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BMJ Open Parents' experience of children with acquired brain injury undergoing neuro-rehabilitation: thematic synthesis protocol

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ABSTRACT

Introduction Children with moderate to severe acquired brain injury frequently require a period of demanding medical and rehabilitative care to optimise their long-term capabilities and quality of life. Usually, the initial acute care is provided in tertiary centres and can last up to 12 months following the original injury. Parents of children with acquired brain injury share that experience with their child and face many different challenges encountered as their child's long-term needs become apparent. Parents are essential partners in care, hence there is a need to better understand their experiences to support them as they face those challenges and adapt to the needs of their child. We aim to synthesise the qualitative evidence exploring parents' experiences of children undergoing neuro-rehabilitative care.

Methods and analysis The Enhancing Transparency in Reporting the Synthesis of Qualitative Research guideline was used in the design of this protocol. The Population, Exposure and Outcome model was used to define inclusion and exclusion criteria and refine search terms. The databases Ovid Embase, Ovid MEDLINE, CINAHL, Scopus and PsychINFO will be searched from 2009 to 2022. Two independent reviewers will review studies, assess quality using the Critical Appraisal Skills Programme and scrutinise and extract the data. Disagreements will be resolved after discussion with the third reviewer. Thematic synthesis using Thomas and Harden's approach will be undertaken to provide the evidence to develop a model for parental support during the first year of their child's neuro-rehabilitation.

Ethics and dissemination Ethical committee approval will not be required as no new data will be collected. The findings will be disseminated through presentations at professional conferences, publications in peer-reviewed journals and shared with the public through relevant charities and local family support groups and networks.

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BACKGROUND

Acquired brain injury (ABI) is the term used to describe traumatic and non-traumatic brain injuries that occur after birth and a period of typical development.¹ ABI can be caused by trauma such as road traffic collision, fall or physical assault; or non-traumatic causes

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Parents of children with acquired brain injury have been consulted in the design of this protocol and amendments were made following their feedback.
- ⇒ This protocol follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidance for reporting thematic synthesis.
- ⇒ A preliminary search using Ovid MEDLINE was used to refine the search strategy.
- ⇒ Only literature published in English will be reviewed which limits the possible findings for this review.
- ⇒ No geographical restrictions for our search will be applied but neuro-rehabilitation services can vary depending on the scope and organisation of services and these will be reported.

such as stroke, infection or brain tumour.² Worldwide, traumatic brain injury (TBI) is the main cause of death and disability in children and young people (CYP) up to the age of 25.^{2,3} For example, every year in the United Kingdom (UK), at least 35 000 CYP with TBI are admitted to hospital; and around 4000 children up to the age of 16 require admission related to non-TBI.⁴ The estimated annual incidence of TBI in England is 400 per 100 000 children younger than 15 years.⁵

In children, brain damage can lead to physical, cognitive, emotional and social impairments.⁶ These impairments can be temporary or permanent, with varying severity.² Severe ABI in young children is associated with worse neurocognitive and psychological outcomes as it impedes the immediate and future development of physical and cognitive skills.⁷ Severe ABI is linked with a greater risk of developing profound disabilities that will be carried into adulthood.⁶ TBI survivors have a lower life expectancy than the general population due to the consequences of these long-term impairments.⁸ Children with ABI can experience social and economic impacts

due to ongoing medical treatment and care costs and are less likely to be employed during adulthood.⁸

Children admitted to the hospital due to severe life-threatening ABI frequently require coordinated intensive medical, and sometimes surgical, interventions to survive.¹ Once medically stable, they require multidisciplinary therapeutic input to aid neurological recovery.¹ Children with moderate to severe ABI often receive intensive neuro-rehabilitation in an acute specialist tertiary hospital setting to promote optimal functional gain before long-term support in community settings.⁶ However, the availability of specialist services can vary within and between different countries depending on numerous factors including resources and expertise available.

In the UK, neuro-rehabilitation is provided by the National Health Service (NHS). Whereas social services delivered by local authorities become involved when there is a need to support the child with an individualised supportive care package, domestic adaptations and any ongoing child protection and special education provision for children with moderate to severe ABI after discharge from specialist medical care. Social services do not normally provide rehabilitation care for this patient group in the UK.⁴ However, the nature and scope of the provision will inevitably vary and this can have an impact on parents' experience and comparability. For example, Sulzer and Karfeld-Sulzer describe the parental challenges of navigating systems and services in the United States of America and particularly access to technology and limitations of insurance coverage.⁹

Goal-based neuro-rehabilitation services are designed to provide children with ABI, and their parents/caregivers, with the support and education to manage symptoms and assist children to achieve the best possible level of autonomy and ability to participate in society.^{3,10} As part of that neuro-rehabilitation, children will access physiotherapy, occupational therapy, speech and language therapy and neuropsychology services. Given the variety and differing levels of neurological sequelae, one of the main aims of neuro-rehabilitation services is to develop a care package that best meets the individual needs of the child and their parents/caregivers.^{3,10} Evidence suggests early and intensive neuro-rehabilitation provision promotes better long-term outcomes and minimises disability.^{2,4}

When a child is admitted as critically ill due to ABI, it is an emotionally demanding and traumatic experience for the parents, siblings and extended family members.¹⁰ Survival will be the parents' priority during the hyperacute stage, and they may begin to focus on regaining function when their child becomes medically stable.¹⁰ Only when children commence neuro-rehabilitation, do parents begin to comprehend the enormity of the injuries and their consequences and often find it harder to cope as long-term needs become apparent.^{8,10} Parents' priorities tend to change with the stage of their child's recovery, which can present challenges to the medical and care teams involved in managing the rehabilitation.

Parents often experience this as a lack of consistency in service provision.⁶ Furthermore, they perceive dissonance between healthcare professionals' biomedical approach, the psychosocial and behavioural aspects of rehabilitation and family-centred care.^{11,12} The evidence of the effectiveness of whole family interventions, although limited, suggests that these might offer better strategies for supporting parents and families and facilitating their involvement in decision-making.¹²

To date, much of the interest has been on the parenting role of family caregivers of children with ABI or medical aspects of care.^{6,7} Failure to consider the needs of the children and family following discharge from acute care, and the children's subsequent developmental transitions, understandably has illuminated the true impact of having a child with ABI presents. Multiple challenges and the psychosocial burden inevitably fall on parents and families, engendering feelings of insecurity, isolation from others and struggling to adapt to the different roles required to care for their child long-term often with concomitant financial implications.^{6,7}

Parents are essential partners in their children's neuro-rehabilitation following ABI providing a large portion of the support that the child requires.⁶ The existing literature underlines the need to further interrogate the parental experience of their child's neuro-rehabilitation management.⁷ This will help to inform the development of services that better meet the needs of children with ABI and their family caregivers.⁷ To the best of our knowledge, there is no existing review that consolidates parents' experiences of their child's neuro-rehabilitation journey during the first year following ABI hence this thematic synthesis.

This protocol aims to explore parents' experiences while their children with ABI are accessing neuro-rehabilitation services during the first year following injury. The review will include studies that explore the parental experience of acute neuro-rehabilitation while their child is in hospital, or inpatient or outpatient rehabilitation after discharge from the hospital up to 1 year following diagnosis.

This review may assist in guiding the future of paediatric neuro-rehabilitation services and may inform the development of neuro-rehabilitation pathways and guidelines. This synthesis has the potential to inform recommendations for a model for parental support during the first year of the child's neuro-rehabilitation. The focus on the qualitative evidence may present additional insights and strengthen the parental voice to inform service configuration.

METHODS AND ANALYSIS

Patient and public involvement (PPI)

Parents of children with ABI have been involved in the design of this protocol to seek advice on the relevance of the topic and the study approach.¹³ Amendments were made to include parental experiences of different

conditions associated with ABI, such as TBI or brain tumours, as parents perceived the experience may be different across various types of ABI.

Search type

This protocol follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidance for reporting thematic synthesis.¹⁴

Search strategy

A preliminary search using Ovid MEDLINE was undertaken with an expert librarian to refine the search strategy. Adaptions have been made to the included search terms and MeSH subject headings.

The following databases will be searched: Ovid Embase, Ovid MEDLINE, CINAHL, Scopus and PsychINFO. Minor adaptions to the search strategy to accommodate the features of each database will be made (online supplemental appendix 1). The authors will keep a literature search log record with the databases, keywords used and the results obtained.

A Population, Exposure, Outcome (PEO) framework was developed to guide the literature search as a broader search strategy is more appropriate to capture the literature on this phenomenon. The focus of this review is parents' experience of neuro-rehabilitation (exposure) of their child following ABI (population).

PEO framework:

Population—children with ABI

Exposure—neuro-rehabilitation

Outcome—parents' experience.

Search terms

The relevant search terms derived from the application of the PEO framework will be used to acquire all relevant

articles for this review (table 1). Truncation and wildcards (*) will be used to expand findings. They will be combined using Boolean operators.

Types of studies included

This review will include qualitative and mixed-method studies. Mixed-method studies will only be considered if the qualitative components can be clearly distinguished from quantitative data. If the qualitative data cannot be extracted from the published article, the authors will be contacted to seek clarification. If no response is obtained within 2 weeks, the study will be excluded.

This review will exclude grey literature to ensure only methodological robust studies are selected that have undergone appraisal or peer review.

Studies published before 2009 will be excluded, as the preliminary search identified no suitable publications before 2009, suggesting this phenomenon has only recently gained interest.¹⁵ Only papers published in full in English will be included. The authors will report the total number of excluded articles and the reasons. There will be no geographical restrictions.

Inclusion and exclusion criteria

Population

The review will include participants with ABI before adulthood up to the age of 18. The usual definition of CYP includes individuals up to the age of 25. Parents' experiences of young adults who sustain ABI are likely to be different compared with children's parents. Young adults will normally use adult neuro-rehabilitation services which are different from paediatric services. If the studies include young adults, and the findings of children are not distinguishable, the publications will be excluded

Table 1 PEO search terms

Search terms\ PEO terms	Population		Exposure neuro- rehabilitation	Outcome	
	Children	ABI		Parents	Experience
Keywords or phrases	Paediatric* Pediatric* Child* Infant* Toddler* Youth Early years Preschool* Pre-school* Adolescen* Juvenile Teenage*	'Acquired Brain Injur*' 'Brain Injur*' TBI Meningitis Encephalitis Stroke 'Arteriovenous Malformation' Aneurysm 'Brain Haemorrhage' 'Cerebral Haemorrhage' Hypoxia 'Hypoxic Injur*' Asphyxiation 'Brain Tumo*' 'Cerebral Tumo*' 'Brain Neoplasm' 'Head Injur*'	Neurorehabilitation Neuro-rehabilitation 'Neurological Rehabilitation' Neuro* Therap* Rehab*	Parent* Mother* Father* Caregiver* Famil* Guardian* Carer*	Experienc* Perspectiv* Perception* Involve* Liv* Impact* Effect* Expectation* Opinion* Perceiv* Think* Thought* View*

ABI, acquired brain injury; PEO, population, exposure, outcome; TBI, traumatic brain injury.

after seeking clarification from the study authors. If no response is obtained within 2 weeks, the review team will exclude these studies.

This review will include publications reporting the experience of any parents/individuals who have parental responsibility for a child with a diagnosis of ABI due to traumatic or non-traumatic causes. This review will include children with oncology conditions that have resulted in an ABI, for example, brain tumours. Some literature includes children with cerebral palsy (CP) within the categorisation of ABI. As the description, classification and presentation of CP are markedly different from ABI, this review will only include studies where $\geq 50\%$ of the participants had a diagnosis of ABI instead of CP. It will exclude brain injuries of genetic or metabolic origin, as children with these conditions have different causes and tend to be degenerative.¹⁶

Exposure

This review will include any study that explores paediatric neuro-rehabilitation services in any setting, such as acute hospital, early discharge service, community rehabilitation and residential neuro-rehabilitation, up to the 1 year post-ABI incident. Studies focusing on changes after 1 year following acute ABI will be excluded as the goals of these services will have a chronic management focus. Studies that offer any specialist contribution within neuro-rehabilitation, such as physiotherapy, occupational therapy, speech and language therapy and psychology will be included.

Outcome

A parent is described as the lawful and/or biological parent of a person. An individual responsible for raising a child is described as having parental responsibility.¹⁷ Therefore, this study will include parents or individuals with parental responsibility. If the studies include other participants who do not have parental responsibility, and the findings specific to parents are not distinguishable from others (e.g. siblings), the publications will be excluded after seeking clarification from the study authors. If no response is obtained within 2 weeks, the review team will report the decision to include or exclude the study.

This review will include studies focusing on lived experiences but exclude parents' anticipated needs.

Study selection

Once the database searches are completed, all 'hits' will be extracted into Rayyaan Software.¹⁸ Following the removal of duplicates, two reviewers (MF and CR) will independently scrutinise the titles and abstracts against the inclusion and exclusion criteria. The reviewers will read the title first and the abstracts later if considered relevant. The two independent reviewers will meet to discuss and any disagreements will be resolved by the third reviewer (AET).

Full articles will be retrieved via NHS and University library services. If the studies cannot be obtained through these libraries, the authors will be directly contacted to request access and 2 weeks will be allowed for a reply. If no reply is obtained or the study cannot be purchased or is unavailable via inter-library loan, they will be excluded and documented. Finally, the three reviewers will repeat the process to reach consensus inclusions.

References included in selected articles will be reviewed to identify any possible 'missed' studies. The same inclusion and exclusion criteria, study retrieval and selection process will be applied to determine whether the referenced articles are suitable for inclusion in the review.

Data extraction

The identified articles will be imported into Mendeley reference management software. The characteristics of the studies included in the review will be presented in a summary table. This will include differential diagnosis within the overall ABI umbrella categorisation, in which neuro-rehabilitation services and which specialists supported the children described, age and any information about children's development/autonomy before the incident if provided, and where the studies were conducted. The quality of the articles will be assessed using the Critical Appraisal Skills Programme (CASP) tool.¹⁹

Strategy for synthesis

Thematic synthesis will be used to integrate the results and interpretations from multiple studies. An inductive approach will be applied to analyse the qualitative data extracted from the included studies.²⁰

The thematic synthesis will involve three main stages as described by Thomas and Harden's work: the free line-by-line coding of the findings of the included studies, the organisation of these 'free codes' to construct 'descriptive' themes and the development of 'analytical' themes.²⁰

A standardised Excel form will be used for data extraction of the findings from the included studies and abstraction within the thematic synthesis.

Once extraction is completed, the three reviewers will independently code each line of data extracted into the Excel form according to 'meaning and content'.

Reviewers will come together to identify similarities and differences between codes and this then will enable the grouping of codes into tentative descriptive themes.²⁰ Once reviewers have agreed on tentative descriptive themes, they will review codes to confirm if they support the developing thematic schema. Any codes that do not fit the developing coding structure will be interrogated to see if new codes or recoding are required and/or propose a new theme.

The reviewers will subsequently group and collapse themes to 'go beyond' the findings of the original studies to develop an abstract analytical thematic synthesis to describe and explain the parental experience of the neuro-rehabilitative care of their children with ABI. Through this discussion, more abstract or analytical

categories might emerge and once consensus is reached, the final themes will be presented in an analytical report and in a summary table.

DISCUSSION

There is increasing evidence exploring the importance of family-centred care in paediatric neuro-rehabilitation.^{6 12} Researchers have begun to explore the barriers, facilitators and benefits of involving parents, while recognising their impact on rehabilitation outcomes.¹² Researchers have demonstrated that children with ABI managed with the active involvement of their family have shown improved outcomes after 1 year of intervention compared with children who were only managed by healthcare professionals.⁶

ABI includes a wide variety of medical conditions and subsequent disablement.¹² Therefore, the variety of journeys these children and their parents will experience are varied and unique. Previous experiences in healthcare are likely to have an influence and shape parents' experiences, relationships with healthcare professionals and views about their involvement in the intensive neuro-rehabilitation period.

The child's development and independence before the diagnosis of ABI are likely to be different across the studies. This variation may be apparent in the included studies with, for example, parents of babies having very different experiences from parents of older children and teenagers.

This protocol only included parents or individuals with parental responsibility. However, other family members may be impacted by ABI and the neuro-rehabilitation experience but this is beyond the scope of this review.

Neuro-rehabilitation services vary according to their settings, the constitution of the multidisciplinary team and resources. These differences may lead to variations in parental experience. We have not applied any geographical restrictions on inclusion criteria as we want to understand experience, but these may limit the level of analysis or abstraction.²⁰ We also recognise that even within the same country, the access and availability of neuro-rehabilitation services can vary.

The search strategy includes only five databases and only literature published in English will be reviewed, which may impose limitations. Contacting authors for requests for data and/or clarification may receive poor responses which may increase the exclusion of studies.

The CASP Qualitative Checklist was chosen to assess the quality of the studies. However, it has been criticised in terms of limited methodological discernment compared with other frameworks.¹⁹

ETHICS AND DISSEMINATION

This protocol follows the ethical principles stated in the Declaration of Helsinki—Ethical principles for medical research involving human subjects. Institutional ethical

committee approval is not required as no new data will be collected.²¹ We will report whether selected studies in the review have stated ethical approval.

The findings of this thematic synthesis may assist in the development of a model or recommendations for parental support for the first year of their child's neuro-rehabilitation and therefore influence clinical practice in paediatric neuro-rehabilitation services. This may then help to improve parents' and patients' experience of accessing paediatric neuro-rehabilitation services.

Depending on the findings of this study, they may identify a need to explore specific themes in more detail in further studies. The findings will also be shared with the public through relevant charities, and local family support groups and networks.

The findings will be shared with clinical experts in paediatric neuro-rehabilitation locally and via professional conferences. Once the thematic synthesis is completed, it will be submitted for publication in a peer-reviewed open-access scientific journal.

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Contributors MF is the guarantor. MF conceptualised the research idea, drafted the protocol and edited and reviewed successive drafts of the manuscript. CR provided mentorship to MF, helped to develop the research idea, critically reviewed multiple drafts, was involved in editing and provided rehabilitation expert input. AET was involved in critically reviewing, editing the protocol and provided qualitative methods expert input. All authors have made substantive contributions to the development of this protocol. All authors read and approved the final manuscript.

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