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Research Article

Acute and Long-Term Services for Elementary and Middle School Children With Early Childhood Brain Injury

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Purpose: The purpose of this study was to investigate the rates of referral to and receipt of acute and long-term services and identify factors that could impact these rates for children who experienced an acquired brain injury (ABI) during early childhood who are now in elementary and middle school.
Method: This was a retrospective chart review and prospective phone survey of 29 caregivers of children with ABIs.
Results: Acutely, two thirds of this sample received hospital-based rehabilitation services, but only 44.8% of families reported receiving ABI-specific education or a referral to educational or rehabilitation services at the time of discharge. At an average of 8.5 years postinjury, children in this sample were largely reported to be performing positively in school. While special education rates did not change significantly over time, 20.7% of the sample reported having unmet educational needs. Additionally, service receipt decreased over time. Various injury and educational factors influenced rates of long-term special education and service receipt.
Conclusions: This study contributes to the emerging literature focusing on long-term outcomes of children with ABI. The results reinforce that children who experience an ABI in early childhood are unlikely to receive ABI-specific education or referrals to educational and rehabilitation services during their acute-care stay and, in the chronic stages of recovery, present with educational and therapy needs that can go unmet. To improve long-term service access for children who experience an early ABI, pathways need to be established within the acute-care setting for education and referrals that connect the child and family to treatment within early intervention and educational systems. Maintaining these pathways long term, particularly for potential social-behavioral and cognitive-communication concerns, could increase access to appropriate services and, thus, decrease unmet needs for children with ABI.

Children in early childhood, between birth and 4 years old, are among the highest risk age group to experience acquired brain injuries (ABIs; Centers for Disease Control and Prevention [CDC], 2019; Chan et al., 2016; Faul et al., 2010). ABI is a category of injury that includes both traumatic and nontraumatic causes. Falls and meningitis are the leading causes of traumatic brain injuries (TBIs) and non-TBIs, respectively, for this age group (Chan et al., 2016; Faul et al., 2010). There is limited research available tracking the outcomes of children who experience an ABI during early childhood, though evidence suggests that children who experience an ABI at a younger age present with unique symptoms not typically reported in older children, such as decreased engagement in play and increased dependence on caregivers (Suskauer et al., 2019). Additionally, experiencing an ABI of any severity during early childhood is known to more negatively impact long-term development and functioning when compared to injuries at an older age (Anderson et al., 2005; Ewing-Cobbs et al., 2006). Particularly, cognitive-communication, social-emotional, and behavioral deficits can present years after injury (Babikian et al., 2015; Jonsson et al., 2013).

As children with a history of childhood ABI begin elementary school, deficits that were not previously evident may begin to pose difficulties in academic and social functioning (Catroppa et al., 2009; Jonsson et al., 2013). In the cognitive-communication domain, children may

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demonstrate difficulties with executive functions, such as maintaining attention on a teacher or remembering and following simple directions, that negatively impact their ability to engage in the classroom (Arnett et al., 2013). Children with social-emotional difficulties may have difficulty recognizing emotions or demonstrating appropriate social cognition (Turkstra et al., 2015). For example, aspects of social cognition can be reflected through impairments of language comprehension and language production, such as recognizing tone of voice or making inferences (Turkstra et al., 2015). Social-emotional challenges following ABI can negatively impact school outcomes and the ability to form and sustain friendships, as participating in the social demands of a school environment with age-appropriate social skills underlie academic success (Cermak et al., 2019).

Adverse behavioral outcomes post-ABI, such as aggression and inappropriate social behaviors, are disadvantageous to positive school performance (Babikian et al., 2015). The impact of an ABI on behavior is widespread, suggesting negative consequences in both the short and long term (Gagner et al., 2019). There exists a higher prevalence of internalizing and externalizing behavior in young children with ABI, persisting chronically postinjury (Babikian et al., 2015). Though limited empirical evidence exists, special education services, speech-language therapy, counseling, and positive behavior supports may improve a child's ability to engage in academic and social settings, increasing long-term achievement and quality of life (Babikian et al., 2015).

Despite best practice recommendations and growing evidence that rehabilitation and educational services improve the long-term outcomes of children with ABI (CDC, 2018), acute and long-term service utilization remains low for children who experience an ABI during early childhood (Greenspan & MacKenzie, 2000; Haarbauer-Krupa et al., 2017, 2018). Reduced service utilization often begins in the acute-care setting with inadequate referrals to address possible areas of need, including cognitive-communication skills (Bennett et al., 2013; Ciccia et al., 2016). Most families do not receive referrals to early intervention or special education services upon their child being discharged from the acute-care or rehabilitation hospital setting (Cronin, 2001; Jimenez et al., 2016; Moore et al., 2016; van Heugten et al., 2017), and if a child is not hospitalized, the chances of referral are even lower. Low service utilization persists long term for children injured between 5 and 15 years old, with only 37%–40% returning for follow-up visits in the first year post-ABI (Fuentes et al., 2018; Greenspan & MacKenzie, 2000; Haarbauer-Krupa et al., 2018). Low long-term service utilization can lead to high rates of unmet need for older children with ABI and likely for children injured in early childhood, although research addressing longer term outcomes for this age group does not yet exist (Fuentes et al., 2018). While previous research offers compelling data highlighting some of the challenges associated with childhood ABI, the literature is limited in the number of studies that have specifically and solely focused on the longer term issues that might exist for children who experience an ABI in early childhood.

Up to 80% of children with a history of ABI present with needs that are not being met in the academic setting (Glang et al., 2008; Haarbauer-Krupa et al., 2017; Kingery et al., 2017). High rates of unmet need have been attributed to decreased awareness of providers and caregivers related to the long-term effects of ABI, the latent presentation of deficits after ABI, and the lack of continuity of services from acute care to educational settings, including long-term monitoring of needs (Glang et al., 2008; Haarbauer-Krupa et al., 2017; Kingery et al., 2017). Again, while this existing evidence provides a framework to begin to understand the presence of long-term unmet needs for children with ABI, additional evidence is needed to describe the trends in service receipt over time and the risk and protective factors that might buffer or amplify long-term needs that are specific to those individuals who have sustained an ABI in early childhood. Additionally, the importance of speech-language pathology services in working with children who sustain an early childhood ABI is underemphasized, potentially due to limited research of, referral to, and receipt of speech-language pathology services.

Given the limited available data on the long-term service needs specific to children who sustain an early childhood ABI, the aim of this retrospective cohort chart review and prospective caregiver phone survey was to determine (a) acute and long-term educational and service receipt, (b) rates of long-term need, and (c) factors that influence long-term educational and service receipt of children who experienced an ABI during early childhood. Based on the limited literature available for this population and studies regarding acute and long-term service utilization for older children with ABI, it was hypothesized that children who experienced early childhood ABI would present with low rates of service receipt and high rates of unmet need into the chronic phase of their recovery that would be influenced by injury and service or educational factors.

Method

Design

This study included retrospective cohort chart review and prospective caregiver phone surveys. Prior to data collection, the study was approved by all necessary institutional review boards.

Participants

Participants were identified from the electronic medical records (EMRs) at one large, urban, academic pediatric medical center in the Midwest of the United States. Diagnostic codes for inclusion in the chart review were based on a previously conducted chart review in pediatric ABI (Ciccia et al., 2016) and codes used by the CDC to identify individuals with ABIs (CDC, 2015), as there are no standard guidelines for code selection in ABI (Chan et al., 2013). Codes were agreed upon by the authors and are listed in

Table 1. The International Classification of Diseases, Ninth Revision, Clinical Modification codes were used as they were the current codes during the time period of hospitalization used for inclusion criteria. Additional inclusion and exclusion criteria, listed in Table 2, were used for chart selection and survey administration.

Data Collection

Chart abstractors and survey administrators included one doctoral student in speech and hearing science, one combined master's/doctoral student in speech and hearing sciences, and one undergraduate student in biology. They were trained by the fifth author who had extensive familiarity with EMRs and has used it regularly for research and clinical documentation. Training for data extraction and collection was conducted in person, with follow-up phone conferencing and e-mail to discuss questions or concerns before and during the process.

An EMR specialist generated a list of patients meeting initial eligibility criteria. Chart reviews were then completed in chronological order, starting with the most recent admissions. After confirming those patients who met inclusion criteria, families were sent a letter introducing the study and were then contacted for a 10-min phone survey that included a series of yes/no and short open-ended questions, listed in Appendix. Answers to short, open-ended questions were transcribed verbatim and coded. For those families who participated in phone surveys, researchers collected the following additional data from participant medical records: date of birth; gender; race; date of injury; International Classification of Diseases, Ninth Revision, Clinical Modification code and description; length of stay; inpatient service receipt (type/duration); and referral to any education or rehabilitation services by any medical professional (e.g., therapist, physician) at discharge. Data collected from caregiver surveys that were retained for analysis included caregiver-reported receipt of ABI education (who/when); child's current grade; rating of child's school performance; type and duration of current or past receipt of special education (Individualized Education Program [IEP]/504 Plan/early intervention) or related services (outpatient/school based); if not receiving special education, caregiver-perceived need of special education, child's challenges, and reason for not receiving. A 504 Plan, under the U.S. Rehabilitation Act, provides accommodations for students with disabilities in the public school setting (U.S. Department of Education, Office for Civil Rights, 2010). A 504 Plan is not as extensive as an IEP but can be beneficial to provide support for students who do not otherwise qualify for an IEP.

For data abstracted from the full medical record and data inputted from surveys, interrater reliability was established between the first and second authors, both PhD students in communication sciences. The second author reviewed six participant records originally abstracted by the first author (six of 29) at random. Interrater reliability was 97.8% (524 of 536 items), and discrepancies were resolved between raters.

Analysis

Data were analyzed descriptively and statistically using JASP 0.11.1. Kendall's τ_b correlation was used to analyze the strength and direction of the association between length of acute-care stay and (a) acute services received, (b) referral to rehabilitation or education services,

Table 1. Codes.

ICD-9-CM code and category	*n* (%)
47.8: Other specified viral meningitis	1 (3.44)
62.5: California virus encephalitis	1 (3.44)
239.6: Neoplasm of the brain (not otherwise specified)	1 (3.44)
323.62: Other postinfectious encephalitis	1 (3.44)
325: Cerebral venous sinus thrombosis	1 (3.44)
348.1: Anoxic brain injury	1 (3.44)
433.01: Occlusion and stenosis of basilar artery with cerebral infarction	1 (3.44)
434.91: Unspecified cerebral artery occlusion with cerebral infarction	3 (10.34)
800.21: Closed fracture of vault of skull with EDH, SDH, and SAH (no LOC)	2 (6.89)
800.6: Open fracture of vault of skull with cerebral laceration and contusion	2 (6.89)
800.7: Open fracture of skull with EDH, SDH, and SAH	1 (3.44)
801.06: Closed fracture of base of skull without mention of intracranial injury (LOC of unspecified duration)	1 (3.44)
801.21: Closed skull base fracture with hemorrhage (without coma)	1 (3.44)
801.89: Open skull base fracture with intracranial hemorrhage and concussion	1 (3.44)
850.11: Concussion with LOC (30 min or less)	1 (3.44)
850.9: Concussion unspecified	2 (6.89)
852.21: Subdural hemorrhage (following injury with no LOC)	2 (6.89)
853.01: Brain hemorrhage without a coma	1 (3.44)
905: Late effect of fracture of skull and face bones	1 (3.44)
994.1: Drowning and nonfatal submersion	4 (13.79)

Note. ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification; EDH = epidural hematoma; SD = subdural hemorrhage; SAH = subarachnoid hemorrhage; LOC = loss of consciousness.

Table 2. Additional inclusion and exclusion criteria.

Variable	Inclusion	Exclusion
Chart review	- Hospitalized at between 6 months to 4 years old (DOB: 9/1/2005 to 8/31/2009) - Admission and discharge dates between 9/2/2005 and 8/30/2013	- Duplicate chart - Incorrect diagnosis - Medically documented history of abuse - Any child who is listed as deceased
Caregiver survey (additional)	- Caregiver of child identified in EMR data extraction - English speaking - Able to answer survey questions	- No response to survey - Non-English speaking - Unable to participate in survey questions

Note. DOB = date of birth; EMR = electronic medical record.

and (c) parent-reported education on ABI. A similar analysis explored the association between current special education and current service receipt and (a) race, (b) gender, (c) mechanism of injury, (d) injury severity, (e) age at injury, (f) inpatient service receipt, (g) length of acute-care stay, (h) referral to services at discharge, (i) receipt of parent education on ABI, (j) time since injury, (k) age at time of survey, (l) current grade, (m) current school performance, (n) past special education or early intervention receipt, and (o) past service receipt. Results were considered significant when $p < .05$.

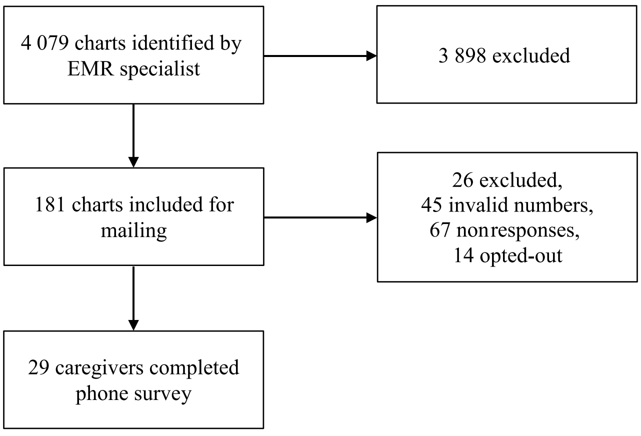
Results

Participants

One Hundred Eighty-One Families Were Initially Contacted Via Letter and Invited to Participate

Twenty-nine caregivers completed the phone survey, representing an 18.71% response rate. A full inclusion flow chart is presented in Figure 1. The mean age of the sample was 2.2 years at the time of injury and 10.8 years at the time of survey. Participants were, on average, 8.6 years postinjury at the time of this survey. The distribution for mechanism of injury was 51.6% traumatic and 48.3% nontraumatic, and most injuries were classified as moderate severity (37.9%) or did not have severity documented (34.5%). Complete demographic and injury information is listed in Table 3.

Figure 1. Inclusion flowchart. EMR = electronic medical record.



Acute Experiences

The mean length of the acute-care hospitalization was 15.0 days (*SD* = 24.2). Nineteen (65.5%) children received at least one service during their acute-care stay. Social work was the most common service received (55.2%), followed by physical therapy (41.1%), speech-language pathology (37.9%), and occupational therapy (37.9%). Complete acute service receipt data are listed in Table 4. There was a moderate, positive correlation between length of acute-care stay and acute services received, which was statistically significant ($\tau_b = .52$, $p < .001$). Children with longer hospital stays were more likely to receive services.

Table 3. Demographic and injury information.

Variable	*M* (*SD*) or *n* (%)
Demographic	
Age at the time of the survey	10.79 years (1.788)
Gender	
Male	19 (65.6%)
Female	34.4 (34.4%)
Race	
White	22 (75.9%)
Black or African American	5 (17.2%)
Asian	1 (3.4%)
Bi- or multiracial	1 (3.4%)
Injury information	
Age at the time of the injury	2.23 years (0.96)
Time since the injury	8.56 years (1.39)
Mechanism	
Traumatic	15 (51.7%)
Fall	6 (20.7%)
Motor vehicle accident	3 (10.3%)
Struck by/against	6 (20.7%)
Nontraumatic	14 (83.1%)
Stroke	4 (13.8%)
Drowning	5 (17.2%)
Infectious disease	3 (10.3%)
Seizure	1 (3.4%)
Tumor	1 (3.4%)
Severity	
Mild	6 (20.7%)
Moderate	11 (37.9%)
Severe	2 (6.9%)
Not documented	10 (34.5%)

Table 4. Acute-care service receipt.

Service	% Children (*n*)	Mean length of service in days (*SD*)
Social work	55.2 (16)	21.19 (28.43)
Physical therapy	41.4 (12)	25.92 (22.33)
Speech-language therapy	37.9 (11)	31.09 (24.33)
Occupational therapy	37.9 (11)	30.64 (25.37)
Early childhood	31 (9)	33.44 (23.18)
Therapeutic recreation	31 (9)	29.56 (17.93)
Massage	27.6 (8)	33.0 (19.82)
Psychology	20.7 (6)	34.67 (21.51)

Severity was not associated with length of acute-care stay ($\tau_b = .35$, $p = .07$).

By the time of discharge, 37.9% of children had a documented referral to education or rehabilitation services. There was a weak, positive correlation between length of stay and referral to education or rehabilitation services at discharge, which was statistically significant ($\tau_b = .38$, $p = .01$). Severity was not associated with referral to education or rehabilitation services at discharge ($\tau_b = -.01$, $p = .96$). By the time of discharge, 44.8% of families were documented to have received parent education on ABI. Contrastingly, during the survey, 41.4% of caregivers recalled receiving parent education on the effects of ABI on a developing brain at any time during their child's rehabilitation, while 51.7% stated they did not recall receiving parent education, and 6.9% were unsure. Length of stay and severity were not correlated with caregiver-reported receipt of ABI education ($\tau_b = .09$, $p = .54$; $\tau_b = -.03$, $p = .90$). Of the caregivers who recalled receiving education, parent education was delivered during acute care ($n = 3$), outpatient services ($n = 3$), at discharge ($n = 1$), or in both acute and outpatient care ($n = 1$). Four parents were unsure when they received education on ABI. Caregivers reported that medical staff were the most common source of parent ABI education ($n = 4$), followed by the doctor ($n = 3$), the neurologist ($n = 3$), and the speech-language pathologist (SLP; $n = 1$). One parent was unsure which professional gave them this information.

Long-Term Experiences

At the time of the survey, the median grade of the children was fifth grade, with a range of first to eighth grade. Most caregivers rated their child's school performance positively: 44.8% excellent, 17.2% good, 31.0% okay, 3.4% bad, and 3.4% failing. Thirteen children (44.8%) were reported to be currently receiving special education services, 12 under an IEP and one under a 504 Plan. One child began receiving special education services within the 6 months prior to participating in this research. All other 12 children (41.4%) were receiving special education services long term ($M = 5.6$ years, $SD = 2.4$). Past special education receipt was most often under special education ($n = 9$), compared to early intervention ($n = 2$) or both special education and early intervention ($n = 1$).

Of the 16 children not receiving special education, caregivers reported a perceived need for special education in 37.5% of cases ($n = 6$). Caregivers qualitatively reported attention, behavior, or overall academic difficulties as the reason they believed their child might benefit from special education services. When asked why their child was not receiving special education services, reasons stated included not eligible ($n = 3$), not tested ($n = 2$), newly emerged needs ($n = 1$), or caregiver does not want their child identified ($n = 1$). Unmet need was not associated with injury severity ($\tau_b = .07$, $p = .81$), age at injury ($\tau_b = -.22$, $p = .25$), parent-reported ABI education ($\tau_b = -.03$, $p = .89$), time since injury ($\tau_b = -.24$, $p = .22$), child's current grade ($\tau_b = -.31$, $p = .13$), or child's age at the time of survey ($\tau_b = -.24$, $p = .22$).

At the time of the survey, 48.3% of children were reported to be receiving at least one therapy service, with caregivers reporting an average service receipt of two therapies. The most common current therapy was counseling (24.1%) delivered in an outpatient setting (71.4%) compared to school-based delivery. Only 17.2% of children were reported to be receiving speech-language therapy, largely delivered in the school setting (80%). When asked about past services received (i.e., at some point after hospitalization but are no longer occurring), 48.3% of children were reported to have received at least one therapy, with an average service receipt of three therapies. The most common past therapy was occupational therapy (41.4%) delivered through outpatient services (75%). Past speech-language therapy was received by 34.5% of children, also delivered primarily through outpatient services (80%). Caregivers most commonly reported that past service receipt was initiated and continued after inpatient services for 2–3 years postdischarge, for all therapy types. Additional information on the frequency and location of past and current service receipt is located in Table 5.

Various factors were explored for their association with current special education and current service receipt, as listed in Table 6. Longer length of acute-care stay, previous receipt of special education or early intervention services (i.e., between the time of injury and at least 6 months before the survey), past receipt of therapy services, and more negative current school performance were significantly correlated with current receipt of special education services. Male gender, longer length of acute-care stay, past receipt of special education or early intervention services, and past service receipt were significantly correlated with current service

Table 5. Therapy service receipt.

	Past		Current	
Therapy	**Frequency**	**Location**	**Frequency**	**Location**
Any	48.3% (14)	Outpatient	48.3% (14)	School
Speech-language	34.5% (10)	80% Outpatient	17.2% (5)	80% School
Physical	31.0% (9)	100% Outpatient	17.2% (5)	60% School
Occupational	41.4% (12)	75% Outpatient	17.2% (5)	80% School
Counseling	3.4% (1)	Outpatient	24.1% (7)	71.4% Outpatient
Other	1 Psychology; 1 deaf education			

receipt. Race, mechanism of injury, injury severity, age at injury, inpatient service receipt, referral to services at discharge, caregiver-reported receipt of education on ABI, time since injury, age at the time of survey, and current grade were not significantly associated with current special education or current service receipt.

Discussion

The findings from this research study partially support the proposed hypotheses and contribute new information to the existing literature on outcomes following early childhood ABI. Parents reported that children in this sample presented with low rates of long-term service receipt and high rates of perceived long-term unmet need, but higher than expected rates of acute service receipt immediately following their ABI. Service and educational factors (i.e., longer length of stay, past receipt of special education or early intervention, past service receipt, positive school performance) were found to be related to current service receipt. On the other hand, some factors, including injury-related factors shown in past studies to be related to long-term outcomes following ABI, were not significantly associated with service receipt in our study sample (i.e., mechanism of injury, injury severity, age at injury, inpatient service receipt, referral to services at discharge, caregiver-reported receipt of education on ABI, time since injury, age at the time of survey, current grade; Anderson et al., 2009; Prasad et al., 2017). Due to the limited number of studies investigating early childhood ABI, comparison of this study to previous literature was challenging and often included referencing studies with older children or a shorter time postinjury.

Demographics and Injury Characteristics

The demographic characteristics of this sample were consistent with broad estimates of individuals with ABI in the United States and Canada. This sample consisted of 66% male and 75.9% White ethnicity, comparable to Chan et al.'s (2016) and Faul et al.'s (2010) estimates that, of children who experience an ABI between birth and 4 years old, 55%–60% are male and 60%–75% are White. The injury characteristics were only available for one third of the sample and were more varied than previous studies, with a younger age at injury and greater time since injury.

The mechanisms of ABI recorded in this study were not consistent with the existing literature for the early childhood age group. From national estimates for TBI, falls are the most common mechanism of early childhood TBI, but

Table 6. Factors associated with long-term special education and therapy service receipt.

Factors	Current special education Kendall's τ_b (*p*)	Current therapy (any) Kendall's τ_b correlation (*p*)
Race	−.205 (.259)	−.123 (.475)
Gender	−.225 (.227)	−.527 (.003*)
Mechanism of injury	.256 (.169)	.117 (.507)
Injury severity	.337 (.138)	.334 (.115)
Age at injury	.224 (.147)	.205 (.164)
Acute services receipt	.298 (.109)	.119 (.501)
Length of stay	.342 (.027*)	.352 (.017*)
Referral to services at discharge	.173 (.339)	.140 (.415)
Past special education or early intervention	.911 (< .001*)	.492 (.005*)
Past therapy	.561 (.001*)	.263 (.112)
Time since injury	−.010 (.948)	.090 (.539)
Age at the time of the survey	.080 (.604)	.138 (.346)
Current grade	.036 (.826)	.071 (.646)
Current school performance	−.598 (< .001*)	.382 (.020*)

Note. *significant ($p < .05$)

this sample had a similar proportion of TBI caused by falls and by being struck by or against (Faul et al., 2010). For non-TBIs, the most common mechanisms of injury in our study sample (i.e., stroke, drowning, infectious disease) were more consistent with a previous study by Chan et al. (2016), indicating that meningitis and anoxia were the predominant causes of injury for young children. While finding similarities and differences with national estimates of ABI mechanism, likely, our results are impacted by our smaller sample size, making it hard to draw larger generalizations.

Acute Experiences

The acute, inpatient experiences of this sample were variable. The length of acute hospital stay for this sample, about 15 days on average, was consistent with previous literature on children with TBIs of any severity, largely skewed to adolescents and teenagers, that found average lengths of stay between 6 and 14 days (Discala et al., 1997; Howard et al., 2018; Reuter-Rice et al., 2017). Only one previous study examined exclusively early childhood TBI, finding an average length of stay of 3 days, but the study included mostly mild–complicated injuries (Haarbauer-Krupa et al., 2018). One study examined childhood non-TBI and found an average length of stay of 13.4 days (Chan et al., 2016). Surprisingly, in our sample, severity was not associated with length of stay, as found in previous studies (e.g., Howard et al., 2018; Reuter-Rice et al., 2017). This negative finding could be attributed to difficulties in severity documentation (e.g., missing data during the chart review, lack of standardized characteristics for clinical determination of severity for non-TBIs) or the skew of the sample toward moderate injury severity. Although variability in length of stay is expected due to the heterogeneity of ABIs, more consistent documentation and reporting of severity and length of stay in clinical practice and research could be helpful in exploring predictors of long-term outcomes for and services received by children who experience an ABI in early childhood.

Children with early childhood ABI in this sample were found to have higher rates of acute service receipt (65.5% receiving at least one therapy) than previous studies focusing specifically on pediatric TBI, with past estimates ranging between 2% and 55% of all children receiving a referral to or receipt of at least one therapy (Bennett et al., 2013; Ciccia et al., 2016). In a study by Bennett et al. (2013) examining therapy services for children 0–18 years old admitted to the intensive care unit with TBI, results showed that older children were more likely to receive services, compared to children injured at younger ages. The higher rates of services received while children in our sample were hospitalized could be due to the greater severity of injuries and the fact that all children had to be admitted for an overnight stay in the hospital in order to be included in our sample, as greater length of stay was associated with greater inpatient service receipt, consistent with Bennett et al. (2013). It is noteworthy, however, that less than 40% of this sample received speech-language therapy services during their hospitalization. Low rates of referral to acute speech-language services are consistent with a small body of literature (Ciccia et al., 2016; Rivara et al., 2012). Although it is possible many children did not need speech-language services during the acute hospitalization, in light of the common cognitive-communication and/or language deficits that can occur after ABI, these findings indicate that there may not be substantial improvement in recognition of the SLP's role in assisting in the assessment and treatment of acute and chronic cognitive-communication challenges following ABI. If children with ABI are not linked to services during their initial medical encounter following an ABI, they may be less likely to be connected to these services later. Due to the negative potential impact of later occurring cognitive-communication challenges on academic and social success (Haarbauer-Krupa et al., 2017), researchers and clinicians should make a concerted effort to educate other professionals about their role in caring for children with ABI and advocating for services.

The medically documented referral rate to educational or rehabilitation services at discharge for this sample (about 38%) was higher than previous studies (10%–25%; Discala et al., 1997; Morgan & Skeat, 2011), but lower than expected for the children in this sample due to the overall higher severity of injury. Based on the more severe injuries experienced by children in this sample, the positive association of length of stay with staff-reported referral rates was expected, but severity was also expected to be associated with length of stay but was not found to be significant (Howard et al., 2018; Reuter-Rice et al., 2017). The variability of length of stay across institutions, including differences in size, practices, and populations served, could impact the findings in this study and limit comparisons with other studies (Straney et al., 2010). Additional investigation is needed to clarify the relationships between length of stay, severity, and other factors with referral rates across institutions.

Parent education regarding ABI was reported by less than half of parents in this survey. Although the authors are not aware of other studies documenting rates of parent ABI education, findings from this study were surprisingly low given the injury severity, level of medical care, and rates of inpatient services received by the sample. The large gap between the injury occurrence and the interview (8.5 years on average) and parental stress during the acute-care stay could have potentially limited the accuracy of the parents' recall (Diaz-Caneja et al., 2005; Short et al., 2009). Reasons for the low rates of referral and parent education on ABI could include inconsistencies in documentation and referral practices, low provider knowledge or comfort with referral options (e.g., unsure where to refer a young child to, latent presentation of deficits following early-childhood ABI), and limited options for pathways for referral post–acute care (Haarbauer-Krupa et al., 2017; Lindsay et al., 2015; Zonfrillo et al., 2012). Future studies can help to clarify the relationship between injury/acute-care factors and referrals for services/parent education. To improve pathways of care for children who experience an ABI during early childhood and increase access to services for the long term, we must identify which children might require additional or long-term services from those who may not.

Long-Term Experiences

Several years after experiencing an ABI, the children in this sample were generally reported to be performing well in school, consistent with reports of milder samples, but unexpected for moderate–severe samples of children with TBI only (Ewing-Cobbs et al., 2006; Kingery et al., 2017; Prasad et al., 2017). Positive reports of school performance could be due to the provision of supports and services that is aiding school performance or to the younger grade levels of the children included in this sample (i.e., half were in elementary school), because deficits in higher level functions might not have emerged yet (Anderson et al., 2005; Babikian et al., 2015; Prasad et al., 2017). As children enter middle and high school, greater academic demands might lead to increased difficulties for the child and poorer academic performance (Babikian et al., 2015). The potentially changing need for supports and services could be captured in longitudinal research studies and with frequent clinical screenings and assessments. Future studies should include more qualitative reports from parents that could clarify the ratings of school performance and assist in determining the supports and services most beneficial for students' academic performance.

Rates of past and current special education or early intervention receipt (41%–45%, respectively) in our sample of children with early childhood ABI were similar to previous studies of children with TBI injured at an older age but with similar time postinjury (Kingery et al., 2017; Prasad et al., 2017). The finding of past services being primarily special education instead of early intervention is consistent with a previous study in early childhood TBI that found low rates of early intervention service utilization (Haarbauer-Krupa et al., 2018). The low referral rates to educational or rehabilitation services at discharge could contribute to the finding that few children with ABI reported receiving past special education or early intervention services. The increase in special education receipt and consistency of special education services over time was unexpected based on previous studies showing that children with TBI often receive fewer services in school the further they are from injury (Fuentes et al., 2018; Slomine et al., 2006).

The rate of perceived unmet need in this sample (about 20%) was comparable to previous studies of older with similar injury severities in more acute recovery (i.e., less than 12 months postinjury; Keenan et al., 2020; Slomine et al., 2006). When compared to Kingery et al.'s (2017) study finding 36%–50% of children with similar injury severity but injured between 3 and 7 years old, the rate of perceived unmet need in this sample was less. Larger, future studies could investigate factors such as socioeconomic status and psychosocial risk and explore additional factors that could better predict which children with ABI are most likely to have unmet needs many years past their injury. The qualitative findings that parents cited social-behavioral and cognitive-communication difficulties as a major reason for needing special education services was consistent with previous literature indicating the later presentation of these deficits (Arnett et al., 2013; Babikian et al., 2015; Keenan et al., 2020; Moore et al., 2016; Slomine et al., 2006).

Rates of long-term therapy receipt were higher than found in some previous studies that reported shorter long-term service utilization (10%–30%; Jimenez et al., 2016; Keenan et al., 2013), but consistent with Kingery et al.'s (2017) findings of about 30% of students with a history of TBI receiving at least some services long term. The delivery of past therapy services mostly in an outpatient setting while current service receipt is focused primarily in schools is similar to Haarbauer-Krupa et al.'s (2018) study on early childhood TBI, albeit with a milder sample. The pattern of service delivery setting could be attributed to poor referral pathways from hospitals to early intervention or education services, while pathways to more traditional outpatient-based rehabilitation are better established (Haarbauer-Krupa et al., 2018). Decreasing rates of service receipt over time, with the exception of counseling, were consistent with previous literature (Fuentes et al., 2018; Slomine et al., 2006). The observed increase in counseling was expected due to the increase in social-behavioral needs over time, but surprising given the underutilization of mental health services post-ABI (Arnett et al., 2013; Babikian et al., 2015; Keenan et al., 2020; Moore et al., 2016; Slomine et al., 2006). Although speech-language services could assist in meeting the cognitive-communication needs of these students as related to academic and social participation, speech-language pathology service receipt decreased over time and appears lower than actual rates of need (Cermak et al., 2019; Savage et al., 2005; Turkstra et al., 2015). Direct speech-language services would likely not be appropriate for all children enrolled in special education. In our sample, five children were currently receiving speech-language therapy and special education, but 14 children were receiving special education or had a parent-reported need for special education but were not receiving speech-language service. This is consistent with findings from Fuentes et al. (2018) that found parents reported that speech-language services are among their greatest unmet service needs. The large discrepancy within the special education group and the parent-reported unmet needs in this sample indicate that opportunities exist for SLPs to provide services that might decrease rates of unmet needs for children who experience early childhood ABI (Fuentes et al., 2018).

Generally, the factors found to be associated with long-term special education and service receipt were consistent with previous literature. Although expected to be associated with special education and service receipt, in addition to current service receipt, males are more frequently serviced in the educational settings compared to females (Hibel et al., 2010). The associations of length of stay, indicating a higher level of acute needs, with long-term special education and service receipt was consistent with previous studies (Howard et al., 2018; Reuter-Rice et al., 2017). For similar reasons, injury severity was expected to be associated with service receipt but, in our sample, was not found to have a significant association. This could be attributed to the difficulties in determining severity from the inconsistencies in chart documentation and lack of standardized characteristics for clinical determination of severity for non-TBIs. The positive association of past service receipt (early intervention, special education, or therapy) with current special education receipt was unexpected, as service receipt rates were expected to decline over time but, in our sample, may indicate persistence of needs or continuation of services over time post-ABI (Fuentes et al., 2018; Slomine et al., 2006). Educational teams should be aware of past service receipt and provide consistent follow-up to determine if past needs reemerge or if new needs present.

In this study, we found that parental ratings of poorer school performance were associated with higher service receipt rates, consistent with a previous study by Kingery et al. (2017). The consistency of these findings supports previous suggestions that experiencing an ABI during early childhood can impact academic performance long term. Furthermore, this finding reinforces that monitoring a student's performance overtime can be useful in determining whether there may be a need for additional therapy supports. Interestingly, time since injury, age at the time of survey, and current grade were not significantly associated with current service receipt. These factors could represent higher expectations as the child progresses through school, when children with ABI are faced with higher developmental expectations and may demonstrate greater academic challenges (Anderson et al., 2005; Babikian et al., 2015; Prasad et al., 2017). A larger study examining outcomes and service receipt at multiple time points (e.g., during elementary, middle school, and high school) might be more sensitive to these associations and better elucidate factors that could predict long-term service needs and receipt.

Limitations

The results of this study should be interpreted in light of several limitations. In the study design, admission to the hospital beyond the emergency department and English speaking was required for inclusion. Specifically, this large, academic, pediatric medical center includes all support services (e.g., occupational, physical, speech therapies) and has its own dedicated rehabilitation unit. Thus, findings regarding acute services received by children with ABI might not be generalizable to other pediatric settings. This study experienced low response rates (18.71%) and survey biases, based on an average response rate between 30 and 50% in similar research areas (i.e., methods and injuries/disorders), and it may be that the individuals who chose to participate in the survey had greater complaints or concerns, skewing the results (Mazor et al., 2002). Additionally, a large amount of the data was based on parent report and not matched with educational records, potentially limiting the accuracy of the results.

Due to inconsistent documentation in the medical charts, severity of the ABI was difficult to obtain, although inconsistent documentation can be a common problem when conducting chart reviews (Vassar & Holzmann, 2013; Whedon et al., 2009). The inconsistency in documentation led to a large number of the injuries being classified with severity as "nondocumented," limiting the number of participants included in these specific analyses and offering a potential reason that severity was not found to be a significant factor in the correlations. Due to a large amount of missing data points for injury severity, the correlations for this variable should be interpreted with caution. These inconsistencies in severity documentation should be considered when generalizing the results of the study.

The children included in this study spanned many grade levels, limiting our ability to determine if specific needs present at certain grades. Including a greater number of participants at each grade level could provide greater power for such analyses.

Due to the generally small size of the sample, this study could not measure the impact of all contributing factors or needs of the participants, making it difficult to directly compare to published studies and impacting the generalization of the results. Despite these limitations, in light of the very limited evidence that exists related to children who sustain ABI during early childhood, the results of the study contributes new knowledge to our understanding of long-term outcomes for children with early childhood ABI, their utilization of medical and educational services, and the role of speech-language pathology in their acute and long-term care.

Future Directions and Implications for Practice

The reported low rates of long-term service receipt, of both special education services and treatment, highlight the importance of identification and follow-up with children and their families from both health care providers and education professionals, including SLPs. SLPs can contribute to decreasing the long-term unmet needs of children with early ABI through referral to early intervention, as well as appropriate identification of and follow-up for any cognitive-communication needs in the acute and chronic phases of recovery after ABI. The unique skill set of the SLP allows for identification of early signs and symptoms of functional communication deficits following an early childhood ABI. Overall, SLPs play a critical role in the rehabilitation and educational services provided to children with early childhood ABI and should continue advocating for their role in assessing and treating these children to promote the long-term success of their clients (Lundine et al., 2019).

The results of this study inform acute and long-term medical and educational speech-language pathology assessment and treatment practices for individuals with a history of early childhood ABI. Acutely, SLPs should advocate for the importance of their specialty during the early stages of recovery post-ABI to ensure the speech, language, and cognitive-communication needs of the child are being addressed. Improving health care providers' knowledge of the scope of SLPs could increase acute and long-term referrals for speech-language services for children with ABI. Additionally, based on the SLP's specialized training and skills, they have the opportunity to educate caregivers on the long-term impacts of early childhood ABI, particularly on cognitive communication and social-behavioral skills. The development and implementation of strategies for family follow-up and education would enable caregivers to become better advocates for their children, thus decreasing unmet needs overtime and improving the chances of educational success.

Conclusions

The findings of this study extend previous research in the field of pediatric ABI, much of which has been focused on children who experience a TBI during their school-age years and provide new evidence related to rates of referral to and the receipt of rehabilitation and educational services after early childhood ABI specifically. Results support previous research findings that some percentage of children who experience an ABI before entering formal schooling present with long-term needs for services. The persistence of needs emphasizes the importance of establishing pathways to care, medically and educationally, for individuals who experience an early childhood ABI. SLPs play a critical role in the care of children with early childhood ABI due to their expertise in cognitive-communication and social-behavior realms. Upon the establishment and implementation of comprehensive pathways, including increasing the awareness of the SLP's role in ABI management with health care and educational providers and caregivers, children with ABI could experience better continuity of care and earlier intervention for any emerging needs, ultimately improving long-term educational and psychosocial outcomes.

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Appendix

Caregiver Survey Questions

Consent was obtained before researchers asked survey questions.

Can you please confirm: Did your child receive services at Nationwide Children's Hospital between March 29, 2002, and September 29, 2009, for a brain injury?

At the time of your child's brain injury, or any time thereafter, did you receive education about the potential long-term educational, emotional, behavioral, or other effects of a brain injury on a developing brain? *(yes/no)*

If yes, Who provided you this information and when?

What grade is your child currently in?

How is your child currently performing in school: excellent, good, okay, bad, failing?

Is your child currently receiving special education services at school?

Does your child currently have a 504 Plan or IEP? *If yes, for how long has (he/she) had a 504 Plan or IEP?*

Has your child received special education services, including early intervention, in the past? *If yes, when and what type (i.e., special education, early intervention, both)?*

Has your child ever had a 504 Plan, IEP, or IFSP in the past? *If yes, when?*

As a result of your child's brain injury, has your child ever received any of the following services in the past: speech-language therapy, physical therapy, occupational therapy, counseling? *If yes, was it at school or outpatient? When?*

Has your child ever received any services not mentioned previously? *If yes, what services? When were they received? How long your child received those services?*

Does your child currently receive any of the following services: speech-language therapy, physical therapy, occupational therapy, counseling? *If yes, at school or outpatient? How long have they been receiving it?*

Is your child receiving any services not mentioned previously? *If yes, what services? How long has your child been receiving those services?*

If no to currently receiving special education and other services, children who have experienced a brain injury at a young age are often not enrolled in special education or support services, although they can often qualify for them. Sometimes children who experience a brain injury have difficulties with staying organized, paying attention, remembering to complete tasks, engaging socially with peers, or with controlling their behavior. Special education and support services can help a student who experienced a brain injury learn or compensate for these types of difficulties. Do you think your child needs special education or support services? *If yes, what is challenging for your child that could be addressed with special education or support services? Can you share the reasons why your child is not receiving the services you feel might be helpful to him/her at this time?*

Thank you very much for providing this information. It helps us to better understand how children progress after a brain injury at a young age.