holding Onto the Positives.

In addition to experiencing good support systems throughout the challenge of a child having a brain injury, participants were able to hold onto the positives through their journey. For one participant, they reflected on how they viewed their child now, in a positive way, and how their bond grew*:*

“Once you recognize that need, then the bonding becomes easier, you know, I can put that behind me, now this is what I have, let's deal with this and go forward… Now I have Kelly, this other child, and I take a good look at her and say, oh, you know, she's a pretty neat kid and, you know” (Smucker, 1996)***.***

Whilst another experienced new meaning through the reinvention of their child:

When [Natalie] first got hurt I braided her hair, she was a warrior and I guess that the medieval women would braid their hair when they went into battle so even if she did have a brain injury, it didn’t matter” (Rennie & Goforth, 2020).

For some, the positives were not just in their child's improvement and progress, but also in their capabilities in helping them get there. An uncle expressed a personal sense of achievement related to the progress of his nephew:

"From a condition of a baby to where he's at now, I feel I did a hell of a good job" (Smucker, 1996)

The Weight of it All

The theme around 'The Weight of it All' highlights the heavy, weighted, challenges that family members experience when a child has a TBI, such as a loss of their own selves and their health, the detrimental impact on family dynamics, and the continuous fight for their child's needs.

Loss of Self and Health.

Although parents' self-sacrifice for their children, this can intensify following child brain injury. Two mothers shared their experiences of putting their life on hold and neglecting themselves:

"Phil kept telling me, 'You have to do something for yourself.' I needed to go to the doctor. I had my period for thirteen months. Since Richard's accident, it never went away. How ridiculous. 'You go to the doctor.' 'No, no I can't.'… I'm stupid, you know. But I was totally neglecting myself." (Smucker, 1996).

"I always put myself on the back burner, for everybody, not just my kids. For my mom, for other people in my family, for my husband, when we were together. I've always done for somebody else, like now I'm raising my cousin's two-year old" (Wilson, 2009).

Whilst one participant had similar experiences of their health being impacted:

"My blood pressure has gone up a few times, I have headaches behind my eyes. I know it is stress, and it's like I was almost going through a depression, but I try to block it out, because I got to do what I got to do." (Wilson, 2009).

Another participant spoke of losing their own identity in the process*:*

"I have no time for me… I kind of lost my identity" (Smucker, 1996).

For some, this loss was in the form of wanting to disconnect socially and avoid others:

"The first time I had to go to the grocery store, it's a little stupid, but I made my girlfriend come with me. And I made her actually check the aisles, each aisle before I went down it, to make sure there wasn't anybody I knew... I didn't want anybody to come and say, 'How is Rachel?'" (Smucker, 1996).

Change to Family Dynamics.

Relationships within the family unit can become affected following a C-TBI, with breakdown to marriages and change to dynamics. One mother spoke about the disconnect from her husband:

*"I was on my own during this past year. I mean, like I said, I don't know how we survived... It would've been nice to have real support for my husband and I… I mean, it's affected our relationship". (*Roscigno et al., 2015).

Whilst a stepfather described the loss of closeness from his wife:

"There's no closeness... I actually will go as far as saying that the day that [step-daughter] was involved in that car accident, I lost my wife emotionally. That's how dramatic it was" (Brown et al., 2013)

Contextual Difference: Being the Sibling.

As well as parental roles within the family unit, siblings have their own role which can result in different contextual experiences. For some families, the strong focus on the injured child meant a shift in attention and time for siblings. One participant described their loss of attention to how their other children were doing:

"You have to watch because sometimes you get so focused on him, that for a while there I lost the progress of the other kids." (Jones et al., 2010).

Whilst one mother described how this shift in attention can create hostility from a sister towards her brother:

"I know she didn't feel that I was fighting for her as much as I should have been, or would have been had she not had all his problems. And it has caused animosity between them" (Roscigno, 2009)

Whilst another parent shared how they took their anger out on the sibling:

"I take my anger out on [sibling], because he's normal, well I don't know what it is, it's because I can't get angry at Seth, because he can't help it, but I can get angry at [sibling] because he can" (Brown et al., 2013)

For some siblings the experience was not always negative. One parent described how one brother protected his injured sibling if anything happened during school:

"If somebody's saying something to Roger (child with injury) on the playground, he'll be there… I don't know whether he's taken it on, that it's his role or it's his job or his duty" (Clark et al., 2008).

The Fight to Getting the Right Support.

Families experience a continuous battle in fighting for the child's needs, through health care and education systems. For some families, this fight was due to needs not being met because of hidden disability, whilst, for others, it was linked to decision making and greater consequences being at stake. One participant shared the need to be active for their child to not be overlook:

"If I had not been a really active parent, I think he might've slipped through the cracks because he does look normal, he does function better than a lot of other students do and because of that, I think he would've just fallen through the cracks." (Todis et al., 2018).

Whilst for other families there was a real battle in ensuring their child was not treated in a restrictive way by exploring alternative options themselves:

“They said that she'd need a nursing home for the rest of her life, and [they] were strongly encouraging us to put in a trach. For them it's kind of an "easy fix." … And, fortunately, one of [my child's] good friends had a contact… And so we just kept doing our research like that, and asking everybody… and they said, ‘You know-I don't know what the rush is. You have until at least ten days’” (Roscigno, 2009).

This experience was similar for an uncle who fought for their nephew to not be put into a home:

They [were] talking about a home for him, and I said, “As long as I ever live, he’ll never go to a home.” So they said, “Well, you’ll never be able to do what you have to do for him.” I said, Well, you don't know what I could do. You don’t know what a person could do.” (Smucker, 1996).

Contextual Differences: Punishment.

How people experience a C-TBI can differ dependant on contextual differences. Some cultures hold the belief that trauma is as a result of punishment. One participant shared their thoughts on God punishing them:

“I’ve done a lot of bad things. But did I do something that bad that I deserve to be punished by God this much?” (Smucker, 1996).

Whilst another explained how they were now paying the price for their child’s injury:

“I know I have done a lot of bad things, and I guess I am paying for my sins” (Wilson, 2009).

Another participant described feeling to blame for the child's injury, with God being aware of this too:

*"This whole thing is my fault. I know there are things in my life that I should have worked on. God knows that too" (*Wilson, 2009).

Not Reaching Out.

Whilst some people fight for support, some people feel unable to reach out due to culture norms. One participant detailed how in their culture, reaching out for help is not something that is done:

*"I'm one of those people that has to have control over everything. I am not going to see anybody [mental health professionals]. We [African Americans] don't do that" (*Wilson, 2009).

For another participant, reaching out for support felt like going against their religion:

"I really wanted to talk to someone, but I felt that asking for help was like doubting God" (Wilson, 2009).

Being the Man.

The role within a family can change how someone perceives and experiences a C-TBI. For fathers, there can be a tendency to feel unable to express emotions. One father shared regret in breaking down emotionally:

"It was hard to break down like that. I couldn't help it, there was nothing I could do [for my child]. I'm not used to being the patient. I'm the man I should have kept it in" (Wilson, 2009).

Whilst another felt unable to express emotion in front of others, with worry about what others would think:

"I have no choice but to keep it together but there are dark days when I cry alone. I won't let anyone see that… what would my family think? What would my girlfriend think?" (Wilson, 2009).

Just Not Good Enough

The theme around 'Just Not Good Enough' focuses on the lack of information and support within both the healthcare and school systems and the negative responses from staff which can impact on how families navigate and experience the brain injury journey.

Lack of Understanding and Information.

Families felt in limbo a lot of the time, with little information being given. One participant shared that a lack of information led to feelings of isolation and loneliness:

"I was sat in a room on my own. That was it, there was no-one there to say anything, or explain what they're doing, or, you know, how long it'd take, and this is normal. Nothing, just left in a room" (Kirk et al., 2015),

"You just feel so alone and you're with this child that you don't really know what you're dealing with" (Kirk et al., 2015).

Sometimes healthcare staff would use medical terminology, or give vague messages, leading to confusion. One participant described feeling scared when listening to medical jargon*:*

"I was like really scared, you know. I mean, I have doctors sitting there, using their doctor terms. And I'm like, could you break that down for me, cause I don't understand what you're saying" (Smucker, 1996),

Whilst others felt lost:

"Because there's experts all around you that talk this other language… you're dependent on their knowledge... so you feel a bit... sort of lost in it all" (Brown et al., 2013).

Beyond health care, the lack of understanding within the school settings was frustrating for many families. One participant shared how teachers knew very little about TBI, how to manage it and the exhaustion it took to teach others:

"*They [School personnel], they really don't know and understand, what exactly, a traumatic brain injury is and how to deal with the person with one… I'm basically having to teach everybody at school how to deal with, you know, this kind of situation" (*Roscigno et al., 2015).

The lack of understanding from staff in the education system was a regular experience for families, adding to the constant battle. One participant shared the blaze response from a teacher regarding shared information:

"One of his teachers said, 'I just got so frustrated with him because I just showed this to him yesterday and he did just fine and today he doesn't know how to do it.' Well, hello? It's the head injury!... I think they just looked through the information I gave them from the hospital like they were looking through a magazine" (Todis et al., 2018).

Whilst another participant described how their child kept being reprimanded for his behaviour with no understanding of the consequences of TBI:

"All he does is ban Z from break times all the time because he said Z is in a trance, he's not listening, and all he does is keep him in on his breaks and he misses his break… this teacher was shouting at me saying he's not listening. I said he does listen I said but he goes into these trances... They've not understood one bit, not one teacher's understood Z, they all keep telling him off all the time" (Kirk et al., 2015).

Lack of Support.

Families can also feel neglected in what support is available to them. One parent described the lack of support groups following the event:

"There's really not a support group for that… I was thinking I really want to maybe set up a support group, but then because I ended up suffering depression… emotionally, I can't do it because it just takes too much out of me" (Brown et al., 2013)

Whilst other families shared wanting support throughout the journey, to have someone to turn to:

"They need something to help the families, to prepare the families. They need someone that can, um, a psychologist, actually, that can make the... explain things and help them get through that process" (Roscigno, 2009)

"There was nowhere to turn to at all and that's all we asked for, we just asked for a phone number, just one number didn't we, just give us one number, someone to talk to, someone to ring" (Kirk et al., 2015)

For one mother, the lack of support led to difficulties trying to explain to her other children what was happening:

"Boy, I would like to have had family-centered care… my problem too was trying to explain it to my, my boys, the rest of the siblings" (Roscigno, 2009)

Negative Responses.

At times, families received news, which was delivered insensitively, adding to the negativity of experiences. One participant described a first interaction with a doctor being overwhelming:

"I don't remember meeting the surgeon before, uh, she went in. You know, neurosurgeons have to have a certain personality, a certain skill level... a certain experience, but he said something that just floored me… the first thing he said- I'm Dr. [name], I'm one of the dah-ta-dah-ta-dah. The first thing I want to let you know is [that] many children and

adults die from the type of injury she suffered. So, I'm like going, that's not what I want to hear. And I just walked away. First of all, at 1:30 in the morning, [that approach] doesn't help! Then for that to be the first thing that came out of his mouth, I just thought his bedside manner sucked... I walked away because I was overwhelmed" (Roscigno, 2009).

One participant shared their devastation and shock at such negativity and lack of hope from staff:

"When [my child] went in for her brain surgery, and she was brought back to the ICU, a nurse came in and told me, "You know she's not going to make it." And I was like, "What?" "And if she does come out of it, she's probably going to be a vegetable." I'm shocked on hearing this, and I, at that point, freaked right out. I demanded her doctor and all that in there, and he said, 'I cannot believe she said that to you'" (Roscigno, 2009).

For others, returning to school with negative responses from teachers added to the turmoil of experiences, adding to the sense of treatment not being good enough. One participant shared a teacher's response to their child wanting to return to school following their injury:

*"And his comment to her was, ''Well it couldn't have been that major, you didn't have very many brains anyways'' So, at 10:30 ... I get a call, [my daughter] is on the phone, she is crying hysterically ... I had to call the teacher and principal and demand a meeting" (*Roscigno et al., 2015).

Discussion

Overview

Previous literature synthesising qualitative research into family members experiences of C-TBI, which captures community settings and contextual differences, is limited. Therefore, this review synthesised whole family experiences of community life following C-TBI, whilst providing insight into contextual difference that may alter such experiences. The review included papers which enabled the voices of different family members such as mothers, fathers, and an uncle. Using articles of qualitative methodology enabled rich data to be elicited and depth of meaning across papers to be investigated.

The three overarching themes presented in this review were ‘Grateful for the Good’, ‘The Weight of it All’, and ‘Just not Good Enough’. Within these themes, contextual differences of gender, culture and role within the family provided insight into holistic experiences.

Whilst a child experiences detrimental changes to their daily functioning following brain injury, families also face challenges. Mothers, fathers, uncles, and siblings can experience their own difficulties when adapting to change that C-TBI can bring. These battles can be direct: fighting for the child to receive support, or indirect: having to teach others who do not understand the consequences of the injury. Where a child’s brain injury can be considered as a hidden disability, there can be overshadowing to the level of care they require. These findings are similar for parents of children with ABI whereby others not understanding their brain injury experiences led to feelings of social isolation and disconnect (Tyerman et al., 2017). Furthermore, adults with brain injuries, and other conditions such as chronic pain or neurodevelopmental disorders, have similar experiences of hidden disability being misunderstood resulting in frustration and exhaustion from having to educate others about their condition and needs (Kattari et al., 2018).

Family members were also battling to understand and adjust to what was happening to the child, whilst finding ways to manage themselves. Some families' coping styles, especially mothers, tended to put others first and lose a sense of themselves in the process. This loss related to not seeking support for their own physical health concerns or having time for themselves. These findings align with parent and spouse experiences following adult TBI in which self-care was often neglected, previously enjoyed hobbies were lost, and no time was spent on the self (Kratz et al., 2017).

For siblings of C-TBI, difficulties stem from being protective of the injured brother or sister whilst also trying to adjust to their parents' altered attention. These findings are similar for siblings of C-ABI who can also experience frustration, annoyance and embarrassment towards their sibling's injury and behaviour, with additional feelings of jealously due to the reduced attention given by parents (Bursnall et al., 2018).

Throughout the review there were glimmers of hope for participants, highlighting that despite the fear, the loss and the change, the child's TBI journey was not all negative. Addressing the secondary question of this review regarding what is helpful, family members were able to reflect on the good support they received from other family members, friends, religious groups, and staff within healthcare and educational settings. The understanding, compassion, and togetherness that this support gave, enabled families to feel able to cope. Staff being supportive in understanding the child's condition, providing clear information, and listening were deemed helpful during the families' journeys. This adds depth to Holloway and Ellis-Hill's (2002) research in which family members of ABI appreciated services being 'expert companions' whereby they help to make sense of the injury whilst showing humanness and positive regard.

In addition, families shared positivity that shone when reflecting on their experiences. Parents were able to establish new connections with their child and create a new sense of meaning from their child’s survival. This aligns with the concept of posttraumatic growth; the psychological shift in how people view and relate to the world around them which enables more meaningful living. Similar has been found within a systematic review of 35 studies into families following their child’s cancer. The children themselves, parents and siblings were able to use their experiences to reach posttraumatic growth including appreciation of life, closeness and connection with family and understanding themselves on a deeper level (Duran, 2013).

A person’s gender, or culture, can have an impact on experiences of C-TBI. For male participants, there was a tendency to avoid being emotional in front of others, to live up to somewhat outdated societal pressures to ‘be the man’. This could be related to the historical view that controlling emotions is associated with dominance, power and competence within the family role and that showing emotions connotes weakness (Timmers et al., 2003). These patterns have also been shown in more recent research, aligning with current findings. Bailey-Pearce et al. (2018) outlined that fathers of children who had received a life limiting diagnosis tended to adopt dismissive coping styles in which they struggled with their emotions; minimising the problem and avoiding talk about the illness or emotional aspects of it. In this review, people of African American heritage viewed reaching out for support as going against their faith and cultural norms. These findings are similar to Asian American culture where people were less likely to seek help and viewed mental health difficulties as needing to be independently managed (Meekyung et al., 2015).

To summarise, this review bridged a gap in the literature for whole family community experiences of C-TBI, where previous reviews tend to focus on certain family members and are somewhat outdated. This review aimed to gain a holistic picture of experiences from the perspective of family members beyond parents, whilst providing insight into contextual differences that can shape perspectives and experiences. The review partially achieved its aims as a further gap was identified: qualitative exploration into sibling's experiences solely related to C-TBI are extremely limited, where samples tend to include other illness/injuries and age ranges border into adulthood. Furthermore, the views of grandparents, who can contribute and hold a significant position in a child's life, is also limited. Whilst reviewing the methodology used within studies and reflection on how people share their stories, it is also clear that results stem from sole reliance on verbal expression during interviews. Arguably, there is scope for expression of experiences through other means, such as creative approaches.

Strengths and Limitations

The review was able to gather data for experiences across a spectrum of child age (1.5-18), with different family members; mothers, fathers and an uncle across experiences that encompassed education, healthcare, and support within the community. It also sheds light into contextual differences that can alter how families experience C-TBI, as well as the positivity that can come out of such a traumatic time. As such, results provide a valuable contribution to understanding the complex, multi-faceted nature of adaptation to life post C-TBI for family members. The results convey how social, cultural, religious, and other aspects of context shape individuals and family sense-making; how there is a potent mix of positive and negative experiences. Many of these experiences are intense and emotive for family members, providing insight into the complexity and emotional load for family’s everyday life. Furthermore, results highlight the importance of engaging with families as a system which might have a mix of shared and unique experiences, possibly shaped by context.

Despite the search strategy being open to all family members, the voice of siblings and grandparents continues to be limited. Across two studies, three participants were grandmothers, however, only one quote across papers was reported which did not add weight within the analysis. Furthermore, the experiences of siblings came from the voice of the parents, thus, is limited in direct contribution and understanding. Although not a synthesis of data, the researcher delved into Sambuco et al.’s (2008) review of sibling experiences following TBI to cross check why no sibling accounts were found in this current review. Within Sambuco et al.’s research the search terms were not stated, thus, robustness of search strategy is questionable. Some papers were quantitative in design and some included participants with multiple traumas or with ABI, despite the research focus being that of TBI. Despite the aim being paediatric TBI, papers reviewed included the time of brain injury up to the age of 28, and some did not focus on community experiences. It may have been beneficial to expand the current criteria to include injured children over the age of 20, however, it is arguable that this borders into adulthood brain injury. Thus, more qualitative research into direct siblings' experiences of C-TBI, with focus on younger children, is needed.

Out of the 12 papers, only five were categorised as ‘core’ and three categorised as ‘central’ to the research question regarding rigour, resonance, and relevance. Thus, it is arguable that despite common themes being found across all studies, not all were fully aligned with the research question, lacking richness. 100% of the included papers were screened by the second reviewer (DS) against inclusion and exclusion criteria, and 20% of papers were checked for CASP quality rating consistency. Ratings were aligned, with any discrepancies discussed. Themes extracted were discussed and agreed with the second author.

By including three thesis papers that were deemed a valuable contribution to the review question, the data was enhanced in richness and core analysis held further robustness. Although there were benefits from these papers to the overall review, a limitation lies within the search strategy not including open dissertations as a database, and although dissertations were not automatically excluded, rigour of searches could be improved.

Future Implications

Findings emphasise the need to improve understanding and awareness of child brain injury for people in services. Similar work within adult populations is being carried out using a theatre piece to share experiences of people with TBI, and their families, to increase understanding for healthcare staff (Colantonio et al., 2008).

The findings also outline what support is missing for families following C-TBI. The offer of support groups, as outlined as a need within the current findings, could help families relate to one another and share emotional turmoil. For some, this may need to be adapted depending on culture contexts, such as offering groups to groups of different culture and religion which may align with belief systems. Furthermore, clinical provisions such as psychology or support workers providing direct contact could be reviewed across services which support children and their families with TBI. Opening this support to other family members such as siblings or grandparents could also address any challenges within family dynamics and create more holistic understanding and management of C-TBI.

The review also highlights the need for awareness and education to be applied within educational settings regarding C-TBI, especially consequences related to ‘hidden disability’. Staff within schools should prioritise understanding TBI and make adaptations for a child’s learning and developmental needs to support families managing transitions. This aligns with the practical guidance provided within paediatric rehabilitation supporting children’s hidden disability when returning to school (Morley et al., 2022). As families battle with a lack of clear communication and guidance from healthcare and educational services, it could be beneficial for services to produce easy-read materials for families which outline the expectations and processes following C-TBI. Providing key information on the potential impact of brain injury and what support avenues may be helpful could enable families to feel more prepared in navigating life post C-TBI. Furthermore, specific advice on how families can look after themselves during the process could tackle the self-neglect that can occur at such difficult times. Additionally, this review highlighted that receiving vague and confusing messages from staff added to family's distress. As such, conducting staff training on communication outlining the unhelpful use of medical jargon and the development of interpersonal skills could alleviate some families sense of feeling isolated or lonely after their child's injury. This training could also extend to considerations of inclusivity such as whether families could be involved in more team discussions and decision-making processes, whilst being mindful of what stage a family is at post injury. This in turn could reduce families feeling in limbo about what is happening post injury. The review also highlighted that there can be a lack of opportunity to process experiences following C-TBI, with some families mentioning the desire to attend a support group, or have someone to talk to. This clinical need could be met with reflective spaces being offered for families, including siblings and other key family members, to share experiences and support one another in the journey. These recommendations are similar to that proposed in Rohrer-Baumgartner et al.'s (2022) protocol of a child ABI rehabilitation programme including seminars, and space, for parents to connect. Moreover, supporting understanding and connection post brain injury for all family members in a group format has been found beneficial within adult ABI in which people felt a sense of belonging (Wolffbrandt et al., 2024). A child TBI version of this approach may be helpful.

More research is needed to address caregiver experiences that go beyond parents. Siblings, grandparents, uncles, and aunties can play a key role in family functioning, thus, gaining insight into their own needs and struggles following C-TBI could be of benefit to the whole family system.

Conclusion

To conclude, family experiences following C-TBI can be negatively impacted by staff who lack knowledge of brain injury and fail to adopt approaches that adjust to a child’s needs. Staff being clear in their communication, proactive in their help and working together with other agencies was helpful for families. The role someone plays within a family system can alter how they manage to cope following TBI. Mothers tend to put others first, neglecting their own health and social needs, fathers can hold in emotions as not wanting to appear weak, and siblings are likely to be pushed aside. Some found solace in other family members, friends and professionals who were able to provide laughter, comfort, and support, with a sense of community being key to what gets some people through. For religious family members, recovery and hope was found in the strength of faith and through the practise of prayer. And for some, not reaching out for help, thus, isolating their coping aligned with their cultural beliefs.

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Chapter 3: Bridging Chapter

The previous chapter outlined a systematic review, synthesising qualitative literature exploring family experiences following C-TBI. Core themes provide insights that add to the wider literature, whilst addressing gaps in literature regarding contextual differences that can influence an individual's experience following a child's brain injury. The review also highlights a gap within C-TBI literature in which the voice of siblings, grandparents, uncles, and aunties is underrepresented.

The synthesis emphasised the importance of feeling heard and supported by others during the journey following child brain injury, whilst highlighting the tendency for family members to neglect their own selves. Child brain injury impacts the whole family unit and can result in disconnect between partners and siblings. However, not all families experience a breakdown in relationships, and some can shine a positive light on their experiences. All papers included in the review used verbal interviews to elicit experiences. As such, little is known about the sharing of stories with the use of a novel, creative, method.

Therefore, the second part of this thesis will explore the use of wool and stones material to address gaps in knowledge about what narratives arise for parents following C-ABI when creative methods are available. This study will also aim to gain insight into adaptation to life post-injury, with particular focus on community experiences.

What narratives arise from parents of a child who has sustained a brain injury when using the ‘wool and stones’ approach?

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Abstract

Aim: This study aimed to explore the narratives of parents following child acquired brain injury (C-ABI) with the use of creative materials.

Method: Seven parents (six mothers and one father) of seven children with ABI's were individually interviewed. A range of wool and stone material which differed in colour, texture, and size were available throughout interviews to provide opportunity to enrich the sharing of experiences. Parents spoken words and material use were analysed using narrative inquiry.

Results: Three core narratives were identified: 1) Suffering and Sacrifice: Throwing Stones 2) Relational Rupture and Harmony: The Forgotten Rock 3) Positive Discovery: The Shinier Stone. Non-verbal contributions were found from red coloured wool representing anger, the heaviness of stones showing heartbreak, and the lining up stones portraying roles, responsibilities, and the changing journey.

Conclusions: Parents can suffer from the disruption and disconnect that follows a C-ABI, whilst others find harmony in the support of others. For some, positive discoveries of hope and growth were found. The use of creative materials enabled non-verbal of emotional challenges, relationship ruptures and personality traits within the family, adding visual representations to the sharing of stories. Further research into the novel research method could be beneficial.

Keywords: Wool and Stones, material, child brain injury, ABI, parent, families, adaptation, coping, support, relationships.

Introduction

Acquired Brain Injury (ABI) is defined as external post-birth damage to the brain known as a traumatic brain injury from causes such as a fall or a motor accident or an internal cause such as a brain tumour, stroke or infection (Chevignard et al., 2010). C-ABI (C-ABI) is the leading cause of mortality and acquired disability (Palanivel & Burrough, 2021) which can have devastating physical, cognitive and emotional consequences (Anderson et al., 2012; Catroppa et al., 2008) resulting in reduced quality of life (Rivara et al., 2011). Due to the complex difficulties post C-ABI, parents can feel loss for the child that once was, the trauma of a life-threatening injury, and the process of hospital admission and procedures (Tyerman et al., 2017; Balluffi et al., 2004) which can result in significant parental stress (An et al., 2011).

The Impact

Following child brain injury, parents can be significantly impacted, not just in the early stages post injury but for months and years afterwards (Rashid et al., 2014). Focusing on one year post C-ABI, Aitken et al. (2009) discovered that parents can feel burden which is an increasing challenge when faced with unmet care needs, continuous anxiety, and disruption to routine. When behavioural difficulties are displayed by the child, this parental distress can be worsened further (Yehene et al., 2021). However, their research was cross-sectional, thus, limited in its application over time. For parents, the unknown in the early stages can lead to concerns for their child's functioning long term. Armstrong and Kerns (2002) found that children can have difficulties meeting developmental milestones which can result in increasing anxiety for parents about their child's future. The parent's worry can also extend to themselves. Hawley et al. (2003) discovered that taking on more of a caring role for the child, leaving paid employment with subsequent financial burden, and attending hospital appointments, parents are anxious around their own financial positions and futures. As a result, social lives can be impacted. Parents report less engagement in social activities, thus, have less support throughout such a distressing period of their lives (Hawley et al.; Benn & McColl, 2004). This research provides a basis into the bearing a child's brain injury can have on parents, however, due to the quantitative nature of these studies, insight into what these experiences are like for parents is limited. Some families, however, may not view their experiences as negative and may positively reframe what has happened. Similar has been found for family members of someone with a TBI whereby positive themes of anchoring, stabilising, connecting, and healing were found (Whiffin et al., 2021). Understanding parents' adaptation to life following C-ABI which captures both the significant challenges and potential hope and sense making of new meaning is limited within research.

Understanding parents' experiences following C-ABI highlights the ongoing emotional, social, and practical struggles. A meta-synthesis exploring the experiences of parenting a child following brain injury highlighted common themes of difficult emotions, isolation, seeking support in an insecure world and parenting a changed child (Tyerman et al., 2017). Perceived detachment and feeling misunderstood by loved ones and health care professionals can also be common for parents (Norman et al., 2023; Kirk et al., 2015; Jones et al., 2010). Also, relationships within the home can become strained. Some parents described the return from hospital being a key period in which adaptations, and prospects, for their different child become clearer (Roscigno & Swanson, 2011). For some, intimate relationships became more distant and insecure whereas, for others, these connections become closer, with more time and acceptance for one another (Tyerman et al.). This research highlights that not all experiences of a C-ABI are negative. However, research predominantly focuses on the negative consequences of a traumatic life experiences, missing a key element of posttraumatic growth (PTG) seen as a useful paradigm for understanding care of an individual's psychological and social care needs in a positive way (Picoraro et al., 2014).

Positive Adaptation

PTG is positive psychological change following a traumatic life changing experience, with themes of increased life appreciation, better interpersonal relationships, greater personal strength, awareness of new possibilities in life and development in spirituality and religion (Picoraro et al., 2014). The construct of PTG focuses on the here and now rather than rumination over past events, resulting in independence and healing of oneself (Calhoun & Tedeschi, 2012). The lack of discovery within stories of PTG could, therefore, result in less understanding of what parents might find helpful during their child's ABI journey. PTG, however, is not the only theoretically defined way of understanding positive outcomes. There are several models and approaches to positive aspects of life post-injury, such as people positively reframing what has happened or using life threads as a metaphor for narrative exploration.

Positive adaptation can occur through narratives shared following a traumatic life event. Nochi (2000) found that people on a previous life trajectory of harmful substance misuse that then had an accident causing a TBI were able to positively view themselves as a better version of their former self. Such adaptations enabled people to be grateful for their current lives, with some even being thankful for the accident happening (Nochi). Positive adjustments can also form when families have good social support (Prati & Peitranatoni, 2009; Zoellner & Maercker, 2006).

Another approach is through the phenomenological understanding and humanising methods to enable people to find their own way of positively adapting to life post injury outlined by Ellis-Hill et al. (2008). They developed a model for life adaptation following stroke based on a metaphor of 'life threads'. Threads represent narrative strands which highlight peoples' identities that may be unaffected, frayed, or broken following stroke (Ellis-Hill et al.). This model encompasses not only deficits, but also considers narrative threads which are not broken and still holding hope and positivity. The authors argue that stroke rehabilitation can open a wider range of narratives about future life, and professionals can engage with a person in a less fragmented way. Although based on an adult population of people with, and families of, stroke, this research broadens considerations into how people's narratives could be accessed beyond talking alone, and the elicitation of these narratives to include the whole of a person. The model has also been applied to help understand families of adults with TBI (Whiffin et al., 2021). Further creative methods could be considered within the research realms of child brain injury.

Creative Approaches in Family Work

Creative approaches in understanding people's experiences have been established within clinical practice. Within family therapy, many creative approaches have helped families to express or process their experiences. Sculpting was developed, using clay figures, to bring awareness to family members experiences and views of relationships (Loeschen, 1998). Historically, research highlighted that, for some, oral communication is used as an avoidance or distancing technique (Satir et al, 1991), however, the use of action with sculpting can add depth to understanding the dynamics and context of family conflict and challenges (Reiter, 2016). Challenging experiences can also be externalised through the creative use of drawing (Serneels, 2013) and photographs (Chan et al., 2012) in family therapy. Furthermore, the origin of the tree of life intervention by Ncube (2006) has evolved for families to share their values, skills, hopes, significant people, contributions to others lives and contributions by others using the different parts of a tree: the roots, trunk, branches, leaves, flowers, and fruit (Haselhurst et al., 2021). The tree of life approach has been found to support parents of children with physical health conditions to find alternative perspectives on their situation and discover skills and resources for tackling the challenges (Haselhurst et al.). This approach has also been found beneficial for individual sessions (Farooq et al., 2021).

Creativity in ABI Research

Supporting parents to reflect on their journey or find new narratives that may hold a sense of new meaning, growth or continuity of identity can be difficult within brain injury rehabilitation. Creative approaches can be used as a research method to access embodied, non-verbal aspects of an experience. The use of coloured wool and stones alongside a reflective space was found to be beneficial for patients sharing their experiences of stroke (Galvin et al., 2020). This study, however, only briefly mentions the use of wool and stones, and the approach was only used once out of the nine sessions. As such, the direct impact of using creative materials to support sharing stories in this case is unknown. These studies both focused on adults with stroke and either consisted of minimal reports of the use of creative materials (Galvin et al.) or was held in a group format (Ellis-Hill et al., 2019) making it difficult to understand how these approaches might be helpful for eliciting experiences including adaptive narratives in individual interviews.

Literature into parents' experiences of child brain injury through creative approaches is limited. Although support does exist for families of brain injury, this relies heavily on trained therapists, thus, the use of wool and stones as a creative intervention for parents may be considered more easily accessible and deliverable. Wool and stones was chosen as an open approach which contained little facilitation and procedure, allowing participants to guide its use and for the researcher to gain initial insights into its potential use. The variation of colour, texture, and size in the materials holds similar creative components to that of other approaches such as the tree of life. Whilst the open and flexible format of the approach may also be more inclusive of participants at different stages of their post-injury stories. Furthermore, although the use of wool and stones has been applied in stroke, more research is needed to detail the ways in which the approach helps facilitate people to engage in their own lived experiences and the articulation of these.

Current Research

This study will explore the potential use of wool and stones, as a creative method, to help parents articulate their experiences and potentially help them find new, adaptive meaning in life post their child's ABI. The research question is: 'What narratives arise from parents of a child who has sustained a brain injury when using the 'wool and stones' approach?.' The purpose behind the research question being broad despite the narrow funnelling of previous literature is based on wanting to openly explore the potential of this novel approach. Additionally, the research does not aim to restrict a person's storytelling or sharing of experiences which may occur if a narrower research question were adopted. This study is the first half of a wider study in which a second researcher (DS) is exploring peoples' experiences of the method and their views on its potential use therapeutically.

Methods

Design

This study used creative methods to facilitate, and open, alternative types of narrative construction. This study used a mix of flexible, semi-structured interviews consisting of open-ended conversation between researcher and participant, and creative materials to explore narratives. Responses from participants created the raw data which was analysed through a narrative approach.

Table 1

Inclusion/Exclusion Criteria

Applied to participants	Relating to the injured child
Parents, guardians or primary caregivers of, and living with, a child with an ABI	Aged between 2 and 19 years at time of injury. Reason being to reflect the aim of recruiting a diverse range of participants, allowing for heterogeneity of age, and associated neurodevelopmental stage at time of injury. Furthermore, this age range predominantly reflected NHS referrals and children in education.
Over 18 years of age	
Parents not experiencing mental health or substance use difficulties to a degree that may act as a barrier for their safe and meaningful participation	
	At least 12 months post injury. Reason being to allow time for acute distress to reduce and to capture lifestyle adaptation and change, which could otherwise be limited if carried out earlier.

Participants

Seven parents of seven children with ABI (Table 2) were recruited from a specialist community paediatric neurorehabilitation service in the National Health Service (NHS) between July 2023 to January 2024. Demographic information of the parents was collected (Table 2). All children had an acquired brain injury resulting from a range of different accidents or illnesses. Six of the children spent time in hospital and one was discharged the same day, with an at-length follow up investigation process.

Table 2:

Participant and family demographic data

Participant Identification Number	Ethnicity	Gender	Child gender	Child Age at Injury	Type of Injury	Time since injury	Family members at home
1	White British	Female	Male	14	TBI from recreational activity	2 years and 3 months	Mum and Son
2	White British	Female	Female	11	ABI, brain haemorrhage	2 years and 5 months	Mum, Dad, two sisters
3	White British	Male	Female	10	ABI, brain haemorrhage	2 years and 1 month	Dad, Mum and two sisters
4	White British	Female	Female	15	TBI from assault	1 year and 9 months	Mum, Dad and two sisters
5	White British	Female	Female	7	TBI following a fall	1 year and 8 months	Mum, Dad, daughter, one half-brother, one half sister
6	White British	Female	Male	17	TBI following car accident	1 year and 2 months	Mum, Dad and two brothers
7	White British	Female	Male	10	TBI following bike accident	4 years and 6 months	Mum, Dad, Nan, brother, and sister

Data Collection

A flexible interview topic guide allowed for exploration on topics of adaptation and support post C-ABI. Within this, questions were of a narrative nature; open-ended, allowing the participants to share their stories in a non-restrictive way. An audio recorder and a video recorder were used. Creative materials, specifically wool and stones of different colours, shades, and textures, were used, to allow exploration into any meaning that might arise from these. A photo was taken at the end of the interview to capture the wool and stones creation by the participant.

Procedure

Clinicians within the child neurorehabilitation service shared research information with people that would potentially meet full inclusion criteria and may be interested in taking part. Parents who gave consent for their contact details to be shared were then contacted by the researcher. All parents were given time to read study information and go through any questions. If happy to proceed, they were asked questions to check eligibility, and interview availability was discussed. Three participants opted to be seen within their home environment, with 4 being seen within a clinic where they were consented for the study.

A range of wool and stones was sporadically laid out on a flat surface, with one pair of scissors. There was no fixed structure on how these were laid out. These materials consisted of light to dark coloured wool, differing in thickness and texture; some rough, some soft. The stones varied in texture and size also, ranging from small to big, with some having sharp edges and bumps, whilst others were smooth and shiny. Participants were introduced to the material followed by no fixed instruction in how to use them, or the scissors (See Appendix K). Audio recordings were made of the interview, and video recordings were used to capture the use of the wool and stones. A flexible topic guide (See Appendix K) was used for conducting the interview. A photo was taken of the ‘wool and stones’ creation which was also used for Part 2 of the study.

Ethical Considerations

The NHS and Health Research Authority (HRA) provided ethical approval for this study (Berkshire Rec, Ref: 23/SC/0068). The University of East Anglia, Faculty of Medicine and Health Sciences Research Ethics Committee also approved the study.

Data Analysis

Narrative inquiry is an approach which does not assume objectivity, however, allows for positionality and subjectivity (Holstein & Gubrium, 2003). There are dual steps for narrative inquiry in which participants interpret their own experiences through their narratives which is then interpreted by the researcher through construction of such narratives (Riessman, 1993). To begin the analysis process, the transcription of data was initially carried out with the aid of software (Otter AI) which was then updated by the researcher for accuracy through relistening to audio recordings. Within transcription, the researcher also made note of emotional expression by the participant. Video recordings and digital photos were also reviewed for interpretation of meaning with the use of the ‘wool and stones’ material. Looking into the relationship of spoken words and the use of movement of the wool and stones material, analysis aimed to provide information into whether words and actions are consistent or contrasting to one another. A novel framework was developed by the researcher in which a ‘square’ of considerations was established. This ‘square’ analysed 1) the function of the narrative, 2) the context of the narrative, 3) whether the audio is convergent with the visual information, or 4) whether it is divergent of it.

Immersion in the data was carried out through the re-listening and re-watching of recordings, followed by re-reading of printed transcripts. Following this, a coding process took place, however, within narrative inquiry it is important that stories are not fragmented with relevant contextual material being omitted (Whiffin et al., 2014). Therefore, as recommended by Huberman (1994), the researcher returned to the research question and generated further questions that directly relate to it, allowing for key issues to be in the foreground without premature interpretation of the data during coding. These questions were: How does the parent make sense of themselves and others within their experiences of child brain injury? What use of materials does the parent use to add to the understanding of these experiences?

Once data was coded, a structural analysis was used (Labov, 2003) to understand personal narratives of parents:

Abstract: The core story
Orientation: When the brain injury happens, where, how and who was affected
Complication: The sequence of events
Resolution: what is the outcome, what change has occurred
Coda: The stories ending, where the story is now
Evaluation: How the participants comment on meaning of their narratives

Working with the structures, codes, quotes and reflections, core narratives were formed whilst maintaining a holistic analytic approach to individual stories. These core narratives were then compared across participants' accounts to highlight any similarities or differences within narratives.

Results

Three core narratives were developed 1) Suffering and Sacrifice: Throwing Stones 2) Relational Rupture and Harmony: The Forgotten Rock 3) Positive Discovery: The Shinier Stone. Similarities and differences across parents' narratives are discussed. The use of creative materials contributed non-verbal expression of emotions, relationships, and personalities within parent's stories, with variation in the use of colour, texture, placement, or size of materials. At times, material use was absent-minded and viewed more as a form of tactile touch or processing aid. A detailed account of the structural analysis, coding and forming of core narratives can be found in Appendix N.

Narratives of Suffering and Sacrifice: Throwing Stones

Parents described many ways in which they suffered, from their frustrated attempts to be heard, multiple personal sacrifices to have their child's needs met, and overwhelming feelings of anger. Within expressions of anger, dark coloured wool was sometimes squeezed, shook, or tightly wrapped, and parents spoke of wanting to throw stones or use scissors to cut out experience.

Some parents suffered through watching their child's suffering. For example, one mother described her heartbreaking experience, using stones to represent the weight she carried of nearly losing her child and the relentlessness of ongoing challenges:

P2: *"To have had such a bubbly, easygoing, happy-go-lucky child to one that is wracked with anguish, frustration, anger, disappointment about her life. Yes, it is heartbreaking. The whole journey is just heartbreaking. But it's now hearing that question: 'when is it going to get better Mum?' […] Definitely the stones relate to all that, those heavy, heavy feelings, and just that weight that you carry with you […] I don't know how parents cope when they've lost a child. Because when you've nearly lost a child, the weight of that, that just* *stays with you […] In the beginning, obviously it's heavy, and it's hard. But as time goes on, all those complexities just add, add, add. So you could have a mountain of these”* ***Made a claw-like shape with both hands and hovered over the pile of stones.***

For many of the parents [P1, P2, P4, P5, P7] the overwhelming feelings of anger continued to prevail because of others misunderstanding and lack of support for their child and family. For example, one mother expressed anger for the not feeling heard and constantly feeling the need to raise her voice towards healthcare staff to receive the right care for her son. Her anger also related to her belief that if her son was assessed when he was younger for his behavioural difficulties, the brain injury would not have occurred. This mother’s need to shout was followed by feelings of guilt. She also referred to herself as liking to be in control which is possibly reflected in her absent-minded, yet organized, use of the materials.

P1: “Everyone just tried to ignore me and thought I was being neurotic but I wasn't… I just wished that somebody listened so instead of being an unheard parent, I am now an angry parent […] I just feel that none of this was necessary […] I caused [injured child] to have such a big team because I shouted, and that ability to sort of advocate. I've never had to do it before. So that's why I feel so awful […] I am not too bothered what people are thinking […] but I still worry that I offend people.” ***She wrapped brown-blue wool around grey stone and took her time undoing knots in the wool as she found them. Then, she wrapped the grey wool around a grey stone, then lined stones next to each other (See Figure 1).***

Figure 1:

A photograph of parent 1's organised, and controlled, wrapped stones.

Some parents' anger came from other family members' lack of understanding which caused a disconnect between her and her brother. Her anger was portrayed through her touching the red wool and desire to throw the stones:

P2 "So we went over to her (Mum) house for dinner […] lots of people are talking. And she [injured child] can't cope with that. So she said to me, Mom, can I can I leave the table? […] she went into their living room and she just sat quietly for a bit. But then she picked up the phone […] So my brother came through and he went. 'Oh Alright, so you're not that tired then [injured child], you just wanted to just get out of it' […] I was furious… all jumbled together all the stones, could throw them at his head. And I was like, are you joking. Don't do that to her. Do you know how hard that is? For her to leave the table like that […] So you know, so that relationship broke down […] ultimately, I will put her first her needs first and… defend her". ***No use of material initially, but when discussing feeling furious she picks up the red wool and squeezes it tightly, then picks up the black wool and***

combines it with the red. She points out the stones when referring to the jumbled stones before continuing to fiddle with the red wool.

For two mothers [P5 and P7], the suffering of their lives no longer being normal led to anger. For one mother, the injury disrupted her perfect world, with lack of understanding from others angering her more. She used stones to represent her anger:

P5: "I would just say anger. And other people don't get it and […] and we had one thing together that was perfect and now we don't […] I would say it's just all these (material) […] just smash them up". ***Moves 10 stones into a pile together.***

For another mother, her anger stemmed from similar change as well as receiving no more support from professionals. She used the rough brown wool to describe her no longer perfect life and related the scissors to wanting to cut out what had happened:

P7: "At the minute, because you haven't got that perfect life, you haven't got even the color, you haven't got that life. You've got the hole that you're digging, that's getting bigger, because you're angry because you've got no help. Because you're not back to where you started, because you'll never be back […] The scissors are just anger […] I want to cut bits out. […] But it's anger because you see people […] you're all lucky because you've all got children and you've never been through anything like this […] And people can say, oh, yeah, I understand. No, you don't understand until it's happened to you". ***Initially points to the red and black wool, then touches the multicoloured wool. When she discusses no longer having that perfect life, she picks up the rough brown wool. She gestures to the scissors on the table when talking about them.***

For one mother, the initial suffering of fighting for her child's support and feeling fully responsible for her child's care turned into the sacrifice of her own mental wellbeing, where she was left feeling drained and exhausted. The processing of her thoughts may have been supported by her absent-minded use of fiddling with the red wool:

P4: "We're (her and husband) having this talk because I've been in a really low place the last month […] and I've got a counselling assessment next week […] He said, I think what's happened is you've fought and fought and fought. And now your body's just gone well, I need to stop. I need to rest, I need to whatever. And I think that's probably why I'm struggling more now". ***Fiddled with red wool absent-mindedly.***

This same mother's mental sacrifice was heightened by her whole family unit suffering from conflict and misunderstanding:

P4: "Her and her sister have started having the odd physical fight. I think it's been twice now […] And I know this sounds really awful. But I've always said to the girls, you know, you treat people how you want to be treated yourself. They're very respectful manners […] But they just broke out into this fight, and I could hear them slapping. But I physically have no energy to intervene, and it sounds awful. But I just said, you know, if you're going to hit her, expect one back, so they done what they needed to do, and it's happened twice. And I think that's partly [injured child] being frustrated and angry and [sibling] being frustrated because she doesn't understand […] And they are very sorry afterwards…It's just draining. When we're here [rehabilitation place] for [injured child's] brain rehab assessment and [staff name] said to us how would you describe your home, I said, toxic […] They (rehab staff) have said, once her rehab starts, it's there for the family as well […] [injured child] and [sibling] will have some sessions together. So, I think that's going to be a really positive thing […] I do know that beneath it all. They're good together and they do love each other, and *they have each other's back. But unfortunately, at the moment, it's just the worst that we're seeing". **Fiddled with red wool absent-mindedly.***

*P4: "I feel like I've lost my little girl that I had before […] I'm just treading on eggshells all the time trying to keep the family together. Sorry (tearful). My youngest daughter's struggling as well, with the changes in her sister. And my husband doesn't really understand the effects of the brain injury […] so he they're kind of arguing a lot […] it sounds really awful for me to say this, but I do think it's broken our family a bit". **Fiddling with red wool absent-mindedly.***

Mental suffering was not only experienced by mothers. A father expressed feeling low in mood once his family begun returning to routine. This father initially expressed being emotionally cut to being open and descriptive in the mental sacrifices he faced. He described his personality during the interview as disciplinarian and organised, which is portrayed through his intermittent organisation of the materials:

*P3: "I like to deal with my problems on my own […] I don't want my mum and dad to know my problems. I don't want (wife) to know, I just deal with it, you know […] And then (wife) comes back and she would say, how's your day? […] And I just said, I'm just really sad […] I don't know, I just felt it for a while. And then we spoke about it […] It's probably because [injured child's] back to school. Everyone else is back to doing their thing […] And I was still part time and […] I just said, look, do you know what I think I will go back full time". **Mostly not engaged with materials. Although when he spoke about being sad, he cupped the beige rope in his hands and scrunched it a few times. He then moved the black wool a few inches left.***

This father also shared his experiences of now worrying about his, and his families, health following his daughter's injury:

P3: "And whenever someone gets ill […] I get really bad like tight chest, Google what's going on [..] that's got worse […] I'm not a worrier at all. That's the only worry […] It's health around me and [wife] and the two kids. And even now, I feel my chest tight, just thinking about the health of the family". ***No material used.***

This father also suffered being a metaphorical 'kicking post' for his daughter's anger, where he used a sharp-edged stone and positioned the scissors to highlight her anger being directed at him. He also used different coloured wool to represent the different personalities and positions within his family:

P3: "Since the brain injury, she [injured child] can be quite cutting with her words. Quite sharp, quite angry with everybody in her real life. I feel that she needed to get this stuff out, she needed to be a complete pain for someone. And she couldn't do it to them (Mum and sister) […] This is 100% me (material) this like military. So that would be tough cord and absolutely organised. So then there's them and there is me (material) and, she has thought right, and I'll put the scissors near it (laughs) […] I think she just found me as a kicking post". ***He picked up tough green wool to represent himself, makes the ball neat. He pointed to the blue and pink wool to represent his wife and his other daughter. He turns the scissors to point to the tough green wool and moves the yellow, sharp edged, stone next to the scissors.***

Narratives of Relational Rupture and Harmony: The Forgotten Rock

Relational rupture and harmony narratives centred around the connections that families have following C-ABI, which can either aid or hinder a parent's experience. Narratives where families, members of the community and professionals worked together, in harmony, included parents who tended to share less ongoing distress in adapting to life post

C-ABI [P1, P3, P5, P6]. For others, ruptures in relationships or resistance to accept support resulted in parents feeling alone and losing a sense of themselves [P2, P4, P7]. Parental and sibling disconnect impacted a family's ability to work together. Use of materials to describe these experiences fluctuated between parents, regardless of whether narratives were around ruptured or harmonised relationships.

One mother shared her experience of feeling isolated in coping, with her partner being physically present but emotionally distant. She used stones to represent how she looks after everyone in her family, whilst she described herself as the forgotten rock. She used the largest stone at the top of the line to signify herself and the overarching responsibility she held. The choice of shiny stone for her husband represented his caring nature, whilst the jagged edged stone showed her injured son's anger:

P7: "And because I'm the rock […] when I'm trying to look after everybody, I'm forgotten about. So, hubby would be this one, I think because it's nice and smooth. So he's very caring and does look after me. But I have to be the bigger rock, [injured child] [laughs] is this one. But then you've got to make matters worse, and you've got my mum […] because she's a challenge as well. And then I think you've got [sibling] […] another challenge. And then I've got two dogs […], but all of them need me". ***Pointed to the big shiny beige stone when referring to herself, picked the smaller shiny grey stone for her husband. She picked the yellow, sharp edged, stone for her son, and the grey stone for her Mum, and the two small white stones for the dogs. She lined up the stones in order: herself, husband, injured child, other child, her Mum, and the dogs (See Figure 2).***

This same mother also experienced her friends disconnecting from her. With this, and her son's changes following ABI, she lost herself in the process and felt lonely. She did not engage with the materials when discussing her friends neglecting her. Possibly, for this mother, the visualisation through wool and stones is most important for those in her family:

"Since the accident, the friends that I had weren't really friends because they didn't know how to support me. So basically, everyone's dropped me. So it is a lonely life. […] people don't know how to deal with [injured child] and he kind of separates himself from life. So then that means that I can't do things. So, my life, is no life sort of thing". ***No material used.***

Figure 2:

A photograph of materials for parent 7's family structure, the black circle showing the hierarchy of responsibility starting with the largest stone for Mum.

Another mother described it feeling impossible to leave the care of her daughter to someone else through guilt and not believing others would understand her needs, causing relational ruptures in others trying to help. She did not use materials for this, possibly due to not feeling the need to:

P2: "And if I'm not there for them 24/7 that makes me a bad parent. I know it doesn't, but I still can't help but feel that way […] so again, it is the guilt […] because, you know, *people say to us, 'oh, you and [husband] need to get out […] we will come and sit with the girls'. But how do I tell those people, they don't want you to sit with them […] Because of the type of child she is, she feels that she has to sit and entertain people […] She wants to spend time with her nanny and granddad. But she's too exhausted to do that […] It's not fair to say we don't get any support. But it's not appropriate to take it".* ***No material used.***

With ongoing sibling rivalry, this mother felt less able to go out, losing a sense of herself:

P2: "I do need some time out because the conflict in this house starts the moment [sibling] is awake […] So yeah, the conflict starts […] So then I feel like, oh for god's sake, you know, that's more on me. I haven't got the energy for more on me […] there's not been a minute to breathe. You know, there's no time for anything". ***No material used.***

For three parents [P3, P5 and P6], their experiences of having a supportive and present spouse aided their ability to cope and work together through the challenges following C-ABI. One mother described not knowing how she would have managed without her husband's support:

P6: "I don't know how I would have got through it without him (husband) being there […] I guess we took it in turns to have the stronger days and the days where you just couldn't do anything. And I think I think we've probably got back to kind of where we were". ***No material used.***

Another mother shared similar experiences, where she and her husband worked together as a team:

P5: "I feel like we were just this team that needed to work together to do everything we needed for [injured child], and we were just kind of on it together as a unit working things out […] and working through each day". ***No material used.***

A father shared being supported by his wife in keeping connected with his friends:

P3: But I have a friend group that I have always met up with […] And I know it's really important to me […] she (wife) knows it's important to me. And she's all for it" ***No material used.***

One mother explained how further support was received from the community around her such as her friends and neighbours:

P6: "So when we were going backwards and forwards from the hospital, one of our friends would just turn up with a takeaway when we got back one night and our neighbours would of make us cottage pies and things and just leave them on the doorstep for we got home so we could just warm them up […] just people's way of saying that they were just thinking of you and were trying to help out". ***No material used.***

Narratives of Positive Discovery: A Shinier Stone

Positive discovery narratives focused on some parent's stories which were more reflective, sharing what they had learnt about themselves and their child, how they viewed their situation now and how they held onto positives for the future. Some parents were able to create new meaning following the disruption to their family, of which positive narratives could be formed.

One father's journey followed a trajectory of developing a sense of emotional connection and responding more compassionately towards his daughter, after initially describing a disciplinary style of parenting:

P3: "I think I just like to be a bit kinder to her and, not that I wasn't kind before, but I'd focus on maybe what she was doing wrong more than, you know, just being a bit kinder, because she needed it". **No material used.**

This father also reflected on being proud of his daughter, whilst using stones to represent traits of her personality and the progress she had made. He may have used a shiny stone to represent his daughter being a better version of herself (See Figure 3):

P3: "This was her before the brain injury, right. She was she's a clever, clever girl […] Then the brain Injury come, and she kind of went into real sharp […] and cutting with how she was. And then slowly, she got better and better. And now, she's better than she was. She's much more grounded. Her characters, she's grown up now […] And she's gone through all of this and like I say to her […] she's got the story that no one else has got […] I'll say to dig deep and I'll tell her to draw from that as well […] Actually […] I'm more proud of her than I would have". ***He picked up the large black stone and spins it 360 degrees when describing his daughter's sharp and cutting behaviour. He then moved the sharp-edged yellow stone next to the black one. When he talked about her getting better, he quickly moved four more stones into a line, ending with a grey shiny one. He points to the grey shiny round stone when saying his daughter is more grounded, then changed this for the shiny brown one. He made a line of 7 stones when he came to the end of his description.***

Figure 3:

Parent 3's use of stones to show their child's progress. The rest of the table shows how this parent organised the materials, aligning with their self-description of an organised personality.

For one mother, her, and her family experienced changing phases within the journey, where positive adjustments to family life post her son's ABI were made. She used the materials at the beginning of her interview to show these phases which was then followed by no interaction with material at all (See Figure 4). Coping for this mother's family meant using humour to lighten the impact of the child's injury:

P6: "I guess he gets quite moody with it. And I would say he's lost his filter [laughs]. […] so my husband had made lunch a few weeks ago […] poached egg on toast. And [injured child], I can't remember what he said, but it was something about how he wouldn't have wanted the ham and… He wouldn't have ever vocalised it. But we kind of just make a joke about it, like 'or you could just say thank you for my lunch' (laughs)". ***No material used.***

Whilst also being realistic in needing to make adaptations when going out as a family:

P6: "I guess it's just finding your new normal, you know that there are things that you can't do. And you just have to be more organized, prepared. And so and always have that backup so that if something that you've got the escape route, yes, [injured child name] can't cope in noisy places […] So I guess, if we got asked to go somewhere, when we book we request, and we kind of say, can we have a corner? Can we have somebody that's quiet?' […] you can still do things, but you just have to be more organised with the doing it". ***No material used.***

Figure 4:

Parent 6's use of material to represent the initial panic (red wool), the middle peak of being on edge (orange wool) and the present time of 'plodding' along (stones) for her child's ABI journey.

For one mother, the positive threads included being grateful that her son's accident happened because the alternative was troublesome:

P1: "I remember him as five. And looking at him and being really frightened for what his future held because he was so different. I don't mean to make it sound so dramatic. I am so upset he has had to go through what he's gone through. Medically, mentally, physically. I'm sad that his life won't be the same as it was… I think we've got a better [injured child]. And he might not see that. But I think he had potential to go on and do something really bad […] part of me is glad that he's now the way he is. Yeah, I think he stands a really good chance at life, he would have been written off, he would have been in youth detention […] He's going to be recognised for what he is after his injury and not for what he was before his injury". ***She continued to tightly wrap the grey wool around the grey stone.***

This mother also reflected on learning when to let go of the fight, especially to preserve her energy. She continued to wrap wool around stones and organise these; the potential need for control may be similar to the need to fight for her son:

P1: *"I have to learn to listen to some people. I'm not always right. Which a lot of the time I feel I am but I've been a single mom, it's I suppose it's a control thing […] I've learned a lot about myself in this, an awful lot […] I know my limits now […] [injured child]'s accident has taught me that I know when I need to stop. I know when it's all too much and I know that one has to step away and what to fight and what not to argue".* **Wrapping the grey stone using the white wool over time, then when discussing limits, picks up the brown-blue wool and the grey stone and begins wrapping this, taking her time.**

Discussion

The aim of this study was to explore parents' experiences following C-ABI with the use of wool and stones which differed in colour, texture, and size. Analysis of seven interviews revealed three core narrative that centred around the suffering and sacrifices families experience through the emotional upheaval which follows C-ABI, the variation of relational support leaving some parents feeling alone in coping, and the positivity discoveries of new meaning and adaptation for some parent's post-injury. The findings provide novelty into how the use of wool and stones can add a visual element to the spoken words of a parent's story.

Suffering and sacrifice narratives revealed that parents continue to struggle with why this has happened to their child, the change to family dynamics and how lives are different. Similarly, Kirk et al. (2015) found coming to terms with a different child was difficult and felt never ending for parents. In the current study, the suffering of trying to be heard and understood by others led to some parents sacrificing their wellbeing, with suffering being portrayed through the heaviness of the stones. Although previous research does not capture the creative expressions of experiences in this way, similar has been found for the suffering narratives. Families have had to fight for their child to be understood and supported which can be exhausting, and some family members have neglected themselves through being responsible for their child (Roscigno et al., 2015; Wilson, 2009). Within this study's findings, the sacrifices to normal family life and needing to fight for professional support led to anger being visually represented with red wool and desire to throw stones. Similarly, Brown et al. (2013) found parents expressed anger towards the injury and others involved, as well as the healthcare staff and processes. Difficulties with care processes was further identified following adult ABI such as limited brain injury knowledge, lack of continuing care and an ongoing need for emotional support for families (Norman et al., 2023).

Relational rupture and harmony narratives revealed that following C-ABI, families, and friends, can be torn apart and bought closer together. Some parents described disconnect between themselves, their partners, and siblings', potentially through lack of understanding for one another's position. These relational ruptures resulted in some parents feeling alone, losing a sense of themselves, and their family broken. Similar has been found for families of adult brain injury in which the closeness towards some family members could lead to distance with others (Whiffin et al., 2021). In the current study, the relationships were sometimes shared through materials being used to describe family characteristics and dynamics. For a father's story, pink coloured wool represented soft and feminine personalities, whilst sharp edged stones represented an angry child, with scissors used to direct this anger. Another parent lined up different textured stones to portray family members being looked after by the leading, forgotten, stone: Mum. Similarly, previous research has outlined that mothers' attempts to fix what has been broken following child brain injury, through constant advocacy and protection, can be unrecognised by the injured child (Glennon et al., 2022). Alternatively, in this current study, some parents described working together to cope. Stories highlighted that siblings could fight with each other, however, also show love at other times, thus, fluctuating between relational rupture and harmony. No rivalry was shared during one parents' account, with only support from family, friends and the community being their experience. This is partially in line with findings from Tyerman et al.'s (2017) review in which some parents experienced increased closeness within their family unit following C-ABI. However, this closeness was met with disconnect from others outside the family home where parents felt judged and misunderstood by friends and other family members (Tyerman et al.). As such, the parents account in this current study highlights the rarity in feeling supported in all aspects of a community following C-ABI. Where relational ruptures occurred, the use of materials tended to be used more to express experiences of C-ABI. However, when relationships were more connected, the use of material was minimal.

Positive discovery narratives revealed that parents' experiences are not always negative. Some were able to reflect on what they had learnt during their experiences. These reflections centred around parents understanding more about their feelings and actions following the trauma of C-ABI; becoming more expressive of emotions, more compassionate towards their child, learning when to let go of control and how to make adaptations. Similar positivity has been found for adults with ABI (Grace et al., 2015; Silva et al., 2012), and for families of adult ABI (Whiffin et al., 2021). Furthermore, some research outlines positive adaptation to how a parent views their child post ABI (Rennie & Goforth, 2020), however, positive discovery in relation to parents own learning and growth following C-ABI is limited.

The only father amongst participants went on a journey of being emotionally cut off and entering proactive mode at the beginning of his child's injury, explaining that he does not tend to show emotion or share his feelings with others. Supporting this, Brown et al. (2013) found fathers tend to use denial as a coping strategy, posing potential difficulties when seeking support. The father within this study became more open about his emotions with his wife, developed more compassion for his injured daughter and became a support for her mental health. One mother described being grateful for the injury saving their child, setting a new trajectory away from the possibility of being involved in crime. Similarly, research identified people reflected on being a better version of themselves following an accident causing TBI which redirected their path away from substance misuse (Nochi, 2000). Furthermore, narratives of positive discovery tended to come from parents who felt more supported during their journey. Positive adaptation following trauma can be associated with social support (Prati & Peitranatoni, 2009), with empathy and understanding within communities guiding posttraumatic development within narratives (Zoellner & Maercker, 2006). Having a supportive community has been found to help families hold hope and stability whilst continuing to heal post adult brain injury (Whiffin et al., 2021).

The use of materials also contributed to conveying a deeper understanding of what characteristics a storyteller may hold and the approaches they may have had when responding to their child's ABI. For example, the visual representation of the father who organised and tidied his materials throughout the interview aligned with his verbal descriptions of his disciplinarian style of parenting. Furthermore, the visual representation of the mother who tightly wrapped wool around stones tightly and lined these up, aligned with her verbal explanation of needing to be in control. This suggests that in addition to the wool and stones having the potential to add to the telling of stories, for portrayal of emotions and family structure, material may also connote characteristics within the parent themselves. Furthermore, it is difficult to know what function, if any, absent-mindedly fiddling with the wool and stones without a creative intention has.

Strengths and Limitations

This study used Yardley's (2000) suggestions of improving quality to provide strength in the robustness of the research. Regarding sensitivity to context, participants perspectives were generated through flexible interviews and non-directive use of materials, to allow parents to tell their story the way they wanted. The social constructivist standpoint also supports the notion that truth lies within the individual's perspective (Denzin & Lincoln, 2011; Amineh & Asl, 2015), thus, due to the individualistic dimension, this type of research does not aim to be generalisable. It is important, however, to consider the homogeneity within the sample, all participants were White British and only one was male. The lack of homogeneity may be due to the limited diversity within the geographical location where recruitment took place, and the tendency for men to not seek support following brain injury (Brown et al., 2013). Thus, men may less likely engage in research of this nature. The basic demographics such as socio-economic status was not captured which may have provided more understanding of the sample's diversity.

Regarding commitment and rigour (Yardley, 2000), in-depth, rich data was collated from seven parents which in the realms of narrative inquiry is a good sample size (Creswell et al., 2003; Staller, 2021). The richness of data allowed similarities and differences across narratives to be explored, whilst the use of wool and stones provided richer understanding of aspects of interviews. Although the non-direct approach to the use of materials allowed the researcher to gain an understanding of their use without influence, it may have been beneficial to allow access to materials prior to interview. Similar to other narrative interview structures, two interviews may have supported this process and enabled participants to become familiar with materials prior to sharing their stories, thus, possibly being more explorative in their use. Also, the narrative approach within the interview may have interfered with the creative use of materials, resulting in people adopting to their usual verbal style of communication. As such, it is possible that facilitating similar research without the use of any directed questions may have elicited more focus on story telling alongside interaction of the materials.

The researcher sought transparency and coherence (Yardley, 2000) by making decisions and sharing interpretations through a reflective diary and engaging in reflective supervision. Although transparency was not sought through member checking of interpretations with participants, Riessman (1993) argued that the final narrative analysis is achieved through ownership of the researcher. A further strength in this study is the role of the researcher having a background in clinical psychology, with skills in reflective listening and holding a curious stance. This enabled rapport to be built quickly between researcher and participant, and the potential of participants being more open in sharing their stories.

Implications for future research and practice

Material use fluctuated between parents, thus, the researcher reflected on how participants with ongoing suffering, sacrifice and ruptured relationships lacking in support were more likely to facilitate using materials to aid their story. This leads to the reflection, and possible future research possibilities, into whether parents who remain significantly challenged following C-ABI may benefit from the use of creative materials to express just how difficult this can be compared to those who have discovered positive adaptation. The novelty of this approach opens the potential for further exploration into wool and stones being used as a creative tool in research to facilitate different understanding of families following C-ABI. There also may be scope into investigating the usefulness of this approach as part of a therapeutic activity to support people to share their experiences. As the research was carried out by a clinical psychologist trainee, the clinical application of the materials without the need for a trained therapist is unknown. Findings from the second part of this study exploring the feasibility of material use, carried out by another trainee (DS), will further support any scope for future research and clinical practise.

Although parents may feel able to express difficult experiences away from the pressures of a group setting, the researcher did consider whether the use of materials was stunted by the 1:1 setting of interviews. The researcher reflected whether relating with, and observing, other's interaction with materials, in a group setting, may elicit further material use to aid storytelling. Previous research into stroke survivors' experiences using creative methods, including wool and stones, was carried out in a group setting and reported as beneficial to participants sharing their stories (Galvin et al., 2020). Therefore, future research using the wool and stones within a group setting may provide further insights into the addition of creative materials in the sharing of parents' stories, post C-ABI.

The narratives of relational ruptures highlight the ongoing clinical need for systemic work to capture holistic experience of families, including siblings, following a child's brain injury. When working with families, challenges as well as hope and adjustment should be explored, to encapsulate any positive adaptation. Supporting this, Bowen et al. (2018) provides guidance and techniques of how to formulate and intervene with families, focusing on factors such as communication, emotions and expectations following adult brain injury, which may be scope for exploring similar support for children and their families. Other research supports the importance of family work following ABI, with suggestions of what is helpful (Norup, 2018).

Future research exploring the use of creative materials within family work may provide insights into whether the method aids people to share their experiences systematically. Creativity used in therapeutic work with families can help connection and exploration, as well as imagination to share problems (Sophir & Koltz, 2024; Shubina, 2017). Future research investigating the use of creative materials alongside siblings sharing their experiences post C-ABI could expand creative interventions for children. Furthermore, the current findings highlight the need for some families to be supported to make sense of, and navigate, their strong emotional responses to the challenging battles faced in life post C-ABI.

Conclusion

Previous research outlines challenges parents face following child brain injury, however, the use of creative methods to aid such narratives was limited. This study contributed useful, initial, findings into the narratives shared by parents when facilitated by the creative use of wool and stones to help aid and express their experiences.

Parents shared, with or without use of materials, that brain injury can lead to family life being disrupted, with siblings fighting and family dynamics and routine being changed. Results highlighted how some parents used dark coloured wool and expressed desires to throw stones when discussing the emotional drain post C-ABI. Relational ruptures can result in some parents feeling alone in their suffering, with some mothers losing a sense of themselves. The weight of these experiences was expressed through descriptions of the heaviness of the stones, or the lining up of stones to represent overarching responsibility for the family.

Some families, however, were able to use their experiences to develop their sense of self, learn when to let go and hold a positive outlook on what had happened to their child. For these narratives, less material was used. Due to the current lack of comparison research, and this research being in the initial stages of exploration, concrete conclusions into the use of creative materials for narrative elicitation of child brain injury cannot be made. Future research may benefit from exploring the use of materials alongside verbal accounts of experiences within a group setting, or through providing materials to parents prior to their interview to allow time for familiarisation. Further research could support future clinical application of creative materials to assess and intervene within systemic family work following child brain injury.

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Chapter 4: Additional Methodology and Design Chapter

This chapter provides additional information on the methods and design sections of the empirical paper, providing further details into the qualitative research design and the narrative inquiry approach.

Method

Researcher's Position and Narrative Theory

This study is qualitative in design employing a social constructionist position. Ontology, considering the nature of reality, and epistemology, what methodology is used to gain this reality, is key within qualitative research and considered throughout this study. As the research holds a social constructivist position, and epistemology is a way of looking at the world and making sense of it, the reality within this research is discovered through the lens of an individual's experiences. These experiences are created through social and individual interaction and interpretation (Denzin & Lincoln, 2011; Amineh & Asl, 2015). Underpinned by social constructivist, narrative theory was adopted for this study (Sparkes & Smith, 2009). Narrative theory allows people to create their own stories following experiences which had, or continue to have, the potential to interfere with normal daily life, with people exploring their personal and shared realities through the construction of narratives (Sparkes & Smith). Narrative theory outlines that a linked sequence of events represents a story which can have a multidimensional purpose of communication from storyteller to audience, with particular interest in the meaning of the story as well as the experience of it (Herman et al., 2012). As such, taking this approach allows for parent's experiences to not be viewed as objective or generalisable, but unique and personal.

Sample Size Considerations

Due to the narrative theory of attaining individual experiences, solo interviews as opposed to joint ones were preferred. Determining sample size in qualitative research is a complex process influenced by factors such as the nature of questions, data type, available resources, and time constraints (Merriam & Tisdell, 2015; Patton, 2002). As narrative inquiry seeks to obtain detailed and rich information about an individual's cultural, historical, lifestyle and identity, emphasis does not sit with large sample sizes (Nigar, 2019). Within narrative inquiry, there is a lack of well-defined criteria or rules for establishing sample size, leading to generally small sample sizes (Vasileiou et al., 2018; Francis et al., 2010; Creswell et al., 2003). The concept of information power is described as the more information the sample holds that is relevant to the research aims, the lower the number of participants needed (Malterud et al., 2016). While narrative inquiry lacks specific guidelines on sample size, qualitative methodologies, generally prioritise data quality over quantity, with less emphasis needed on sample size and more into the novelty and richness of data being used to derive narratives (Staller, 2021). The final seven interviews within this study contained information power (Malterud et al.), with richness and depth to data attained per participant and the research question being answered.

Procedure

Patient and Public Involvement

Prior to the finalisation of the study's design, researchers carried out Patient and Public Involvement (PPI) to collate feedback on recruitment materials and interview guides. The PPI members consisted of parents, both mothers and fathers, of children of differing ages. Feedback, such as simplifying the language used within the participant information sheet, was taken into consideration when amendments to study materials were made.

Recruitment

As well as staff sharing information about the research, a research poster was used (See Appendix G). A total of 14 people shared an interest in the study and gave consent to be contacted. Out of these, seven people did not participate; four were uncontactable, one declined due to time commitment and one declined without a reason being given, and one did not meet inclusion criteria.

Materials

Alongside the video and audio recorder, a tripod was used as part of the study's equipment. Each set of wool and stones material was contained in lunch boxes for ease of transfer, specific details on their texture, size and colour can be seen in Table 1.

Table 1

Specifics on wool and stones used.

Wool		Stones	
Texture and Thickness	**Quantity and Colour**	**Texture and Size**	**Quantity and Colour**
Soft and thick	1X Red 1X Dark Blue	Rough and Small	9X White 2X Clear Yellow (jagged edges)
Soft and thin	1X White 1X Dark brown 1X Blue Green 1X Pink 1X Light Blue	Rough and Medium	3X White 5X Grey 1X Brown
	1X Black 1X Grey 1X Multicoloured, dark 1X Multicoloured, light	Rough and Large	1X Grey
Rough and medium (rope like)	1X Brown (extra rough) 1X Dark Green	Smooth and Medium	1X Off White 1X Black
	1X Beige 1X Orange	Smooth and Large	1X Black 1X Brown 1X Grey 2X Brown Yellow

Ethical Considerations

Informed Consent

Informed consent was given by all participants after time was given for them to read the participant information sheet and discuss any questions they had with the researcher. The opportunity to ask questions occurred at two different stages, during a telephone call prior to the interview, and again at the time of interview.

Risk and Benefits

Duty of care was key as the study explicitly addressed challenges of emotionally adjusting to life after a child's brain injury, thus, it was anticipated that parents may be in a vulnerable place. Although distress was anticipated, the wellbeing of participants was considered throughout interviews. Participants were reminded that if, at any time, they wanted to have a break during the interview they could. After the interview, participants were provided with an interim debrief, an opportunity to reflect on how they were feeling and were provided a list of support avenues. These support avenues were provided again at the end of Part 2 of the study. Once completed both parts of the study, participants received a £20 voucher as an appreciation of their participation.

Confidentiality

All personal information was anonymised and identifiable information from transcripts was replaced with a placeholder e.g. [injured child] being used in place of the actual child's name. Data was stored on a secure server and only accessed by members of the research team.

Data Analysis

Within the structural analysis process, the researcher followed the principles of narrative inquiry whereby focus was on 'sequences': the order of events shared to create a story subjectivity and 'consequences': the interpretation of what happens next from the storyteller (Riessman and Quinney, 2005), these elements make distinctions for narrative analysis from thematic and grounded theory approaches (Floersch et al., 2010). The focus on sequences was captured within the ‘complication’ of the structural analysis, whilst the focus on consequences was within the ‘coda’ component.

During the data collection and analysis, a self-reflective journal was used in facilitating the collaborative construction of the narrative between the participant and the researcher. It served as a tool to document additional observations or insights into how the researchers felt, thought, or reacted within the interviews, potentially linking to any relational aspects of the participants' narratives, as suggested by Manning et al. (2017). Additionally, reflective supervision with academic supervisors was carried out to achieve the same goal. Furthermore, Riessman (1993) outlined that stories have more than one interpretation, thus it is the researchers’ work that create the final analysis and take ownership of their work. As such, member checking was not employed within this study, aligning with principles of narrative analysis. Consequently, the analysis resulted in a narrative being co-created by the participants and the researcher.

Chapter 5: Discussion and Critical Evaluation

This chapter details the findings, strengths, and limitations for both the systematic review and the empirical paper, and a discussion of where the thesis positions itself within the wider literature. Reflections from the researcher and a conclusion will be posed at the end of the chapter.

Summary of Findings

Overall, this thesis aimed to explore the experiences of families following child brain injury. For the systematic review, the aim was to synthesis family experiences of community adaptation post C-TBI, whilst considering contextual difference that may influence these. For the empirical paper, the aim was to explore parents' experiences following C-ABI using a creative method of wool and stones material which varied in colour, texture, and size.

The rationale behind these two pieces of work is centred around the gaps in research. Firstly, no previous review has been conducted which 1. synthesises family experiences of C-TBI, 2. contains inclusion criteria of all family members voices, and 3. considers contextual differences which may influence individual experiences. As such, this current systematic review aimed to bridge these gaps. Secondly, no previous research exploring the use of creative materials in understanding parents' adaptive narratives of C-ABI has been caried out. Literature is also limited in understanding positive experiences or where parents find meaning post C-ABI, thus, this work aimed to close these gaps.

The overall thesis overall focused on application of qualitative methods to attempt a deeper understanding of the context-dependent experiences and narratives of families impacted by a child brain injury. The novelty of the method used in the empirical paper is enabled by the bottom-up approach that tends to occur within qualitative research, allowing for initial insights and emergences of a novel idea whilst consideration the researchers' stance and interpretative style (Willig, 2019). Qualitative research centres on seeking in-depth, enriched detail to gain meaning of experiences, attitudes, and behaviours, in a naturalistic setting. This approach allows participants to make their own ‘sense making’ regarding their own personal reflections on an experience, answering ‘why’ rather than ‘what’ when it comes to the research question (Willig). As such, this thesis used qualitative methods throughout.

The systematic review found three overarching themes: ‘grateful for the good’, ‘the weight of it all’, and ‘just not good enough’. These themes shared insights into families’ experiences of fighting battles to receive good care and for others to understand their child, with this being further challenged when the injury is ‘hidden’. These findings aligned with previous research (Tyerman et al., 2017; Kattari et al., 2018). Further results within this review outlined that families struggled to adjust to what was happening to their child, with some parents, especially mothers, losing a sense of who they were, which also links with previous research (Kratz et al., 2017). Findings also included the idea that siblings face difficulties adjusting to receiving less attention from their parents whilst also being protective over their injured sibling. Similar has been found previously (Bursnall et a, 2018). Moreover, gratefulness for other people’s support and hope for their child was found within the review, similar to positive adaptation experiences in previous research of adult ABI and childhood cancer (Holloway & Ellis-Hill, 2022; Duran, 2013). However, it is important to note what the review found that previous research does not. Contextual differences such as gender influencing a father’s experience of child terminal illness (Bailey-Pearce et al., 2018) and culture influencing the likelihood of seeking support (Meekyung et al., 2015), contextual differences for the experiences of families post C-TBI was a new insight within this review. For some African Americans, the concept of reaching out for support was not regarded as the norm, whilst the trauma they had experienced with their child was sometimes viewed as punishment from God. The review highlighted that fathers felt the need to hold emotions in and held concern over judgement from others if being seen as upset. For siblings, the relationships with their parents, as well as their injured sibling can be impacted, highlighting the contextual difference of role within a family impacting on experiences post C-TBI. Although sibling experiences were described by some studies within the review, a limitation of the research was that these were reported by parents. Thus, firsthand accounts of sibling's experiences of their brother or sisters TBI continues to be lacking.

The empirical paper found three core narratives: 'Suffering and Sacrifice', 'Relational Rupture and Harmony', and 'Positive Discovery'. These narratives shared insights into parents' experiences of struggling to adjust to what has happened to their child, how their family has been impacted and how their sense of normal is lost. Parents suffering continued when they felt unheard and misunderstood by others, leading to some having to fight for their child's support. For some, the sacrifices they made within their journey resulted in their own mental health difficulties. These findings align with previous research (Norman et al., 2023; Kirk et al., 2015; Roscigno et al., 2015; Brown et al., 2013; Wilson, 2009). Further findings within the current study outlined that some parents felt close to their loved ones which helped them through, whilst others felt disconnected and unsupported by those around them. For some, they lost a sense of who they were and felt neglected. For the lack of support, and loss, similar has been found in adult TBI research (Whiffin et al., 2021) and research into mothers' identity following child brain injury (Glennon et al., 2022). For the experiences of closeness and togetherness helping parents get through, similar has been found in previous research (Prati & Peitranatoni, 2009; Zoellner & Maercker, 2006). Findings included the idea that not all experiences are negative, one parent was grateful their child's injury happened as it possibly saved them from getting into trouble, similar to the appreciation found in adult TBI research (Nochi, 2000). Other discoveries highlighted that positive adaptations of using humour and adjusting to a new way of living can occur for some families. Similar has been found previously in adult research (Whiffin et al.; Grace et al., 2015; Silva et al., 2012). However, the current findings of positive discovery gained new insights into how some parents might reflect on their own ways of managing difficulties and adapt their sense of self. One parent learnt when to let go of control and the need to reserve her energy, whilst another developed his ability to share his feelings and become more compassionate as a father. Thus, this provides an understanding into how some parents may not just reflect on how they view their child and the positive adaptations to life post brain injury, but some may also positively adapt how they approach challenges, through self-reflection and self-adjustment.

Although literature already details some information about the use of creative methods to aid sharing of experiences in areas such as stroke (Galvin et al., 2020; Ellis-Hill et al., 2008), the most pivotal new insight within this current study comes from the use of the wool and stones and what this added to parent’s narratives. The novel findings show how the use of material can add a visual element to the spoken words of a parent’s stories following C-ABI. Having wool and stones available through the telling of stories enabled emotions to be portrayed using colours and textures. For example, some parents moved dark coloured wool and shared a desire to throw stones to represent their anger. The availability of wool and stones also supported the visualisation of the roles and responsibilities within family structures. For example, one parent lined up stones to show all the family members they are responsible for, whilst another used different coloured wool to describe personalities and positioned the scissors to emphasise where their injured child’s anger was directed. Furthermore, the use of wool and stones also provided insight into traits of a parent such as the need to be in control, or organised. For example, throughout one parent’s interview, they continually wrapped wool tightly around stones and formed an orderly line.

Additionally, the sensory touch of the wool and stones achieved through fiddling with wool or wrapping wool around stones may have supported the cognitive and emotional processing of sharing experiences. This theory aligns with the broader literature on how individuals process and work through traumatic experiences. Using creative materials can offer an alternative and suitable treatment for trauma, as the nonverbal and experiential aspects of art therapy provide visual, and wordless, approach to support the processing of traumatic memories (Schouten et al., 2019). Art therapy methods such as drawing, painting, and collage have been integrated into treatments for posttraumatic stress disorder (PTSD). The creative engagement in art can facilitate stages of trauma processing, including stabilisation, accessing, and expressing traumatic and positive memories, and making sense of past and present emotions. This process is then integrated into new artwork with a focus on future opportunities (Schouten et al.). These interventions have been found to help individuals feel less stressed, more relaxed, experience fewer intrusive thoughts, and feel more confident and hopeful about the future (Schouten et al.). Similarly, a systematic review of 20 studies found that art therapy, including creative drawing, visual journals, and pottery, aids in processing trauma memories and helps people to fosters a holistic self-view and positive self-identification. However, the review noted that the studies were generally of low quality and relied heavily on case studies. Creative materials can also help individuals access deeply embedded trauma memories that have not yet surfaced. For example, art therapy through drawing, painting, sculpting, and photography has been shown to help alleviate symptoms of anxiety, PTSD and dissociation in children who have experienced sexual trauma (Laird & Mulvihill, 2022). The authors suggest that art therapy may offer a communication platform that helps construct narratives when verbal communication is limited. In relation to the current study, there is a theoretical consideration that using materials such as wool and stones could provide a therapeutic foundation to help parents process and transform non-verbal representations of difficulties experienced following their child's ABI.

Critical Review

The systematic review aimed to capture the experiences of various family members dealing with C-TBI and partially succeeded by including the perspectives of mothers, fathers, and uncles. However, the voices of siblings were only represented through their parents' accounts, and the views of grandparents were not heard despite two studies including three grandparents among their participants. The review gathered data on experiences across a wide age range at which the child sustained their injury (1.5-18 years) and covered areas such as education, healthcare, and community support. It also highlighted contextual differences that affect how families experience C-TBI and revealed the potential for positive outcomes from such traumatic events. The results demonstrate how social, cultural, religious, and other contextual factors influence individual and family sense-making, showing both positive and negative experiences. These experiences are often intense and emotional, offering a deep understanding of the complexity and emotional burden on families' daily lives. Furthermore, the findings emphasise the importance of engaging with families as a system with similar and unique experiences shaped by specific contexts. Consequently, the findings contribute valuable insights into the complex, multifaceted nature of family adaptation to life post C-TBI.

Of the 12 papers reviewed, only five were categorized as 'core' and three as 'central' to the research question regarding rigor, resonance, and relevance. This suggests that while common themes were identified, not all studies were fully aligned with the research question and some lacked depth. In terms of review quality, all included papers were screened by a second reviewer (DS) against inclusion and exclusion criteria, and 20% were checked for consistency in CASP quality ratings. The inclusion of three thesis papers, which provided rich data and strengthened core analysis, added value to the review. However, a limitation was identified in the search strategy, which did not include open dissertations as a database. Although dissertations were not automatically excluded, improving the rigor of searches could enhance future reviews.

The empirical study offered insights into using a novel method involving wool and stones to creatively explore parents’ narratives following C-ABI. To enhance the quality of the research, the study's methodology drew on principles using Yardley’s (2000) reflections on the dilemmas in qualitative research quality. Sensitivity to context was maintained by generating participants' perspectives through flexible interviews and a non-directive use of materials, allowing parents to narrate their stories with minimal influence. However, the sample lacked diversity, as all participants were White British and only one was male. This homogeneity could be attributed to the limited diversity within the geographical location of recruitment and the tendency for men to avoid expressing emotions or seeking support following brain injury (Brown et al., 2013), possibly making them less likely to engage in such research.

Interviews with seven participants provided in-depth, rich data, which is a suitable sample size for narrative inquiry research (Creswell et al., 2003; Staller, 2021). The richness of the data allowed for exploration of similarities and differences across narratives, whilst the use of wool and stones enriched the understanding of interview aspects. Participants were given the choice of conducting the interview at home or in a clinic, with the researcher's flexibility aiming to make participants feel comfortable, thus more open in their storytelling.

The non-directive approach to using materials helped the researcher understand their use within narratives without influence. However, as the materials were only seen by the participants on the day of the interview, their lack of familiarity with the wool and stones may have hindered their use. As such, there two key limitations. Firstly, not allowing enough time for participants to be familiar with the materials or guidance in their use to foster creative engagement as opposed to leaving them with one opportunity to explore the materials. Secondly, narrative analysis can typically involve a second interview whereby organising the material that came from the first interview into a narrative structure between research and participant in the second interview could have occurred. Consequently, the single interview structure may have been restrictive in both the construction of material use and narratives.

Following Yardley (2000) principles, the researcher aimed for transparency by noting decisions and sharing interpretations through a reflective diary and supervision. Although member checking of interpretations with participants was not conducted, Riessman (1993) argued that the final narrative analysis is ultimately the researcher's responsibility. A notable strength of the study was the researcher’s background in clinical psychology with skills such as reflective listening and being curious. These skills likely helped rapport building and possibly made participants more comfortable and open in sharing their stories. However, this strength also presents a potential limitation, as the creative use of wool and stones may have been influenced by the researcher’s psychological skills, thus, limiting its potential application beyond the realms of psychology.

Suggestions for Future Research

From the systematic review, more research is needed to address family experiences that go beyond parents. Siblings, grandparents, uncles and aunties can play a key role in family functioning, thus, gaining insight into their own needs and struggles following C-TBI could be of benefit to the whole family system. Additionally, the inclusion of diverse family members might highlight different or greater significance across cultures to provide further understanding of contextual experiences. Given the valuable contribution found within the three thesis papers, this review could be readdressed by a future researcher to include greater diversity of literature sources such as open dissertations. In doing so, a variety of family members voices, and further contextual differences may be found.

From the empirical paper, material use varied among parents, leading the researcher to observe that those experiencing ongoing suffering, sacrifice, and ruptured relationships with little support were more likely to use materials to aid their storytelling. This suggests that parents facing significant challenges following a child's ABI might benefit from using creative materials to express their difficulties, compared to those who have found positive adaptation. The novelty of this approach presents opportunities for further exploration into using wool and stones as creative tools to facilitate understanding in research on families dealing with child brain injury. It might also be of benefit to consider conducting future studies without directed questions and more focus on material interaction. Additionally, there is potential to investigate the usefulness of this approach as a therapeutic activity, helping people share their experiences post-ABI. Since the research was conducted by a clinical psychology trainee, the application of these materials without a trained therapist remains uncertain. Therefore, there is scope to discover whether the use of wool and stones during storytelling differs when facilitated by healthcare professionals outside of psychology.

Although a group setting may elicit reluctance in some parents to express difficulties post C-ABI, the researcher reflected on whether the 1:1 nature of interviews stunted material use. Thus, there is scope for further research to explore the use of materials to aid narratives of life post ABI for parents, within a group setting, similar to the research methodology carried out by Galvin et al. (2020). Furthermore, future research could also investigate the use of wool and stones during family work, including the exploration of sibling experiences. This research may shed light into the usefulness of creative materials in helping individuals to express themselves amongst their family through a traumatic and challenging time.

Implication for Theory and Practise

The systematic review highlighted the need to enhance understanding and awareness of child brain injury among services. Raising awareness in TBI have been carried out within adult populations (Colantonio et al., 2008). The current review also revealed a lack of support groups for families, which could help them share and cope with the emotional challenges following the injury. These groups could be adapted to various contexts, such as aligning with specific religious or cultural values and practices. Additionally, clinical support services should aim to include other family members who may feel less heard, such as siblings or grandparents, to foster a holistic approach to adapting to life after a child’s TBI.

Furthering the support received post TBI, the review also emphasised the need of increased awareness within education systems, particularly in relation to 'hidden disability'. The practical guidance provided by a paediatric rehabilitation service (Morley et al., 2022) aligns with the idea of educational staff prioritising TBI education and adjustments.

The narratives of relational ruptures in the empirical paper highlighted the ongoing need for systemic work within clinical settings to capture the holistic experiences of families, including siblings, following a child's brain injury. When working with these families, it is important to explore both challenges and avenues for hope and adjustment, to identify opportunities for positive adaptation. Bowen et al. (2009) offer guidance and techniques for formulating and intervening with families, focusing on communication, emotions, and expectations following adult brain injury, which could potentially be adapted for children and their families. Other research also underlines the importance of involving families in post-ABI interventions with suggestions as to what helps (Norup, 2018), which is later supported by trials of family interventions showing improved quality of life and reduced burden (Soendergaard et al., 2023). Given the novelty of the research, the clinical application of using wool and stones may be premature, suggesting a need for further investigation in this area.

Researcher's reflections

My interest in families of child brain injury stems from my work experiences prior to clinical training. I worked in a neurorehabilitation unit for adults, and I attended a conference which involved families of C-ABI, which was emotionally driven and extremely thought provoking. I hold a strong belief that not everyone expresses themselves best through talking, therefore, I wanted to work on a project that gave families a platform to go outside the box. I would describe my experiences of carrying out this project as an emotional rollercoaster, with some large loop-the-loops to endure and some tear-jerking moments.

Before interviews began, I was aware that I might get emotionally pulled in, and I was right. Some interviews I found more emotionally charged than others and these tended to be with the parents who became tearful when talking and who felt less supported and more alone. The stories were sometimes hard-hitting and traumatic, however, some were quite upbeat and positive, with laughter being shared. I reflect on my naivety that all stories would be full of sadness and consider how some brain injury diagnoses might look similar on paper, but the social context of families, and personalities of parents, really support my social constructivist standpoint that all stories are individual. The stories really taught me the value of social support and connectiveness in families, which made me reflect on my own.

Prior to the first interview, I was apprehensive to how parents would respond to the novelty of the study's approach. I found myself feeling an inward pressure for parents to use the wool and stone materials in ways that would mean I can write amazingly, ground-breaking findings, but this is not the way research works. After the first couple of interviews, I relaxed into my new frame of thinking that whatever a parent decides to do with the materials – or not – is telling. My reflections can be seen in some examples of reflective extracts I wrote after interviews (See Appendix P). What struck me with the materials is the go-to use of the red wool for expressions of anger. Almost all parents used the red wool in some way, whilst some materials such as the dark blue were hardly touched. I also found myself surprised that no-one used the scissors to cut pieces of wool to varying lengths, again a preconception of mine about how materials would be used. After completing interviews, I felt a strong need to do the analysis justice, for parents to feel heard, even if for the first time.

From listening to parents' stories, and from seeing the lack of sibling representation within the systematic review, I have reflected on how interesting it would be to carry out a similar study for siblings, especially as I think children would get even more creative - but this is me jumping the gun. I feel truly honoured that parent's trusted me enough to share their raw experiences. I now reflect on my expanded willingness to contribute to research in the future if the opportunity arises, as without the participants contributions, these pages would be blank.

Conclusion

This thesis outlines the complex and multi-faceted difficulties that families are faced with following child brain injury. It also highlights that not all experiences are negatively focused, with some families adapting and reflecting positively. Both papers emphasise the impact and challenges that siblings endure, without their direct voice being heard. The novel findings of using wool and stones materials suggests that the use of colour, size and texture can add visual representations to narratives. Future research would benefit from further exploration into the usefulness of this creative approach.

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Appendix A: PRISMA Checklist

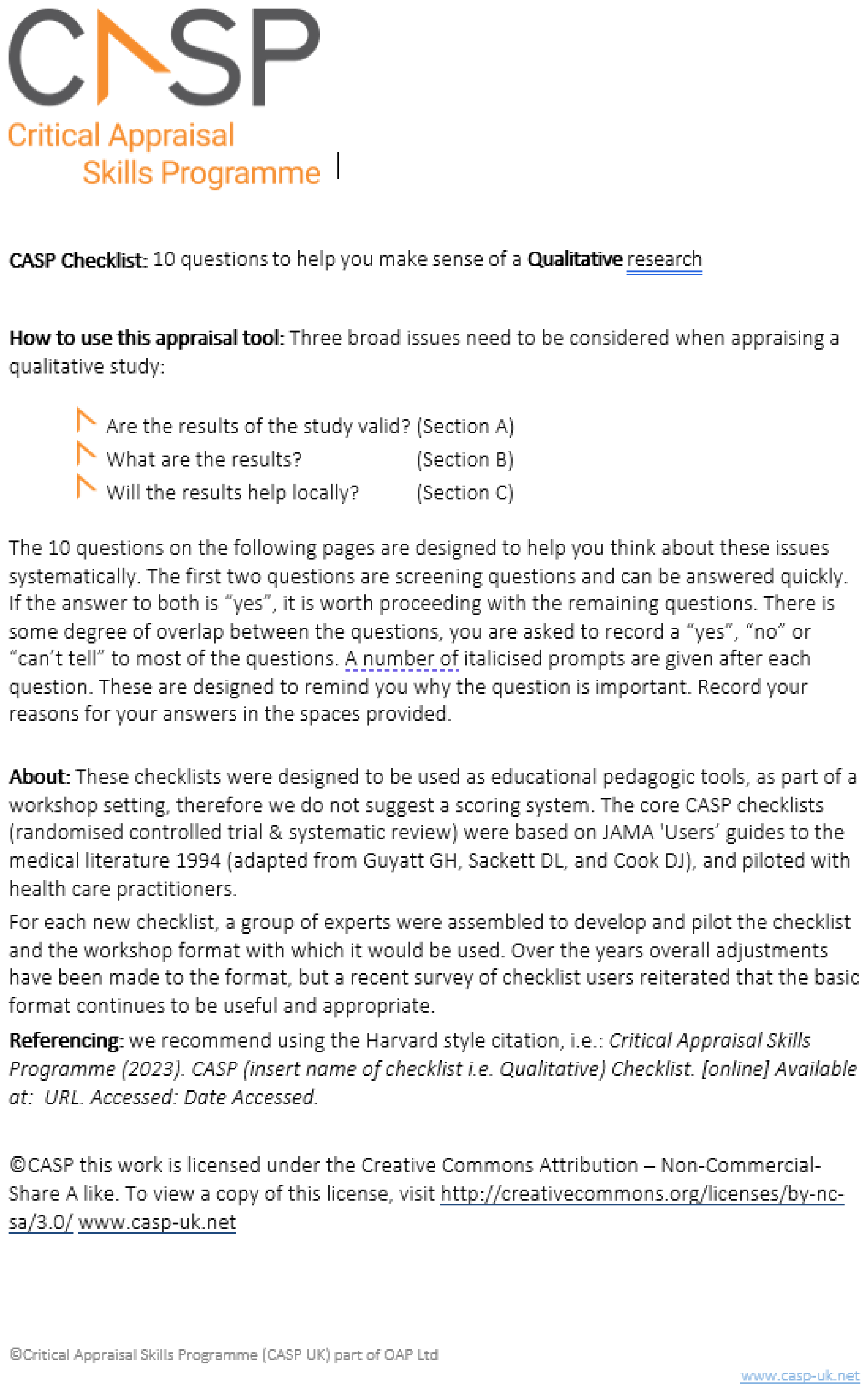
Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 2
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 18 and 19
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 12
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 19 and 20
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 12
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 20 and 21
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 24 and 25
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 12 and 22
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 27-31
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	-
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 12
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	-
Synthesis	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and	Page 27-31

Section and Topic	Item #	Checklist item	Location where item is reported
methods		comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	-
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 27-31
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	-
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	-
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	-
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	-
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 22-23
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 24-25
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 25
Study characteristics	17	Cite each included study and present its characteristics.	Page 27-31
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	-
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	-
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 27-31
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	-
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	-
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	-
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	-
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 158
DISCUSSION			

Section and Topic	Item #	Checklist item	Location where item is reported
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 48-51
	23b	Discuss any limitations of the evidence included in the review.	Page 51-53
	23c	Discuss any limitations of the review processes used.	Page 51-53
	23d	Discuss implications of the results for practice, policy, and future research.	Page 53
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 19
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 19
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	-
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	-
Competing interests	26	Declare any competing interests of review authors.	-
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	-

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix B: CASP Tool



CASP
Critical Appraisal
Skills Programme

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

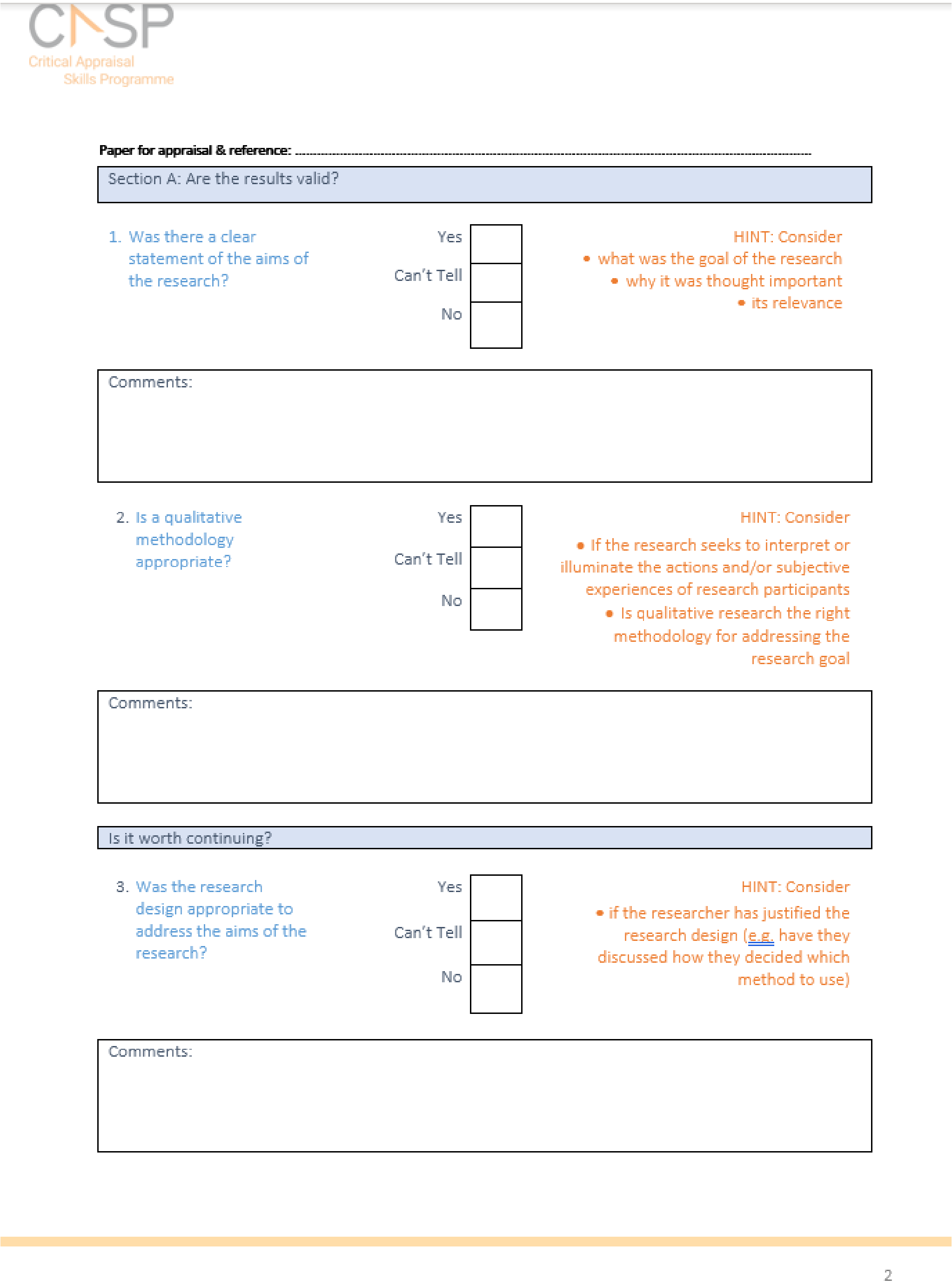
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2023). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



CASP
Critical Appraisal
Skills Programme

Paper for appraisal & reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

CASP
Critical Appraisal
Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal
Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix C: Extended Version of Characteristics Table

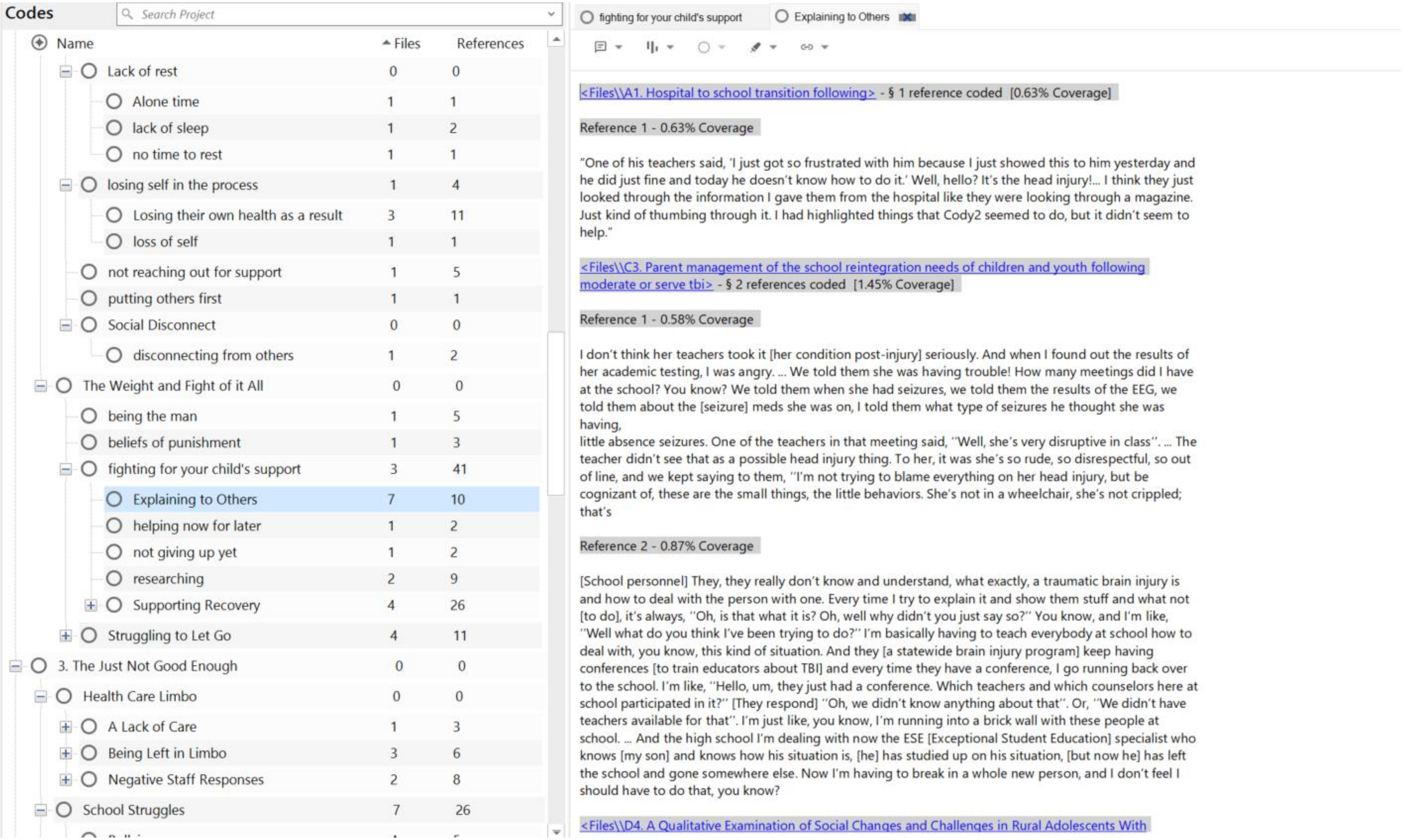
Author(s) (and Date)	Focus of Study	Methods of Data Collection	Analysis Used	Family member(s) included and total sample size of these	**Mechanism of C-TBI** (written verbatim)	Age range /presumed age (based on study criteria) at time of child's injury (y)	**Time since injury (m=months, y=years)**	Severity and type of child injury	Findings from relevant sample (family) perspectives	Categorisation of Core, Central, and Peripheral (CASP Rating)
Clark et al. (2008)	Family relationships and support and services.	Semi-structured interviews	Interpretative phenomenological analysis.	All mothers N=10	4 pedestrian road traffic accident, 3 road traffic accident, 2 falls, 1 sports injury	4-13	2y 1m-6y 11m	7 moderate the severe. 3 others less clear.	Analysis generated themes of 'changes to and loss of the past child', 'effects on mother's health'. 'mothers process of coping and support', 'changed roles', 'effects on the whole family' and 'contact with services'.	Core (7)
Brown et al. (2013)	Parenting a child with TBI	Focus Groups or individual telephone interviews	Thematic Analysis	7 mothers, 2 fathers/ stepfathers, 1 Grandmother	2 suspected but unconfirmed non-accidental injuries, 1 non-accidental injury, 3 motor vehicle accident, 1 sport, 1 fall	1.5-9	2y 6m-12y 6m	4 moderate, 4 severe	Parents need to adjust to and manage their child's difficulties and can also experience significant emotional distress, relationship discord and burden of care. Parents can feel isolated and the importance of empowerment, support and information were emphasised. Coping styles of disengagement and avoidance was often reported, despite acknowledgement that these were not beneficial.	Core (7)
Smucker. (1996)	Empowerment following child brain injury.	Interviews.	Grounded theory.	11 mothers, 6 fathers and, 1 uncle. N=18	4 auto accident, 1 gun shot, 1 fall, 1 skiing accident, 1 sledging accident,	6-15	<1y – 3y	5 mild-moderate, 7 severe TBI.	16/18 parents described empowerment as a reiterative process of learning, acting and reflection. An ongoing process that shaped their	Core (9)

					2 hit by car, 2 bike vs car				approach to each new problem and challenge of parenting the child. The relationship with the child served as a basis for action and for empowerment.	
Roscigno (2009)	Initial aim: Social experiences following moderate to severe TBI. Additional aim: What's it like to be a parent of a child with moderate-severe TBI.	Interviews	Descriptive phenomenological investigation	34 mothers alone, 8 fathers; 5 couples interviewed together N=42 1 parent was a biological grandparent but gained parental custody, unknown if classified as mother or father for the study	18 motor vehicle accident, 6 car verses child, 4 recreational vehicle, 5 sports/recreational related accident, 3 blunt force trauma, 2 firearm	6-18	4-36m	All moderate to severe.	Parents were emotionally overwhelmed by their child's injuries and the lack of support following. Themes that emerge were 1. grateful to still have my child, 2. grieving the child I knew 3. running on nerves. 4. grappling to get what your child and family need. Parents reported many barriers because of others' being insensitive to their children's and families' condition.	Core (9)
Wilson (2009)	Sources of stress and coping strategies for African American caregivers of youth with TBI.	Semi-structured interviews	Grounded theory	11 mothers, 4 fathers; two couples interviewed together N=15	All motor vehicle accidents	5-17	Not reported	All moderate-severe based on criteria, does not specifically state.	Caregiver experience of 'trying to make it through' where African Americans feel pressured to adhere to cultural and religious expectations when faces with challenges when caring for child. Stress created feelings of uncertainty, fear and often self-doubt when trying to adjust.	Core (9)
Gauvin-Lepage and Lefebvre (2010)	Social inclusion with TBI	Semi-structured interviews	Content analysis	3 mothers and 1 father; one couple interviewed together N=4	1 skiing accident, 1 traffic accident also involving Mum, 1 bicycle accident	11-14	1-3y	3 moderate TBI	Perceptions affect different aspects of their lives such as the child's personal experiences, the family, friends, the environment and school. Several repercussions were notes which either facilitate or limit the social inclusion for the child.	Central (9)
Jones et al. (2010)	Day to day occupations of parents who care for childing in the	Interviews	Constant comparative analysis used in grounded theory.	4 mothers and 3 fathers N=7	Not reported	2-5	2-6y	All severe TBI.	Analysis revealed a central caregiving category, structuring for security, encompassing	Central (9)

	home after severe TBI.								interdependent processes: 'Holding things together' focused on protecting the child while 'joining my child with others' explains how parents plan for their participation. Both mediated by the support of others and require practical knowledge.	
Kirk et al. (2014)	Experiences of BI and information and support needs.	Semi-structured interviews	Framework approach	18 mothers, 9 fathers/stepfathers and 2 grandmothers N=29	11 road traffic accident, 5 fall, 3 off-road bicycle/motorcycle accident	3-16	6m-6years	19 severe.	Parents had unmet information and emotion support needs relating to impact of TBI on child, current and future treatments, rehab plan, behaviour management, assessing services and supported. Needed support coming to terms with witnessing the accident and loss of former child. Lack of community support related not only to service availability but to lack of understanding of impact of BI, especially when not visibly obvious.	Central (7)
Roscigno et al. (2015)	School reintegration needs	Semi-structured interviews	Conventional content analysis following descriptive phenomenology	34 mothers, 8 fathers; 5 couples interviewed together N=42 1 parent was a biological grandparent but gained parental custody, unknown if classified as mother or father for the study	18 motor vehicle accident, 6 car verses child, 4 recreational vehicle, 5 sports/recreational related accident, 3 blunt force trauma, 2 firearm (extracted from 2009 paper as not reported in this paper)	6-18	4-36m	25 severe TBI, 12 moderate TBI.	Themes centred around legal versus moral basis for helping the child, inappropriate state and local services that did not consider needs education plan. Parents perceived that coordinated and collaboration leadership with school personnel lessened families workload. Families who home-schooled has unique challenges.	Central (8)
Chisholm and Bruce. (2001)	Experiences and perceptions of factors that may have influence	Interviews	Content analysis	Caregivers, does not specify N=10	Not reported	5-15	Not reported	Mild to severe, numbers in each category not stated.	Families experienced sustained uncertainty and described the impact on family relationships.	Peripheral (5)

	the injury event; parenting a child with TBI, perceptions of what resources are available and how those resources influenced their experiences.								Social support was found to be a mediating factor, the need for ongoing support and services to help adaptation to new roles, cope with new challenges and manage consequences were described.	
Todis et al. (2018)	Hospital to school transition	Semi-structured interviews	Thematic analysis	Parents (does not specify mothers or fathers) n=23	Not reported	4-15	Not reported	15 severe TBI 5 mild/moderate TBI	Two themes: inconsistent approaches to hospital and school transitions and lack of educator awareness about the student's injury.	Peripheral (6)
Rennie and Goforth (2020)	Social adjustment and interaction, environmental variables especially those related to rural status	Interviews	Iterative approach based in grounded theory	All mothers N=3	1 fall off playground equipment, 3 car accident	8-16	2-7y	2 moderate TBI, 2 mild TBI.	Four themes emerged 1) personal change, environmental response, social needs and facilitators and inhibitors of intentional changes.	Peripheral (5)

Appendix D: Systematic Review Coding Framework; NVIVO Example



Name	Files	References
Lack of rest	0	0
Alone time	1	1
lack of sleep	1	2
no time to rest	1	1
losing self in the process	1	4
Losing their own health as a result	3	11
loss of self	1	1
not reaching out for support	1	5
putting others first	1	1
Social Disconnect	0	0
disconnecting from others	1	2
The Weight and Fight of it All	0	0
being the man	1	5
beliefs of punishment	1	3
fighting for your child's support	3	41
Explaining to Others	7	10
helping now for later	1	2
not giving up yet	1	2
researching	2	9
Supporting Recovery	4	26
Struggling to Let Go	4	11
3. The Just Not Good Enough	0	0
Health Care Limbo	0	0
A Lack of Care	1	3
Being Left in Limbo	3	6
Negative Staff Responses	2	8
School Struggles	7	26

<Files\\A1. Hospital to school transition following> - § 1 reference coded [0.63% Coverage]

Reference 1 - 0.63% Coverage

"One of his teachers said, 'I just got so frustrated with him because I just showed this to him yesterday and he did just fine and today he doesn't know how to do it.' Well, hello? It's the head injury!... I think they just looked through the information I gave them from the hospital like they were looking through a magazine. Just kind of thumbing through it. I had highlighted things that Cody2 seemed to do, but it didn't seem to help."

<Files\\C3. Parent management of the school reintegration needs of children and youth following moderate or serve tbi> - § 2 references coded [1.45% Coverage]

Reference 1 - 0.58% Coverage

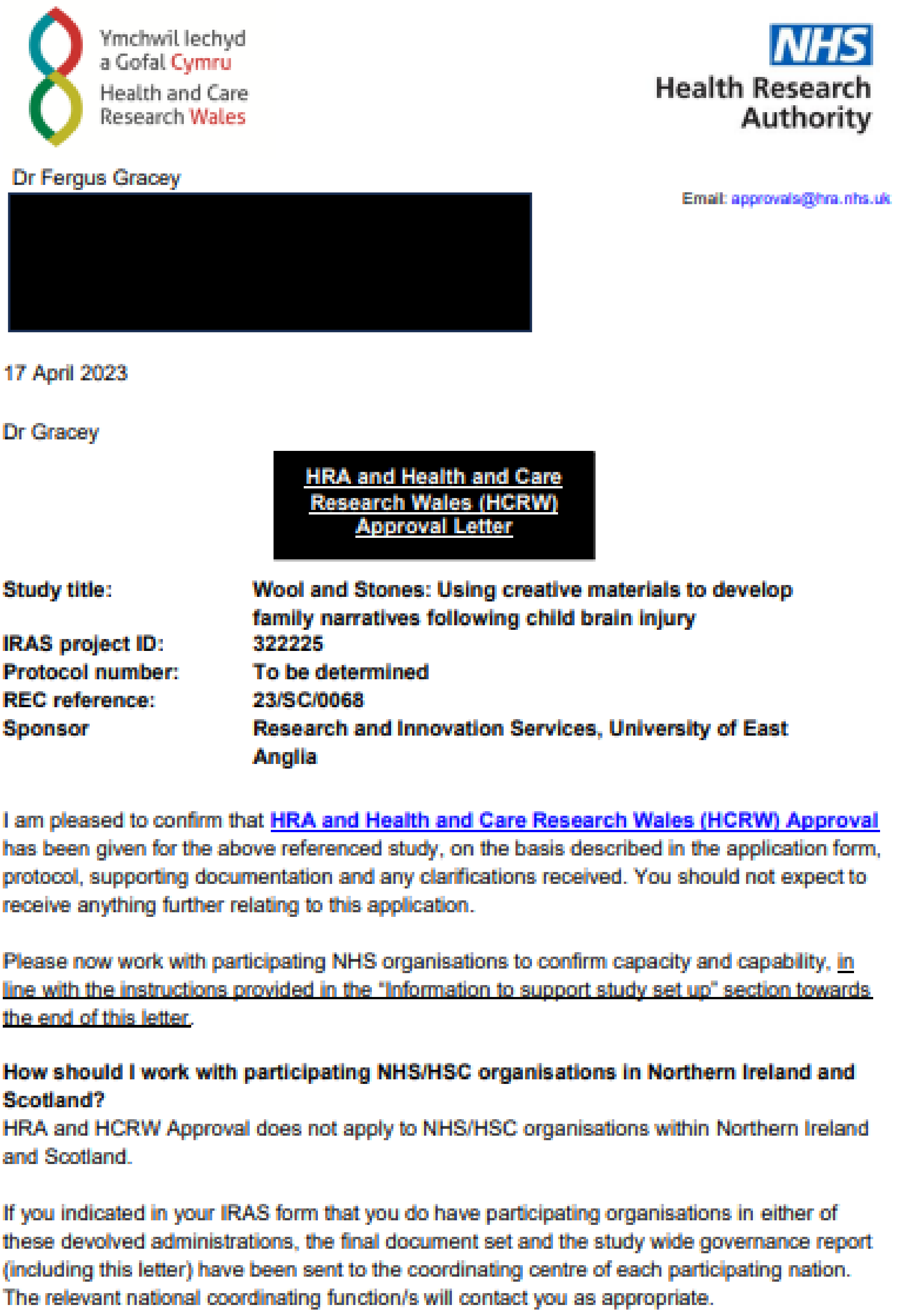
I don't think her teachers took it [her condition post-injury] seriously. And when I found out the results of her academic testing, I was angry. ... We told them she was having trouble! How many meetings did I have at the school? You know? We told them when she had seizures, we told them the results of the EEG, we told them about the [seizure] meds she was on, I told them what type of seizures he thought she was having,
little absence seizures. One of the teachers in that meeting said, ''Well, she's very disruptive in class''. ... The teacher didn't see that as a possible head injury thing. To her, it was she's so rude, so disrespectful, so out of line, and we kept saying to them, ''I'm not trying to blame everything on her head injury, but be cognizant of, these are the small things, the little behaviors. She's not in a wheelchair, she's not crippled; that's

Reference 2 - 0.87% Coverage

[School personnel] They, they really don't know and understand, what exactly, a traumatic brain injury is and how to deal with the person with one. Every time I try to explain it and show them stuff and what not [to do], it's always, ''Oh, is that what it is? Oh, well why didn't you just say so?'' You know, and I'm like, ''Well what do you think I've been trying to do?'' I'm basically having to teach everybody at school how to deal with, you know, this kind of situation. And they [a statewide brain injury program] keep having conferences [to train educators about TBI] and every time they have a conference, I go running back over to the school. I'm like, ''Hello, um, they just had a conference. Which teachers and which counselors here at school participated in it?'' [They respond] ''Oh, we didn't know anything about that''. Or, ''We didn't have teachers available for that''. I'm just like, you know, I'm running into a brick wall with these people at school. ... And the high school I'm dealing with now the ESE [Exceptional Student Education] specialist who knows [my son] and knows how his situation is, [he] has studied up on his situation, [but now he] has left the school and gone somewhere else. Now I'm having to break in a whole new person, and I don't feel I should have to do that, you know?

<Files\\D4. A Qualitative Examination of Social Changes and Challenges in Rural Adolescents With

Appendix E: HRA Ethical Approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Fergus Gracey
[redacted]

Email: approvals@hra.nhs.uk

17 April 2023

Dr Gracey

HRA and Health and Care Research Wales (HCRW) Approval Letter

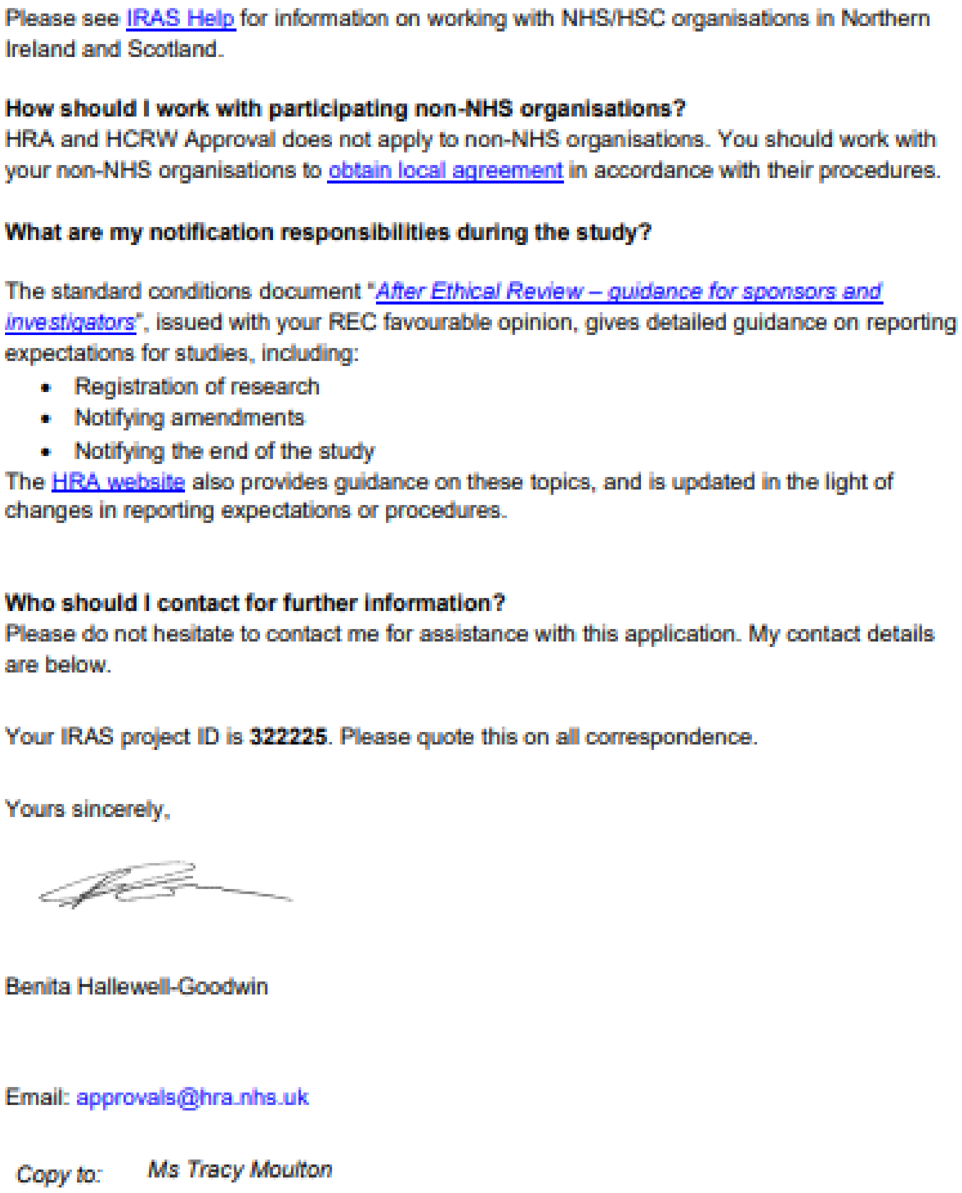
Study title: **Wool and Stones: Using creative materials to develop family narratives following child brain injury**
IRAS project ID: **322225**
Protocol number: **To be determined**
REC reference: **23/SC/0068**
Sponsor **Research and Innovation Services, University of East Anglia**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

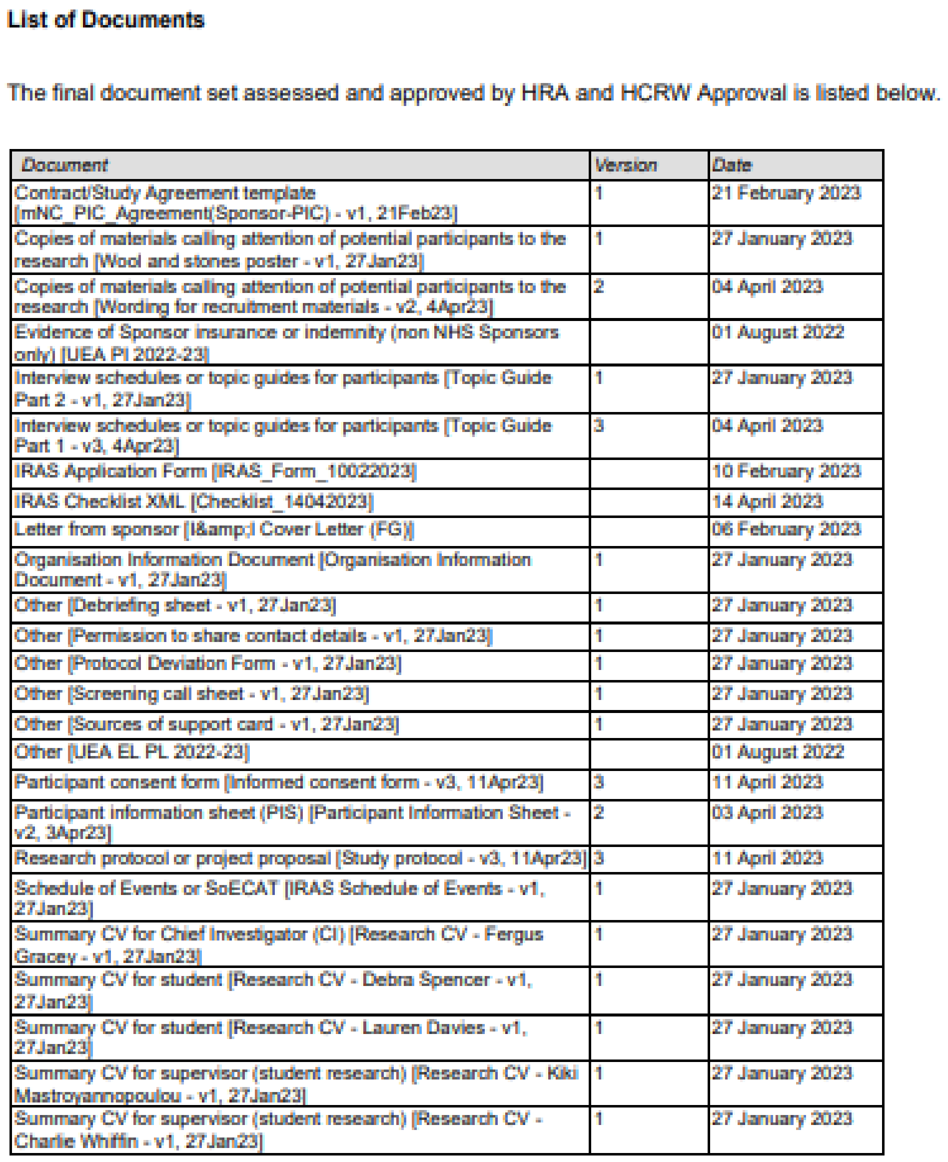
Your IRAS project ID is **322225**. Please quote this on all correspondence.

Yours sincerely,

Benita Hallewell-Goodwin

Email: approvals@hra.nhs.uk

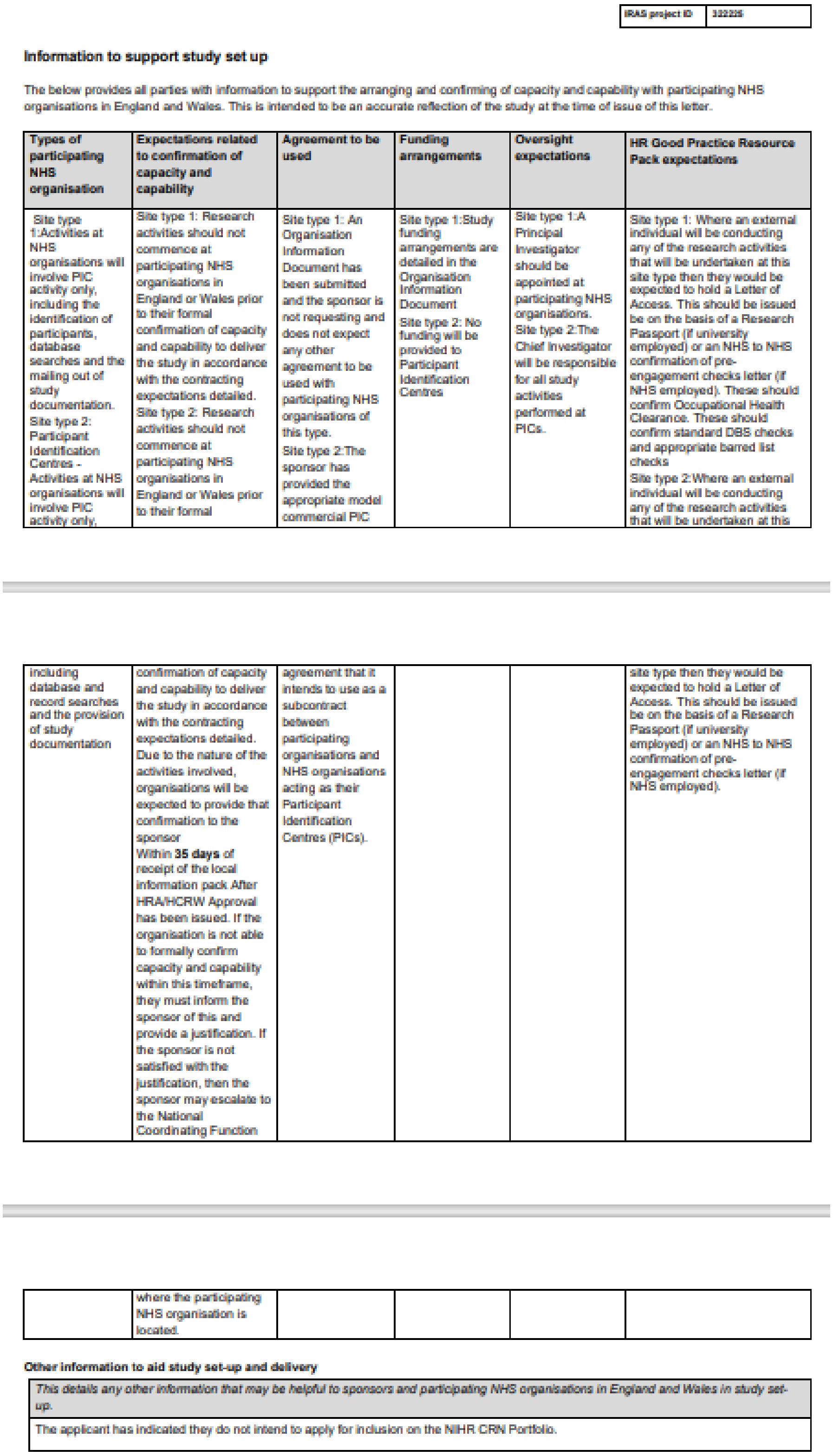
Copy to: *Ms Tracy Moulton*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [mNC_PIC_Agreement(Sponsor-PIC) - v1, 21Feb23]	1	21 February 2023
Copies of materials calling attention of potential participants to the research [Wool and stones poster - v1, 27Jan23]	1	27 January 2023
Copies of materials calling attention of potential participants to the research [Wording for recruitment materials - v2, 4Apr23]	2	04 April 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA PI 2022-23]		01 August 2022
Interview schedules or topic guides for participants [Topic Guide Part 2 - v1, 27Jan23]	1	27 January 2023
Interview schedules or topic guides for participants [Topic Guide Part 1 - v3, 4Apr23]	3	04 April 2023
IRAS Application Form [IRAS_Form_10022023]		10 February 2023
IRAS Checklist XML [Checklist_14042023]		14 April 2023
Letter from sponsor [I&I Cover Letter (FG)]		06 February 2023
Organisation Information Document [Organisation Information Document - v1, 27Jan23]	1	27 January 2023
Other [Debriefing sheet - v1, 27Jan23]	1	27 January 2023
Other [Permission to share contact details - v1, 27Jan23]	1	27 January 2023
Other [Protocol Deviation Form - v1, 27Jan23]	1	27 January 2023
Other [Screening call sheet - v1, 27Jan23]	1	27 January 2023
Other [Sources of support card - v1, 27Jan23]	1	27 January 2023
Other [UEA EL PL 2022-23]		01 August 2022
Participant consent form [Informed consent form - v3, 11Apr23]	3	11 April 2023
Participant information sheet (PIS) [Participant Information Sheet - v2, 3Apr23]	2	03 April 2023
Research protocol or project proposal [Study protocol - v3, 11Apr23]	3	11 April 2023
Schedule of Events or SoECAT [IRAS Schedule of Events - v1, 27Jan23]	1	27 January 2023
Summary CV for Chief Investigator (CI) [Research CV - Fergus Gracey - v1, 27Jan23]	1	27 January 2023
Summary CV for student [Research CV - Debra Spencer - v1, 27Jan23]	1	27 January 2023
Summary CV for student [Research CV - Lauren Davies - v1, 27Jan23]	1	27 January 2023
Summary CV for supervisor (student research) [Research CV - Kiki Mastroyannopoulou - v1, 27Jan23]	1	27 January 2023
Summary CV for supervisor (student research) [Research CV - Charlie Whiffin - v1, 27Jan23]	1	27 January 2023



IRAS project ID	[illegible]

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

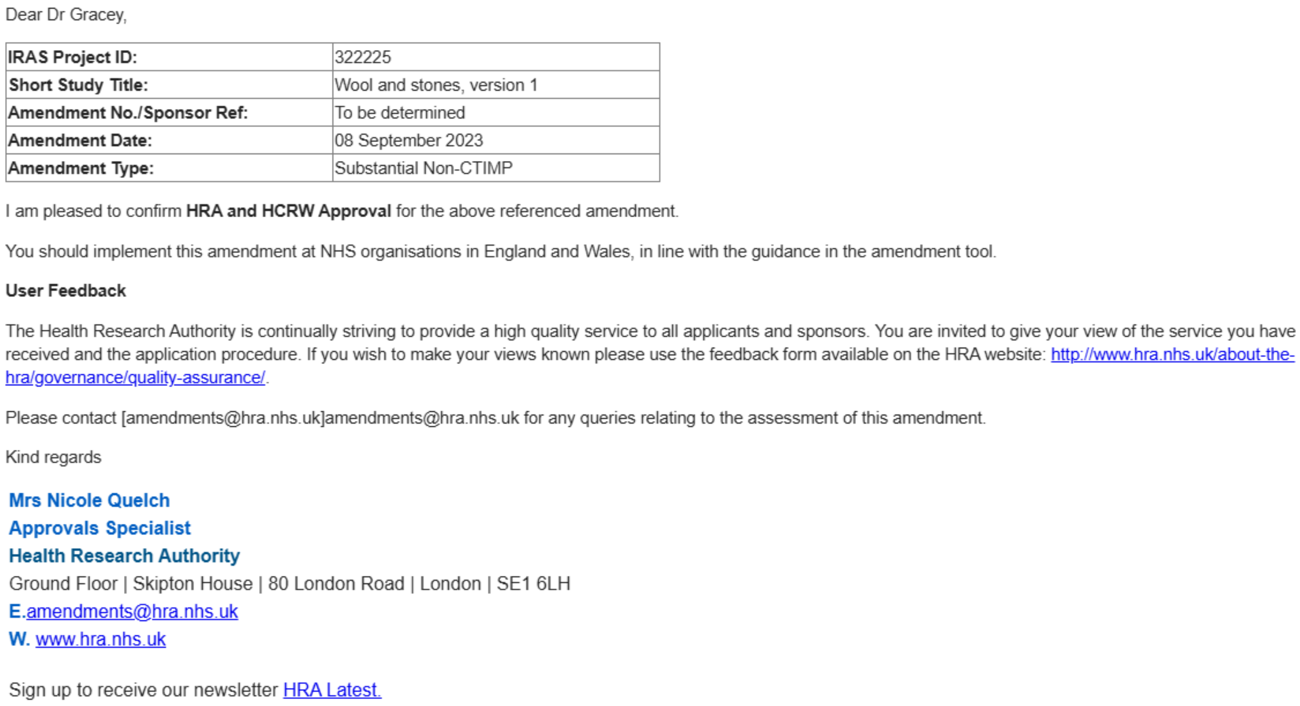
Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Site type 1:Activities at NHS organisations will involve PIC activity only, including the identification of participants, database searches and the mailing out of study documentation. Site type 2: Participant Identification Centres - Activities at NHS organisations will involve PIC activity only, including database and record searches and the provision of study documentation	Site type 1: Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed. Site type 2: Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed. Due to the nature of the activities involved, organisations will be expected to provide that confirmation to the sponsor Within **35 days** of receipt of the local information pack After HRA/HCRW Approval has been issued. If the organisation is not able to formally confirm capacity and capability within this timeframe, they must inform the sponsor of this and provide a justification. If the sponsor is not satisfied with the justification, then the sponsor may escalate to the National Coordinating Function where the participating NHS organisation is located.	Site type 1: An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type. Site type 2:The sponsor has provided the appropriate model commercial PIC agreement that it intends to use as a subcontract between participating organisations and NHS organisations acting as their Participant Identification Centres (PICs).	Site type 1:Study funding arrangements are detailed in the Organisation Information Document Site type 2: No funding will be provided to Participant Identification Centres	Site type 1:A Principal Investigator should be appointed at participating NHS organisations. Site type 2:The Chief Investigator will be responsible for all study activities performed at PICs.	Site type 1: Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm Occupational Health Clearance. These should confirm standard DBS checks and appropriate barred list checks Site type 2:Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix F: Substantial Amendment Approval

(Received October 2023, inclusion criteria changed from injury being 18 months ago, to 12 months).



Dear Dr Gracey,

IRAS Project ID:	322225
Short Study Title:	Wool and stones, version 1
Amendment No./Sponsor Ref:	To be determined
Amendment Date:	08 September 2023
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact [amendments@hra.nhs.uk]amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Mrs Nicole Quelch
Approvals Specialist
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.amendments@hra.nhs.uk
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

Appendix G: Recruitment Poster

Are you the parent/carer of a child with brain injury?

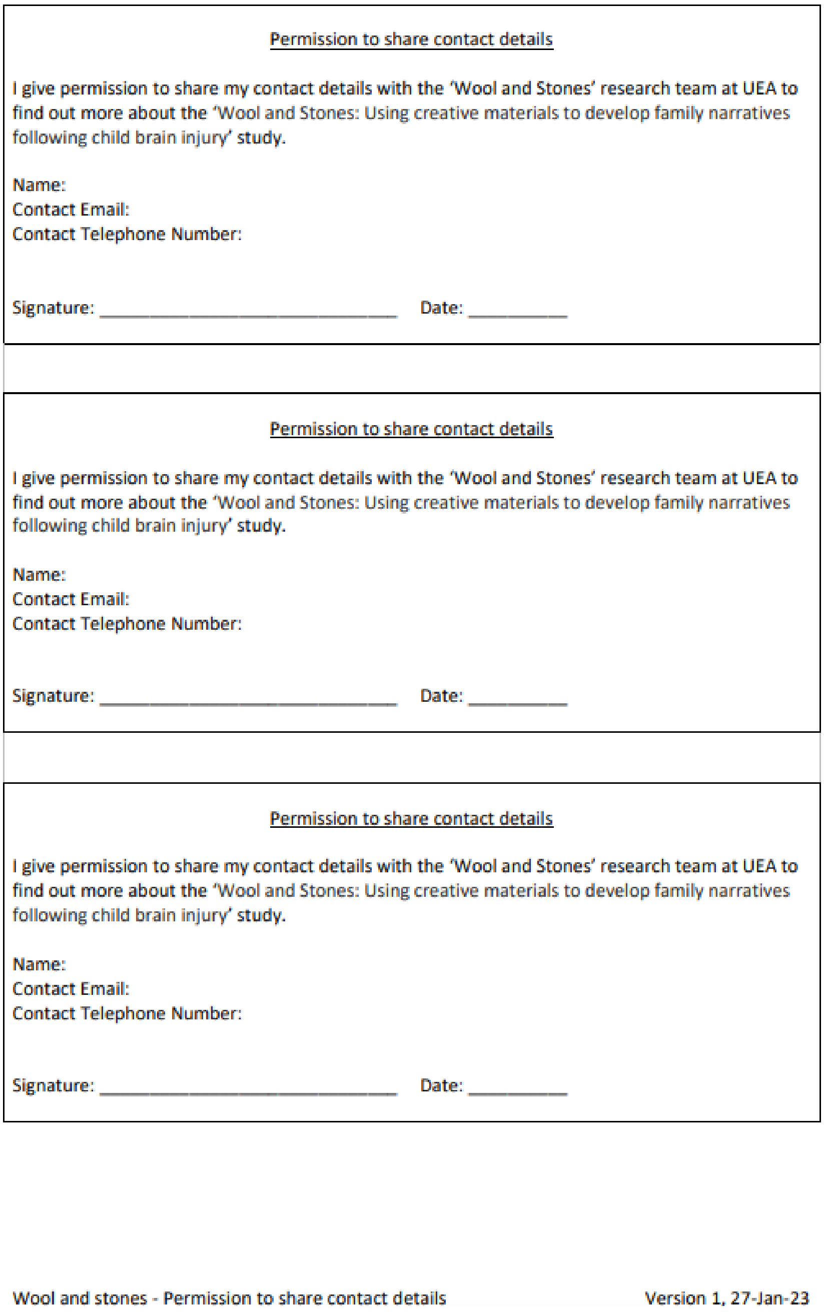
We are exploring a **novel creative approach** for **sharing your experiences**

- Would you like to help co-design a novel creative approach to understanding parents'/carers' own experiences following child brain injury?
- The study involves two parts, each lasting approximately 45 to 90 minutes
- If you complete the study, you will receive a £20 voucher as a token of gratitude
- Please contact lauren.davies@uea.ac.uk or [redacted] for more information

UEA University of East Anglia [redacted]

Wool and stones poster, v1, 27-Jan-23

Appendix H: Permission to Share Contact Details Form



Permission to share contact details

I give permission to share my contact details with the 'Wool and Stones' research team at UEA to find out more about the 'Wool and Stones: Using creative materials to develop family narratives following child brain injury' study.

Name:
Contact Email:
Contact Telephone Number:

Signature: ______________________________ Date: __________

Permission to share contact details

I give permission to share my contact details with the 'Wool and Stones' research team at UEA to find out more about the 'Wool and Stones: Using creative materials to develop family narratives following child brain injury' study.

Name:
Contact Email:
Contact Telephone Number:

Signature: ______________________________ Date: __________

Permission to share contact details

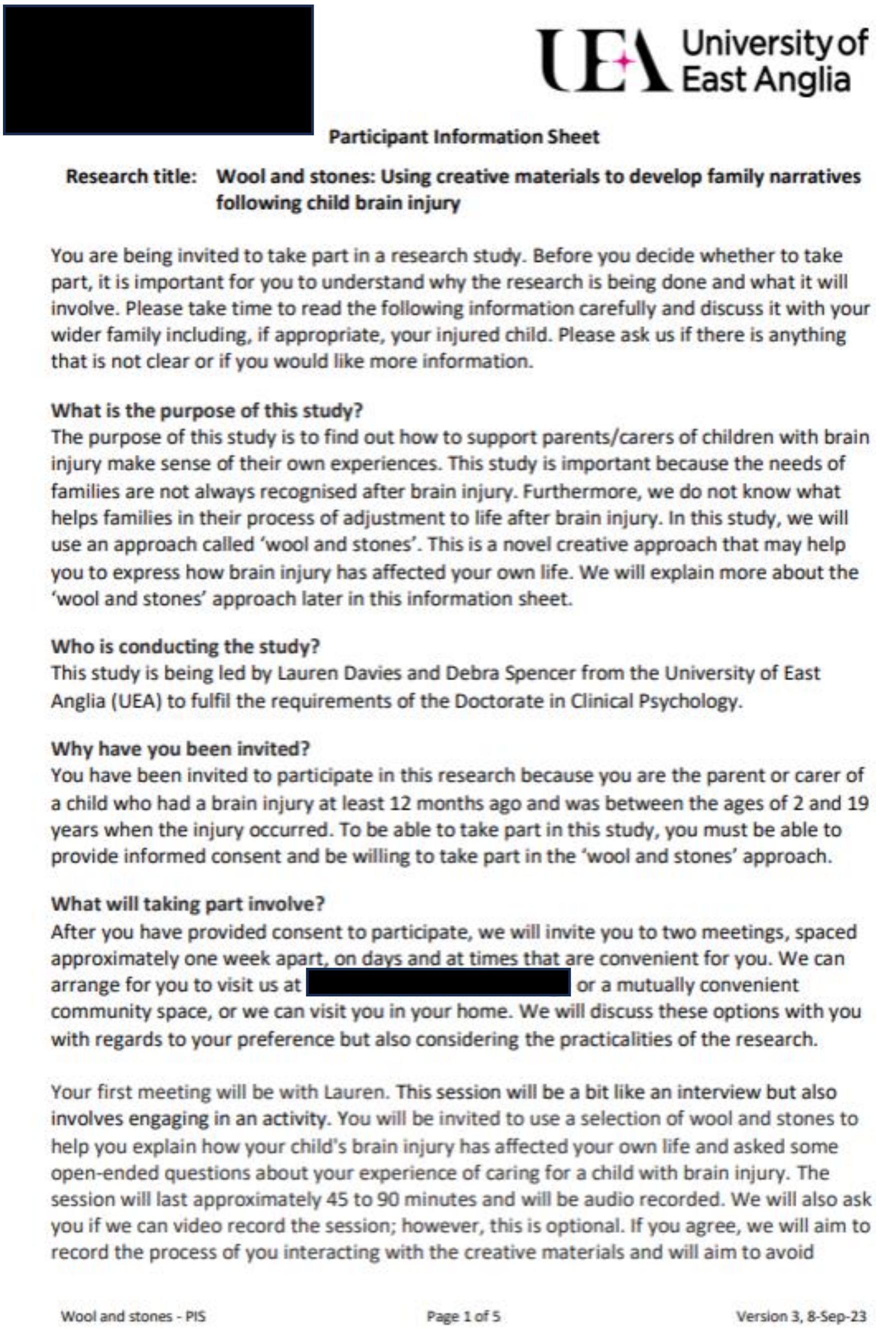
I give permission to share my contact details with the 'Wool and Stones' research team at UEA to find out more about the 'Wool and Stones: Using creative materials to develop family narratives following child brain injury' study.

Name:
Contact Email:
Contact Telephone Number:

Signature: ______________________________ Date: __________

Wool and stones - Permission to share contact details Version 1, 27-Jan-23

Appendix I: Participant Information Sheet



[redacted]

UEA University of East Anglia

Participant Information Sheet

Research title: Wool and stones: Using creative materials to develop family narratives following child brain injury

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your wider family including, if appropriate, your injured child. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

The purpose of this study is to find out how to support parents/carers of children with brain injury make sense of their own experiences. This study is important because the needs of families are not always recognised after brain injury. Furthermore, we do not know what helps families in their process of adjustment to life after brain injury. In this study, we will use an approach called 'wool and stones'. This is a novel creative approach that may help you to express how brain injury has affected your own life. We will explain more about the 'wool and stones' approach later in this information sheet.

Who is conducting the study?

This study is being led by Lauren Davies and Debra Spencer from the University of East Anglia (UEA) to fulfil the requirements of the Doctorate in Clinical Psychology.

Why have you been invited?

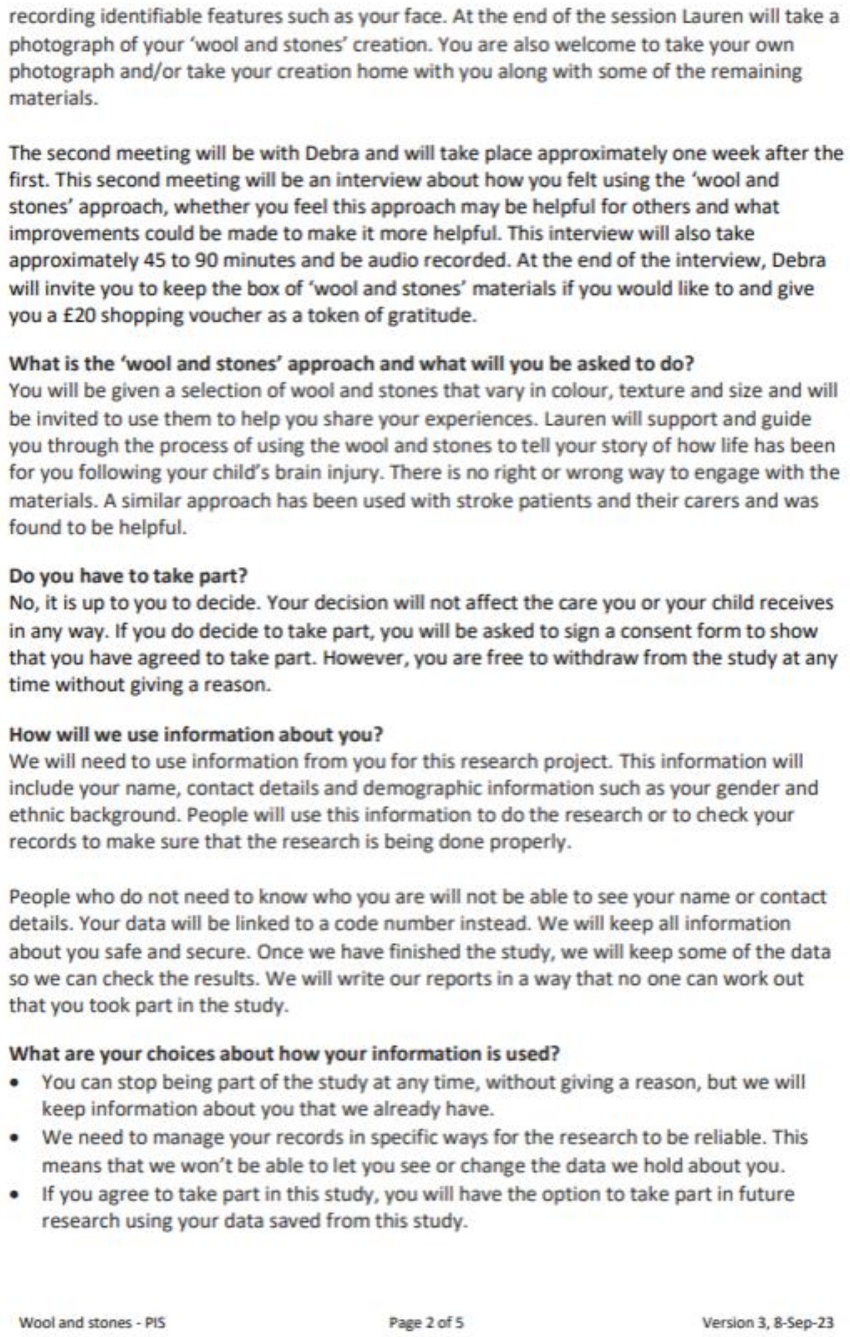
You have been invited to participate in this research because you are the parent or carer of a child who had a brain injury at least 12 months ago and was between the ages of 2 and 19 years when the injury occurred. To be able to take part in this study, you must be able to provide informed consent and be willing to take part in the 'wool and stones' approach.

What will taking part involve?

After you have provided consent to participate, we will invite you to two meetings, spaced approximately one week apart, on days and at times that are convenient for you. We can arrange for you to visit us at [redacted] or a mutually convenient community space, or we can visit you in your home. We will discuss these options with you with regards to your preference but also considering the practicalities of the research.

Your first meeting will be with Lauren. This session will be a bit like an interview but also involves engaging in an activity. You will be invited to use a selection of wool and stones to help you explain how your child's brain injury has affected your own life and asked some open-ended questions about your experience of caring for a child with brain injury. The session will last approximately 45 to 90 minutes and will be audio recorded. We will also ask you if we can video record the session; however, this is optional. If you agree, we will aim to record the process of you interacting with the creative materials and will aim to avoid

Wool and stones - PIS   Page 1 of 5   Version 3, 8-Sep-23



recording identifiable features such as your face. At the end of the session Lauren will take a photograph of your 'wool and stones' creation. You are also welcome to take your own photograph and/or take your creation home with you along with some of the remaining materials.

The second meeting will be with Debra and will take place approximately one week after the first. This second meeting will be an interview about how you felt using the 'wool and stones' approach, whether you feel this approach may be helpful for others and what improvements could be made to make it more helpful. This interview will also take approximately 45 to 90 minutes and be audio recorded. At the end of the interview, Debra will invite you to keep the box of 'wool and stones' materials if you would like to and give you a £20 shopping voucher as a token of gratitude.

What is the 'wool and stones' approach and what will you be asked to do?
You will be given a selection of wool and stones that vary in colour, texture and size and will be invited to use them to help you share your experiences. Lauren will support and guide you through the process of using the wool and stones to tell your story of how life has been for you following your child's brain injury. There is no right or wrong way to engage with the materials. A similar approach has been used with stroke patients and their carers and was found to be helpful.

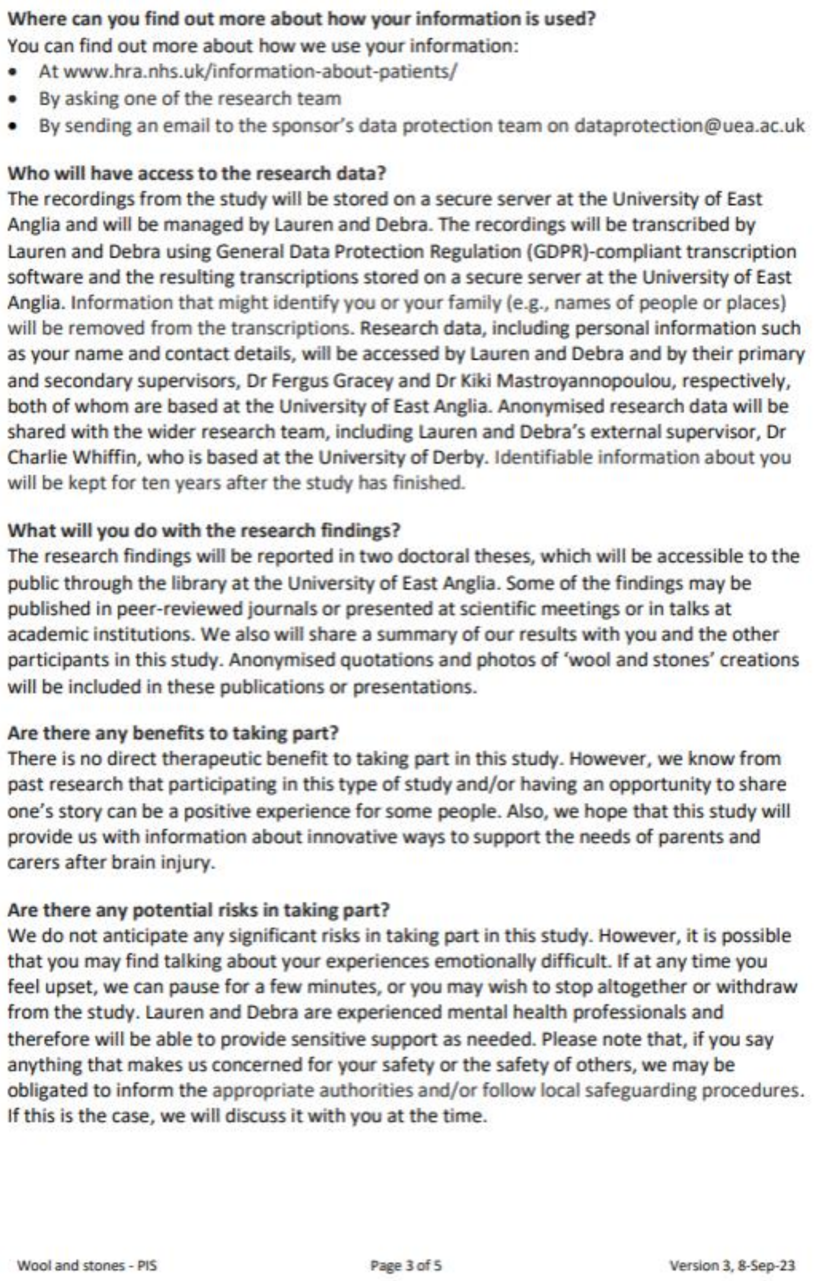
Do you have to take part?
No, it is up to you to decide. Your decision will not affect the care you or your child receives in any way. If you do decide to take part, you will be asked to sign a consent form to show that you have agreed to take part. However, you are free to withdraw from the study at any time without giving a reason.

How will we use information about you?
We will need to use information from you for this research project. This information will include your name, contact details and demographic information such as your gender and ethnic background. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will be linked to a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.



Where can you find out more about how your information is used?
You can find out more about how we use your information:

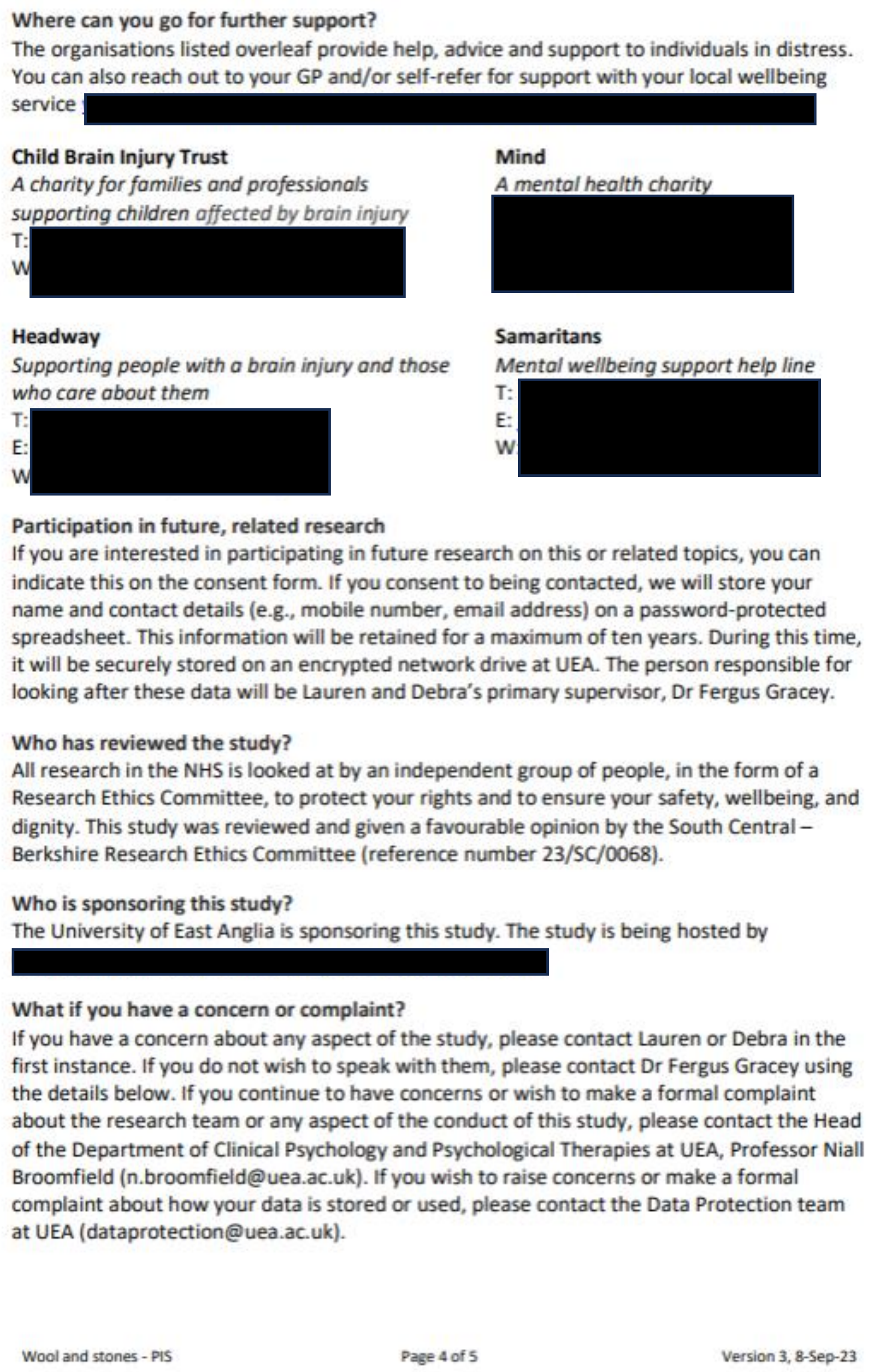
- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By sending an email to the sponsor's data protection team on dataprotection@uea.ac.uk

Who will have access to the research data?
The recordings from the study will be stored on a secure server at the University of East Anglia and will be managed by Lauren and Debra. The recordings will be transcribed by Lauren and Debra using General Data Protection Regulation (GDPR)-compliant transcription software and the resulting transcriptions stored on a secure server at the University of East Anglia. Information that might identify you or your family (e.g., names of people or places) will be removed from the transcriptions. Research data, including personal information such as your name and contact details, will be accessed by Lauren and Debra and by their primary and secondary supervisors, Dr Fergus Gracey and Dr Kiki Mastroyannopoulou, respectively, both of whom are based at the University of East Anglia. Anonymised research data will be shared with the wider research team, including Lauren and Debra's external supervisor, Dr Charlie Whiffin, who is based at the University of Derby. Identifiable information about you will be kept for ten years after the study has finished.

What will you do with the research findings?
The research findings will be reported in two doctoral theses, which will be accessible to the public through the library at the University of East Anglia. Some of the findings may be published in peer-reviewed journals or presented at scientific meetings or in talks at academic institutions. We also will share a summary of our results with you and the other participants in this study. Anonymised quotations and photos of 'wool and stones' creations will be included in these publications or presentations.

Are there any benefits to taking part?
There is no direct therapeutic benefit to taking part in this study. However, we know from past research that participating in this type of study and/or having an opportunity to share one's story can be a positive experience for some people. Also, we hope that this study will provide us with information about innovative ways to support the needs of parents and carers after brain injury.

Are there any potential risks in taking part?
We do not anticipate any significant risks in taking part in this study. However, it is possible that you may find talking about your experiences emotionally difficult. If at any time you feel upset, we can pause for a few minutes, or you may wish to stop altogether or withdraw from the study. Lauren and Debra are experienced mental health professionals and therefore will be able to provide sensitive support as needed. Please note that, if you say anything that makes us concerned for your safety or the safety of others, we may be obligated to inform the appropriate authorities and/or follow local safeguarding procedures. If this is the case, we will discuss it with you at the time.



Where can you go for further support?

The organisations listed overleaf provide help, advice and support to individuals in distress. You can also reach out to your GP and/or self-refer for support with your local wellbeing service [redacted]

Child Brain Injury Trust

A charity for families and professionals supporting children affected by brain injury

T: [redacted]
W

Mind

A mental health charity

[redacted]

Headway

Supporting people with a brain injury and those who care about them

T: [redacted]
E:
W

Samaritans

Mental wellbeing support help line

T: [redacted]
E:
W

Participation in future, related research

If you are interested in participating in future research on this or related topics, you can indicate this on the consent form. If you consent to being contacted, we will store your name and contact details (e.g., mobile number, email address) on a password-protected spreadsheet. This information will be retained for a maximum of ten years. During this time, it will be securely stored on an encrypted network drive at UEA. The person responsible for looking after these data will be Lauren and Debra's primary supervisor, Dr Fergus Gracey.

Who has reviewed the study?

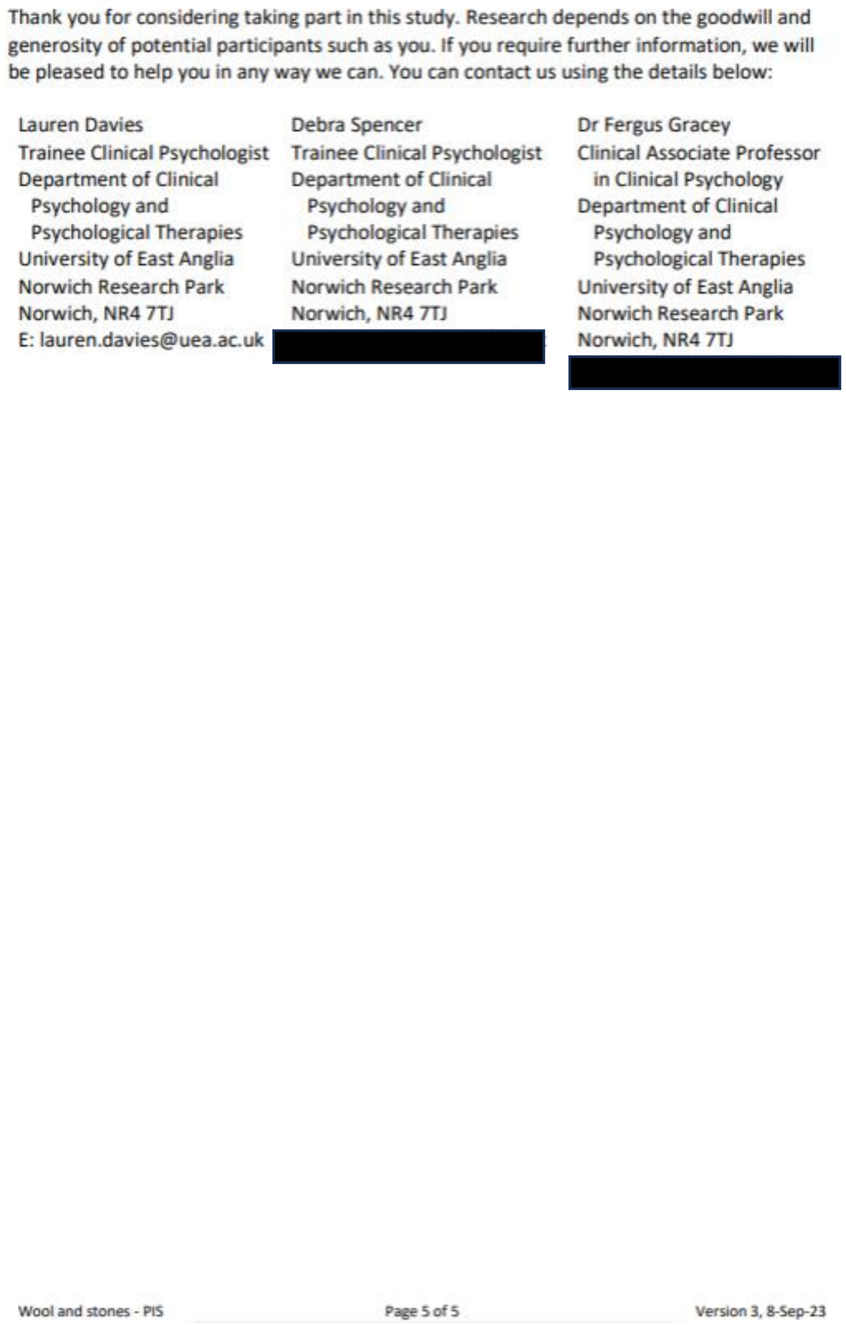
All research in the NHS is looked at by an independent group of people, in the form of a Research Ethics Committee, to protect your rights and to ensure your safety, wellbeing, and dignity. This study was reviewed and given a favourable opinion by the South Central – Berkshire Research Ethics Committee (reference number 23/SC/0068).

Who is sponsoring this study?

The University of East Anglia is sponsoring this study. The study is being hosted by [redacted]

What if you have a concern or complaint?

If you have a concern about any aspect of the study, please contact Lauren or Debra in the first instance. If you do not wish to speak with them, please contact Dr Fergus Gracey using the details below. If you continue to have concerns or wish to make a formal complaint about the research team or any aspect of the conduct of this study, please contact the Head of the Department of Clinical Psychology and Psychological Therapies at UEA, Professor Niall Broomfield (n.broomfield@uea.ac.uk). If you wish to raise concerns or make a formal complaint about how your data is stored or used, please contact the Data Protection team at UEA (dataprotection@uea.ac.uk).



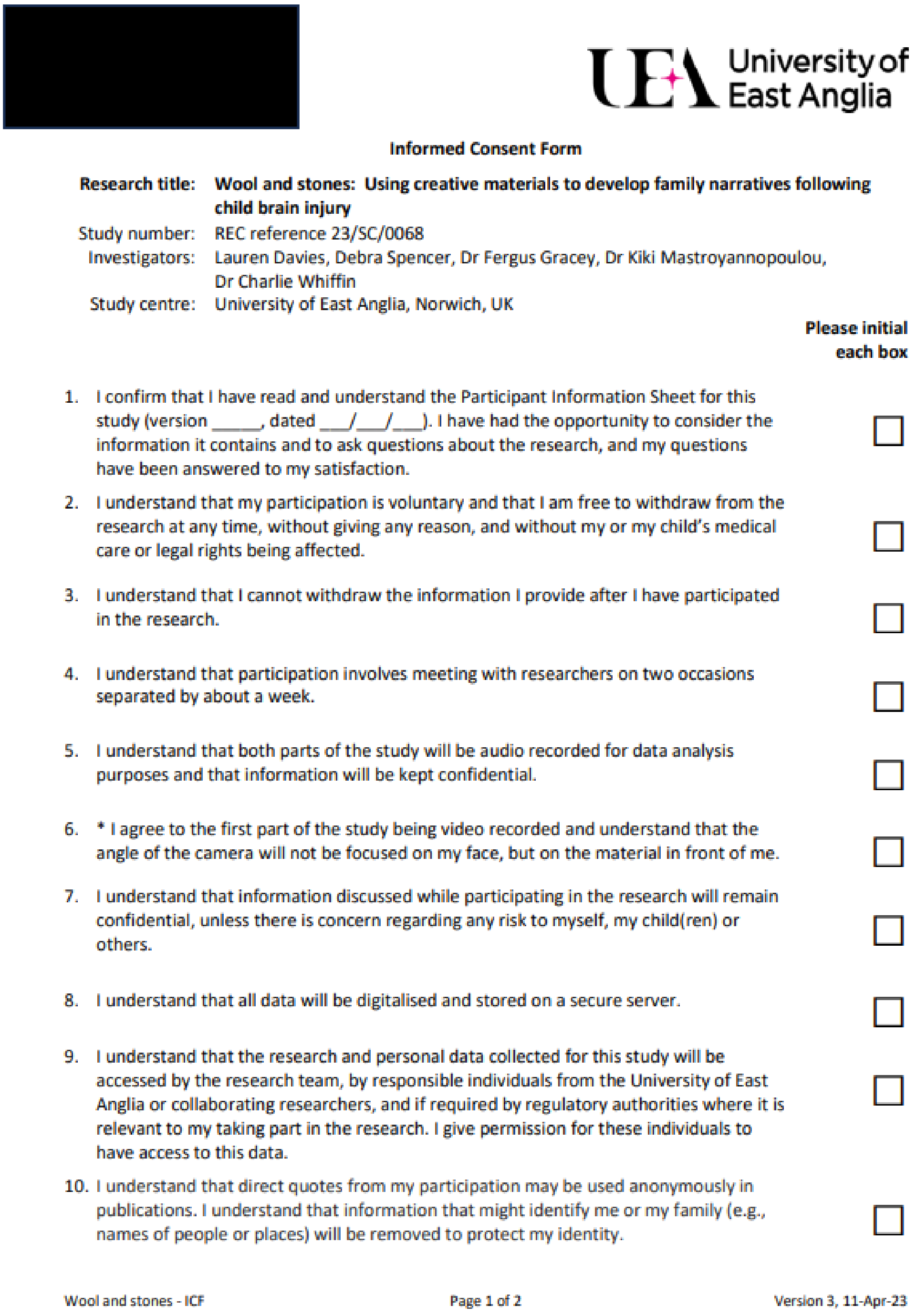
Thank you for considering taking part in this study. Research depends on the goodwill and generosity of potential participants such as you. If you require further information, we will be pleased to help you in any way we can. You can contact us using the details below:

Lauren Davies
Trainee Clinical Psychologist
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
E: lauren.davies@uea.ac.uk

Debra Spencer
Trainee Clinical Psychologist
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
[redacted]

Dr Fergus Gracey
Clinical Associate Professor in Clinical Psychology
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
[redacted]

Appendix J: Informed Consent Form



[redacted]

University of East Anglia

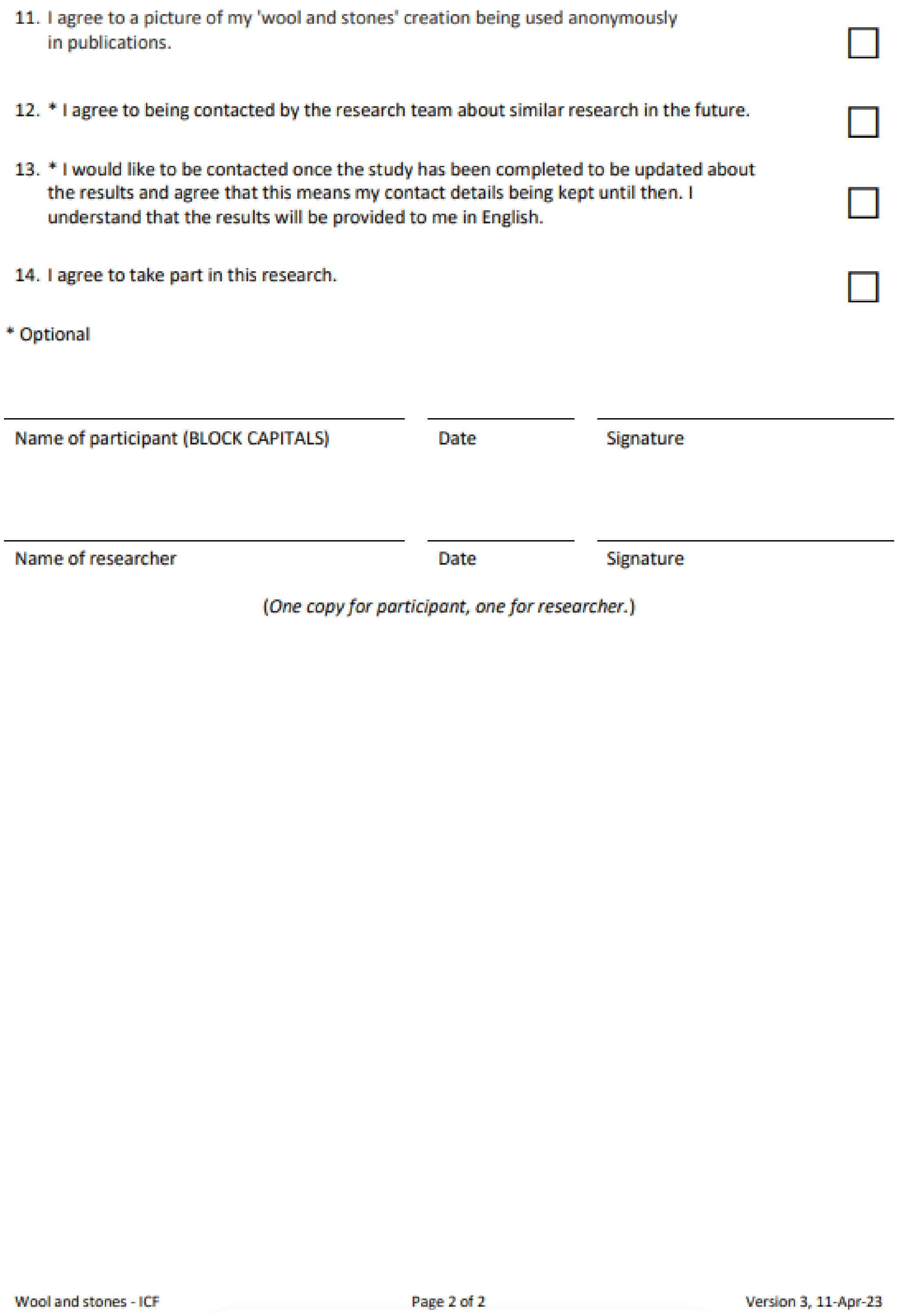
Informed Consent Form

Research title: **Wool and stones: Using creative materials to develop family narratives following child brain injury**
Study number: REC reference 23/SC/0068
Investigators: Lauren Davies, Debra Spencer, Dr Fergus Gracey, Dr Kiki Mastroyannopoulou, Dr Charlie Whiffin
Study centre: University of East Anglia, Norwich, UK

Please initial each box

1. I confirm that I have read and understand the Participant Information Sheet for this study (version _____, dated ___/___/___). I have had the opportunity to consider the information it contains and to ask questions about the research, and my questions have been answered to my satisfaction. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason, and without my or my child's medical care or legal rights being affected. ☐
3. I understand that I cannot withdraw the information I provide after I have participated in the research. ☐
4. I understand that participation involves meeting with researchers on two occasions separated by about a week. ☐
5. I understand that both parts of the study will be audio recorded for data analysis purposes and that information will be kept confidential. ☐
6. * I agree to the first part of the study being video recorded and understand that the angle of the camera will not be focused on my face, but on the material in front of me. ☐
7. I understand that information discussed while participating in the research will remain confidential, unless there is concern regarding any risk to myself, my child(ren) or others. ☐
8. I understand that all data will be digitalised and stored on a secure server. ☐
9. I understand that the research and personal data collected for this study will be accessed by the research team, by responsible individuals from the University of East Anglia or collaborating researchers, and if required by regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data. ☐
10. I understand that direct quotes from my participation may be used anonymously in publications. I understand that information that might identify me or my family (e.g., names of people or places) will be removed to protect my identity. ☐

Wool and stones - ICF Page 1 of 2 Version 3, 11-Apr-23



11. I agree to a picture of my 'wool and stones' creation being used anonymously in publications. ☐

12. * I agree to being contacted by the research team about similar research in the future. ☐

13. * I would like to be contacted once the study has been completed to be updated about the results and agree that this means my contact details being kept until then. I understand that the results will be provided to me in English. ☐

14. I agree to take part in this research. ☐

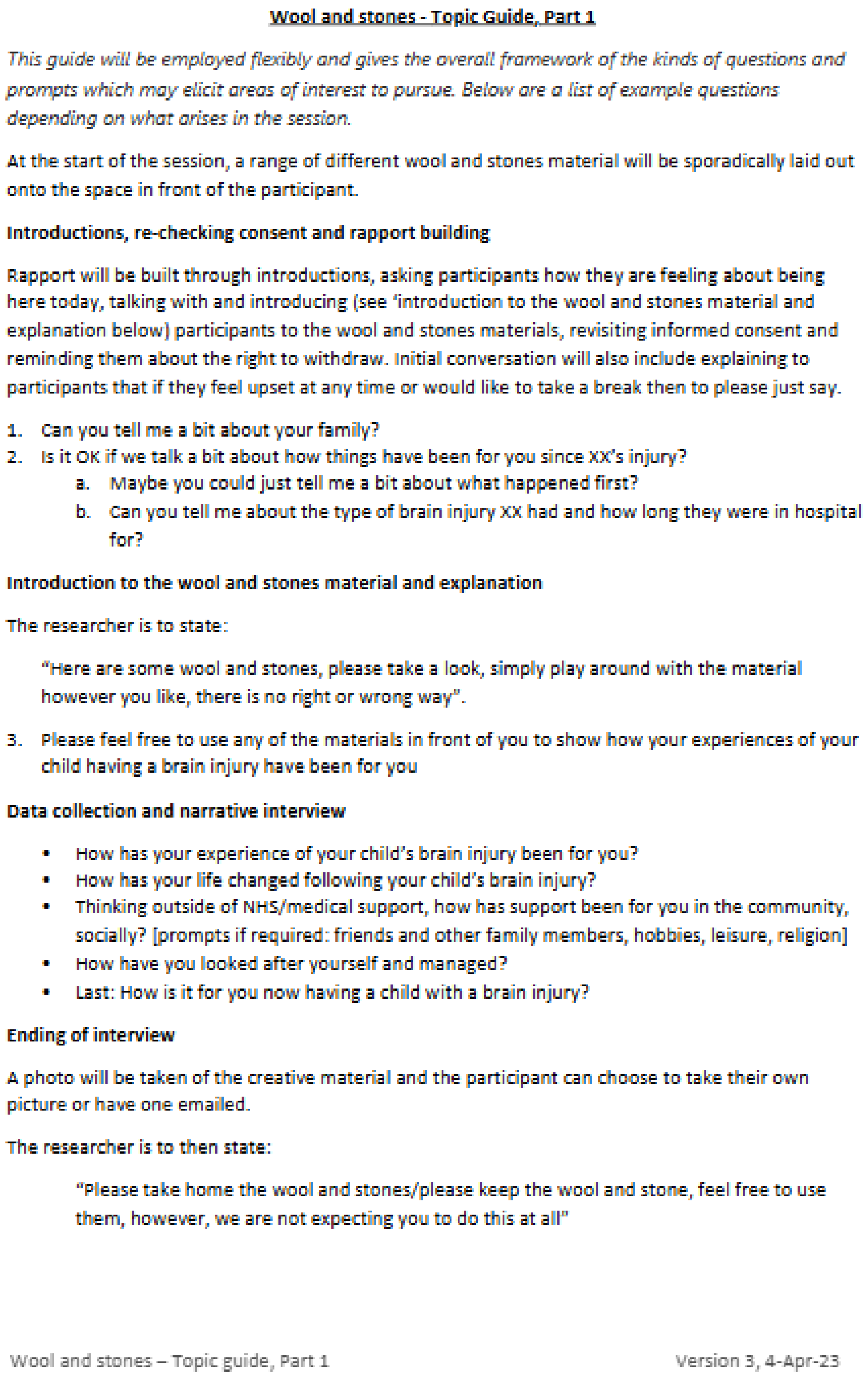
* Optional

Name of participant (BLOCK CAPITALS) Date Signature

Name of researcher Date Signature

(One copy for participant, one for researcher.)

Appendix K: Topic Guide



Wool and stones - Topic Guide, Part 1

This guide will be employed flexibly and gives the overall framework of the kinds of questions and prompts which may elicit areas of interest to pursue. Below are a list of example questions depending on what arises in the session.

At the start of the session, a range of different wool and stones material will be sporadically laid out onto the space in front of the participant.

Introductions, re-checking consent and rapport building

Rapport will be built through introductions, asking participants how they are feeling about being here today, talking with and introducing (see 'introduction to the wool and stones material and explanation below) participants to the wool and stones materials, revisiting informed consent and reminding them about the right to withdraw. Initial conversation will also include explaining to participants that if they feel upset at any time or would like to take a break then to please just say.

1. Can you tell me a bit about your family?
2. Is it OK if we talk a bit about how things have been for you since XX's injury?
   a. Maybe you could just tell me a bit about what happened first?
   b. Can you tell me about the type of brain injury XX had and how long they were in hospital for?

Introduction to the wool and stones material and explanation

The researcher is to state:

> "Here are some wool and stones, please take a look, simply play around with the material however you like, there is no right or wrong way".

3. Please feel free to use any of the materials in front of you to show how your experiences of your child having a brain injury have been for you

Data collection and narrative interview

- How has your experience of your child's brain injury been for you?
- How has your life changed following your child's brain injury?
- Thinking outside of NHS/medical support, how has support been for you in the community, socially? [prompts if required: friends and other family members, hobbies, leisure, religion]
- How have you looked after yourself and managed?
- Last: How is it for you now having a child with a brain injury?

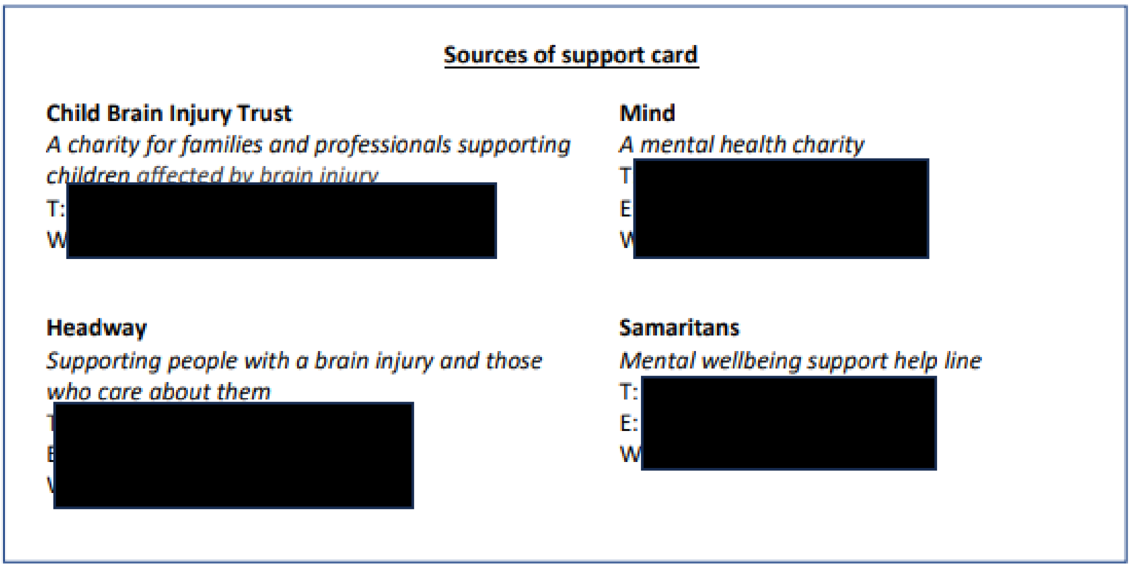
Ending of interview

A photo will be taken of the creative material and the participant can choose to take their own picture or have one emailed.

The researcher is to then state:

> "Please take home the wool and stones/please keep the wool and stone, feel free to use them, however, we are not expecting you to do this at all"

Appendix L: Sources of Support Card



Sources of support card

Child Brain Injury Trust
A charity for families and professionals supporting children affected by brain injury
[redacted]

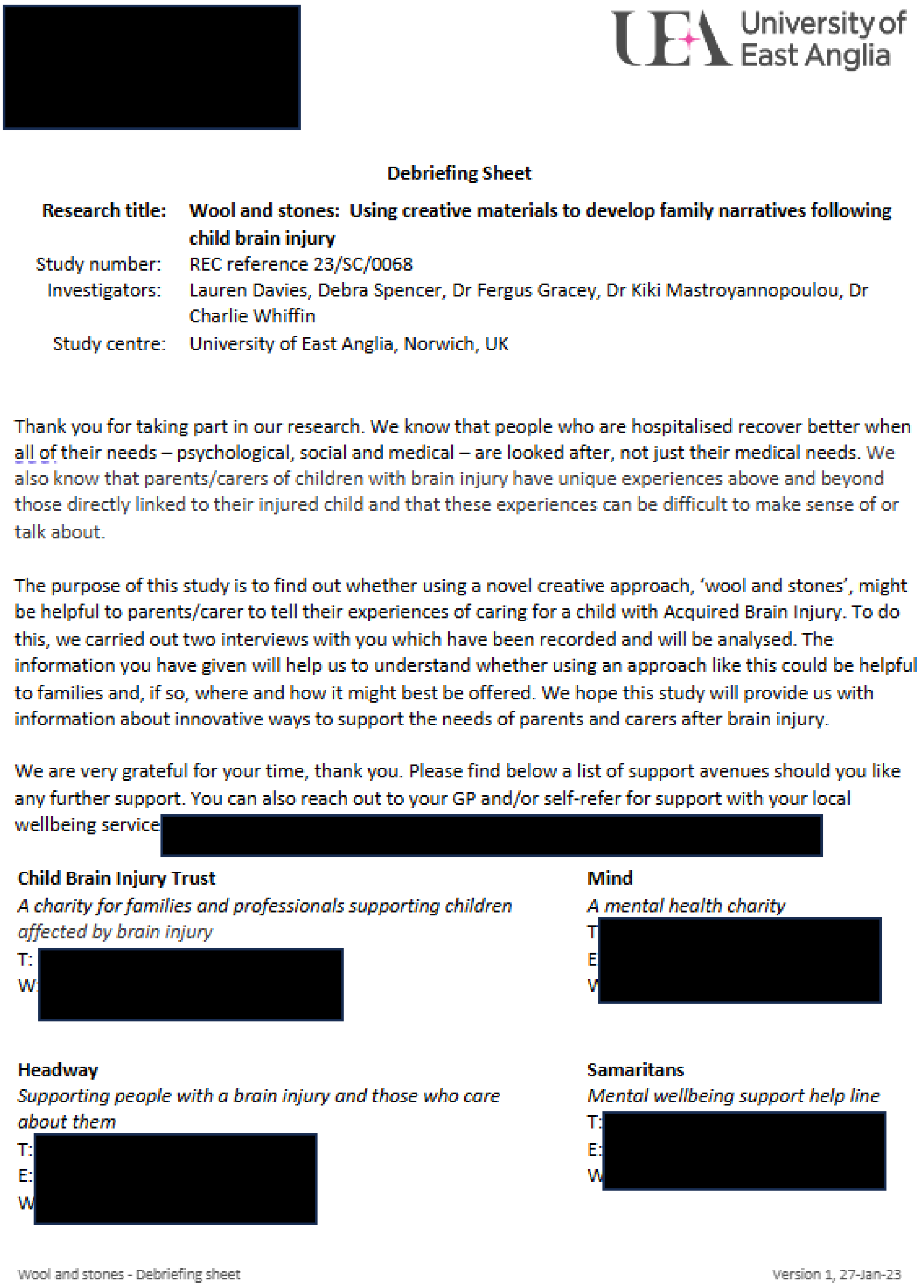
Mind
A mental health charity
[redacted]

Headway
Supporting people with a brain injury and those who care about them
[redacted]

Samaritans
Mental wellbeing support help line
[redacted]

Appendix M: Debrief Sheet

(provided after Part 2 of the study)



[redacted]

University of East Anglia

Debriefing Sheet

Research title: **Wool and stones: Using creative materials to develop family narratives following child brain injury**
Study number: REC reference 23/SC/0068
Investigators: Lauren Davies, Debra Spencer, Dr Fergus Gracey, Dr Kiki Mastroyannopoulou, Dr Charlie Whiffin
Study centre: University of East Anglia, Norwich, UK

Thank you for taking part in our research. We know that people who are hospitalised recover better when all of their needs – psychological, social and medical – are looked after, not just their medical needs. We also know that parents/carers of children with brain injury have unique experiences above and beyond those directly linked to their injured child and that these experiences can be difficult to make sense of or talk about.

The purpose of this study is to find out whether using a novel creative approach, 'wool and stones', might be helpful to parents/carer to tell their experiences of caring for a child with Acquired Brain Injury. To do this, we carried out two interviews with you which have been recorded and will be analysed. The information you have given will help us to understand whether using an approach like this could be helpful to families and, if so, where and how it might best be offered. We hope this study will provide us with information about innovative ways to support the needs of parents and carers after brain injury.

We are very grateful for your time, thank you. Please find below a list of support avenues should you like any further support. You can also reach out to your GP and/or self-refer for support with your local wellbeing service [redacted]

Child Brain Injury Trust
A charity for families and professionals supporting children affected by brain injury
T:
W [redacted]

Mind
A mental health charity
T
E
V [redacted]

Headway
Supporting people with a brain injury and those who care about them
T:
E:
W [redacted]

Samaritans
Mental wellbeing support help line
T:
E:
W [redacted]

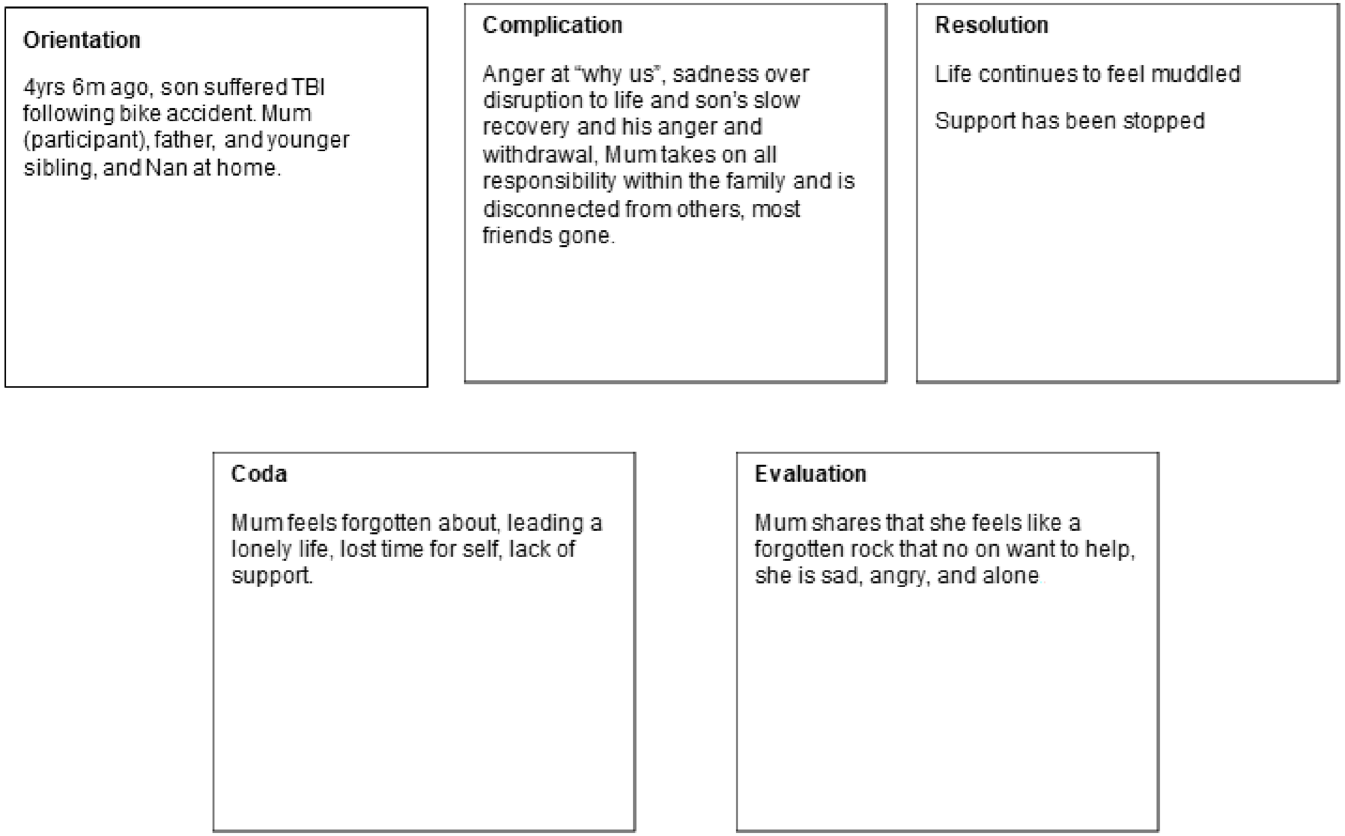
Wool and stones - Debriefing sheet

Version 1, 27-Jan-23

Appendix N: Analysis Example

Structural analysis, initial coding, and forming of narratives table.

Structural analysis



Orientation

4yrs 6m ago, son suffered TBI following bike accident. Mum (participant), father, and younger sibling, and Nan at home.

Complication

Anger at "why us", sadness over disruption to life and son's slow recovery and his anger and withdrawal, Mum takes on all responsibility within the family and is disconnected from others, most friends gone.

Resolution

Life continues to feel muddled

Support has been stopped

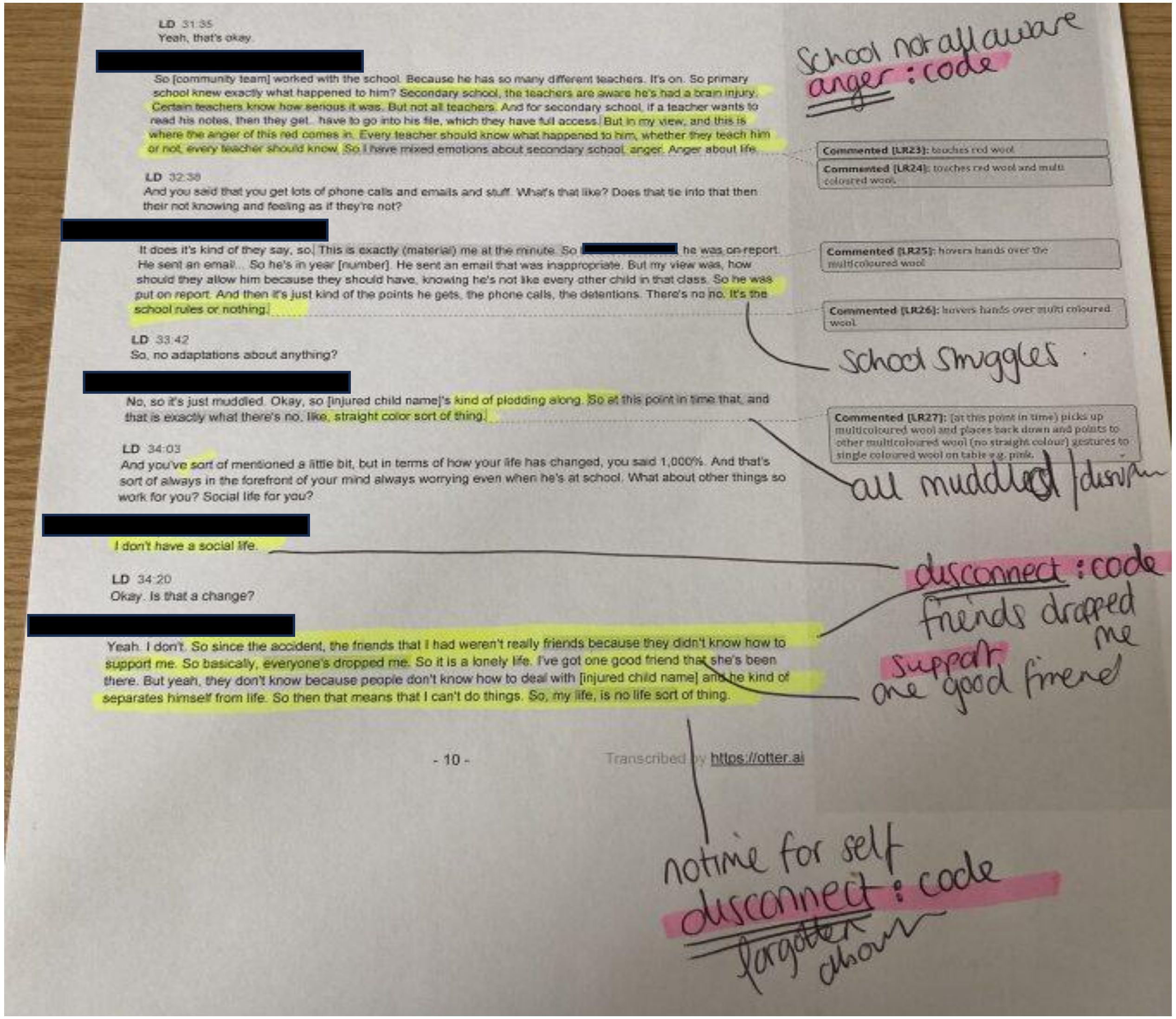
Coda

Mum feels forgotten about, leading a lonely life, lost time for self, lack of support.

Evaluation

Mum shares that she feels like a forgotten rock that no on want to help, she is sad, angry, and alone.

Initial Coding



LD 31:35
Yeah, that's okay.

[redacted]
So [community team] worked with the school. Because he has so many different teachers. It's on. So primary school knew exactly what happened to him? Secondary school, the teachers are aware he's had a brain injury. Certain teachers know how serious it was. But not all teachers. And for secondary school, if a teacher wants to read his notes, then they get.. have to go into his file, which they have full access. But in my view, and this is where the anger of this red comes in. Every teacher should know what happened to him, whether they teach him or not, every teacher should know. So I have mixed emotions about secondary school, anger. Anger about life.

LD 32:38
And you said that you get lots of phone calls and emails and stuff. What's that like? Does that tie into that then their not knowing and feeling as if they're not?

[redacted]
It does it's kind of they say, so. This is exactly (material) me at the minute. So [redacted] he was on report. He sent an email... So he's in year [number]. He sent an email that was inappropriate. But my view was, how should they allow him because they should have, knowing he's not like every other child in that class. So he was put on report. And then it's just kind of the points he gets, the phone calls, the detentions. There's no no. It's the school rules or nothing.

LD 33:42
So, no adaptations about anything?

[redacted]
No, so it's just muddled. Okay, so [injured child name]'s kind of plodding along. So at this point in time that, and that is exactly what there's no, like, straight color sort of thing.

LD 34:03
And you've sort of mentioned a little bit, but in terms of how your life has changed, you said 1,000%. And that's sort of always in the forefront of your mind always worrying even when he's at school. What about other things so work for you? Social life for you?

[redacted]
I don't have a social life.

LD 34:20
Okay. Is that a change?

[redacted]
Yeah. I don't. So since the accident, the friends that I had weren't really friends because they didn't know how to support me. So basically, everyone's dropped me. So it is a lonely life. I've got one good friend that she's been there. But yeah, they don't know because people don't know how to deal with [injured child name] and he kind of separates himself from life. So then that means that I can't do things. So, my life, is no life sort of thing.

- 10 -

Transcribed by https://otter.ai

Commented [LR23]: touches red wool

Commented [LR24]: touches red wool and multi coloured wool.

Commented [LR25]: hovers hands over the multicoloured wool

Commented [LR26]: hovers hands over multi coloured wool.

Commented [LR27]: (at this point in time) picks up multicoloured wool and places back down and points to other multicoloured wool (no straight colour) gestures to single coloured wool on table e.g. pink.

School not all aware
anger : code

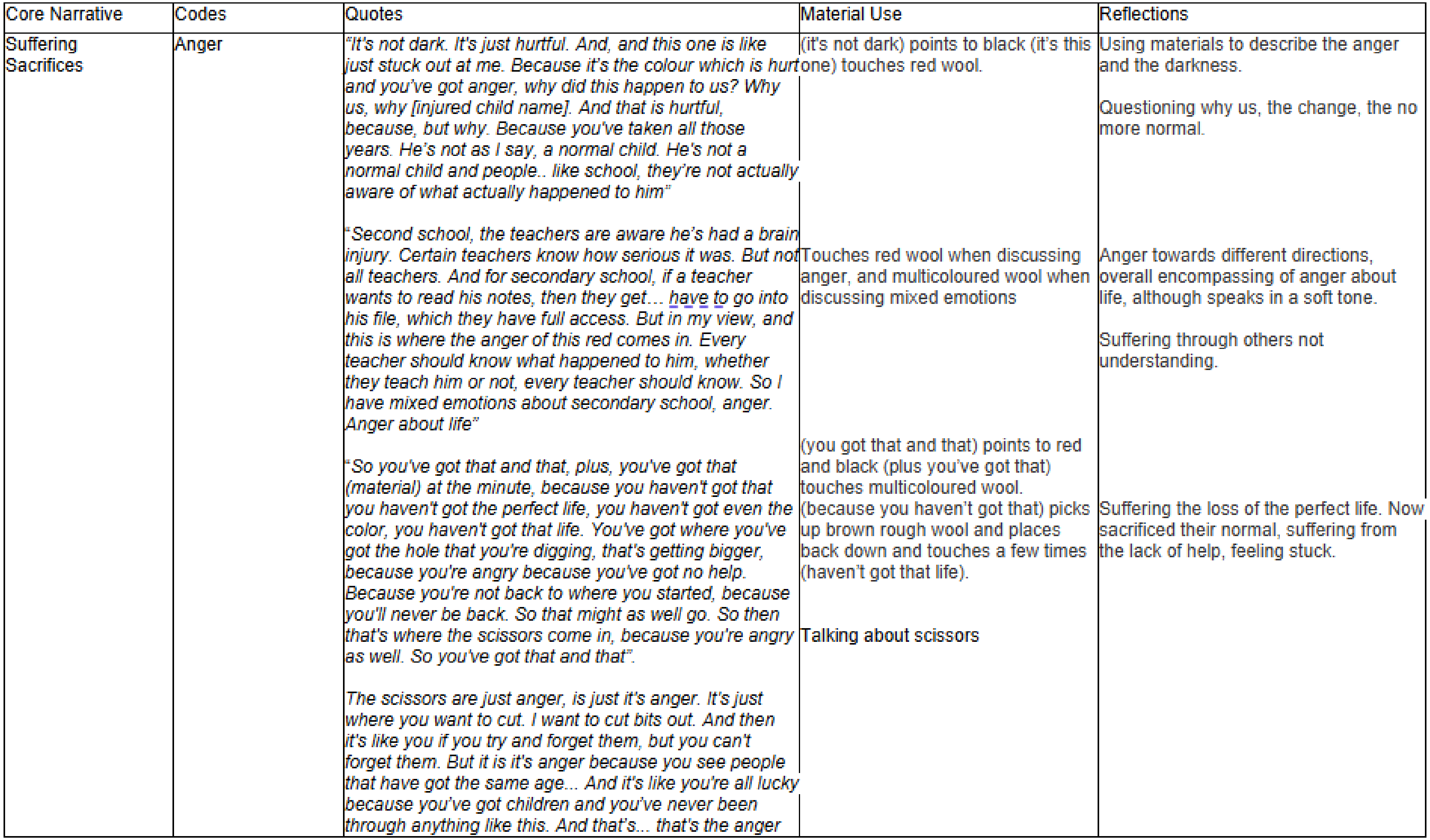
School struggles

all muddled / disrup

disconnect : code
friends dropped me
support
one good friend

notime for self
disconnect : code
forgotten about

Forming of Narratives



Core Narrative	Codes	Quotes	Material Use	Reflections
Suffering Sacrifices	Anger	*"It's not dark. It's just hurtful. And, and this one is like just stuck out at me. Because it's the colour which is hurt and you've got anger, why did this happen to us? Why us, why [injured child name]. And that is hurtful, because, but why. Because you've taken all those years. He's not as I say, a normal child. He's not a normal child and people.. like school, they're not actually aware of what actually happened to him"*	(it's not dark) points to black (it's this one) touches red wool.	Using materials to describe the anger and the darkness. Questioning why us, the change, the no more normal.
		"Second school, the teachers are aware he's had a brain injury. Certain teachers know how serious it was. But not all teachers. And for secondary school, if a teacher wants to read his notes, then they get… have to go into his file, which they have full access. But in my view, and this is where the anger of this red comes in. Every teacher should know what happened to him, whether they teach him or not, every teacher should know. So I have mixed emotions about secondary school, anger. Anger about life"	Touches red wool when discussing anger, and multicoloured wool when discussing mixed emotions	Anger towards different directions, overall encompassing of anger about life, although speaks in a soft tone. Suffering through others not understanding.
		"So you've got that and that, plus, you've got that (material) at the minute, because you haven't got that you haven't got the perfect life, you haven't got even the color, you haven't got that life. You've got where you've got the hole that you're digging, that's getting bigger, because you're angry because you've got no help. Because you're not back to where you started, because you'll never be back. So that might as well go. So then that's where the scissors come in, because you're angry as well. So you've got that and that".	(you got that and that) points to red and black (plus you've got that) touches multicoloured wool. (because you haven't got that) picks up brown rough wool and places back down and touches a few times (haven't got that life). Talking about scissors	Suffering the loss of the perfect life. Now sacrificed their normal, suffering from the lack of help, feeling stuck.
		The scissors are just anger, is just it's anger. It's just where you want to cut. I want to cut bits out. And then it's like you if you try and forget them, but you can't forget them. But it is it's anger because you see people that have got the same age… And it's like you're all lucky because you've got children and you've never been through anything like this. And that's… that's the anger		

		that you haven't been through. And people can say, oh, yeah, I understand. No, you don't understand until it's happened to you.		
Relational Ruptures and Harmony	Disconnect	*"So since the accident, the friends that I had weren't really friends because they didn't know how to support me. So basically, everyone's dropped me. So it is a lonely life. I've got one good friend that she's been there. But yeah, they don't know because people don't know how to deal with [injured child] and he kind of separates himself from life. So then that means that I can't do things. So, life, is no life sort of thing"* *"Not knowing what he could do and what he couldn't do. Not knowing what life would be like because you're so used to, you're so used to having been like stuck in that and being wrapped in wool, that you're afraid it's like being a baby again. Taking those steps, learning even for me and for [injured child] taking those steps".*	None	Not using materials to visually represent anything with friends – is it more important to show family through them? Are the friends who have neglected her worth the use of wool and stones?
	Responsibility	*And because I'm the rock, so that's me (material). I'm the rock. They both, everyone falls on me. So then that's where my time, I don't get time. Because when I'm trying to look after everybody, I'm forgotten about. And that is, basically, yeah…So hubby would be this one, I think because it's nice and smooth. So he's very caring. And hubby does look after me. But I have to be the bigger rock. [injured child] [laugh] is this one, [injured child] is this one. But then you've got to make matters worse, and you've got my mum. So she's gonna be this one. Because she's a challenge as well. And then I think you've got [sibling]. So [sibling]is another challenge. So [sibling] can be this one. So, this is, and then you see, and then I've got two dogs. So, these are my dogs as well. Don't forget my dogs because they are part of the family. So, this is me. This is hubby. This is [injured child name]. This is mum. This is [sibling]. And then this is the two dogs, but all of them need me.*	Points to big shiny stone. (hubby would be this one) picks smaller shiny grey stone (but I have to be the bigger rock) points to the lighter beige stone (injured child is this one) picks up yellow clear stone (and then you've got my mum) picks up grey stone (and then sibling) picks grey stone (then the dogs) picks two small white stones and lines up; mum, dad, injured child, sibling, grandmother then dogs.	Using stones to indicate different roles in family, from largest having overall responsibility (her) and the following stones representing everyone she is responsible for. Refers to self as the forgotten rock, little support for her, no time for her, relationships are broken, they are ruptured. When she refers to herself as lonely, this is sad, adds to the previous suffering and sacrifice.
	No more support	*"Hard, very hard. Very. It's a challenge. It's hard. It's a challenge. It's complicated. Because you think, after all the guidance that you've had from [community team] and, and the help and the support, and there's nothing now. So, who do you turn to? Because then you're like a rock,*	Refers to stone	A forgotten rock – at a loss, left without support, relationships ruptured, and suffering continues

		a rock, that's on the floor that nobody wants to know. Nobody wants to help. And it's hard. It is really hard. *There is nobody that you can say, Oh, can you have [injured child]? while I say I had my hair done? There's no, you're kind of just put on hold. Things are put on hold.* *I have to do a quick walk (of the dog). Yes. Because then I have to come back. Yes. So it's not like, as a family, you'd say, oh, we'd go out. Even like holidays, he doesn't want to do it. He doesn't want to, because the perception of people, which is quite horrible.* *"On that day, it happened. My life stopped [tearful] You're alright, so yeah, it's just yeah. That's where the scissors come in"*	Refers to scissors	
	Constantly on	*"I would say, 1,000% it's changed. It's changed where you're more aware of what's happening you're more aware of. So he's at school. I worry about him. So it's not where I can just think oh, yeah, he's at school. He'll be fine. No, the amount of emails I get, the phone calls I get, the when I pick him up might have to assess if it's safe to drive before I drive off because he's angry. Because if depends on how his days gone. As soon as he gets in that car, he blows. So it's kind of ... and even at home. It's not like having two children. And that's the thing. It's not. You're always having to check on him. You're always having to. He's at the front of your mind. Not in the back of your mind where he's [age]. He should be able to. And you can't. If there's a bang, I automatically think, it's him when actually, it's not him. He's tired a lot more. So he's asleep a lot more, but that's his injury. So if he doesn't sleep, then that's where the rockiness of that, because he's not 100% and the balance".* *"I go to [name of activity] on a* [redacted] *But I still have [sibling]. So, because she was a very clingy child. She clung to me. It's kind of where I go now, she goes with me.. So for me to be here (for research interview), it's*	Touches two yellow clear stones (rockiness) None	Not having time for self again, little support, change in relationships. Sacrifices. [redacted] is something to help manage, but this comes with having responsibility of daughter who goes with, linking with the idea of being constantly on, not having time for self fully.

		fantastic [laughs]… Yeah, so that's, that's my time, even though I've got [sibling]"		
	Support	*"It was with [community rehab team], it was fantastic because they knew what they were doing. They knew. So they weren't like when we come in here and done [injured child] training. Nothing phased them. So they would be like this (material) because nothing. They've seen it all before when I was sat here. I was embarrassed. I was upset. But they were like my rock. And I would say they were like this one (material). Because they were fantastic".* *"And like, when [injured child] was in [hospital]'s, she'd come down to get me away from.. so when he was in intensive care. We had a coffee and then I went back up, but that half an hour, because I wouldn't leave his side. That half an hour, done me the world of good. And even now, she's there to talk. So she, she is my rock. She is because even though I've got hubby, and this happened to both of us".* *"It's kind of when I see her it's forgetting all of this. So yes, [injured child's] at home. But it's like, I have a normal life. And then I go back to an unnormal life. So you could say this is normal life (material). This is normal life, all of that normal life. But this isn't normal life. So just to go to hers or go for a coffee or go for a walk, I've got kind of a normal life. But then in the back of my head, I know I haven't, because I'm going back to all of this (material). And I'm going to this (material) "*	Touches initial shiny black stone and picks it up to show researcher and places back down. Touches initial shiny stones (She's my rock) Waves hands over all material (both of us) Waves hands over material (forgetting all this) Picks up and puts back down the pink wool (this is normal life) points to baby blue wool (but this isn't normal life) picks up multicoloured wool. Points to lined up stones, cups multicoloured material with hands and I'm going to this)	Some relational harmony within the one good friend, allowing that space away. Reflects on previous support which is no longer available – change in relational harmony, now being ruptured.

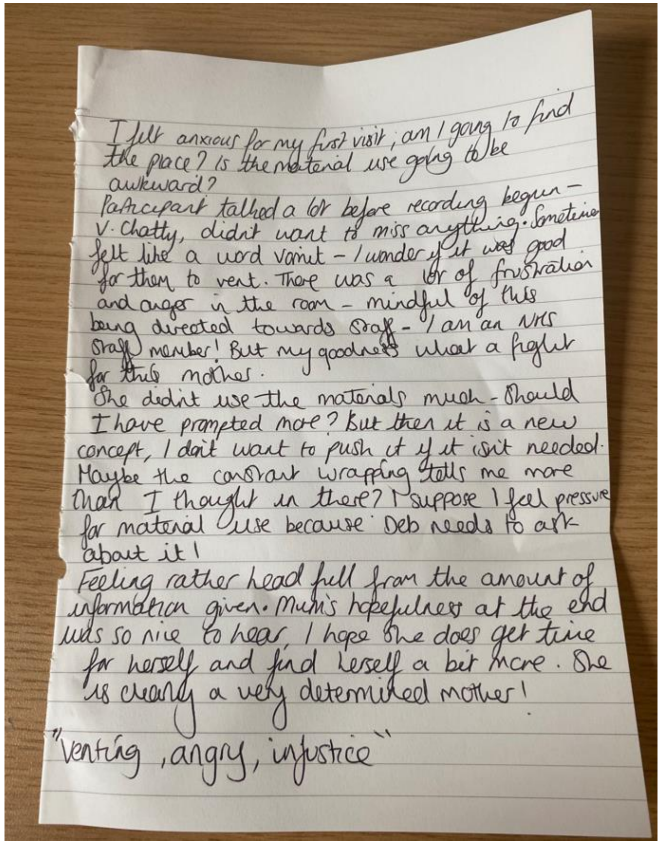
Appendix O: All other wool and stones pictures

P2:

P4:

P5:

Appendix P: Reflexive Diary Extracts



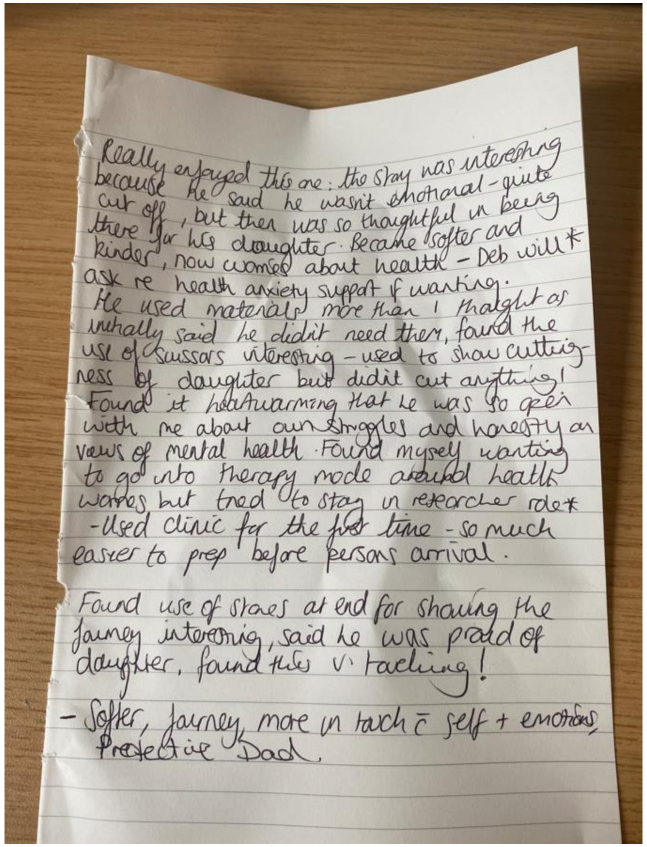
I felt anxious for my first visit; am I going to find the place? Is the material use going to be awkward?

Participant talked a lot before recording begun - v. chatty, didn't want to miss anything. Sometimes felt like a word vomit - I wonder if it was good for them to vent. There was a lot of frustration and anger in the room - mindful of this being directed towards staff - I am an NHS staff member! But my goodness what a fight for this mother.

She didn't use the materials much - Should I have prompted more? But then it is a new concept, I don't want to push it if it isn't needed. Maybe the constant wrapping tells me more than I thought in there? I suppose I feel pressure for material use because Deb needs to ask about it!

Feeling rather head full from the amount of information given. Mum's hopefulness at the end was so nice to hear, I hope she does get time for herself and find herself a bit more. She is clearly a very determined mother!

"Venting, angry, injustice"



Really enjoyed this one: the story was interesting because he said he wasn't emotional - quite cut off, but then was so thoughtful in being there for his daughter. Became softer and kinder, now worries about health - Deb will* ask re health anxiety support if wanting.

He used materials more than I thought as initially said he didn't need them, found the use of scissors interesting - used to show cutting-ness of daughter but didn't cut anything! Found it heartwarming that he was so open with me about own struggles and honesty on views of mental health. Found myself wanting to go into therapy mode around health worries but tried to stay in researcher role*

- Used clinic for the first time - so much easier to prep before persons arrival.

Found use of stones at end for showing the journey interesting, said he was proud of daughter, found this v. touching!

- Softer, journey, more in touch c̄ self + emotions, Protective Dad.

Appendix Q: Author Guidance for Submission to Neuropsychological Rehabilitation

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