

Unmet Rehabilitation Needs After Hospitalization for Traumatic Brain Injury

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abstract

OBJECTIVES: In this study, we describe unmet service needs of children hospitalized for traumatic brain injury (TBI) during the first 2 years after injury and examine associations between child, family, and injury-related characteristics and unmet needs in 6 domains (physical therapy, occupational therapy, speech therapy, mental health services, educational services, and psychiatry).

METHODS: Prospective cohort study of children age 8 to 18 years old admitted to 6 hospitals with complicated mild or moderate to severe TBI. Service need was based on dysfunction identified via parent-report compared with retrospective baseline at 6, 12, and 24 months. Needs were considered unmet if the child had no therapy services in the previous 4 weeks, no psychiatry services since the previous assessment, or no educational services since injury. Analyses were used to compare met and unmet needs for each domain and time point. Generalized multinomial logit models with robust SEs were used to assess factors associated with change in need from pre-injury baseline to each study time point.

RESULTS: Unmet need varied by injury severity, time since injury, and service domain. Unmet need was highest for psychiatry, educational services, and speech therapy. Among children with service needs, increased time after TBI and complicated mild TBI were associated with a higher likelihood of unmet rather than met service needs.

CONCLUSIONS: Children hospitalized for TBI have persistent dysfunction with unmet needs across multiple domains. After initial hospitalization, children with TBI should be monitored for functional impairments to improve identification and fulfillment of service needs.



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WHAT'S KNOWN ON THIS SUBJECT: Rehabilitation services help improve functional outcomes for children with traumatic brain injury (TBI). In previous studies, authors found that many children with TBI have unmet rehabilitation needs 12 months after injury, but these studies were conducted over 10 years ago.

WHAT THIS STUDY ADDS: In this study, we show that children hospitalized for TBI have persistent unmet needs for rehabilitation and educational services in the 2 years post-TBI. Children with both complicated mild and moderate to severe TBI had unmet service needs.

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Children who sustain traumatic brain injuries (TBIs) can experience long-term impairments and disability across a variety of functional domains.^{1,2} Rehabilitation services can improve a child's functional outcomes after TBI.^{3–5} However, less than half of children hospitalized with severe TBI receive rehabilitation services during their acute care admissions.⁶ Among children with Medicaid insurance who were hospitalized with TBI, 29% received outpatient rehabilitation therapies in the first year after TBI, and only 12% received outpatient rehabilitation in the second and third years after TBI.⁷

Many children with TBI have need of, but do not receive, outpatient rehabilitation services. In previous studies, researchers have found that up to 31% of children hospitalized with TBI have unmet or unrecognized need for health care services 1 year after injury, with the level of need varying by type of service.^{8,9}–Slomine et al⁸ found that children with Medicaid insurance were more likely than children with private insurance to report unmet needs at 3 and 12 months after TBI; those with previous behavioral disorders were more likely than those without to have unmet need 3 months after injury. However, authors of the previous studies used single measures to identify dysfunction, and the use of and unmet need for educational services were not addressed. Additionally, the studies were conducted more than 10 years ago, indicating the need for additional research to determine if children continue to have unmet needs for services after TBI.

In this study, we describe the unmet service needs during the first 2 years after injury of children who were hospitalized for TBI and examine the association between child, family, and injury-related characteristics and unmet

needs in 6 specific service areas: physical therapy (PT), occupational therapy (OT), speech therapy (ST), mental health services, educational services, and psychiatry services. We hypothesized that the proportion of children with unmet needs would rise with time after injury, and the greatest unmet need would be for services addressing cognitive and communication dysfunction. We additionally hypothesized that children with Medicaid insurance would have higher levels of unmet needs than children with private insurance. By characterizing risk factors for specific unmet service needs, providers may better identify children with needs for health services, and interventions may be developed to remove barriers to service delivery and use.

METHODS

Study Population

A prospective cohort of children hospitalized with TBI between March 2013 and February 2015 was assembled from 6 hospitals in the United States: Harborview Medical Center of the University of Washington in Seattle, Washington; Nationwide Children's Hospital in Columbus, Ohio; Children's Hospital of Philadelphia in Philadelphia, Pennsylvania; Children's Hospital of Pittsburgh of the University of Pittsburgh Medical Center in Pittsburgh, Pennsylvania; Egleston Children's Hospital in Atlanta, Georgia; and Texas Children's Hospital in Houston, Texas. Postinjury interviews were conducted at 6, 12, and 24 months after injury by research staff at New York University Langone Medical Center. The institutional review board at each site approved the study procedures.

Inclusion criteria for the study were children between 8 and

18 years of age at the time of injury and admission to a study hospital for treatment of a complicated mild traumatic brain injury (cmTBI), moderate TBI, or severe TBI within 30 days of injury. Children were excluded if they did not speak English, had penetrating TBI, sustained a spinal cord injury, had previous psychiatric hospitalization, or did not survive to hospital discharge.

In this study, cmTBI was defined as a TBI in which the patient had a Glasgow Coma Scale (GCS) score of 13 to 15 on initial evaluation that returned to normal (GCS = 15) by 24 hours after injury, with the initial head computerized tomography scan revealing intracranial injury. Moderate and severe TBI were combined because of sample size and were defined as a TBI with a GCS score at 24 hours of <15 or a worst postresuscitation GCS score of <13.

Assessments

Research personnel approached the parents of eligible children during hospitalization or shortly after discharge for those with brief hospitalizations and requested parental consent and child assent. Baseline interviews with consenting families were conducted within 30 days of injury. In the baseline interview, researchers gathered information on demographic characteristics of the family, responding parent, second parent, and child's pre-injury functional status using standardized assessments. Structured interviews with parents and children were conducted via telephone or online at 6, 12, and 24 months post-TBI. Parent proxy ratings were used for this analysis. Although many measures were collected,¹⁰ those used for this analysis included the following: the Pediatric Quality of Life Inventory

TABLE 1 Measures Used to Identify Dysfunction and Service Need

Measures	Dysfunction Identified by Measure	Service Need Indicated by Dysfunction
PROMIS Physical Function Mobility short form	Mobility	PT, physiatry
PedsQL Physical Functioning (items 1–3)		
PedsQL Physical Functioning (items 4–6)	Self-care	OT, physiatry
Neuro-QoL Pediatric Applied Cognition General Concerns short form	Cognition	ST, educational services, physiatry
TBI-QoL Executive Function short form		
TBI-QoL Communication short form	Communication	
PedsQL School Functioning	Academic	Educational services, physiatry
PedsQL Emotional Functioning	Mental health	Mental health services, physiatry
PROMIS Anxiety		
PROMIS Depression		
UCLA PTSD Reaction Index		

A score of 10 points below the parent-reported retrospective baseline indicated dysfunction for all the measures except the UCLA PTSD Reaction Index; if the UCLA PTSD Reaction Index indicated PTSD, mental health dysfunction was identified. Physiatry services were needed if there was dysfunction in any domain. A service need was considered met if the child received a therapy service in the 4 weeks before the interview; physiatry needs were considered met if the child had seen a physiatrist in the time since the previous interview; educational service needs were considered met if the child received any new IEP or Section 504 plan since the study began.

4.0 (PedsQL)¹¹; Patient-Reported Outcome Measure Information System (PROMIS)¹² Physical Functioning Mobility, Depression,¹³ and Anxiety¹³ item banks; Quality of Life in Neurologic Disorders (Neuro-QoL) Pediatric Applied Cognition scale,¹⁴ Traumatic Brain Injury Quality of Life (TBI-QoL) Executive Function and Communication item banks¹⁵; the University of California, Los Angeles (UCLA), Posttraumatic Stress Disorder (PTSD) Reaction Index¹⁶; and Family Assessment Device.¹⁷ Previous analysis has been conducted to demonstrate the psychometric validity of the pediatric and parent-proxy versions of the PROMIS, Neuro-QoL, and TBI-QoL item banks in a pediatric TBI sample.¹⁰ The Assessment Center data collection platform was used for data collection.^{18,19}

At each follow-up time point, parents indicated whether their child had received any of the following services since the injury: evaluation for a new learning disability or special education, new educational services (ie, placement in special education, individualized education plan [IEP], or Section 504 plan),

rehabilitative therapies (speech-language, occupational, physical, or other) in a health care or school setting, mental health services, or specialty treatment by a physiatrist or rehabilitation medicine doctor.

Measuring Dysfunction

T-scores were used in many of the measures, such that 10 points represents a difference of 1 SD²⁰; for the standardized measures, one-third of a SD generally correlates with a clinically meaningful difference. We conservatively used a score 10 points worse than the retrospectively assessed, pre-injury baseline to define dysfunction for the following domains: mobility, self-care, cognition, communication, behavior and/or mental health, and academics. The measures, dysfunction identified by each measure, and service need indicated by an area of dysfunction are shown in Table 1.

Defining Service Need

Therapy services were defined as needed if there was dysfunction in

a given domain. PT services were needed if the child had mobility dysfunction. OT services were needed for self-care dysfunction. Cognitive or communication dysfunction indicated a need for ST services. Mental health services were needed if a child had mental health dysfunction. Children were considered to have a need for educational services if they had academic, cognitive, or communication dysfunction. A need for physiatry services was based on the presence of dysfunction in at least 1 domain. Services were not considered needed if no dysfunction was identified in that domain (Table 1).

Defining Need Categories

Service need was divided into 3 categories: no need, met need, and unmet need. A service need was considered met if the child received the therapy service in a health care setting or at school within the 4 weeks before the interview. We assumed that the receipt of therapy services at least every 4 weeks was necessary to be considered ongoing therapy services. Physiatry needs were considered met if the child had seen a physiatrist or rehabilitation medicine specialist in the time since the previous interview. If children had received any new IEPs or Section 504 plans since the study began, they were considered to have had their educational service needs met. If a child had dysfunction in a domain and did not have his or her service need met for that domain, he or she was considered to have unmet need.

Other Variables

Demographic variables included age, sex, race, ethnicity, insurance status, highest educational level achieved

by a parent, household income, and urban status of the household. Pre-existing conditions have been shown to influence health care use after TBI in previous research.⁸ For this study, preexisting conditions were classified as “brain-related” (previous TBI, learning disability, attention disorder, mental health disorder, headaches, epilepsy, or other neurologic problems) or “other” (birth defects, treatment of a chronic medical condition, hearing or visual impairment, sleep disturbance, or asthma). Previous therapy or educational service use was also recorded. Discharge disposition was dichotomized as either to home or inpatient rehabilitation.

Data Analysis

Baseline functioning and demographic variables were stratified by TBI severity. Dysfunction after injury at 6, 12, and 24 months was also stratified by TBI severity. Met and unmet needs were classified for each of the 6 service domains at each time point. Generalized multinomial logit models were used to assess the factors associated with the longitudinal change in status of need from pre-injury baseline to 6, 12, and 24 months after injury. The dependent variable in the model had 3 categories (no need, met need, and unmet need), but only unmet need versus met need is reported because we were particularly interested in the factors associated with unmet need among children who had need for services. Demographic, injury-related, and pre-injury status variables were included in the final model for each service domain if they were significantly associated with unmet need for that service domain in univariate analysis. To account for clustering by site, robust SEs were computed. Analyses were conducted separately for the 6 service domains needs.

Analyses were conducted by using SAS version 9.3 (SAS Institute, Inc, Cary, NC) data analytic software.

RESULTS

Study Population

A total of 306 eligible parent-child dyads were approached, with 170 (55%) consenting to participate in the study. Follow-up rates for the parent surveys were 78%, 76%, and 63% at 6, 12, and 24 months, respectively. Study population characteristics are shown in Table 2. There were 123 children with cmTBI and 47 with moderate to severe TBI. The sample was composed mostly of male teenagers, predominantly non-Hispanic and white and living in urban areas. Those with more severe injuries were more likely to be from households making <\$50 000 per year and to have received therapy service before TBI. Consistent with their more severe injury, children with moderate to severe TBI were more likely than those with cmTBI to receive rehabilitative services during acute care hospitalization and be discharged to inpatient rehabilitation units (Table 2).

Dysfunction After TBI

In all domains, children with more severe TBI were more likely than those with cmTBI to have parent-reported dysfunction. For children with moderate to severe TBI, the physical, cognitive, and academic domains were most affected, with over half those children having parent-reported dysfunction in each of these domains at each follow-up assessment. The academic, mental health, and cognitive domains were most affected in children with cmTBI, with parents rating over one-third of these children as having dysfunction at each time point in those domains. Among children with cmTBI, the

reported rates of academic and self-care dysfunction increased with time since injury, whereas rates of physical, communication, and behavioral and/or mental health dysfunction decreased slightly (Table 3).

Unmet Service Needs After TBI

As shown in Fig 1, the proportion of children without need for services in a given domain remained relatively stable in the 2 years after injury, with the exception of an increasing need for educational services with increased time since injury. Unmet need was highest for psychiatry and educational services. Children with moderate to severe TBI had greater levels of service need, both met and unmet, than those with cmTBI for all domains. Unmet need among children with moderate to severe TBI increased with time since injury for all service domains, with the greatest increase in unmet need for ST and educational services. This increase in unmet need over time was due to a decrease in met need and not a change in the proportion of children without needs.

Multivariate Analysis

In Table 4, we show the factors independently associated with unmet need compared with met need in each service domain after adjustment for demographic, pre-injury status, and injury-related variables. Compared with 6 months after TBI, children 12 months after TBI were more likely to have unmet needs for OT and psychiatry services, and at 24 months after TBI, they were more likely to have unmet needs for PT, ST, and psychiatry services. Older age was associated with increased unmet need for ST services compared with the youngest group of children in the study. Children with cmTBI were

TABLE 2 Sample Characteristics at Baseline

	cmTBI, <i>n</i> = 123	Moderate to Severe TBI, <i>n</i> = 47
Mean age (SD)	13.2 (3.0)	13.7 (2.7)
Age group in y, <i>n</i> (%)		
8–11	40 (33)	13 (28)
12–14	31 (25)	12 (25)
15–18	52 (42)	22 (47)
Sex, <i>n</i> (%)		
Male	88 (72)	36 (77)
Female	35 (28)	11 (23)
Race, <i>n</i> (%)		
White	98 (80)	39 (83)
African American	15 (12)	5 (11)
Asian and/or Pacific Islander	3 (2)	0 (0)
Other	7 (6)	3 (6)
Ethnicity, <i>n</i> (%)		
Hispanic	13 (11)	6 (13)
Non-Hispanic	110 (89)	41 (87)
Location of hospital, <i>n</i> (%)		
Seattle, Washington	52 (42)	29 (62)
Columbus, Ohio	16 (13)	12 (26)
Philadelphia, Pennsylvania	26 (21)	2 (4)
Houston, Texas	5 (4)	2 (4)
Pittsburgh, Pennsylvania	12 (10)	2 (4)
Atlanta, Georgia	12 (10)	0 (0)
Mechanism of injury, <i>n</i> (%)		
MV occupant	12 (10)	13 (28)
MV pedestrian or cyclist	15 (12)	14 (30)
Other vehicle	25 (21)	10 (21)
Sports	19 (16)	2 (4)
Assault	6 (5)	0 (0)
Fall	30 (25)	5 (11)
Other	13 (11)	3 (6)
Parental education, <i>n</i> (%)		
High school	34 (27)	20 (43)
College	64 (52)	22 (47)
Graduate	13 (11)	4 (8)
Unknown	12 (10)	1 (2)
Household income, <i>n</i> (%)		
<\$50 000	39 (32)	22 (47)
\$50 000–100 000	32 (26)	12 (25)
>\$100 000	35 (28)	8 (17)
Unknown	17 (14)	5 (11)
Insurance status, <i>n</i> (%)		
Medicaid	34 (28)	20 (43)
Commercial	68 (55)	22 (47)
Other government	2 (2)	2 (4)
Self-pay	8 (6)	2 (4)
Unknown	11 (9)	1 (2)
Rural or urban household, <i>n</i> (%)		
Urban	103 (85)	37 (79)
Rural	18 (15)	10 (21)
Preexisting comorbidities, <i>n</i> (%)		
None	41 (34)	18 (39)
Brain-related only	28 (23)	6 (13)
Other only	19 (15)	6 (13)
Brain and other	34 (28)	16 (35)
Received rehabilitation therapy services before injury, <i>n</i> (%)		
No	112 (93)	37 (84)
Yes	8 (7)	7 (16)
IEP and/or special education before injury, <i>n</i> (%)		
No	96 (79)	36 (78)

proportionally more likely than those with moderate to severe TBI to have unmet needs for PT, OT, mental health services, educational services, and physiatry services. Children who had preexisting brain-related health conditions before TBI were less likely to have unmet need for mental health and educational services. Household income of $\geq \$50\,000$ was associated with less unmet need for PT and physiatry services compared with lower incomes. Children discharged to inpatient rehabilitation after acute hospitalization were less likely to have unmet need for ST services.

DISCUSSION

In this longitudinal multisite cohort study of children hospitalized for TBI, those with both moderate to severe TBI and cmTBI displayed impairments across functional domains, with elevated need for health care and educational services after injury. Overall, children with moderate to severe TBI had greater levels of service need, either met or unmet, than those with cmTBI for each domain. However, over 25% of children with cmTBI had unmet service need for ST, mental health services, educational services, and physiatry services at each time point. When controlling for other variables among children with service needs, those with cmTBI were more likely to have unmet needs compared with those with moderate to severe TBI for all service domains except ST. Children with moderate to severe TBI likely have more obvious functional impairments than those with milder injuries, and thus have their need for services more readily identified and met by their health care providers.

Other child, family, and injury-related variables were independently

TABLE 2 Continued

	cmTBI, <i>n</i> = 123	Moderate to Severe TBI, <i>n</i> = 47
Yes	26 (21)	10 (22)
Services during acute hospitalization, <i>n</i> (%)		
Physiatry	30 (25)	41 (89)
OT	47 (39)	44 (96)
PT	51 (43)	45 (98)
ST	69 (58)	41 (89)
Discharge disposition, <i>n</i> (%)		
Home	117 (95)	14 (30)
Inpatient rehabilitation	6 (5)	33 (70)

Children could have received multiple services during acute hospitalization. MV, motor vehicle.

TABLE 3 Dysfunction at 6, 12, and 24 Months After TBI

	Overall 6 mo: <i>n</i> = 132 12 mo: <i>n</i> = 129 24 mo: <i>n</i> = 107	cmTBI 6 mo: <i>n</i> = 95 12 mo: <i>n</i> = 90 24 mo: <i>n</i> = 69	Moderate to Severe TBI 6 mo: <i>n</i> = 37 12 mo: <i>n</i> = 39 24 mo: <i>n</i> = 38
Physical dysfunction, mo			
6	43 (33)	21 (22)	22 (59)
12	33 (26)	12 (13)	21 (54)
24	31 (29)	9 (13)	22 (58)
Self-care dysfunction, mo			
6	20 (15)	6 (6)	14 (38)
12	25 (19)	11 (12)	14 (36)
24	25 (23)	10 (14)	15 (39)
Cognitive dysfunction, mo			
6	49 (37)	29 (31)	20 (54)
12	50 (39)	31 (34)	19 (49)
24	43 (40)	22 (32)	21 (55)
Communication dysfunction, mo			
6	30 (23)	18 (19)	12 (32)
12	27 (21)	14 (16)	13 (33)
24	22 (21)	11 (16)	11 (29)
Mental health dysfunction, mo			
6	48 (36)	31 (33)	17 (46)
12	56 (43)	34 (38)	22 (56)
24	39 (36)	21 (30)	18 (47)
Academic dysfunction, mo			
6	61 (46)	40 (42)	21 (57)
12	61 (47)	37 (41)	24 (62)
24	59 (55)	34 (49)	25 (66)

Data are presented as *n* (%).

associated with only certain service domains. Children ages 8 to 11 years old were more likely than adolescents to have their ST needs met. Children with preexisting conditions affecting the brain were more likely to have their post-TBI mental health and educational needs met than children

without preexisting conditions. Children from households with incomes of $\geq \$50\,000$ were more likely than those from lower-income households to have their PT and physiatry needs met. When controlling for all other variables, including injury severity, children

discharged to inpatient rehabilitation after hospitalization were more likely to receive ST services compared with those discharged to home.

In general, in this study, we found a higher level of unmet need after pediatric TBI than in previous studies.^{8,9} We employed a broader definition of dysfunction and a narrower definition of the types of health services that would meet the needs of a child with dysfunction in the specific domains, and these differences may explain why we found increased unmet need for domain-specific services. Authors of a previous multicenter study defined dysfunction on the basis of a PedsQL scale score that was 2 SDs from the population norm,⁸ whereas we defined dysfunction as 10 points (1 SD from the population norm) different from the child's baseline pre-injury scale score. Our definition of dysfunction was more liberal, but it allows children who have made progress but still remain below their previous baseline to be identified as having functional impairment and in need of services.

In the current study, children with moderate to severe TBI showed increases in the proportion of unmet service needs across all domains from 6 to 24 months after injury. The levels of unmet need may have risen because after a period of time, children stopped therapy services, perhaps because the health care provider or family felt the child was no longer benefitting from the services or the family found treatment too costly, as found in a previous multicenter study, in which researchers specifically investigated reasons for unmet need.⁸ In a cohort study of early childhood TBI survivors, researchers found that at an average 6.8 years after injury, 69% of children had potential educational service needs.²¹ This is similar to the findings in our study of educational service need at 24 months postinjury,

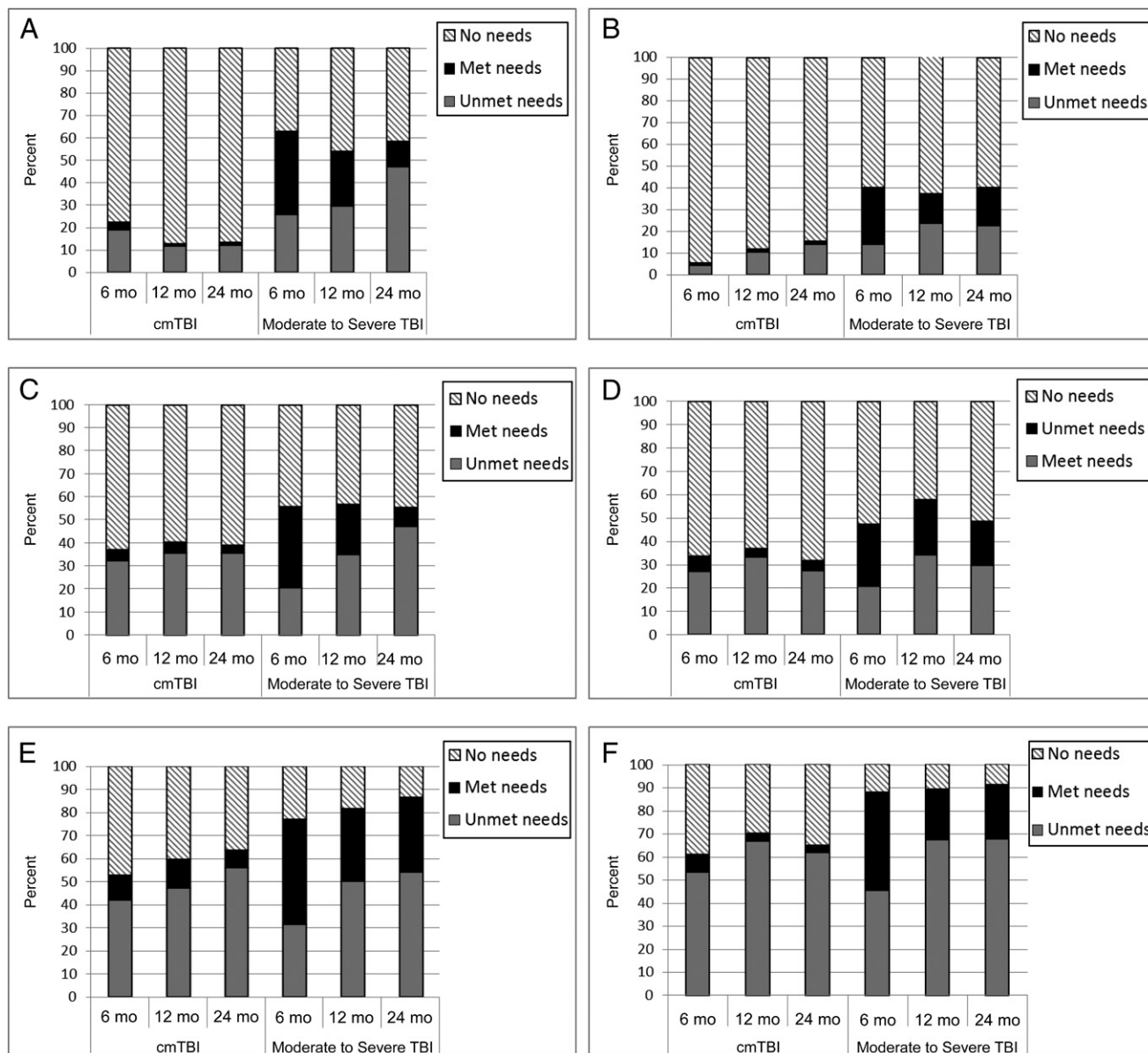


FIGURE 1

Service needs after TBI hospitalization at 6, 12, and 24 months after injury. At 6 months, cmTBI $n = 95$, and moderate to severe TBI $n = 37$. At 12 months, cmTBI $n = 90$, and moderate to severe TBI $n = 39$. At 24 months, cmTBI $n = 69$, and moderate to severe TBI $n = 3$. A, PT. B, OT. C, ST. D, Mental health services. E, Educational services. F, Physiatry.

reinforcing the requirement for ongoing monitoring of children's functional impairments and service needs years after TBI.

Several study limitations may affect the interpretation of these results. Baseline, pre-injury functional status was reported shortly after the TBI and may have been affected by recall bias,²² affecting our determination of dysfunction in this study. However,

authors of other studies similarly use a retrospective baseline,^{8,9} and by measuring the retrospective baseline before 1 month after injury, the "good old days" bias is minimized.²² Service need was determined solely by indication of dysfunction as defined by scores on a variety of parent rating scales; parents and health care providers or school personnel might determine service need differently. We did not collect

data regarding parent-reported met versus unmet need, which would allow greater understanding of the barriers to accessing and using health care services experienced by children with TBI. Receipt of care from physicians other than physiatrists was not included in this analysis, so we do not know whether the children received coordination of their rehabilitation services from their primary care provider. However,

TABLE 4 Factors Associated With Unmet Versus Met Service Need Across Domains Among Children With Dysfunction After TBI and Need for Services

Characteristics	Odds Ratio (95% CI)					
	PT	OT	ST	Mental Health Therapy	School Accommodations	Physiatry
Time after TBI, mo						
6	Ref	Ref	Ref	Ref	Ref	Ref
12	1.61 (0.55–4.73)	4.67 (1.10–19.95)*	1.87 (0.68–5.16)	1.87 (0.69–5.06)	1.52 (0.70–3.32)	2.90 (1.17–7.20)*
24	4.41 (1.25–15.59)*	3.78 (0.90–15.77)	5.33 (1.52–18.66)*	2.11 (0.71–6.26)	2.22 (0.96–5.18)	3.12 (1.20–8.11)*
Age, y						
8–11	—	Ref	Ref	—	—	—
12–14	—	8.71 (1.24–61.05)*	6.18 (1.24–30.84)*	—	—	—
15–18	—	1.22 (0.28–5.29)	3.52 (1.10–11.26)	—	—	—
Pre-existing condition						
None	—	—	—	Ref	Ref	—
Brain-related	—	—	—	0.25 (0.07–0.88)*	0.15 (0.05–0.47)*	—
Other	—	—	—	0.12 (0.03–0.46)*	0.43 (0.11–1.67)	—
Brain and other	—	—	—	1.24 (0.35–4.46)	0.19 (0.06–0.57)*	—
TBI severity						
cmTBI	Ref	Ref	—	Ref	Ref	Ref
Moderate to severe TBI	0.12 (0.04–0.39)*	0.07 (0.01–0.39)*	—	0.12 (0.04–0.32)*	0.26 (0.12–0.57)*	0.10 (0.04–0.23)*
Disposition after acute care hospitalization						
Home	—	—	Ref	—	—	—
Inpatient rehabilitation	—	—	0.06 (0.02–0.18)*	—	—	—
Previous special education services						
No	—	Ref	—	—	—	—
Yes	—	0.24 (0.06–1.01)	—	—	—	—
Household income						
<\$50 000	Ref	—	—	—	—	Ref
≥\$50 000	0.26 (0.09–0.75)*	—	—	—	—	0.21 (0.08–0.51)*
Unknown	0.37 (0.06–2.39)	—	—	—	—	0.70 (0.15–3.22)

Only variables with significant univariate relationships with unmet need compared with met need were included in the multivariate model. Other variables considered included sex, insurance, race and/or ethnicity, family function, urban or rural location, parental education, and pre-injury therapy services. CI, confidence interval; Ref, reference category; —, not applicable.

* $P < .05$.

given the TBI-specific care provided by physiatrists, we felt it important to understand how many children received physiatry services after TBI. Finally, in this study, we did not include children with limited English proficiency. In Washington state, only 26% of pediatric rehabilitation services reported providing language interpretation.²³ Children with limited English proficiency experience additional barriers to accessing appropriate services, likely resulting in a higher burden of unmet service needs. Further investigation of post-TBI service use and outcomes of children with limited English proficiency is warranted.

Children hospitalized for TBI frequently have persistent dysfunction with substantial levels of unmet need across multiple

functional domains. Among children with service needs, those with moderate to severe TBI and in the first 6 months after injury had a lower risk of unmet service needs, whereas children with cmTBI or who have had more time elapse since injury have higher levels of unmet need. Thus, all children with TBI, but especially those with cmTBI or who are in the chronic phase of recovery, should be assessed for functional impairments to determine if additional services will improve their outcomes.

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ABBREVIATIONS

cmTBI: complicated mild traumatic brain injury
GCS: Glasgow Coma Scale
IEP: individualized education plan
Neuro-QoL: Quality of Life in Neurologic Disorders
OT: occupational therapy
PedsQL: Pediatric Quality of Life Inventory 4.0
PROMIS: Patient-Reported Outcome Measure Information System
PT: physical therapy
PTSD: posttraumatic stress disorder
ST: speech therapy
TBI: traumatic brain injury
TBI-QoL: Traumatic Brain Injury Quality of Life
UCLA: University of California, Los Angeles

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REFERENCES

1. Catroppa C, Godfrey C, Rosenfeld JV, Hearn SS, Anderson VA. Functional recovery ten years after pediatric traumatic brain injury: outcomes and predictors. *J Neurotrauma*. 2012;29(16):2539–2547
2. Rivara FP, Koepsell TD, Wang J, et al. Disability 3, 12, and 24 months after traumatic brain injury among children and adolescents. *Pediatrics*. 2011;128(5). Available at: www.pediatrics.org/cgi/content/full/128/5/e1129
3. Rice SA, Blackman JA, Braun S, Linn RT, Granger CV, Wagner DP. Rehabilitation of children with traumatic brain injury: descriptive analysis of a nationwide sample using the WeeFIM. *Arch Phys Med Rehabil*. 2005;86(4):834–836
4. Kramer ME, Suskauer SJ, Christensen JR, et al. Examining acute rehabilitation outcomes for children with total functional dependence after traumatic brain injury: a pilot study. *J Head Trauma Rehabil*. 2013;28(5):361–370
5. Zonfrillo MR, Durbin DR, Winston FK, Zhao H, Stineman MG. Physical disability after injury-related inpatient rehabilitation in children. *Pediatrics*. 2013;131(1). Available at: www.pediatrics.org/cgi/content/full/131/1/e206
6. Bennett TD, Niedzwecki CM, Korgenski EK, Bratton SL. Initiation of physical, occupational, and speech therapy in children with traumatic brain injury. *Arch Phys Med Rehabil*. 2013;94(7):1268–1276
7. Jimenez N, Symons RG, Wang J, et al. Outpatient rehabilitation for Medicaid-insured children hospitalized with traumatic brain injury. *Pediatrics*. 2016;137(6):e20153500
8. Slomine BS, McCarthy ML, Ding R, et al; CHAT Study Group. Health care utilization and needs after pediatric traumatic brain injury. *Pediatrics*. 2006;117(4). Available at: www.pediatrics.org/cgi/content/full/117/4/e663
9. Greenspan AI, MacKenzie EJ. Use and need for post-acute services following paediatric head injury. *Brain Inj*. 2000;14(5):417–429
10. Bertisch H, Rivara FP, Kisala PA, et al. Psychometric evaluation of the pediatric and parent-proxy Patient-Reported Outcomes Measurement Information System and the Neurology and Traumatic Brain Injury Quality of Life measurement item banks in pediatric traumatic brain injury. *Qual Life Res*. 2017;26(7):1887–1899
11. Varni JW, Limbers CA. The pediatric quality of life inventory: measuring pediatric health-related quality of life from the perspective of children and their parents. *Pediatr Clin North Am*. 2009;56(4):843–863
12. Cella D, Riley W, Stone A, et al; PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *J Clin Epidemiol*. 2010;63(11):1179–1194
13. Irwin DE, Stucky B, Langer MM, et al. An item response analysis of the pediatric PROMIS anxiety and depressive symptoms scales. *Qual Life Res*. 2010;19(4):595–607
14. Lai JS, Nowinski C, Victorson D, et al. Quality-of-life measures in children with neurological conditions: pediatric Neuro-QOL. *Neurorehabil Neural Repair*. 2012;26(1):36–47
15. Tulskey DS, Kisala PA, Victorson D, et al. TBI-QOL: development and calibration of item banks to measure patient reported outcomes following traumatic brain injury. *J Head Trauma Rehabil*. 2016;31(1):40–51
16. Steinberg AM, Brymer MJ, Kim S, et al. Psychometric properties of the UCLA PTSD reaction index: part I. *J Trauma Stress*. 2013;26(1):1–9
17. Byles J, Byrne C, Boyle MH, Offord DR. Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Fam Process*. 1988;27(1):97–104
18. Gershon R, Rothrock NE, Hanrahan RT, Jansky LJ, Harniss M, Riley W. The development of a clinical outcomes survey research application: Assessment Center. *Qual Life Res*. 2010;19(5):677–685

19. Gershon RC, Rothrock N, Hanrahan R, Bass M, Cella D. The use of PROMIS and assessment center to deliver patient-reported outcome measures in clinical research. *J Appl Meas.* 2010;11(3):304–314
20. HealthMeasures. PROMIS. 2017. Available at: www.healthmeasures.net/score-and-interpret/interpret-scores/promis. Accessed March 28, 2017
21. Kingery KM, Narad ME, Taylor HG, Yeates KO, Stancin T, Wade SL. Do children who sustain traumatic brain injury in early childhood need and receive academic services 7 years after injury? *J Dev Behav Pediatr.* 2017;38(9):728–735
22. Brooks BL, Kadoura B, Turley B, Crawford S, Mikrogianakis A, Barlow KM. Perception of recovery after pediatric mild traumatic brain injury is influenced by the “good old days” bias: tangible implications for clinical practice and outcomes research. *Arch Clin Neuropsychol.* 2014;29(2):186–193
23. Moore M, Jimenez N, Rowhani-Rahbar A, et al. Availability of outpatient rehabilitation services for children after traumatic brain injury: differences by language and insurance status. *Am J Phys Med Rehabil.* 2016;95(3):204–213

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