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To cite this article: Jennifer P. Lundine, Angela H. Ciccio, Christine Koterba & Ann Guernon (2022): Factors that Influence Follow-Up Care for Families of Children with Acquired Brain Injury: A Scoping Review, *Brain Injury*, DOI: [10.1080/02699052.2022.2051741](https://doi.org/10.1080/02699052.2022.2051741)

To link to this article: <https://doi.org/10.1080/02699052.2022.2051741>



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Published online: 24 Mar 2022.



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Factors that Influence Follow-Up Care for Families of Children with Acquired Brain Injury: A Scoping Review

Jennifer P. Lundine ^{a,b}, Angela H. Ciccia ^c, Christine Koterba ^d, and Ann Guernon^e

^aDepartment of Speech & Hearing Science, The Ohio State University, Columbus, Ohio, USA; ^bDivision of Clinical Therapies & Inpatient Rehabilitation Program, Nationwide Children's Hospital, Columbus, Ohio, USA; ^cCase Western Reserve University, Department of Psychological Sciences, Communication Sciences Program, Cleveland, Ohio, USA; ^dDepartment of Pediatric Psychology & Neuropsychology, Nationwide Children's Hospital, Columbus, Ohio, USA; ^eCollege of Nursing and Health Sciences, Speech-Language Pathology Program, Lewis University, Romeoville, Illinois, USA

ABSTRACT

Purpose: To describe factors that contribute to medical/rehabilitation service access following pediatric acquired brain injury (ABI) and identify gaps in the literature to guide future research.

Materials & Methods: The PRISMA framework for scoping reviews guided this process. Peer-reviewed journal databases were searched for articles published between 1/2008 and 12/2020, identifying 400 unique articles. For full inclusion, articles had to examine a variable related to the receipt or initiation of medical/rehabilitative services for children with ABI. Review articles and non-English articles were excluded.

Results: Nine studies met full inclusion criteria. Included studies identified factors focused on four primary areas: understanding brain injury education/recommendations and ease of implementing recommendations, ease of scheduling and attending appointments, age/injury factors, and sociocultural factors. Well-scheduled appointments and simple strategies facilitated families' access to care and implementation of recommendations. An overwhelming number of recommendations, socioeconomic variables, and transportation challenges served as barriers for families and schools.

Conclusions: This scoping review offers several directions on which researchers can build to improve access to care and recommendation-implementation for families who have a child with an ABI. Enhanced understanding of these factors may lead to better service access, reduction of unmet needs, and enhanced long-term outcomes for children with ABI.

ARTICLE HISTORY

Received 16 June 2021
Revised 11 February 2022
Accepted 6 March 2022

KEYWORDS

Brain injuries; child; health services accessibility; rehabilitation; aftercare; scoping review (publication type)

An acquired brain injury (ABI) is a traumatic or non-traumatic injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. Examples include stroke, traumatic brain injury (TBI), anoxic brain injury, and brain tumor. An ABI experienced during childhood increases the risk for negative consequences across multiple domains that can extend into adulthood (1–5). Non-injury factors, such as socioeconomic status, family functioning, and parenting style, can also affect outcomes (6,7) and potentially contribute to one's ability and/or choice to seek follow-up care, such as attending scheduled appointments (8). Experts agree that children with ABI should be followed longitudinally and across settings (6,9,10), yet research shows that many youth with ABI have both unmet and unrecognized needs years after their injury (6,11–15).

The variety of injury types associated with ABI and differing levels of severity contribute to whether children receive consistent follow-up services following ABI. For example, length of hospitalization is related to referrals for services after discharge. Research indicates that children with longer hospitalizations after TBI are more likely to be connected to ancillary services, including occupational, physical, and/or speech-language therapy, that can extend into the chronic phase of

recovery (16). This is especially true for children who are admitted to inpatient rehabilitation (17). However, the majority of children with ABI never report to (and are subsequently not admitted to) the hospital and may not receive support, therefore missing the opportunity to be connected to ancillary services (18–21).

Existing medical and educational support systems are often-times fractured and inconsistent, which further complicates care for children with ABI and can lead to unmet or unrecognized needs after injury (6,11,22). Because of the variety of health conditions that are associated with ABI, children do not follow a uniform course of care such as moving from the emergency department, to floor admission, to rehabilitation, and eventual discharge home. Instead, children may be seen for medical care in any number of settings including emergency departments, pediatrician offices, or specialty clinics. This heterogeneity complicates care provision, linkage of individuals with ongoing care, and family education (19). Connecting with the appropriate specialty provider can be especially challenging for children with ABI who are only seen by their pediatrician. A survey of pediatricians indicated that they feel they are not in the best position to provide long-term follow-up for children with ABI, specifically those with TBI (23). Yet, these same

CONTACT Jennifer P. Lundine  Lundine.4@osu.edu  Department of Speech & Hearing Science, The Ohio State University, 110 Pressey Hall, 1070 Carmack Rd, Columbus, OH 43210, USA

 Supplemental data for this article can be accessed on the [publisher's website](#).

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pediatricians also reported challenges in referring children to specialty care, citing long wait times and limited availability of pediatric-focused providers (23) and difficulty determining which children need long-term care (10). For families, an unclear continuum of care makes it hard to determine which service provider(s) would be best able to meet their child's needs.

The needs of children with ABI also change over time, which may increase the chances for unmet or unrecognized issues well after the initial diagnosis. Overall, the highest unmet needs reported past the acute recovery period are for physical medicine/rehabilitation, education, speech therapy, and mental health services (11,24). These needs are impacted by injury-related variables, as well as family factors such as lack of transportation or scheduling difficulties (6,13,25). Children with more severe injuries often receive more intense follow up services, but high rates of unmet need have been reported across injury severity groups, in children with complicated mild to severe TBI specifically (11,12). Despite unmet needs, research also indicates that families often miss follow-up appointments (25,26) and report trouble understanding the long-term consequences of an ABI that occurs during development (27).

To improve medical and rehabilitation follow-up for children with ABI, we need to better understand the factors that may impact a family's choice or ability to seek follow-up care or incorporate recommendations. For children with ABI, guidance for follow-up care and clear evidence of barriers to long-term care are limited. This knowledge gap may impact care, which could ultimately impact a child's outcomes following ABI, and thus prompted the current scoping review study. A scoping review allows researchers to examine existing evidence to determine gaps in our knowledge and reasonable next steps for research (28,29). We conducted this scoping review to guide future studies focused on improving access to and receipt of services following ABI. This review asked the following question: What factors contribute to the initiation or receipt of medical or rehabilitative services following pediatric ABI?

Methods

This scoping review is modeled off the PRISMA framework for scoping reviews (PRISMA-ScR) described by Tricco et al. (30) and guided by additional work by Arksey and O'Malley (31) and Colquhoun et al. (32).

Search strategy and study selection

In July 2018, a medical librarian and the first author conducted searches of the following databases: Ovid MEDLINE, CINAHL, PsycINFO, Cochrane Library, and Web of Science. The search strategy and development of search terms involved an iterative process amongst all authors and the medical librarian to ensure that searches were identifying relevant literature before the final terms were confirmed. Search terms are shown in Table 1. Because pandemic-related challenges delayed the completion of this manuscript and to ensure we included all

Table 1. Search terms.

Research component	Research terms
#1 brain injury	(traumatic brain inj*) OR (acquired brain inj*) OR (brain inj*) OR (TBI) OR (head inj*) OR (stroke) OR (anoxia) OR (encephalitis) OR (meningitis) OR (brain tumor) OR (posterior fossa tumor)
#2 caregivers	(parent*) OR (caregiv*) OR (mother) OR (father)
#3 adherence	(compliance) OR (adherence) OR (attitudes)
#4 treatment	(treatment) OR (intervention) OR (therapy) OR (follow up) OR (written instruct*) OR (discharge instruct*) OR (discharge summar*)
#5	#1 AND #2
#6	#1 AND #3 AND #4
#7	# 1 AND #2 AND #4

recently published, relevant studies (33), we completed an updated search in December 2020. This secondary search included only papers published between 2018 and 2020.

Upon search completion, titles and abstracts were exported into Rayyan QCRI (34), a web-based application for systematic reviews. After duplicates were removed, 2 research volunteers evaluated titles and abstracts to identify papers that warranted additional review. When the reviewers did not agree, the first author served as a third reviewer.

In the second review stage, articles were fully screened. Each of the studies was assigned to 2 authors who independently reviewed the full-text of the study to determine whether it met the inclusion criteria. In cases of disagreement, a third author independently reviewed the paper to determine eligibility.

Inclusion criteria

Inclusion criteria was as follows: (a) participant ages included the postnatal period (>1 month of life) through 21 years of age, (b) participants experienced an ABI (not, for example, cerebral palsy, epilepsy, etc.), and (c) the study included an examination of at least one variable related to factors that contribute to the receipt or initiation of medical or rehabilitative services (not information geared toward medical management) following ABI. Researchers excluded expert opinion papers, dissertations, presentation abstracts, and review articles (i.e., systematic reviews, meta-analyses). However, hand searches of review article reference lists were conducted to screen for additional papers that might meet the inclusion criteria. Articles written in languages other than English were also excluded. Studies published before 2008 were excluded to limit papers to those published in the last decade.

Data extraction

Based on the aim of this review, researchers used a data extraction spreadsheet to record key variables from each included study (see Supplementary Material). Authors were assigned one or more full-text article(s) to independently read and tabulate. Researchers recorded data on (1) year of publication and location of study (2), study aims, design, and population (3), medical and/or rehabilitation variables and how they were assessed (4), barriers and facilitators to follow-up care, and (5) additional notes or findings of interest. For reliability purposes, the first author consolidated and verified data extraction forms

by comparing forms to the original article. Synthesis and discussion amongst the authors took place until consensus was reached regarding the data presented in the included paper and the aims of this review. As this review aimed to describe the existing evidence related to our topic, we did not assess the scientific level of evidence of included studies as is accepted practice for a scoping review (30–32).

Results

Following full article screening, 6 articles met criteria to be included in this review after the first search in 2018 and 3 additional papers were added after the secondary search in 2020 (Figure 1). Table 2 shows the study characteristics of the 9 included studies and Table 3 shows the factors found to be associated with follow-up care for families of children with ABI.

Study characteristics

Studies were published (in print or online) between 2011 and 2020. (Note: Lever et al. (35) is listed as published in 2019, but was available in Epub before print version in 2018 and thus was available for inclusion in the first round of this review.) Seven studies were conducted in the United States, 1 in Australia, and 1 in South Africa. Six studies involved youth with TBI (3 included only mild TBI/concussion (36) and 3 included all severity levels (26,35,37)). Two studies examined follow-up in youth with central nervous system cancer diagnoses (38,39)

and one study examined children diagnosed with tuberculosis-associated meningitis (40). Seven of the 9 included studies involved prospective caregiver (35,36,40–43) and teacher (38) surveys or interviews, while Spaw et al. (37) and Lundine et al. (26) used retrospective chart review. Five studies included school-age children (i.e., those between the ages of 5–18 years (36,38,39,42,43); and the remaining studies included younger children through 18 years of age (26,35,37,40). Collectively, the studies reviewed identified 4 categories of factors that influenced families' ability or choice to follow recommendations after ABI: 1) understanding brain injury education/recommendations and ease of implementing recommendations, 2) ease of scheduling and attending appointments, and 3) age and injury factors, and 4) sociocultural factors.

Understanding brain injury education/recommendations and ease of implementing recommendations

Several included studies identified understanding of ABI education and/or recommendations as a factor that impacts whether a family or school is able to adhere to recommendations. Furthermore, the ease at which recommendations can be carried out also appears to impact implementation (35,38–40,42,43). In children with concussion (42) and more severe brain injuries (35), when caregivers reported increased understanding of the effects of brain injury and expressed greater concern and worry for their child, they were more likely to attend follow-up appointments and implement recommendations. Similarly,

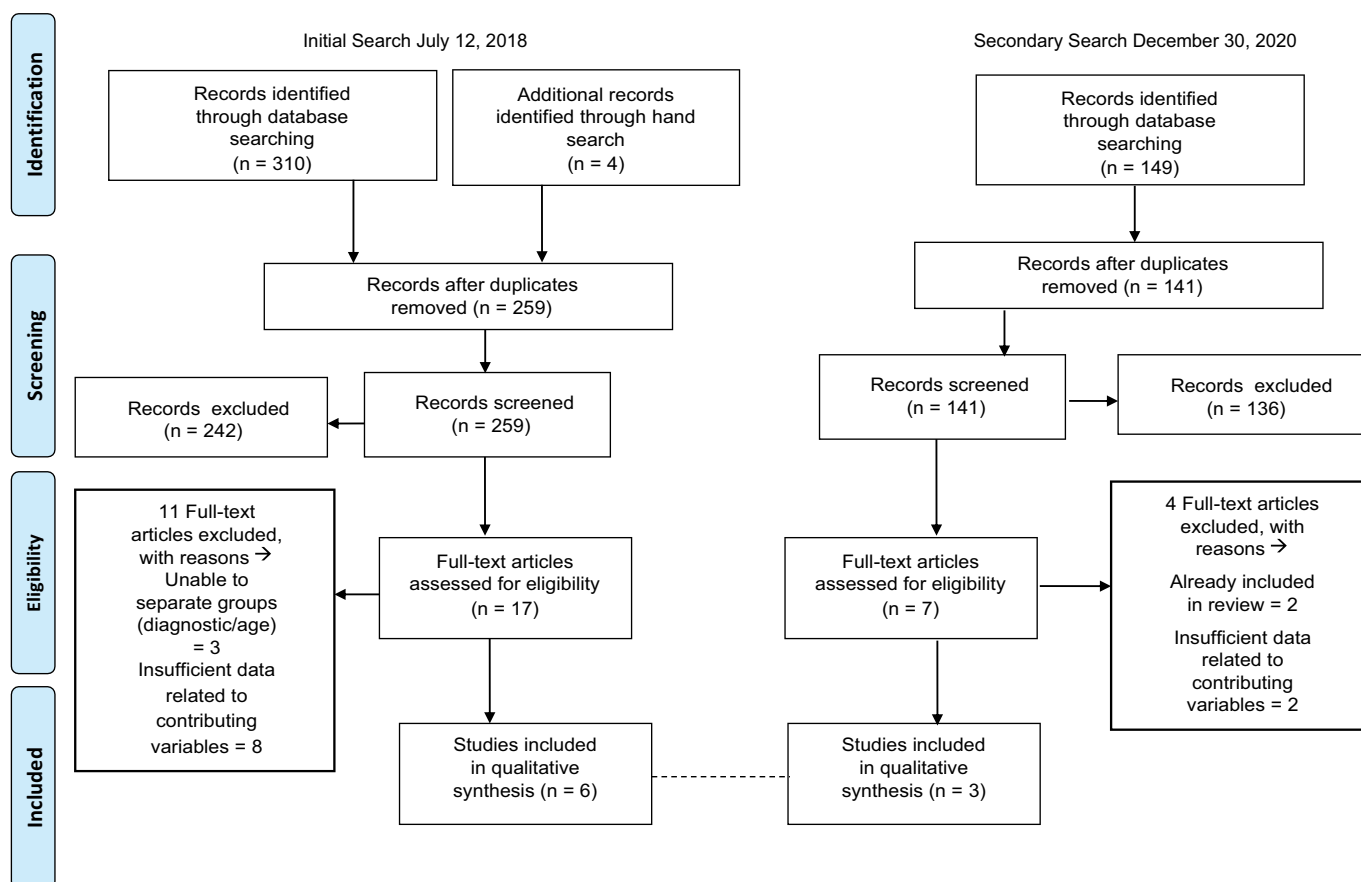


Figure 1. Prisma flow diagram.

Table 2. Characteristics of studies included in full review.

Authors, year	Study population (n)	Location of study	Methodology to assess variables
Cheung et al., 2014	Brain tumor: 15 families with children who had history of brain tumor & neuropsychology report within 2 years of study; 17 parents & 8 teachers interviewed	Australia: Neuropsychology visits associated with large, urban children's hospital	Caregiver & teacher interviews
Currie et al., 2019	Concussion (n = 183); 8–18 years (average 12 years)	U.S.: Urban children's hospital	Caregiver interviews, 30-days after concussion
Hwang et al., 2014	Concussion (n = 150); 8–17 years (average 13.5; SD 2.5 years)	U.S.: Urban children's hospital	Caregiver telephone survey 2-weeks and 4-weeks after discharge
Keenan et al., 2020	Concussion (n = 63); parents of children ages 5–18 years	US: Urban children's hospital, emergency department	Quasi-experimental, prospective study examining parent understanding of standard discharge instructions versus expanded discharge instructions
Lever et al., 2019	TBI (n = 159); Caregivers of children 2–18 years with TBI	U.S.: Urban children's hospital	Caregiver survey following hospital admission
Lundine et al., 2020	TBI (n = 368); Children ages 2–18 years		Retrospective chart review
Quillen et al., 2011	Central nervous system cancer survivors (n = 20) who experienced chemo and/or cranial radiation; 7–19 years (average 12.5; SD 3.6 years)	U.S.: Oncology and behavioral health departments associated with a large, urban children's hospital	Parent interview
Spaw et al., 2018	TBI (n = 352); mild-severe; excluded non-accidental trauma; 2–18 years	U.S.: Urban children's hospital	Retrospective chart review
van Elsland et al., 2012	Tuberculosis-associated meningitis (n = 11); children ages 0–15 years; caretaker ranged between 24–57 years	South Africa: Children's hospital in Western Cape Province	Caregiver interviews

SD = standard deviation; TBI = traumatic brain injury; U.S. = United States

Keenan et al. (43), examined adherence in families who received standard discharge instructions and those who received expanded discharge instructions that included specific information regarding concussion. Families who received the expanded discharge instructions reported better understanding of their child's injury and how best to manage it. They also were more likely to follow recommendations regarding return to school, sports, and outpatient appointments (43). In contrast, Van Elsland and colleagues (40) found that families who reported that discharge information was difficult to understand were less likely to adhere to home-based treatment programs for children with meningitis.

In studies examining students with a history of central nervous system cancer and related treatment and return to school, families and educators reported that recommendations to support the child's success were more regularly implemented when they were practical, simple, and tailored specifically to the student (38). On the other hand, barriers included difficulty understanding how to implement the recommendations without major modifications and receiving too many recommendations at one time (38). A student's reluctance and a family's fear that the child's school placement would be negatively impacted were also identified as barriers (38,39). Perceived communication challenges, which could also impact ease of implementation, were additional barriers identified in these studies. Parents reported that they did not know who to contact at the school to address difficulties, felt that teachers did not understand their child's needs, and recommendations sometimes were not carried over year to year (38,39).

Ease of scheduling & attending appointments

Studies also identified factors related to scheduling appointments that influence a family's ability or decision to seek follow-up care after a brain injury (35,37,40,43). Using

retrospective chart review for children discharged from a large, urban children's hospital following TBI, families with appointments scheduled in multiple hospital departments were less likely to return for scheduled follow-up visits than those who were scheduled in only one department (37). Prospective surveying of families who had children hospitalized with TBI reported they were less likely to attend follow-up appointments when there were scheduling conflicts or if they forgot their appointments. An additional barrier included using appointment scheduling systems that were not "user-friendly" or easy to use. But, this same study found that families reported that well-coordinated appointments increased the likelihood that they would attend (35). Long waiting times at the hospital also posed a barrier for families in returning for follow-up appointments (40). In a prospective study involving families of children with concussion, families who scheduled an appointment within the first 7 days after first seeking medical care were significantly more likely to attend follow-up visits with their primary care provider than those who had not yet scheduled their follow-up appointment within the first week (43).

Age and injury factors

Age and injury related variables, both important to outcome after brain injury, were also investigated in the studies included in this review. One retrospective chart review study found that older children with TBI were more likely to return for scheduled follow-up appointments in the first year after injury than were younger children (37). Studies examining injury-related factors that may increase a family's likelihood to return for later services found that adolescents with sports-related concussion were more likely to comply with medical recommendations to seek clearance before returning to their sport than were adolescents with non-sports-related concussion (36). While researchers did not

Table 3. Variables and findings related to follow-up in included studies.

Authors, year	Variables examined	Findings: Barriers to care	Findings: Facilitators for care
Cheung et al., 2014	(1) Parent & teacher understanding of neuropsychology reports (2) Implementation rates for recommendations (3) Perceived effectiveness	(1) Patient's reluctance toward recommendations (desire to be independent) especially as child ages (2) Too many recommendations at one time (3) Teachers changing & lack of teacher understanding (4) Insufficient communication between school & parents (5) Instructional recommendations that required teachers to modify teaching methods & provide individual support for the student OR those that require organizational/logistical resources (6) Parts of written report difficult to understand (7) Lack of continuity between different classes (older students) or between grades (younger students)	(1) Recommendations tailored specifically to the patient and his/her family and "less disruptive to the norm" (2) Practical and simple recommendations that reflect standard teaching practices
Currie et al., 2019	Attendance at Primary Care Provider follow-up visit within 1 month of concussion	"Thought child did not have any needs"	(1) Females (2) Parents showed increased concerns related to concussion (3) Those who scheduled an appointment by 7-days from concussion Those with sports-related concussion
Hwang et al., 2014	Compliance with step-wise return-to-play protocol (no return until asymptomatic & given medical clearance)		Expanded discharge instructions
Keenan et al., 2020	Parent understanding of concussion diagnosis & management, when to return to school/sports, seek further care, and outpatient follow-up		
Lever et al., 2019	Follow-up appointment attendance	(1) No need for follow-up (2) Schedule conflicts (3) Lack of resources (4) Bad appointment scheduling system (5) Forgot about appointment (6) Long driving distance	(1) Good hospital experience (2) Identified need (3) Sufficient resources (4) Well-coordinated appointments
Lundine et al., 2020	Attendance at first post-discharge follow-up appointment	Families living less than 15 minutes from hospital and also lived in an area with lowest median household income, highest percentage of people living in poverty, and highest percentage of people without cars	Families living within 30–60 minutes from hospital and higher rates of median household income
Quillen et al., 2011	Implementation of recommendations from neuropsychological reports	(1) Fear that their child would be placed in special education, "labeled" in school, or removed from the gifted program (2) Uncertainty about who to contact at the school (3) Schools' need to perform more testing or perceived unwillingness to implement recommendations (4) Challenges navigating the school environment	
Spaw et al., 2018	Full, partial, or non-adherence with recommended follow-up visits within hospital network	Follow-up in more than 1 department	(1) Private insurance (2) Older age at injury (2) Motor vehicle crash (compared to bike or sports injuries)
Van Elsland et al., 2012	Adherence to home-based treatment & caregiver perception of disease	(1) Discharge information was difficult for parents to understand (2) Difficulty with medication administration at home & side effects (3) Lack of access to health-care facility (4) Long waiting times at the hospital (5) Hidden costs of transportation	(1) Repayment of travel costs for medical visits (2) Seeing the child flourish at home (versus inpatient stays at the hospital)

ask families why they did not seek medical clearance before returning to play, they hypothesize that those with sports-related concussion may be more closely monitored by a physician or athletic trainer (36). Another study found that children and adolescents whose TBI was due to a motor vehicle collision were more likely to return for scheduled follow-up appointments compared to those with bicycle or sports-related injuries, regardless of injury severity (37,40).

Sociocultural factors

Several sociocultural factors, including demographic and socioeconomic factors, were identified as contributing to families' decisions or abilities to seek follow-up care or implement recommendations following pediatric ABI. The impact of

biological sex, often identified as an important variable for ABI outcome, was inconsistent in the studies included in this review. In one study, female patients, aged 8–18 years, were more likely to attend a follow-up appointment with their primary care provider within 1-month of visiting the emergency department for concussion (42). Spaw et al. (37), however found that sex did not play a role in predicting whether children returned for their follow-up appointments following hospitalization for TBI.

Socioeconomic factors have also been found to affect a family's decision or ability to seek follow-up care following an ABI. Parents reported that sufficient resources (referring broadly to resources such as transportation, insurance, child-care availability, time off work) facilitated follow-up attendance, whereas lack of resources served as a barrier to later care access (35). Similarly, families reported lack of access to

a health care facility, hidden transportation costs, or long travel distance as obstacles to following recommendations for care after the initial ABI diagnosis (35,40). Lundine et al. (26), completed a retrospective chart review study examining a family's distance from the hospital and their attendance at the first post-discharge follow-up appointment. Researchers found that families living between 30 and 60 minutes from the hospital had significantly higher odds of returning for follow-up than those living closest to the hospital, but these differences disappeared when socioeconomic factors were included in the model. Families who lived within 15-minutes of the hospital lived in an area with the lowest median household income, highest percentage of people living in poverty, and highest percentage of people without cars. Findings highlight that distance alone may not be the critical factor to accessing care, rather that socioeconomic status could play a larger role. In fact, socioeconomic facilitators to access care later in the recovery period included families with private insurance (compared to Medicaid/Medicare or no insurance). Families with private insurance were more likely to return for follow-up visits after TBI (37) and those who received repayment for travel costs to medical visits also showed greater rates of discharge recommendation implementation and follow-up care (40).

In addition to demographic and socioeconomic factors, social factors including caregiver confidence appeared to contribute to accessing follow-up care. For example, van Elstrand et al. (40) identified administration of at home medications and side effects as barriers to care. Researchers identified factors including a caregiver seeing their child flourish at home versus in the hospital made families more likely to comply with medication recommendations (40).T

Discussion

The purpose of this scoping review was to summarize the existing research examining barriers and facilitators that contribute to the initiation or receipt of medical or rehabilitative services following pediatric ABI to identify meaningful areas for future research. The 9 studies included in this review involve both TBI and non-TBIs in children and present both facilitators and barriers to later care or recommendation implementation for rehabilitative care. These studies presented four main areas for consideration: understanding brain injury education/recommendations and ease of implementing recommendations, ease of scheduling and attending appointments, age and injury factors, and socio-cultural factors. The results of this scoping review are consistent with Levesque et al.'s (44) conceptual framework related to patient-centered access to health care. Their framework identified system and individual-level factors influencing care access that are reflected in the findings from this scoping review and can be used to guide future studies focused on improving a family's ability and choice to seek care for unmet needs and to improve implementation of medical and rehabilitation recommendations for children with ABI.

In order for families to be active, engaged participants in their child's brain injury recovery process, they must be able to understand the injury, the implications of the injury, and how the recommendations being made aim to help both the child and the family. For example, concussion is the most common ABI experienced by children and adolescents (45); however, families are often unaware of the consequences of a concussion or the implications of multiple concussions. Research indicates that a second concussion sustained prior to full recovery from the first injury puts an individual at risk for greater cognitive compromise and/or lengthier recovery. However, this is understudied and less well understood in children and adolescents (46,47). The potential risks associated with multiple concussions underscore the importance of following medical recommendations when it comes to returning to sports, but as Hwang et al. (36) and Keenan et al. (43) found, these recommendations are not consistently followed. The reasons for families not following concussion recommendations are likely complicated, but one contributing factor may be related to a family's understanding, acceptance, and awareness that concussion often requires medical, and possibly rehabilitative, intervention. Further complicating matters is the fact that definitive research regarding the long-term effects of concussion in children is limited, making it challenging to establish clear evidence-based guidelines. More research is needed to clarify best practices that promote recovery so that children and adolescents who sustain concussion can safely return to both physical and academic activities. Safe return to activities requires the study of effective education to facilitate caregiver and child understanding and implementation of these important protocols. As an example, Reed and colleagues (48,49) have published studies exploring new ways (e.g., smart phone apps) to educate families and adolescents about concussion management. Though they have not yet shown if those strategies are effective, this is an interesting area to watch.

Additionally, the current review identified that families may have trouble understanding the impact of the invisible aspects of ABI and how to mitigate negative consequences following ABI. For example, in the caregiver survey study by Lever et al. (35), parents reported that they were unlikely to attend scheduled follow-up appointments when they perceived their child to be "doing well." Similarly, school recommendations were less likely to be followed when parents feared their child's school placement would be negatively impacted (39). Research shows that ABI can result in chronic, and later-developing changes in a child's social, emotional, cognitive, and behavioral functioning (6,12). As such, it is important that families understand potential long-term consequences and can determine when their child might have subtle difficulties that would benefit from intervention. If a family is missing follow-up appointments because their child seems "fine," or is not notifying the school about their child's diagnosis for fear of negative consequences, later-developing problems could go unnoticed and untreated. Research must continue to focus on studying children with ABI longitudinally so that the

potential developmental consequences of these injuries are better understood. Additionally, more work could be done to determine how best to educate families about the potential for later-developing consequences, especially for early childhood injuries (50).

This scoping review identified several factors that are specific to whether families or schools implement educational recommendations for children with ABI including length, complexity, and timing of accommodations and recommendations (38,39). We know that hospital-to-school transition planning is particularly important for children with ABI (51), as medical follow-up may be limited, and schools are the primary location for rehabilitation/management into the chronic phases of recovery. Overall, these studies suggest that families and educators need ongoing information and guidance to successfully implement educational/school/classroom recommendations for children with ABI (27,52). Caregivers and educators reported feeling overwhelmed by the number and complexity of recommendations provided in a neuropsychological report, making them less likely to implement even the simplest (or most important) strategies (38). If school personnel feel overwhelmed by a long list of possible accommodations, and thus are not executing them effectively, it is the student who will ultimately suffer. As noted by educators who participated in these surveys (38), schools are more likely to implement the simplest accommodations immediately upon the child's return to school (timing of the implementation), but they are less likely to consider new supports as the child moves further from the actual injury. This is pertinent since research shows that students with TBI who are not connected with special education services within the first year post-injury are less likely to be connected with special education services later (53). As discussed in expert opinion papers (10,54) and qualitative research (52,55), families need support navigating the school system and advocating for the needs of children with ABI, just as educators need training to understand how an ABI can affect learning and behavior. Additionally, researchers and clinicians may need to consider different methods to deliver and/or prioritize recommendations to increase the chances that children with ABI are receiving the support they need both at home and at school. Attention must also be paid to the age and developmental level at diagnosis. For example, children who sustain an ABI before entering formal schooling must be appropriately identified so that early intervention and education services can be initiated. The needs of older children will likely differ somewhat, and modifications to their educational plan may need to be made in order to continue providing appropriate educational service and address increasing demands across the school continuum. The studies included in the current review provide evidence to support these recommendations (38,39).

Several studies identified that the ease of scheduling and attending follow-up appointments is one factor that can affect a family's medical or rehabilitative care access for their child with an ABI. Straightforward and consistent methods to schedule follow-up appointments may be helpful for increasing the chances that families will follow-up with later care appointments. Furthermore, when scheduling happens closer to the injury and families do not have to wait more than a week to be seen, adherence understandably increases.

As we make greater efforts to understand and address inequities that exist in our current healthcare delivery system, we should consider sociocultural factors and how they may limit a family's ability (or choice) to seek additional care. This is especially important in cases of chronic or long-term conditions, such as pediatric ABI. Several studies included in the current review identified that lack of resources including, but not limited to, insurance, transportation, or financial resources can affect a family's return for later care after ABI (26,35,40). While not addressed in any of the studies identified for the current review, health disparities for those with ABI, including race/ethnicity, insurance status, and language and literacy barriers, have been documented in the literature (56–59). Exploring social determinants of health and ways to overcome these challenges is an area in great need of research so that the most vulnerable populations of children and youth who experience an ABI receive appropriate support. Future research should focus on the modifiable factors identified through this review, but attention should be paid to the identification of other social determinants of health that play a role in ABI outcome and may require unique solutions.

Study limitations

Methodological limitations of the existing literature and this scoping review could be addressed in future work. Due to the scope of this topic, it is possible that articles were not identified or included based on our key word choices. That said, because our search identified studies of children with both traumatic and non-traumatic diagnoses, this scoping review appears representative of research that exists on this topic. While we accept that there are diagnosis-specific needs, this review shows that despite differences in diagnosis, severity, and age, issues with access to services still exist. Follow-up care may differ across these variables; however, results of our scoping review indicate that barriers and facilitators are similar across severity of injury, type of injury, and age at injury. The medical needs and support services in these populations may be vastly different, but with respect to initiation and receipt of services, the experience has important similarities that, once identified, can be examined more closely in prospective research and clinical quality improvement projects. We acknowledge that the small number of studies included in this review are heterogeneous in terms of included participants. Ethnic background, health literacy, and social determinants of health likely also play a role in family's accessing medical services and implementing recommendations and this could not be adequately addressed in this review. This is especially true as clinicians and researchers recognize a changing focus on the chronicity of needs long after the initial medical diagnosis. The exception to this statement is related to concussion, where more research is needed to clarify if or when a mild TBI might lead to lasting effects in a developing brain.

Conclusions

This scoping review summarizes the existing evidence to identify directions for clinicians and researchers to continue to improve medical and rehabilitation follow-up care for children with ABI.

Researchers and clinicians could immediately begin to study how modifying family and school recommendations and improving ease of appointment-scheduling affect care access. As identified in this review, researchers studying interventions for children and adolescents with ABI should also include analyses to study how sociocultural factors including demographic and socioeconomic factors influence access to care. This would allow researchers, medical professionals, and policy makers to address systemic issues that might limit a family's ability to access follow-up care or implement necessary recommendations. Engaging key stakeholders, like parents, children with ABI, educators, and medical providers, is important for future studies to help researchers understand the most critical variables that could facilitate improved access to follow-up care (60). Future prospective research could integrate the results from this scoping review with the conceptual framework described by Levesque et al. (44) to study how changes to system or individual-level factors might positively influence access to care. Ultimately, an improved understanding of factors that help and hinder families from seeking follow-up care may lead to better service access, reduction of unmet needs, and improved long-term outcomes for children with ABI.

Acknowledgments

The authors would like to thank Julie Haarbauer-Krupa for her advisory contribution to this work. Additionally, we are grateful to Alison Gehred for her assistance with the literature search and Joy Reed and Laura Martin for their help with initial abstract reviews. The authors wish to thank the ACRM Pediatric-Adolescent Brain Injury Task Force members for reviewing and providing feedback on the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Jennifer P. Lundine  <http://orcid.org/0000-0002-9113-7875>

Angela H. Ciccio  <http://orcid.org/0000-0003-2189-4827>

Christine Koterba  <http://orcid.org/0000-0002-1334-8415>

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