

A scoping review of the needs of children and other family members after a child's traumatic injury

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Abstract

Objective: To review children's and their families' needs after a child's traumatic injury and assessment tools to measure needs.

Data sources: Medline, Embase, CINAHL and PsycINFO databases (2005–September 2017) were searched and screened for papers (of any design) investigating children's and families' needs after a child's traumatic physical injury.

Review methods: Data regarding children's and families' needs were extracted by two independent raters. Methodological quality of the identified papers was not assessed. Thematic content analysis drew out the key needs.

Results: A total of 12 studies were identified, involving 932 participants including 105 injured adolescents and 827 family members or professionals. The needs of children under 12 years were identified indirectly from families or professionals. Most studies focussed on traumatic brain injuries. Two groups of needs were identified: person-related and service-related. Person-related needs were categorized into adolescent-specific needs, need for support with cognitive, emotional, social and physical problems and help with practical problems. Service-related needs were categorized into the need for information, educational needs and support during care transitions (specifically access to community-based services). These needs were largely unmet, particularly regarding information, emotional support and care transitions, which were compounded by professionals' limited understanding of the children's difficulties. We found no published measurement tools to assess children's and families' needs after a child's traumatic injury.

Conclusion: The evidence about children's and families' needs following a child's traumatic injury was limited, but needs for information, emotional support and access to community-based services were consistently unmet.

Keywords

Traumatic brain injury, unmet needs, traumatic physical injury, rehabilitation

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Introduction

Injury is the most frequent cause of death and disability in children and young people after the first year of life.¹ For example, ~5000 children per year are hospitalized with traumatic injuries in the United Kingdom, 20% of which are considered serious.² Consequently, paediatric trauma is recognized as an area that requires specialist rehabilitation from a multidisciplinary team to optimize the injured child's activity, social participation and well-being, while reducing stress on carer/family.³ The post injury needs are often multi-faceted and include psychological and social difficulties, as well as physical injuries.⁴ Over the past 20 years, there has been increasing recognition that trauma care, particularly rehabilitation, is often sub-optimal.⁴⁻⁸

There is therefore an imperative to improve the quality of and access to rehabilitation for children with traumatic injuries, but there is little research to inform service delivery. We know little about whether existing rehabilitation services meet the needs of injured children and how this impacts on their recovery from a physical, social and psychological perspective. A first step to designing and commissioning effective, evidence-based rehabilitation services is to understand the nature and extent of the children's (and their families') needs and how best to measure them. Thus, this study will explore the state-of-the-evidence regarding (1) the needs of children with traumatic injuries and their families and (2) methods of measuring their needs.

'Need' is a complex concept and numerous definitions have been proposed, without consensus.⁹⁻¹² In this study, need is defined as *a problem that significantly interferes with daily life*.^{11,12}

The types of need to be considered have not been pre-specified, nor the help or services that may be required to address the problems and needs.

Method

Identification of papers

An exploratory scoping review was undertaken.¹³ Relevant papers were identified by searching Medline, Embase, CINAHL and PsycINFO databases from 2005 to September 2017. Keywords

relating to assessments, needs and trauma were used and limits were set to include papers only involving children (Supplementary Appendix 1). One author (S.J.) screened titles and abstracts and then two authors (S.J. and S.F.T.) independently screened full texts to determine which papers met the following inclusion criteria.

Inclusion and exclusion criteria

Papers that addressed the following were identified for inclusion:

- The needs of children (aged 0–18 years) following traumatic physical injuries affecting any part of the body, resulting in an admission to hospital.
- The needs of parents, carers (unpaid) and other family members of children with traumatic physical injuries.
- Needs identified by injured children, their parents, carers, other family members, healthcare and education providers.
- Needs identified throughout the rehabilitation process in hospital and community settings.

Papers that addressed the following were excluded:

- Needs of injured young adults aged >18 years.
- Isolated dental trauma.
- Only burn injuries.
- Only non-traumatic brain injuries.
- Non-accidental injuries, including sexual trauma.
- Birth trauma.
- Investigation of outcome measures, goal planning and treatment tools, where the focus was on the children's functional abilities or health status, rather than their needs.
- Assessment of needs before the participating children sustained traumatic injuries.
- Needs following post-traumatic stress or emotional trauma, rather than physical trauma.

If a paper included a mixed sample of traumatic and non-traumatic and/or non-accidental injuries, the paper would be excluded unless the data for

traumatic injuries could be extracted or over 50% of participants had traumatic accidental injuries. We also looked at assessment protocols which may be used to identify needs.

As this was a scoping review to establish the state of the evidence, we did not assess the quality of the papers which met the selection criteria.¹³ Two authors (S.J. and S.F.T.) independently extracted and tabulated information relating to the setting, participants, type of needs assessed, and the topics addressed during the data collection. For papers regarding needs assessments, we planned to extract data regarding their psychometric properties and clinical utility.

Thematic content analysis was used to draw out key needs from the identified papers.^{14,15} The identified papers were read several times independently by two of the authors (S.J. and S.F.T.) to familiarize themselves with the content. They then discussed the data to generate and agree upon the codes for the thematic analysis. The main findings relating to injured children's and families' needs were identified and coded. The codes were analysed, grouped and then sub-categorized into types of need. Finally, the findings were iteratively summarized and clustered until consensus was reached.

For papers about assessment of children's and families' needs, data about the setting, participants, method, clinical utility of the tools, psychometric properties tested and the results would be extracted using well-established methods.¹⁵⁻¹⁷

Results

The search identified 2401 potentially relevant papers, which reduced to 50 once duplication was removed and titles and abstracts were screened (Figure 1). A total of 12 papers were identified after the full texts were examined. No papers regarding the psychometrics or clinical utility of measurement tools, to assess the needs of children with traumatic injuries and/or their families, were identified. Thus, this part of the review was not taken any further. No papers which included assessment protocols to identify children's needs were found.

The identified papers included 932 participants,¹⁸⁻²⁹ including 105 injured adolescents,^{19,20} 418 parents (57 mothers, 25 fathers, 336 unspecified

parents),^{18,19,21-24,28} 302 unspecified primary carers,²⁵ 66 other family members (5 brothers, 2 sisters, 2 grandmothers, 57 unspecified),^{26,28,29} and 41 healthcare providers (occupational therapists, physiotherapists, psychologists, nurses, social workers, surgeons)²⁷ and unspecified numbers of teachers,²⁴ general practitioners, school counsellors and nurses.²⁰ A summary of the identified papers can be found in Table 1.

Only five papers specifically focussed on the needs of the injured child,^{20,22-25} the others focussed on the families' needs,^{18,26,29} or a combination of both.^{19,21,27,28} Papers directly collecting data from the injured child were limited to adolescents.^{19,20} The needs of younger children were ascertained indirectly from their family or professionals. Two papers involved health professionals and teaching staff,^{20,27} in addition to the injured adolescents.²⁰

Eight papers specifically focussed on children with solely traumatic brain injuries,^{19,21,23-25,27-29} two papers involved children with head, orthopaedic and/or spinal cord injuries,^{22,26} and two did not specify the type of traumatic injury.^{18,20} No papers included children with chest or abdominal trauma or orthopaedic injuries in isolation. The age range of the children involved was wide, from pre-school/nursery age to teenagers.¹⁸⁻²⁹ Most identified papers examined the participants' long-term problems except Kirk et al.,²⁸ Falk et al.²⁹ and Foster et al.,¹⁸ who focussed on the families' needs during the acute and sub-acute phases of care.

All the included papers were exploratory and most used a cross-sectional design.^{18-20,23,24,26-29} The most common method of data collection was face-to-face semi-structured interviews^{18,19,21,24,26,28} (see Table 1 for further details).

Key themes

Two main groups of needs were identified: person-related needs and service-related. Person-related needs were sub-categorized into six types: adolescent-specific needs and needs for support with cognitive, emotional, social, physical problems and practical difficulties (detailed in Supplementary Table 2a). Service-related needs were sub-categorized into needs for information, educational support

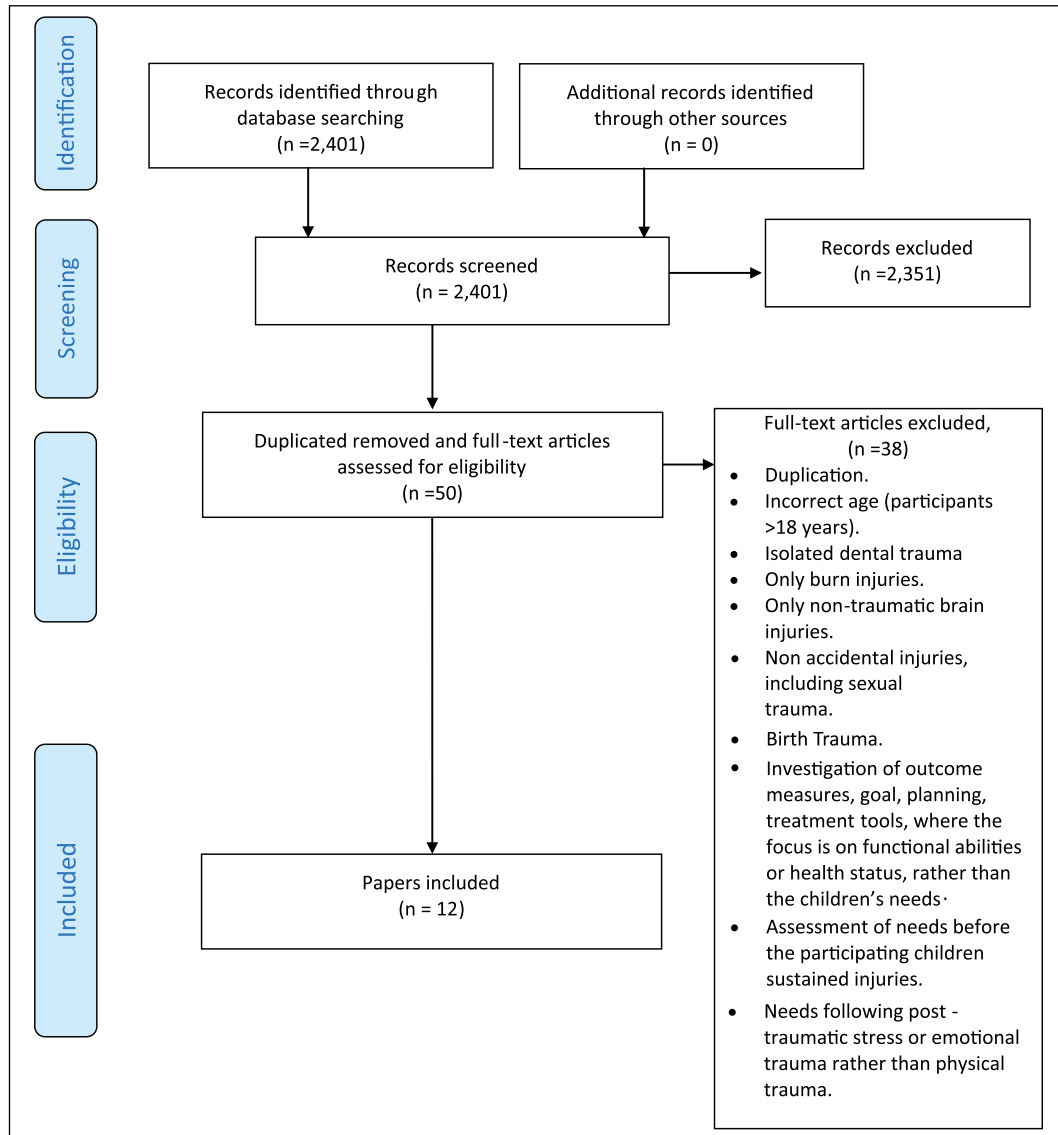


Figure 1. Flowchart of study selection process.

and support across care transitions (detailed in Supplementary Table 2b). The types of needs are summarized below.

Adolescent-specific needs

Adolescents had some specific needs which related to their age and developing independence. These

were to be recognized as an individual, feel in control of their situation, be involved in decision-making and the opportunity to have confidential discussions, not involving their parents.^{19,27} Adolescents wanted to be cared for with other teenagers and benefit from their peer support.^{19,20,27} Specialist healthcare providers in traumatic brain injury believed that adolescents who had left home

Table 1. Details of the participants, types of need assessed, methods and the main topics explored in the identified studies.

		Author											
		Foster et al. ¹⁸	Rosignio et al. ²¹	Bugel ²⁶	Karver et al. ²²	Kirk et al. ²⁸	Falk et al. ²⁹	Gagnon et al. ¹⁹	Gfroerer et al. ²³	Glang et al. ²⁴	Sabin et al. ²⁰	Slomine et al. ²⁵	Swaine et al. ²⁷
Recruited from	4 Specialist paediatric TCs, Australia	Not specified	Paediatric Hospital, USA	Level 1 TC in 3 Paediatric Hospitals and 1 General Hospital, USA	Level 1 TC, UK	Emergency Ward of Hospital, Sweden	2 Paediatric TCs, Canada	1 Paediatric Hospital, USA	3 Hospitals, Oregon, USA	1 Paediatric Adolescent Level 1 TC, USA	4 TCs, USA	2 Paediatric TCs, Canada	
Injured children	30 Children, 0–13 years hospitalized with a critical injury (ISS > 15 requiring ICU stay), type of injury not specified	37 Children, 6–18 years at time of TBI, moderate to severe TBI	6 Children, 8–18 years with traumatic injury within past three months requiring in-patient hospitalization for acute rehabilitation; 3 TBI, 2 multiple orthopaedic trauma and 1 spinal cord injury	139 Children, 3–7 years with mixed injuries: 47 mild–moderate TBI, 18 severe TBI, 74 orthopaedic injuries (bone fractures)	19 Children, 3–18 years with severe TBI, <six months previously	57 Children, 1 month to 15 years (mean = 5.2 years), with severe head injuries (GCS < 9) 7 skull fractures, 20 head injuries, 16 brain injuries, 14 post concussion complaints	15 Adolescents (12–16 years, mean = 14.3 years) with mild TBI	66 Children (25 primary school age) and 41 secondary school age) with moderate to severe TBI	56 Children (4–18 years, mean = 12.5, SD = 3.8) moderate or severe TBI requiring hospital stay of at least one night	90 Adolescents (12–18 years) with intentional and unintentional traumatic injuries. Type of injury not specified	288 Children (5–15 years) with TBI (abbreviated Injury Score 2 > and/or hospitalized for at least one night)	302 Primary carers of injured children	41 Expert healthcare providers in TBI
Participants	40 Parents of injured children (26 mothers and 14 fathers)	42 Parents or guardians of injured children (2 brothers, 5 sisters)	7 Siblings of injured children (2 brothers, 5 sisters)	172 Parents of injured children (No further detail)	27 Parents and 2 family members of injured children (18 mothers, 9 step/fathers, 2 grandmothers)	57 Families of injured children (No further detail)	15 injured adolescents and 15 parents (13 mothers, 2 fathers)	66 Parents of injured children (No further detail)	56 Parents (No further detail)	90 Injured adolescents and unspecified number of general practitioners, school nurses, school counsellors	302 Primary carers of injured children (No further detail)	41 Expert healthcare providers in TBI	

(Continued)

Table 1. (Continued)

Types of needs assessed	General	Educational	General	Information and emotional support needs	Information	General	Educational	Emotional and depressive needs	Healthcare utilization	General
Method of assessing need and data collection time frame	1 face-to-face structured interview Within 2years of child's injury	2 semi-structured interviews (1st face to face, 2nd telephone)	1 semi-structured face-to-face interview 3 months post injury not specified for each interview	1 semi-structured face-to-face interview Interviews conducted at 7-72months post injury	1 single open-ended question posted to patients' families Survey Question sent to families three months post injury	1 semi-structured face-to-face interview Interview time not specified	1 'Back to School Questionnaire' and further I semi-structured face-to-face interview Questionnaire and interview three months after child's return to school	1 telephone interview with adolescents to complete measures relating to: depressive and emotional symptoms I telephone interview semi-structured interview with GP, nurse, school counsellor Interviews 4 to 6 months injury	2 telephone interviews to assess healthcare utilization Quality of life of the injured child 3 and 12 months post injury	Focus group of healthcare professionals to discuss the needs of adolescents with TBI Results validated with a postal survey Time frame not relevant for this type of study
Main topics explored	Parents' experiences of having a critically injured child, parents' main needs, how needs were met and by whom	Parents' perceptions of child's school reintegration processes and impact on the family	Changes and constants in the sibling's life since their brother/sister were injured	Changing support needs of injured children and their parents across the different care trajectories	Information following a child's head injury	Impact of TBI on the injured adolescent and their parent's life, their needs, the quality of services received	Support needed and provided for injured children returning to school Access and satisfaction with services received	Nature of emotional and behavioural problems Detection of post-traumatic stress, depression and alcohol use	Frequency of input from healthcare and education services	Needs of injured adolescents and their parents Hierarchy of adolescent needs

ISS: Injury Severity Score; ICU: intensive care unit; TBI: traumatic brain injury; GCS: Glasgow Coma Scale; GP: general practitioner; TC: trauma centres.

and/or were working would be managed most appropriately by adult services.²⁷

Need for support with emotional problems, cognitive problems and social problems

The need for support with cognitive, emotional and social problems (including behavioural problems) was frequently highlighted by participants who felt their needs were often unrecognized and unmet.^{20–25,28,29} This was the case for children (and their families) with orthopaedic injuries,²² as well as those with traumatic brain injury.^{19,21,23–25,27–29}

Children needed help with feelings of frustration and depression (sometimes including suicidal thoughts^{21,28}) which stemmed from being unable to do what they could prior to their injury, being viewed differently by other children and being bullied (or fear of being bullied).^{18,21,28} Children wanted to be accepted by their peers and to have their problems recognized and their needs addressed. However, this rarely happened particularly once discharged from hospital and returning to school.^{21,28}

Most parents reported a need for support for themselves as well as their child.^{18,19,28,29} They often struggled with feelings of guilt surrounding the child's accident; wondering if they could have stopped it happening or managed the situation differently.^{18,28,29} Once in hospital, uncertainty regarding the injuries, potential for recovery, fears about changes to their child's appearance and confronting the fact that their child may never be the same again were of concern.^{18,19,28,29}

Several aspects of hospital-based care were identified which could contribute to meeting these needs. These included the following:

- Opportunities to develop trusting relationships with healthcare professionals, other injured children, parents and families, to share their 'emotional burden', discuss their feelings and be reassured.^{18,19,27–29}
- Being involved in decision-making processes.^{19,26–28}

After discharge, families reported that they often felt unprepared for the responsibility of caring for their injured child, which they found overwhelming.^{18,28} They described difficulty obtaining information and accessing help and services (detailed in the relevant sections below). Unsurprisingly, parents often felt abandoned by services^{18,28} and felt they were forced to act as an advocate for their child.^{21,28}

Need for help with physical problems

As might be expected in research where studies on children with traumatic brain injuries and concerning long-term support predominate, the need for help with physical problems was identified less frequently than those for cognitive, emotional and social problems, and the needs were felt to be recognized and met more often.^{18–21,23,25,28}

The identified studies consistently recognized that regular post-discharge review appointments were important for ongoing symptom management, health maintenance and to facilitate return to physical and academic activities.^{19,20,25} Four studies identified the need for rehabilitation including speech therapy, occupational therapy, physiotherapy and audiology to address physical problems.^{23–25,28}

Need for help with practical difficulties

Parents needed help to balance spending time with, and caring for, their injured child with work and home commitments. This help was often provided by family and friends.¹⁸ They also required help finding affordable accommodation, parking and refreshments plus help to complete insurance and benefit claims from healthcare professionals.^{18,21}

Need for information

In the early stages, parents,^{18,19,27,29} siblings²⁶ and injured adolescents¹⁹ needed information about diagnosis and the immediate plan of care, the child's prognosis for survival and recovery, and updates about any developments.^{18,19,27,29} Although parents and adolescents wanted information to be readily available, the desired detail varied.^{19,28,29} Some felt

they were given insufficient information.^{19,28} While others, particularly during acute care, acknowledged that they were unable to absorb much detail and only wanted simple, essential information.²⁸ Similarly, healthcare providers felt that the provision of information was important, but that too much information during acute care may lead children to focus unduly on their symptoms.²⁷

In the post-acute stages, injured children and families reported the need for information about what to expect from the recovery process; possible sequelae to the injuries and activity restrictions: what was normal; how to provide everyday care and prevent further injuries; what care/services would be provided after discharge and how to optimize return to activities and school.^{18-21,24,27-29} After discharge, primary care providers, educational and community services were parents' main source of information. However, this was frequently problematic as relevant referrals were not made and staff often had insufficient knowledge to provide the information needed.^{18,20,21,23-25,27,28}

Need for support across care transitions

Injured children and their families viewed transitions between care settings, particularly discharge from hospital and return to school as key points when their needs were often unmet.^{18-21,23-25,27,28} Information about community and educational services was considered particularly poor,^{18-21,23-25,27,28} which was compounded by lack of communication between the families, healthcare professionals and educational services.^{18-21,24,25,27,28} This meant that referrals from specialist trauma centres to primary care, community, social and education services were often not made.^{20,21,25,28} Consequently, injured children and their family had great difficulty accessing the support and services they needed.^{20,21,25,28}

Furthermore, staff from community, primary care and education services often had insufficient understanding of the child's injuries and their impact, to support return to everyday activities and education.^{19-21,24,25,27,28} For example, symptoms such as difficulty concentrating, poor memory or fatigue were often misinterpreted as bad behaviour or laziness.^{19,21,28} This was most keenly felt when the child had no physical signs of an injury.^{21,28}

Families identified the following as ways to improve transitions between care settings:^{18-21,24,25,27,28}

- Specialized services with knowledgeable, expert staff providing long-term support including regular reviews and ongoing telephone support to facilitate return to physical and academic activities.^{19,21,25,27,28}
- Provision of a key worker to negotiate links between hospital, community and education services.^{19,27,28}
- A collaborative environment with co-ordinated systems and clear leadership.^{18,21,27,28}
- Home visits, multidisciplinary meetings and information exchange (including written information about the injury) between the family and all relevant services to ensure an effective handover.^{18,20,21,28}

Need for educational support

Return to education was considered an important transition, and the extent to which needs were met was mixed.^{19,21,23,24,27,28} As noted above, parents felt their child's need for educational support was difficult to access and they often had to advocate for their child themselves.^{21,24,28} This frequently involved the need to:

- Educate teachers about their child's injuries and the impact on academic performance, behaviour, activity (particularly sports) and the adjustments needed.^{19,21,24,27,28}
- Monitor the school environment to ensure adaptations, accommodations, specialist services and individualized educational plans (such as a personal assistant, special needs classes, home-school programmes) were in place and adhered to.^{21,23,24,28}
- (In some cases) move schools, hire tutors and set their own curriculum, often involving support groups or educational psychologists.^{21,28}

Discussion

The results of this review indicate that the needs of children with traumatic injuries and/or their families

are often unmet, particularly the need for information, emotional support, and support during care transitions. Healthcare and educational professionals often showed limited awareness and understanding of the nature of the children's injuries and the resultant challenges they caused. In turn, this hindered referrals to appropriate services and meant that symptoms were often misinterpreted, particularly those which were not physically obvious, such as fatigue, cognitive problems or pain. Clearly further work is needed to develop interventions, resources and/or staff development opportunities to address these shortcomings. The need to increase awareness and understanding of the difficulties injured children face and to develop effective pathways to ensure comprehensive and timely access to services have been clearly identified. If successful, such interventions and service developments should improve equity of access, quality of services and outcomes. Currently, there is negligible evidence about how to achieve this, but there is a body of knowledge from other sudden-onset disabling conditions with an uncertain trajectory for recovery, such as adult neurological rehabilitation, with important principles that may be suitable for adaptation to childhood trauma.^{30–33}

The identified papers focussed primarily on the long-term needs of children with traumatic brain injuries. Further work is needed to establish the needs of children with other types of injuries, such as orthopaedic, chest or abdominal injuries in whom physical problems may predominate, and to more thoroughly understand children's and their families' needs in the (sub)acute stages of rehabilitation and how needs change over time.

Most of the identified papers asked the injured child's family (primarily parents) about their child's and/or family's needs rather than directly involving the injured child. The only injured children who participated themselves were adolescents.^{19,20} Although in the clinical setting, the injured child and their family are generally considered a single unit, it cannot be assumed that families accurately present the injured child's views.^{34,35} Further work to directly report injured children's views is warranted, despite the methodological and ethical challenges involved.

In addition to reviewing children's and families' needs, we aimed to review ways to measure their needs. This proved impossible as no standardized

measurement tools were identified from the searches. Comprehensive, psychometrically robust, user-friendly measurement tools are needed to accurately identify and understand the scale and nature of children's and families' problems and to identify what is needed to address these problems. Work to develop such a tool is underway.

This study has several limitations. The searches were restricted from 2005 to September 2017, as we wanted to ensure our findings reflected reasonably current practice. However, relevant papers published before this period may have been missed. Additionally, 'need' is difficult to define and may be expressed using a variety of terms, so it is possible that using the key search term 'need' did not identify all relevant papers. As this review aimed to explore the scope of evidence regarding injured children's needs, we did not evaluate the quality of identified papers nor exclude those of poor quality, so the strength of this evidence needs to be treated with some caution. Furthermore, the predominance of participants with traumatic head injuries and a focus on long-term support means that generalizability should be viewed cautiously and not extrapolated to all types of injury and all stages of rehabilitation. Nevertheless, the consistency of the main needs, and the similarities with other research on patients' and families' needs in adults with severe trauma and other sudden on-set disabling conditions suggests convergence.^{30–33,36–38}

Clinical Messages

- Injured children and their families need information and support for cognitive, emotional, social and physical problems, help with practical difficulties, and during education and care transitions.
- Adolescents have specific needs.
- These needs are often unmet.
- Development of suitable tools to measure injured children's and families' problems and needs is warranted.

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Declaration of Conflicting Interests

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