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Parents' experience of children with acquired brain injury undergoing neurorehabilitation: a systematic review

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ABSTRACT

Background This systematic review aims to synthesise the qualitative evidence exploring parents' experiences of children with acquired brain injury (ABI) undergoing neurorehabilitation during the first year post-injury.

Methods A systematic review of qualitative research was conducted using thematic synthesis with Thomas and Harden's approach. The population, exposure and outcome model was used for the search strategy. The electronic databases Ovid Embase, Ovid MEDLINE, CINAHL, Scopus and PsycINFO were searched from 2009 to 2023. The review included qualitative and mixed-method studies published in English only. Grey literature was excluded. There were no geographical restrictions. Reporting within the review followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guideline. The studies' quality was appraised using the Critical Appraisal Skills Programme tool.

Results Three studies met the inclusion criteria and were included in the synthesis, representing the experiences of 30 parents. The quality assessment showed that the three included studies met most quality indicators. Following thematic synthesis, four analytical themes were identified: school unpreparedness, parents as advocates and navigators, parents as monitors, and parents recognising the impact of ABI on their child. The reviewers proposed a group of recommendations for services reviewing their parental support.

Conclusion This review highlights some challenges parents of children diagnosed with ABI experience during their child's neurorehabilitation journey. This review has suggested potential improvements that could be made in paediatric neurorehabilitation services when reviewing their parental support and care pathways. These will ultimately influence parents' and children's experience of paediatric neurorehabilitation services.

INTRODUCTION

Acquired brain injury (ABI) is the term used to describe traumatic and non-traumatic brain injuries (TBI) that occur after birth and a period of typical development.¹ Worldwide, TBI is the leading 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 UK, at least 35 000 CYP with TBI are

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Research has explored the experience of parenting a child with acquired brain injury (ABI). However, there is no previous systematic review of parents' experience of their children's neurorehabilitation following ABI despite the essential parental role in neurorehabilitation.

WHAT THIS STUDY ADDS

⇒ This review highlights four themes on the challenges parents of children with ABI experience during their child's neurorehabilitation journey in the first year postdiagnosis: school unpreparedness, parents as advocates and navigators, parents as monitors and parents recognising the impact of ABI on their child.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This review recommends services to prepare parents and schools for the 'return to school', improve communication throughout neurorehabilitation journey and educate parents about resources and empower them in becoming future advocates for their children. These recommendations may help improve paediatric neurorehabilitation services and review of existing pathways. These recommendations may help future studies addressing the parents' experience of neurorehabilitation services.

admitted to hospital, and around 4000 children up to age 16 require admission related to non-TBI.⁴

Brain damage can lead to physical, cognitive, emotional and social impairments in children.⁵ 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.⁶ Severe ABI is linked with a greater risk of developing profound disabilities that will be carried into adulthood.⁵ Children with ABI can experience social and economic impacts due to ongoing medical treatment and care costs, and they are less likely to be employed during adulthood.⁷

Children with moderate to severe ABI often receive intensive neurorehabilitation

in an acute specialist tertiary hospital setting to promote optimal functional gain before long-term support in community settings.⁵ However, the availability of specialist services can vary within and between different countries depending on numerous factors, including resources and expertise available.^{5 8} For example, in the UK, neurorehabilitation is provided by the National Health Service. Local authorities provide social and education services and become involved where there is a need to support a child with ABI. These individualised packages of care can include, domestic adaptations, and any ongoing child protection requirements, and special education provision for children with moderate to severe ABI after discharge from specialist medical care. Social services in the UK do not usually provide rehabilitation care for this patient population.⁴ Irrespective, and in common with other countries, there is considerable variability in service provision.^{5 8} This will impact on parents' individual experience.

Considering the variety and differing levels of neurological sequelae, one of the main aims of neurorehabilitation services is to develop a package of care that best meets the individual needs of the child and their parents/caregivers.^{3 9} Evidence suggests early and intensive neurorehabilitation provision promotes better long-term outcomes and minimises disability.^{2 4}

When children commence neurorehabilitation their parents begin to comprehend the enormity of the injuries and the uncertainty about the recovery, and often, parents find it harder to cope as long-term needs start to become apparent.^{10 11} Further to this, as described by Sulzer and Karfeld-Sulzer⁸, parents describe an ambiguous loss as they do not know to what extent their children will recover, which makes their grieving process more challenging. 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.⁵ Further, they perceive dissonance between healthcare professionals' biomedical approach, the psychosocial and behavioural aspects of rehabilitation and family-centred care.^{11 12}

Returning home with a child newly diagnosed with ABI requires adaptation to a whole new lifestyle.⁸ The overall impact on the family of having a child with ABI and the long-term outcomes might be related to multiple factors, including the family's prefunctioning, injury severity, level of disability and behavioural impairment, perceived presence of unmet needs, socioeconomic status and parents' coping style.⁸ Furthermore, family and parental coping have been described in the literature as impacting the child's outcome following ABI.¹³ The evidence of the effectiveness of whole family interventions, although limited, suggests these might offer better strategies for supporting parents and families and facilitating their involvement in decision-making.¹²

Parents are essential partners in their children's neurorehabilitation following ABI, providing a large

portion of the child's support.⁵ The existing literature underlines the need to interrogate further the parental experience of their child's neurorehabilitation management.⁶ This will help to inform the development of services that better meet the needs of children with ABI and their family caregivers.⁶ To our knowledge, no previous review consolidated parents' experiences of their child's neurorehabilitation journey during the first year following ABI, hence this systematic review.

This review aimed to explore parents' experiences while their children with ABI are accessing neurorehabilitation services during the first year following injury. This review included studies that explore the parental experience of acute neurorehabilitation while their child is in hospital or inpatient or outpatient rehabilitation after discharge from the hospital up to 1 year following diagnosis.

METHODS

Study design

The review protocol was registered in the PROSPERO database (CRD42022333182) and a comprehensive protocol published¹⁴ with full details of search strategy including search terms.¹⁵ This review followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidance for reporting thematic synthesis.¹⁶

Patient and public involvement

Parents of children with ABI were involved in the protocol design to seek advice on the relevance of the topic and the study approach.¹⁷ Amendments were made to include parental experiences of conditions associated with ABI, such as TBI or brain tumours, as parents perceived the experience may differ across various types of ABI.

Types of studies included

This review included qualitative and mixed-method studies published in English and excluded grey literature. Studies published before 2009 were excluded, as the preliminary search identified no suitable publications before 2009, suggesting this phenomenon has only recently gained interest.¹⁸ There were no geographical restrictions.

Inclusion and exclusion criteria

Population: The review included participants with ABI before adulthood up to 18 years. If the studies included young adults and the findings of children were not distinguishable, the publications were excluded. This review included publications reporting the experience of any parents/individuals who have parental responsibility for a child with a diagnosis of ABI only. The review excluded children with cerebral palsy (CP) and brain injuries of genetic or metabolic origin, as children with these conditions have different causes and tend to be degenerative.¹⁹

Exposure: This review included any study that explored paediatric neurorehabilitation services in any setting up to the 1-year post-ABI diagnosis.

Outcome: This study included parents or individuals with parental responsibility. The publications were excluded if the studies included other participants who did not have parental responsibility and the findings specific to parents were not distinguishable from other family members. This review included studies focusing on lived experiences but excluded parents' anticipated needs.

Search strategy

A population (children with ABI), exposure (neurorehabilitation) and outcome (parents' experience) (PEO) framework was developed to guide the literature search.¹⁴ A preliminary search using Ovid MEDLINE was undertaken with an expert librarian to refine the search strategy. Adaptions were made to the included search

terms and MeSH subject headings. Searches were run in June 2022 and 30 April 2023 before study completion, to ensure that the review considered the most recently published research. The authors searched Ovid Embase, Ovid MEDLINE, CINAHL, Scopus and PsychINFO databases using the search strategy.¹⁴

Study selection

All 'hits' were extracted into Rayyaan Software, and duplicates were removed.²⁰ Two reviewers (MF and CR) independently scrutinised the titles and abstracts and retrieved all potential articles. They met to discuss the studies, and any disagreements were resolved by the third reviewer (AET). The reviewers screened the reference lists of the papers selected and in addition scrutinised papers relevant to the topic identified through systematic searching but not initially included in the final review for various reasons (figure 1). This second 'snowball'

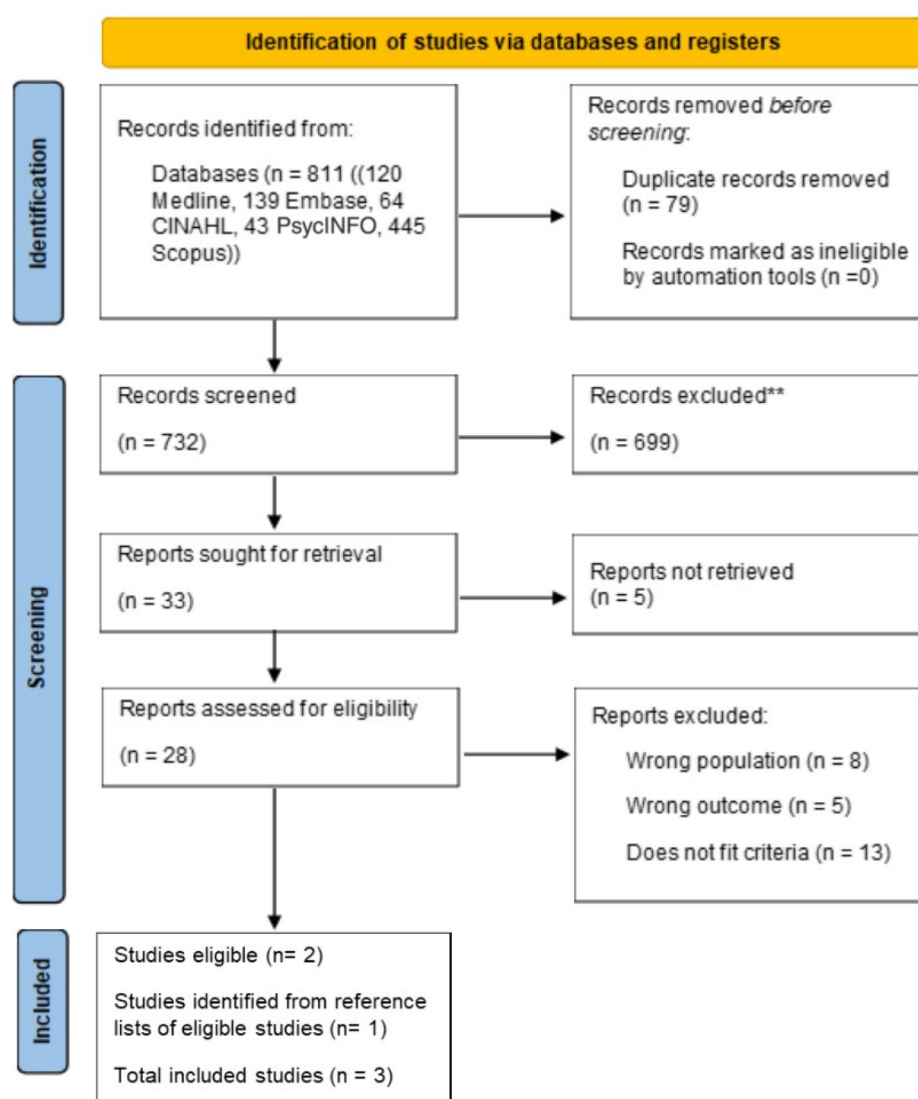


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart for the systematic review.

** - Records excluded after initial screening of titles and abstracts.

approach produced a further paper that met the review criteria.

Data extraction and quality appraisal

The reviewers extracted information regarding the characteristics from the included studies, tabulated and extracted the data (quotes) for the synthesis. The quality of the articles was assessed by one of the first reviewers (MF) using the Critical Appraisal Skills Programme (CASP) qualitative tool.²¹ This assessment of the quality was reviewed by the second reviewer (CR) to ensure they agreed on the quality of the studies. Any disagreement was resolved by consulting the third reviewer (AET).

Synthesis

The reviewers used thematic synthesis to integrate the results and interpretations from multiple studies. They used an inductive approach described by Thomas and Harden's (2008) work to analyse the qualitative data extracted from the included studies.²² After the data extraction, the three reviewers independently coded each line of data extracted into the Excel form according to 'meaning and content'. The reviewers met to identify similarities and differences between codes, which enabled coding grouping into tentative descriptive themes.²² Duplicate themes were merged. The reviewers reached a consensus for their chosen analytical themes until theoretical saturation was achieved. After agreeing on tentative descriptive themes, the reviewers scanned the codes to confirm if they still supported the developing thematic schema. Any codes that did not fit the developing coding structure were interrogated to see if new codes or recoding were required and/or proposed a new theme.

RESULTS

Search outcomes and quality of studies

The database searches identified 811 results. A total of two studies met all inclusion criteria, and another study was identified by following the 'snowball' approach, making it three studies included in this systematic review (figure 1). Thirty parents' views were reported in the included studies and the characteristics of the three studies are presented in a summary table (table 1). The quality assessment of all the included studies showed that all CASP quality indicators were met (online supplemental file 1). This ensured that only studies with rigorous methodology were included in this review. All the studies selected stated their ethical approval.

Thematic analysis

The following four analytical themes evolved during the reviewers' meeting and are discussed below.

Theme 1: school unpreparedness

Parents commonly reported on the return to school. Parents experience that the school system is unable to

adapt to a child who has changed and needs support rapidly. This was evident in the studies reported by McKevitt *et al.*²³ and Gagnon *et al.*²⁴ On the other hand, parents think schools would adapt much more easily to a child with a congenital disability than to a child with an acquired injury. This issue was even more evident in McKevitt *et al.*'s²³ work, which focused on parents of younger children who had sustained a stroke. In McKevitt *et al.*,²³ participants revealed a greater parental burden, likely related to more severe presentations and/or physical impairment:

I think most schools are used to dealing with, like, ADHD, autism, behavioural things, asthma, and I suppose, if a child is born with a condition, those things are already in place when the child goes into the school. But when you're suddenly gone, "Here's this child with special needs" the schools go, "Oh, my God. What are we going to do?" (line 13, page 93).²³

Theme 2: parents as advocates and navigators

Given the schools' unpreparedness with the return to school, parents felt that the responsibility relied on them and needed to constantly advocate for their children. Parents also experienced a lack of communication and information in the return to school process and this was particularly clear in Gagnon *et al.*'s²⁴ work:

We monitor them. Where I would have noted something... I would have liked a link between euh... the hospital and schools in a certain way. If there was for example a programme that was there for cases like this, like him when he could not follow in class for a certain time... (line 19, page 168).²⁴

As advocates, they try to learn to 'navigate the systems' and find the need to speak louder for their children to access the required services.

Theme 3: parents as monitors

Parents report they are constantly monitoring their child by comparing them to other children and where they are in their recovery. This theme was supported by all the studies included in the review. This is shown in McKevitt *et al.*'s²³ work:

So she just needs a bit more time to process information and work her response... (line 34, page 91).²³

They often report the need to monitor physical impact, but parents always seek improvement. When parents see some improvement, they find accepting their child's condition easier. This leads them towards processes of enablement of their children but also challenges parents to accept their children's long-term needs truly. Parents readjusted their expectations as shown by Ammann-Reiffer and Graser²⁵:

Table 1 Summary of selected studies

Author, year	Country	Study design	Data collection method	Theory/model used	Children's age at the time of study	Total number of parents	Time since injury for ABI at the time of study	Clinical setting
Amman-Reiffer and Graser, 2021 ²⁵	Switzerland	Qualitative descriptive approach	Focus group Interview	Mind-maps	Neuromotor disorders (1 traumatic brain injury 1 Encephalopathy 1 Stroke 3 Cerebral palsy 1 Congenital ataxia)	7	0–1 years	Paediatric rehabilitation centre
Gagnon <i>et al</i> , 2009 ²⁴	Canada	Qualitative phenomenological study	Semi structured interviews	Grounded theory Strauss and Corbin (1998)	Traumatic brain injury	15	0–1 year	Paediatric trauma centre
McKevitt <i>et al</i> 2019 ²³	England	Qualitative	Semi structured interviews	Thematic Analysis Braun and Clarke (2006)	Stroke	12	1–5 years	Specialist centres
ABI, acquired brain injury.								

Like I said, I'm just happy that he can walk (table 4, page 317).²⁵

Gagnon *et al*'s study focused on mild TBI in adolescents. In addition to their model on needs perceived by adolescents and their parents after a mild TBI, it was also found that their study revealed further on parents' own experience. Parents had their child under constant surveillance irrespective of setting. As a parent in Gagnon *et al*'s study described their experience in while their child was inpatient:

I didn't want to leave her, I didn't want to leave her if something happened, but I wanted to be with her at home. I didn't want to leave her and go to work. (line 41, page 167).²⁴

Theme 4: parents recognise the impact of ABI on their child

This theme was supported by all three studies included in this review. Gagnon *et al*'s work also demonstrated parents' experience of recognising their child's ongoing physical impact:

But she had a lot problems like I said, she doesn't compete anymore, it really stops her... She only did dances and she taught the smaller kids. It really affected her a lot... That's the problem because she looks like she's ok but there are a lot of things she doesn't do anymore. She did double jumps, she doesn't anymore, she's afraid of falling so she cut that completely. Finished. Because you need to jump in competitions. (line 45, page 166).²⁴

Parents navigate their loss and grieving for the child they had. Also, parents go through the ongoing process of identifying the brain injury's impact on their child, which sometimes can be invisible at first glance to others.

DISCUSSION

Summary of findings

This systematic review of the qualitative literature highlights some of the challenges parents of children diagnosed with ABI experience during their child's neurorehabilitation journey in the first year post-injury. The most reported theme was the unpreparedness of educational providers for the child's return to school. Parents identified that schools were not prepared to receive a child with an ABI back and a supported transition process remained lacking. The second most reported theme was parents' role as advocates and navigators for their children. Parents feel the need to advocate for their children when they return to school. Parents do not know the education and care systems they can access, so they learn through their experience of those services. Following on from becoming their child's advocates, parents also become their child's monitors. Parents are always looking

for change throughout their child's rehabilitation and remain on constant surveillance. Through their personal experience, parents learn to identify the ongoing impact of the brain injury on their child, which others might not notice.

Findings in the context of existing research

To the best of the reviewers' knowledge, this is the first systematic review to explore parents' experience of children with ABI while their children are accessing neurorehabilitation services. Given this, limited studies have been published that can be compared with the findings. Previous literature has 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.⁵ Previous recommendations for service provision for CYP with ABI suggest supporting families to be accepted as part of the team members and as individuals who advocate well for their children.⁶ This would allow parents to be empowered and to get experienced and valued as advocates for their children.

Previous research has explored parents' information and emotional support needs across transitions following their child's TBI.¹⁰ Parents found it challenging when their children returned to school, and they identified a lack of communication between hospital and school, and teachers were not prepared to support their child's needs.¹⁰ Parents desire further support in the transition between services within the hospital and also in the community. They expect better communication between the hospital and the other services so the school can be prepared to support their child's needs.

Another review in the same patient group noted that parental anxiety and criticism of care increased at times of uncertainty, for example, in transition between services, including transfer from higher-staffed wards to less-staffed wards and discharge into community services.⁶ Parents wish for more support, including more information and emotional support in their child's neurorehabilitation transition stages. Therefore, these concerns need consideration when developing and reviewing ABI pathways.

Previous qualitative research has explored the quality of life of children with ABI from the parents' perspective.²⁶ Reviewers identified an existing relationship between children with ABI quality of life and distress and parental perception of inadequate support.²⁶ Therefore, ensuring parents of children with ABI are well-informed, emotionally supported and empowered can impact their children's long-term outcomes.

ABI includes a wide variety of medical conditions and subsequent disablement.^{1 2} It is also important to note that how much input they will require from services varies depending on their condition and location, for example, children with mild ABI do not attend hospitals in some countries. Therefore, the variety of journeys these children and their parents will experience are varied and

unique. This is to some extent evident when comparing Gagnon *et al's*²⁴ work on parents of teenagers with mild TBI and McKevitt *et al's*²³ work on parents of younger children who had a stroke, with the first reporting more on the need for information and the latter reporting more significant burden and greater physical impairment of their children.

Limitations

This review included only three studies, more studies are required to understand parents' experiences in the broader context. Excluding other languages, studies examining parents' experience after 1 year of diagnosis and parents of children with CP limited reviewing some relevant articles.

Neurorehabilitation services vary according to their settings, the constitution of the multidisciplinary team and resources. These differences may lead to parental experience variations in different parts of the world. However, all the selected studies were from Western countries and specialist centres, limiting the analysis and abstraction level.²² The review team contacted some of the authors to seek additional information but received no response which led to the exclusion of potential articles.

Service implications and future research

This review recommends:

- ▶ Parents and schools receive specific training and resources focusing on 'return to school' and support for ongoing need.
- ▶ Sound methods for communication are embedded from the beginning of neurorehabilitation across all services, including the child's schools who will be supporting transition and ongoing throughout their school career.
- ▶ Educate parents regarding systems for accessing resources and services available to them in order to prepare them better to fulfil their advocate role to navigate the system.

This review is based on a limited number of studies drawing on the experience of parents living in Western countries. Given the variability of resources understanding parents' experience in low-income and middle-income countries would add much to comprehending parents' and children's experience of services and neurorehabilitation pathways.

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Contributors MF is the guarantor. MF conceptualised the research idea, drafted the protocol, conducted the search, reviewed the selected studies and edited and reviewed successive manuscript drafts. CR provided MF mentorship, helped develop the research idea, reviewed the selected studies, critically reviewed multiple drafts and provided rehabilitation expert input. AET was involved in critically reviewing, facilitated consensus among the reviewers in the selection

process 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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Supplementary table 1: Quality of the selected studies

Author, year	CASP Qualitative Checklist Questions										Comments
	1	2	3	4	5	6	7	8	9	10	
Ammann-Reiffer & Graser, 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Item 6 - Could have provided further clarification. - Ethical authorisation was not needed as confirmed by the ethics committee. All participants gave their written informed consent.
Gagnon et al., 2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Item 6 – Would have benefited from further justification. - The study received approval from the Institutional Review Boards of the two participating Centres.
McKevitt et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Item 3 - Appropriate but could have a further justification of the choice made. - Ethical approval was obtained from the local Research Ethics Committee.