

A scoping review of the needs of children and young people with acquired brain injuries and their families

Authors

Rachel Keetley^{1,2}, Kathryn Radford², and Joseph C Manning^{1,3,4}

1 Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, Nottingham, UK.

2 Division of Rehabilitation and Ageing, School of Medicine, The University of Nottingham, Nottingham, UK.

3 School of Health Sciences, The University of Nottingham, Nottingham, UK.

4 Centre for Innovative Research across a Life Course, Faculty of Health and Life Sciences, Coventry University, Coventry, UK.

Corresponding Author:

Rachel Keetley

Team Leader Children's Physiotherapy

D Floor East Block,

Queen's Medical Centre

Derby Road,

Nottingham

NG7 2UH

0115 8493326

Rachel.keetley@nottingham.ac.uk

Abstract

Understanding the needs of children and young people (CYP) with acquired brain injuries (ABI) is essential in delivering pathways of care and providing effective rehabilitation.

Aim: To identify relevant literature and key themes relating to the nature and extent of needs (met, unmet or unrecognised) of CYP with ABI and their families.

Method: Scoping review. Sixteen electronic bibliographic databases were searched using terms relating to children, brain injury and need. Papers were screened against eligibility criteria by two independent reviewers. No date limits were applied. Data was extracted by the lead author regarding the needs of CYP with ABI and their families and thematic analysis conducted to identify the key themes. Methodological quality was not assessed.

Results: A total of 28 articles were identified including three systematic reviews, one scoping review, two practice recommendation articles and 22 original research studies. Participants included CYP with ABI, parents, siblings and professionals. Four key themes were identified; CYP-related impairment needs, support needs, return to school and long-term aftercare.

Conclusion: CYP with ABI and their families report extensive needs, many of which are often unmet or unrecognised by those supporting the CYP. Needs transcend the health, social care and education domains.

Keywords

Acquired brain injury, traumatic brain injury, rehabilitation, education, care, children, young people, adolescents, paediatric, needs.

Background

Acquired brain injury (ABI) in children and young people (CYP) is defined as a traumatic (such as a fall or road-traffic collision) or non-traumatic (such as a stroke, infection, or brain tumour) injury to the brain that has occurred since birth (1). It is estimated that each year in the UK 40,000 CYP sustain an ABI, with traumatic brain injury (TBI) being the most common cause of death or disability (2, 3).

With advances in critical care, mortality has reduced, however CYP may go on to experience significant neurological impairment and life-long disability (4, 5). The physical, cognitive, emotional and behavioural sequelae of ABI are well described within the literature as are factors impacting on recovery such as age at onset, severity, mechanism of injury and family, environmental and psychosocial factors (6-9). The long-term impact of these impairments on the quality of life of CYP and their families can be significant (10, 11).

Acute and post-acute neuro-rehabilitation for CYP with ABI is delivered by 16 regional specialist centres across the UK. National service specifications for paediatric neurorehabilitation aimed for equitable provision across the country, however, there is widespread concern regarding the variability of service provision and a drive towards identifying and commissioning optimum rehabilitation models (2, 5, 12). Research regarding rehabilitation for adults with brain injury has demonstrated the benefits and cost effectiveness of comprehensive rehabilitation models, this is yet to be fully investigated in paediatric rehabilitation or the impact on the life course of the CYP and family (13, 14).

Understanding the needs of the population is essential in delivering pathways of care and providing effective rehabilitation. A scoping review of the literature was required in order to map the current relevant literature and synthesize that knowledge as a

preliminary step towards conducting a systematic review regarding the needs of the population (15).

Objective

The objective of this scoping review was to identify relevant literature and key themes relating to the needs of CYP with ABI and their families and the nature and extent of those needs, met, unmet or unrecognised.

Inclusion criteria

A scoping review protocol was formulated using the Joanna Briggs Institute (JBI) methodology for scoping reviews (16). The following eligibility criteria were set:

Inclusion criteria

- Participants:
 - CYP aged 0-18 with an ABI (traumatic brain injury (TBI) and non-traumatic brain injury (NTBI))
 - Parents/family members of CYP with ABI
 - Education, health or social care professionals involved in the care of CYP with ABI

- Concept

Defining and measuring 'need' is complex and challenging as a person's perceived need reflects their individual, cultural and societal values (17). As this scoping review was exploratory in nature it was decided that a broad search strategy would be employed to try to capture a breadth of evidence whilst maintaining specificity to the topic area and population. Definitions of need were

adopted from the existing literature and therefore defined as a problem that significantly interferes with daily life (18) and further categorised into 'met need' (services received), 'unmet need' (perceived need but not receiving services) and 'unrecognised need' (not used or needed a service but reported impairments/limitations) (19, 20).

- Context
 - CYP in any healthcare or educational setting, worldwide

Exclusion criteria

- Adults over 18 years
- CYP with birth injuries or congenital disorders
- Studies focusing on experiences, functional or health status related outcomes, interventions or service provision rather than needs
- Policies and guidelines where need is not explicitly discussed

Types of sources

A search of PROSPERO International Prospective Register of Systematic Reviews revealed no ongoing reviews in this topic area. Sixteen electronic bibliographic databases (Medline, CINAHL, Embase, Pedro, Web of Science, JBI, Cochrane Library, PROSPERO, UK Clinical trials gateway, NIHR Journal Library, EuropePMC, Clinical trials.gov, ISRCTN registry, NICE Evidence search, PsychINFO) were searched between April and July 2018. Additional grey literature searches were conducted (Google, James Lind Alliance, NICE guidelines, Kings Fund).

Search Strategy

The search strategy was formulated using the JBI Scoping review methodology and PICO framework (Table 1). An initial search of Medline and CINAHL was conducted to identify relevant articles and keywords. The search strategy was adapted to the individual database requirements and terms were deliberately kept broad to ensure all relevant literature was identified. Searches using all identified keywords were then undertaken across all included databases. Grey literature sources and reference lists were reviewed for additional articles. No date limits were imposed, however, only English language articles were included due to lack of funding for translation.

Papers meeting the inclusion criteria were classified according to level of evidence provided by the research design. Table 2 shows the classification for each type of question.

Data extraction, summary and synthesis

The PRISMA guidelines for preferred reporting items for systematic reviews and meta-analysis and flowchart were used. The initial identification and screening of titles was conducted by the first author (RK). Two reviewers independently screened all abstracts to assess eligibility against the inclusion and exclusion criteria and by the first author from full articles if not clear within the abstract. Any discrepancies were resolved through discussion. Full texts were obtained for all shortlisted articles. The results were charted using the JBI recommendations using the following headings: author, year of publication, country of origin, aims/purpose, study population and sample size, methodology/methods, findings/outcomes, key findings related to scoping review question. From the results chart, key themes relating to the needs of

the population were identified and synthesised. The quality of the articles was not assessed as this is a scoping review to identify relevant evidence (16).

Results

The searches identified 327 potentially relevant articles which were screened and 60 full-text articles were assessed for eligibility (Figure 1). A total of 28 articles met the inclusion criteria and were examined in-depth with data tabulated. Three qualitative systematic reviews (4, 7, 21), one scoping review (18) and two practice recommendation articles (22, 23), (Table 3) and 22 original research studies were identified (Table 4) (6, 10, 11, 17, 19, 20, 24-39).

Literature Reviews

Jones et al (18) conducted a scoping review of the needs of children and other family members after a traumatic injury. Twelve papers met the inclusion criteria, with the majority of the papers focusing on CYP with TBI. Key themes that emerged were needs specific to adolescence, support needs for emotional, cognitive and social problems, physical difficulty needs and support around care transitions and return to education.

Three qualitative systematic reviews representing level one evidence were identified. Two focussed on the experiences of return to school for parents (7) and clinicians and educators (21). One included six studies and a total of 106 parents of CYP with mild, moderate and severe ABI (2-20yrs old), 0-11 year's post-injury (7). Another included 10 studies with a total of 27 CYP, 45 parents/guardians, 55 education professionals and 33 clinicians participating (21). There was no overlap of studies between the two reviews and each study's quality was assessed. Both reviews presented strong

themes of the need for effective information, communication and collaboration between the child, parents and health and education professionals.

Manning et al's (4) systematic review of the long-term psychosocial impact reported by childhood critical illness survivors included three studies and a total of 51 participants which included CYP with ABI. A number of outstanding and ongoing needs (met and unmet) were identified regarding support (information, emotional, social and overall wellbeing) highlighting the need for long-term psycho-social support.

Expert reviews/recommendations

Two papers were identified which presented a review of the needs of CYP with TBI and ABI along with recommendations for intervention and service provision. The first presents a review of the pertinent issues regarding paediatric TBI (23). The common needs of CYP with TBI and their families (information, parent and family emotional support, school liaison difficulties, persistent physical, cognitive and behavioural difficulties) are presented whilst emphasising the bespoke needs of each CYP and family and the need for individualised support. Long-term support, training and collaborative working between the family and professionals are recommended as critical to ensuring the long-term success of this population. Practice recommendations for service provision for CYP with ABI are also provided by international group of professionals from the International Paediatric Brain Injury Society (22). They advocate long-term holistic family-centred support, the need to raise awareness of the needs of the CYP with ABI, provide education to all involved in their care and for greater collaboration across the care pathway to ensure coordinated and effective provision of services (22).

Research studies

A variety of research designs were used within the 22 original research studies included, representing level two and three evidence, the most common data collection method being interviews (Table 4).

Not all studies reported participant numbers fully. From those that did, participants included CYP (n=137), parents (n=1282), siblings (n=2), and health and educational professionals (n=187). One article solely reported needs perceived by the CYP themselves (33), 15 were on parents experiences or perception of theirs and their CYPs needs (6, 10, 11, 19, 20, 24-26, 28-30, 34, 35, 37, 39), two on professionals experiences and needs (32, 38) and four a combination of the above (17, 27, 31, 36). Fifteen articles focussed specifically on the needs of CYP with TBI and their families (6, 10, 11, 17, 19, 20, 25-27, 30, 32-35, 38), three specifically on the needs of CYP with brain tumours (24, 29, 36), one on the needs of CYP critical care survivors, including CYP with ABI (31) and three on the needs of CYP with ABI (TBI and NTBI) (28, 37, 39).

Themes

Four themes emerged from the analysis, CYP-related impairment needs, support needs, and return to school and long-term aftercare. Identified needs were also mapped onto the International Classification of Functioning, Disability and Health (ICF) constructs to reflect evidence gaps (Figure 2) (40).

CYP-related impairment needs

Significant needs were reported relating to ongoing physical, cognitive, psychological, emotional, behavioural, and social impairments that transcended and varied across the age spectrum.

Younger CYP (3-7 year olds) were found to have significant long-term behavioural needs with parents reporting unmet needs in relation to managing these (30). The specific needs of CYP in adolescence, defined as a specific and important development stage between the ages of 10 and 19 (41) are identified in three studies. Adolescents, their parents and service providers reported needs in relation to facilitating activity and participation and managing limitations and restrictions in activities of daily living, return to school and physical activities and psychosocial functioning (17, 37, 38). In two studies, CYP with TBI and CYP critical care survivors (including CYP with ABI) identified 'longing for everydayness' and needing support to work towards being 'normal' including physical rehabilitation and social support to access and engage with peers (4, 33). Unmet needs were reported by parents of CYP with ABI in relation to CYP medical and social needs (39) and CYP communication, emotional, social and overall wellbeing, reported by CYP themselves as well as parents (31).

Consistently, the need for long-term surveillance, ongoing monitoring and intervention is recommended as CYP-related impairment needs may change as different challenges present at each developmental stage particularly as they reach adolescence and transition into adulthood (17, 30, 31).

Support needs

Parents of CYP with ABI experience substantial caregiver burden and this is amplified when there is the parental perception of unmet health care needs (6). Parents and CYP have high needs for information and emotional support from professionals across the care trajectory, with many parents reporting a lack of support and unmet needs in this area (10, 11, 17, 24, 28, 29, 31, 34).

The need for bespoke information and support for adolescents and their parents was identified in two studies focusing on the needs of adolescents with mild TBI by the adolescents themselves, their parents and service providers (17, 38). This was also highlighted by Jones et al (18) and relates to adolescents' developmental stage, the need to be recognised as an individual, to be involved and in control.

Several studies highlighted the importance of recognising the impact of the ABI on the whole family and that family and sibling support represented a significant unmet need (4, 28, 36). Roscigno and Swanson (34) describe parents 'grappling' to get what their child and family needs and a fruitless search for community and parental and CYP peer support. Social support and engagement with peers are important for CYP and families as they adjust to life post-ABI but they need help to facilitate this (31, 33). The need for support and guidance from one key professional was highlighted in a study of the experience of CYP with brain tumours and their parents (36). The importance of effective communication and the key worker role to coordinate information and support to CYP and parents was also recommended in two other studies (10, 29) and in the practice recommendations (22).

Return to school

Five studies specifically investigated return to school experiences for CYP with ABI/TBI, their parents, education and healthcare professionals (25-27, 32, 35). Parents describe the need for educational support for CYP with ABI, effective communication, information sharing, training and collaboration between the school, family and healthcare professionals (25-27, 35). Roscigno et al (35) describe parents needing to negotiate with schools to get the help their CYP needed and that where there was coordinated collaboration this lessened their workload. Teachers reported the need for healthcare professionals to provide schools with information about brain

injury and the long-term consequences and for collaboration with healthcare professionals in planning and implementing effective returns to school (27, 32).

Long-term aftercare

Several studies describe unmet needs in aftercare and follow-up of CYP with ABI (10, 11, 19, 20, 24, 28, 31, 36, 39). Whilst one study of CYP with brain tumours reported that parents were generally aware of the long-term sequelae but lacked knowledge of services available (24), other studies reported unmet or unrecognised health care needs across the care trajectory from discharge home through to 12 years post-injury (10, 11, 19, 20). Given the widely reported long-term and developing needs of CYP with ABI, specialist follow-up, particularly at key transition points (e.g. after discharge home, school transitions) is recommended to ensure needs are identified and addressed in an appropriate manner through timely and repeated screening (19, 20, 24, 31). A range of mechanisms to support coordination, communication and collaborative and creative partnerships between all stakeholders are advocated - integrated care pathways, holistic family-centred care models, protocols, key working, case management (10, 19, 28, 31, 36, 39).

Discussion

This scoping review has identified extensive needs of CYP with ABI and their families, many of which are often unmet or unrecognised by those supporting the CYP across the care trajectory.

The lack of awareness and understanding of the long-term consequences of an ABI for CYP and their families reported in the evidence ultimately underpins all the reported needs, met, unmet or unrecognised. As is recommended in the majority of the articles,

there is a desperate need for increased awareness of the needs of this population across health, education and social care services in order that needs are recognised and addressed in a timely and appropriate manner. There is general agreement throughout the identified articles that specialist follow-up and integrated care pathways are required to ensure all CYP have access to services to support them and their families to optimise their recovery, address needs as they arise throughout their development and realise their potential.

The voice of CYP with ABI themselves is limited within the identified studies. Perceived needs are personal and while it is important for parents to report their perceived needs of their CYP, it should be questioned as to whether this truly reflects the needs of CYP themselves. Parents and families also have specific needs relating to their ability to support their CYP and the impact that the ABI has had on them themselves as individuals. Whilst there are several studies including parents' voices, there is little evidence investigating the impact on siblings. Research including the voice of CYP is scant, however there is increased focus and recognition of the importance of their voices being heard and represented within research. Whilst this poses ethical and methodological challenges, it is vital to include them in future research so that their perspective and needs are reported (18, 42, 43).

As reported in the literature, teachers and healthcare professionals involved in the care of CYP with ABI also have needs in terms of supporting CYP effectively as they return to school and reintegrate into the community. Education is required to support them to assist CYP during the transition process and in the long-term, particularly to identify new or emerging needs that may become apparent years after the injury occurred. Including all members of the multi-disciplinary team across health, care and

education sectors in future research is imperative when considering the holistic needs of the CYP and those supporting them.

Mapping the needs onto the ICF demonstrates the large focus on impairments (body structure and function), environmental factors and return to school (activity and participation). There is minimal focus on personal factors, such as psychological and emotional support needs of CYP themselves and out of school activity and participation, including other aspects of community life, such as clubs, hobbies and sports. These gaps warrant further investigation. Research has shown that community participation in CYP with ABI is reduced compared to their peers, however, needs relating to this were not the focus of studies identified in this scoping review (43-45). Future work should consider using the ICF as a framework and incorporate the voice of CYP themselves to ensure comprehensive investigation of the holistic needs of CYP with ABI and their families (46).

This scoping review has identified evidence regarding the range of needs of this population from studies conducted using a variety of research methods. Whilst three systematic reviews and the scoping review identified represent higher levels of evidence relating to the range of needs of CYP with ABI, they do not give a sense of proportion in terms of the numbers affected. No level one evidence of population-based assessments of prevalence of need or service availability, cost or use were identified representing an evidence gap. A mixed methods systematic review of the available evidence is required to develop actionable findings that can inform further research, policy and practice as well as population-based studies of the prevalence of need and service availability and use (47).

Strengths and limitations

This scoping review was systematically conducted using a recognised methodology (16). Extensive searches of the databases were conducted and a broad range of literature was identified and screened by multiple reviewers to minimise bias. The search strategy and methods employed for data extraction and synthesis have been transparently reported.

Some limitations do exist. Defining need is complex and as such, it is possible that the broad search strategy did not identify all relevant articles using the search terms and key words identified. It is possible that evidence of prevalence of need related to outcomes, problems or extent of unmet need may have been excluded through not including studies describing functional or health status related outcomes, experiences or service provision. Grey literature was included in the search and several opinion pieces, policies and guidelines were identified but did not meet the eligibility criteria for this scoping review as did not discuss need specifically. Studies reported in languages other than English were also excluded, leading to ethnocentricity of the findings. Advice was sought from an information specialist regarding the search strategy and every attempt to identify all relevant articles was made using an iterative process, as recommended in the JBI methodology (16).

Implications for practice and future research

The aim of this scoping review was to identify the extent of the evidence, therefore the quality of the articles was not assessed. Whilst a systematic review of the evidence is required in order to inform practice and future research, this scoping review does provide an insight into the evidence regarding the range of needs of CYP with ABI and their families for clinicians. This is important in raising awareness and identifying future

research directions. Only five of the studies include relatively small UK samples and none studying the CYP with ABI population as a whole meaning there is no evidence of prevalence of need within the UK. There is a need for services to evaluate the provision to CYP with ABI in their area and investigate the needs and unmet needs of the population to inform the development of services to meet national service specifications and guidelines as well as the local needs of their specified population.

Conclusion

Relevant research and key themes relating to the needs of CYP with ABI and their families have been identified through this scoping review. CYP with ABI and their families have wide-ranging needs associated with CYP-related impairments, support needs, return to school and long-term aftercare. It is evident that the needs of CYP with ABI and their families transcend health, care and educational domains across the care pathway. Their needs are about living life to the full and participation in all areas of society. Future research with this population must do the same and be child and family centred and holistic in nature.

Conflicts of Interest

The authors declare no conflicts of interest.

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Table 1: JBI scoping review search strategy

Search Stage	Search Terms	Databases Searched
Initial search:	PICO framework: - Children and Young People - Acquired Brain Injury - Needs	MEDLINE CINAHL
Search terms, MESH headings, keywords identified and second search completed.	- Children and young people, Child*, adolescen*, youth, paediatric - Acquired brain injury, ABI, traumatic brain injury, TBI, brain injur*, stroke, brain neoplasms - Needs, needs assessment, unmet needs, health needs, health demands	MEDLINE, CINAHL, Embase, Pedro, Web of Science, JBI, Cochrane Library, PROSPERO, UK Clinical trials gateway, NIHR Journal Library, EuropePMC, Clinical trials.gov, ISRCTN registry, NICE Evidence search, PsychINFO
Grey literature search		Google, James Lind Alliance, Kings Fund, NICE guidelines
Reference list search of included articles		

Table 2: Levels of evidence according to research design (adapted from French et al., 2008)

	Range of needs	Prevalence of need	Service availability/use
Level 1	Qualitative syntheses of need/experience	Population/area-based need assessments, or systematic reviews of need prevalence	Population/area-based surveys of service availability, cost, use
Level 2	Qualitative studies collecting data from patients/carers	Longitudinal cohort or matched comparative studies	Intervention studies that include qualitative process/outcome evaluations
Level 3	Multiple case-studies	Correlation/cross-sectional studies, secondary analyses	Satisfaction surveys, audits

Figure 1. PRISMA flow diagram of the scoping review process

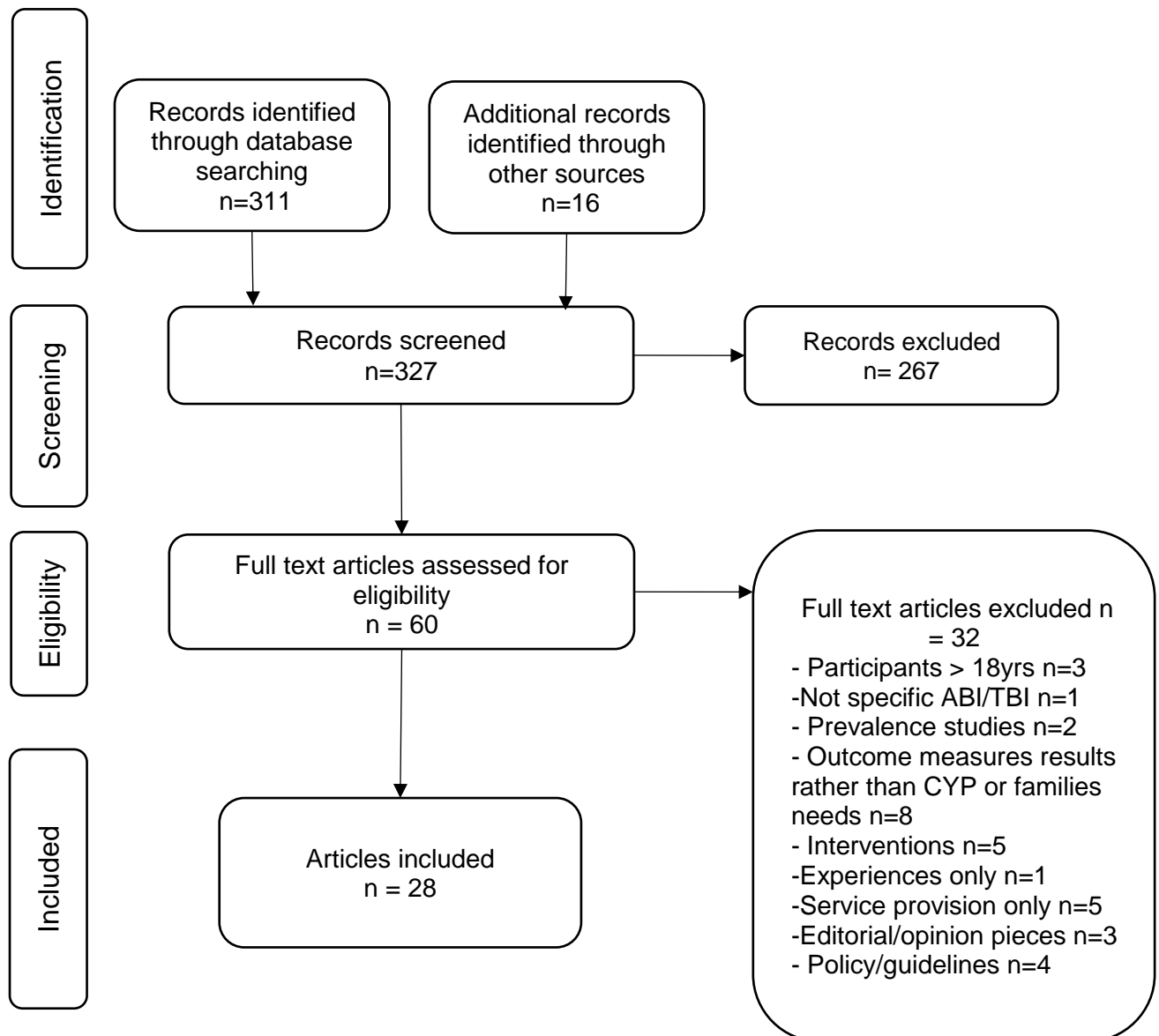


Table 3: Results – Systematic, scoping reviews and recommendation papers

	Year	Country of origin	Participants			Methods	Level of Evidence	Time since injury/ diagnosis	Needs identified	Theme
			CYP	Parents/ Family	Professionals					
Andersson et al	2016	Australia		Parents of 106 CYP with mild, moderate and severe ABI (2-20yrs)		Systematic review of qualitative research (6 studies included) exploring parents' experiences of return to school with ABI	1	0-11 years	Parents experience stress when child's needs not met. Need for appropriate information, respectful communication and productive collaboration between school, health professionals and family	Return to school
Hartman et al	2015	Canada	27 CYP with ABI (4-18yrs)	45 parents/guardians	55 education, 33 clinicians	Systematic review of qualitative studies (10 included) regarding clinician and educator experiences facilitating return to school	1	7 months - 5 years	Lack of training and education regarding transition process, lack of communication and preparation. Need for education, support, communication, collaboration.	Return to school
Jones et al	2018	UK, Australia, USA, Sweden, Canada	105 adolescents with traumatic injuries including TBI	418 parents, 302 primary carers - unspecified, 66 family members	41 health care professionals, unspecified numbers of teachers/ community providers	Scoping review of needs of children and family members after a child's traumatic injury (12 papers included)	3	3 months - 6 years	Adolescent specific needs, Support needs for emotional, cognitive, social, physical difficulties, across care transitions/return to school	Child-related impairments Support Return to education
Manning et al	2013	UK	51 critical illness survivors including ABI			Systematic review - thematic synthesis method (3 studies included)	1	8 months - 7 years	Identified number of outstanding and ongoing needs - Information to fill in missing picture, time to grieve for former self and explore and understand experiences, need to accept -adjustment to	Support

									new physical, psychological and social reality	
McKinlay et al	2016	International	CYP with ABI		International Paediatric Brain Injury Society	Development of practice recommendations for CYP with ABI services	3	n/a	Lack of consideration to needs of child and family post discharge and at key developmental transitions. Sense of abandonment and anxiety among families. Need to support the family holistically long-term and acknowledge ABI as a chronic condition that impacts all family members through collaborative working between all stakeholders, increased education and training and use of case managers	Long-term aftercare Support
Savage et al	2005	USA	CYP with TBI		4 professionals	Review of pertinent issues - 4 professional viewpoints - focus on family stress, educational, cognitive-communicative and behavioural challenges	3	n/a	Bespoke needs - Information, parent and family emotional support, liaison with school difficulties, persistent physical, cognitive and behavioural difficulties. Need for support and training and collaborative working	Child-related impairments Support Long-term aftercare

Table 4: Results of original research studies

	Year	Country of origin	Participants			Methods	Level of Evidence	Time since injury/ diagnosis	Needs identified	Theme
			CYP	Parents/Family	Professionals					
Aitken et al	2009	USA		312 Parents of CYP with TBI (5-15yrs)		Empirical study - 3 x telephone interviews (baseline, 3 and 12 months) using PedsQL, Child Health Questionnaire and baseline interview including questions regarding needs/unmet needs	3	0-12 months	Substantial caregiver burden. Parental perception of unmet healthcare needs strongly related to family burden outcomes	Support
Aukema et al	2011	Netherlands		42 parents of CYP with brain tumours		Survey regarding aftercare in 5 domains of long-term sequelae (neurocognitive, physical, emotional, social and parenting problems)	3	1 year post treatment end (mean 8yrs since diagnosis)	Considerable aftercare needs: physical, neurocognitive, social, emotional, parenting. Most unmet need- parenting problems. Parents had awareness of long-term sequelae but lacked knowledge of services available. Need for timely, repeated screening and specialist aftercare/ follow-up.	Long term aftercare
Gagnon et al	2008	Canada	15 adolescents with mild TBI (12-16yrs)	15 parents		Qualitative cross sectional study focusing on experiences of adolescents and parents after mild TBI. Semi-structured in-depth interviews with adolescent and parent.	3	0-12 months	Needs related to impairments, activity limitations and participation restrictions. Information needs, need for support from professionals to optimise recovery and needs specific to adolescence	Child-related impairments Support

Gfroerer	2008	USA		Parents of 66 school age children with moderate or severe TBI		Interviews - asked to identify areas of concern and needs, whether support was available, how difficult to get it and satisfaction.	2	< 2 years	Perceived relatively few school based supports, given the actual academic, behavioural and social challenges experienced. Need for appropriate post TBI support from hospital and school	Return to school
Glang et al	2008	USA		56 parents of CYP with mild, mod or severe TBI (4-18yrs)		Prospective study - questionnaire and interview about hospital-school transition and education services provided 3 months after return to school	2	0-12 months	Educational support needs and need for effective link between hospital and school on transition	Return to school
Greenspan and Mackenzie	2000	USA		95 parents of CYP (5-15yrs) with head injury (TBI) d/c from 2 acute Maryland hospitals.		Parental telephone interviews and review of hospital records - CYP's use of medical, rehab and social services during the year since the injury.	2	1 year	Unmet need was highest for children with least severe head injuries. Need for PT, OT and MH services was unrecognised for 33% CYP with physical limitations and 40% of CYP with behavioural problems. Need for thorough evaluation and treatment during f/up visits as well as during initial hospitalization for ABI.	Long-term aftercare
Hawley et al	2004	UK	67 CYP with mild, moderate or severe TBI (5-15yrs)	Parents (unspecified number)	Teachers (unspecified number)	Cross-sectional study. Postal questionnaires, interviews and outcome measures (KOSCHI, Children's Memory Scale, Wechsler Intelligence Scale for Children-3rd edition UK, Weschler Objective Reading Dimensions	3	0-6 years since injury	Need for hospital professionals to provide schools with info about TBI and long term consequences so children get appropriate support	Return to school

Hermans et al	2012	Netherlands		Parents of 33 CYP with ABI (12 TBI, 21 NTBI)		Pilot study. Telephone semi-structured interviews	2	2-4 years	Ongoing problems - physical, cognitive, behavioural, social. Unmet needs evident - information, medical, family support, return to school support. Need for improved communication and holistic follow-up of CYP with ABI through collaborative models between all services and parents	Child-related impairments Support
Jackson et al	2007	Australia		53 parents of CYP < 18yrs diagnosed with a brain tumour		Prospective study. Questionnaire interview at diagnosis, 6 months, 1 yr. and 2 yrs. Parents perceptions of hospital experience	2	0-2 years	High information needs from diagnosis - 2 yr. point. Need for effective communication/support	Support
Karver et al	2014	USA		65 parents of CYP (3-7rs) with mild, moderate or severe TBI and 74 parents of CYP with Orthopaedic Injury		Part of a larger prospective follow-up study. Parents completed outcome measures at 18 and 38 months after injury investigating clinical need (presence of behavioural problems) and utilization of behavioural therapy services	2	18-38 months	Long-term behavioural health needs following TBI and Orthopaedic Injury. Importance of monitoring and intervention	Child-related impairments
Kirk et al	2014	UK		29 parents/carers of children with severe TBI.		Qualitative semi-structured interviews	2	6-72 months	Unmet information and emotional support needs across care trajectory particularly following d/c home. Need for range of mechanisms to support coordination and	Support

									communication- integrated care pathways, protocols, key working and case management.	
Limond et al	2009	UK		Parents of 47 children with mild or moderate-severe TBI		Retrospective cross sectional study. Standardised questionnaires (PedsQL, Strengths and Difficulties questionnaire) Views regarding parental experiences of care and ratings of service provision obtained.	3	1-5 years	43 % had cognitive, emotional and behavioural difficulties impact on daily life. Unmet needs in lack of specialist follow-up and support	Child-related impairments Support
Manning et al	2017	UK	3 CYP PICU survivors of critical illness (including ABI), 3 CYP who had used health services	6 parents of CYP, 2 siblings	8 health care professionals, a commissioner and a manager	Multi-stakeholder consultation event - 2 groups parents and HCPs and children and siblings using write/draw and focus group techniques	2	unspecified	Unmet needs - support, information, communication, emotional, social and overall wellbeing. CYP needing support to be 'normal' and for physical rehabilitation and accessing and engaging with peers. No support for siblings. Lack of integration in care pathway. Need for follow-up, surveillance and interventions	Child-related impairments Support
Massey et al	2015	Australia	CYP with TBI		5 teachers	Semi-structured interviews	3	<5yrs	Need for collaboration between health care professionals and teachers	Return to school
Roscigno and Swanson	2011	USA		42 parents of CYP with moderate to severe TBI (6-18yrs)		Semi-structured interviews	2	4-48 months	Grappling to get what my child needs. Searching for community - no support groups	Support

Roscigno et al	2011	USA	39 CYP with TBI (6-18yrs)			Semi-structured Interviews with child x 2 12-15 months apart.	2	4-36 months	Longing for everydayness. Social support important to how adjusted to changes and losses	Child-related impairments Support
Roscigno et al	2015	USA		42 parents of CYP with moderate to severe TBI		Interviews x2 at 15 months and 27 months.	2	< 5years	Perceived needs related to planning, implementing and evaluating return to school - inappropriate state and local services that did not consider needs specific to TBI. Need for coordinated collaboration.	Return to school
Slomine et al	2006	USA		302 caregivers of CYP with TBI (288 completed full study)		Telephone interview at 2 and 12 months. Health care needs categorised as - no need, met need, unmet need unrecognised need on basis of child's use of post-acute services, caregivers report of unmet need and caregivers report of child's functioning as measured by PedsQL	2	3-12 months	Substantial proportion had unmet or unrecognised health care needs during first year of injury. Need for paediatricians to be involved in post-acute care follow-up to ensure child's needs are addressed in timely and appropriate manner.	Long-term aftercare
Soanes et al	2009	UK	10 CYP with brain tumour (4-13yrs)	18 parents of CYP		Longitudinal, exploratory and descriptive case study, multiple methods of data collection (modified mosaic approach, draw and write technique, semi-structured interviews with children over 12 and parents)	2	0-12 months	Need for support and guidance from 1 key professional, recognise impact on whole family, information pathway	Support

Soo et al	2008	Australia		32 parents of CYP with ABI (27 TBI, 5 NTBI)		Validation study of Paediatric Care and Needs Scale (PCANS)	2	8-206 months	Wide range of long-term care and support needs particularly activities of daily living and psychosocial functioning	Child-related impairments Support
Swaine et al	2008	Canada	CYP with mild TBI		8 experts (focus group), 33 professionals (questionnaire)	Qualitative - focus group and questionnaire regarding identifying specific needs of adolescents with mild TBI.	2	n/a	Need for information and support for adolescents and parents when returning to activities (school and physical)	Support
Vilela et al	2008	Canada		27 parents of children with ABI		Demographic data and telephone interview including standardised questionnaires (Child Behaviour Checklist, Service and support questionnaire, Interpersonal support evaluation list, Family Environment Scale, AIMS Interview-Child Version	3	mean = 12.9 years	Unmet medical and social needs. Need for collaborative and creative partnerships between private and public sectors to meet needs.	Child-related impairments Support

Figure 2: Identified needs mapped onto ICF

