

Attending Follow-up Appointments After Pediatric Traumatic Brain Injury: Caregiver-Perceived Barriers and Facilitators

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Objective: To examine barriers and facilitators for follow-up care of children with traumatic brain injury (TBI). **Setting:** Urban children's hospital. **Participants:** Caregivers of children (aged 2-18 years) discharged from an inpatient unit with a TBI diagnosis in 2014-2015. **Design:** Survey of caregivers. **Main Measures:** Caregiver-reported barriers and facilitators to follow-up appointment attendance. **Results:** The sample included 159 caregivers who completed the survey. The top 3 barriers were "no need" (38.5%), "schedule conflicts" (14.1%), and "lack of resources" (10.3%). The top 5 identified facilitators were "good hospital experience" (68.6%), "need" (37.8%), "sufficient resources" (35.8%), "well-coordinated appointments" (31.1%), and "provision of counseling and support" (27.6%). Caregivers with higher income were more likely to report "no need" as a barrier; females were less likely to do so. Nonwhite caregivers and those without private insurance were more likely to report "lack of resources" as a barrier. Females were more likely to report "good hospital experience" and "provision of counseling and support" as a facilitator. Nonwhite caregivers were more likely to report "need" but less likely to report "sufficient resources" as facilitators. **Conclusions:** Care coordination, assistance with resources, and improvements in communication and the hospital experience are ways that adherence might be enhanced. **Key words:** barriers, facilitators, follow-up, pediatric, traumatic brain injury (TBI)

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EACH YEAR in the United States, an estimated 700 000 children younger than 19 years experience a traumatic brain injury (TBI), making it the leading cause of death and disability for this age group.¹ A variety of detrimental symptoms can occur after pediatric TBI (pTBI), including headaches, attention and memory problems, sleep disturbances, personality changes, and deficits in academic and cognitive skills.²⁻⁴ While children with TBI often appear to recover quickly, they are especially vulnerable to long-term consequences that might appear as they age.⁵ Because some symptoms related to TBI are subtle, the injury itself may be "invisible" after immediate hospitalization and acute care treatment.^{6,7} While children with mild TBI sometimes report symptoms 3 months to 1 year postinjury,⁸⁻¹⁰ children with moderate to severe TBI may report symptoms many years after injury.¹¹ Evidence now suggests that TBIs, especially moderate and severe, can be chronic, continually evolving disease processes rather than acute injuries with predictable consequences.¹²⁻¹⁴ Some

children who have had a TBI with newly emerging behavioral, cognitive, and social challenges may not receive appropriate rehabilitation and support services.^{15–18} Inpatient and outpatient rehabilitation is now accepted as standard of care after TBI to improve functioning, increase independence, and prevent later developing complications.^{19–21} Delays in comprehensive rehabilitation can lead to diminished outcomes and hinder recovery.²²

Despite the presumed benefits of rehabilitation after pTBI, a critical gap exists between the services needed by survivors and their families and the receipt of these services. Previous studies have reported unmet needs in 30% to 50% of pediatric patients with TBI.^{11,16,17,23} Follow-up visits are critical to identify unmet needs and newly arising deficits so that they can be addressed. Despite the importance of follow-up visits, literature reveals that a significant proportion of children with TBI miss these recommended appointments.^{24,25}

Children must rely on their caregivers to ensure attendance at all follow-up appointments. To improve adherence, the barriers that caregivers face need to be identified. Caregiver-perceived barriers to follow-up that have been reported for non-TBI conditions include geographic distance, dislike of the clinical environment, conflicts with work schedule, lack of childcare support, transportation problems, and forgetting.^{26–29} However, no study has looked at the issue of barriers to return for follow-up care for the pTBI population. The goal of this study was to identify the barriers and facilitators for follow-up care faced by caregivers of children with TBI. Once these barriers are identified, interventions can be developed to improve adherence rates for follow-up visits. The ultimate goals of future interventions would be increased service provision and better long-term outcomes for individuals with pTBI.

METHODS

Setting

This project was conducted at a large, urban children's hospital that is also a level 1 pediatric trauma center. Its rehabilitation unit has accreditation from the Commission on Accreditation of Rehabilitation Facilities. This study was approved by the hospital's institutional review board.

Patients

Our institution's trauma registry was used to identify patients between the ages of 2 and 18 years who were discharged from an inpatient unit between January 1, 2014 and December 31, 2015, with an *International Classification of Disease, Ninth Revision, Clinical Modification* diagnosis code indicating a TBI (800.0-801.9; 803.0-804.9;

850.0-854.1; 950.1-950.3; and 959.01). Medical record reviews of the identified patients were performed, and information gathered included demographic variables, injury and hospitalization details, and follow-up appointment characteristics.

Survey creation

Two focus groups were conducted with caregivers of children with TBI who had been inpatients. One group comprised caregivers whose children had attended all scheduled follow-up visits in the year after discharge. The other group comprised caregivers whose children missed at least 1 appointment (see Table, Supplemental Digital Content 1, available at: <http://links.lww.com/JHTR/A261>, for composition). Participants suggested potential factors that served as facilitators and barriers to follow-up adherence (see Document, Supplemental Content 2, available at: <http://links.lww.com/JHTR/A262>, for a complete list). On the basis of the ideas generated during focus groups, a survey (see Survey, Supplemental Digital Content 3, available at: <http://links.lww.com/JHTR/A263>) was designed to examine caregiver-perceived barriers and facilitators to return for follow-up care. To test caregiver interpretation of the questionnaire, cognitive interviews using a verbal probing approach were conducted with 2 parents of children with TBI who were currently admitted to our pediatric rehabilitation unit.³⁰ The final survey collected demographic information and information on caregivers' experiences in relation to follow-up attendance.

Survey participation (January 2017-July 2017)

Four hundred twenty-three children with TBI were identified as potential participants, and invitation letters were mailed to 394 families that were included in the study based on inclusion/exclusion criteria (see Figure 1). After 19 families opted out, surveys were mailed to the remaining 375 automatically enrolled families. To increase the response rate, 3 rounds of phone calls were made to nonresponders, offering the options of having the survey remailed or completing it over the phone. Eighty families were unreachable (see Figure 1).

Statistical analysis

All data analyses were performed using SAS Enterprise, version 7.1 (SAS Institute, Cary, North Carolina). Trauma registry, medical record review, and survey data were merged by medical record number. Characteristics of children with TBI whose caregivers completed the survey were compared with those whose caregivers did not. To adjust for survey nonresponse, poststratification weights, using insurance status, were applied

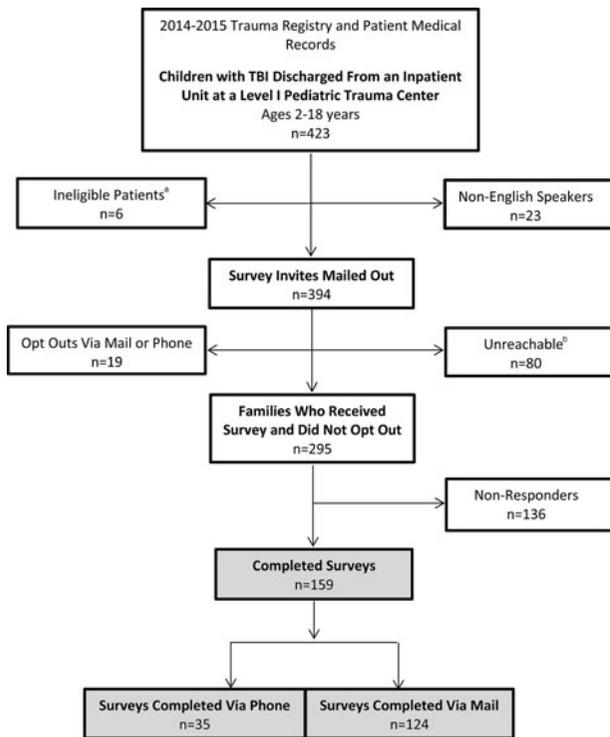


Figure 1. Patient enrollment flowchart. ^aIneligible patients: Care outside of the study period, ED visit only, deceased, misclassified TBI diagnosis, or preexisting brain condition (genetic). ^bUnreachable: Wrong/invalid addresses, wrong/invalid phone numbers, hang up after listening on phone, or state's custody. ED indicates emergency department; TBI, traumatic brain injury.

to all further analyses, as it was the only characteristic by which participating caregivers differed (see Table 1). Weighted results are a means of representing all caregivers invited to participate in our survey and not just the survey respondents. Other notable differences across the categories of race and some of the measures of severity (Injury Severity Score, number of injuries, and length of stay) were suggestive of true differences but were not statistically significant. Descriptive statistics were generated to characterize the caregivers who completed the surveys. The most frequently identified barriers and facilitators ($\geq 15\%$ reported) were used for further analysis. Logistic regression models were used to identify predictors of reporting the top 3 barriers and the 5 facilitators. In each logistic regression model, the outcome variable was whether or not the caregiver had reported that barrier or facilitator. Since insurance, education level, and household income were all highly correlated, each of these indicators was evaluated in separate models. Head Abbreviated Injury Scale score was added as a covariate in models examining caregiver-reported "need" and "no need" for follow-up care. Odds ratios, 95% confidence intervals, and P values for each variable were calculated, and the significance level was set as $P < .05$.

RESULTS

One hundred fifty-nine families of children with TBI completed the survey and 136 did not respond, 19 opted out, and 80 were unreachable (see Figure 1), resulting in a response rate of 40.4%. The children of caregivers who completed the survey were very similar in characteristics to those who did not complete it (see Table 1), with the exception that those who did not were more likely to be uninsured or covered by Medicaid ($P < .0001$).

Table 2 shows the sample and weighted statistics of caregiver characteristics. Insurance status was used to weight our analysis because respondents and nonrespondents differed significantly on this variable. Weighted results are a means of representing all caregivers invited to participate in our survey and not just the survey respondents. Weighted information is reported here. The mean age of caregivers was 40.3 years. The majority of respondents were female (90.6%), white (82.5%), did not have a bachelor's degree or higher (80.8%), had 2 or more children (92.3%), and had help with childcare (75.9%). About 52% of caregivers reported that their household income in the past year was less than \$50 000. Most caregivers reported that their child did not have chronic health problems (73.1%) and did not see doctors outside our institution's network (86.5%) for TBI-related symptoms after discharge. Most caregivers believed that every child with TBI should have follow-up visits even when symptoms are absent (76.6%).

Caregiver-perceived barriers and facilitators are listed by frequency in Table 3. The top 3 reported barriers were "no need" (38.5%), "schedule conflicts" (14.1%), and "lack of resources" (10.3%). About 15% of caregivers reported that they never missed appointments. The top 5 reported facilitators were "good hospital experience" (68.6%), "need" (37.8%), "sufficient resources" (35.8%), "well-coordinated appointments" (31.1%), and "provision of counseling and support" (27.6%). We stratified the rankings of barriers and facilitators by follow-up appointment adherence. Compared with caregivers who had never missed a visit, those who missed 1 or more visits were more likely ($P < .05$) to report "no need," "lack of resources," and "bad scheduling system" as barriers but were less likely to report "sufficient resources" as a facilitator.

Barriers

Tables 4 to 6 show caregiver characteristics associated with reporting the top 3 barriers. Female caregivers were less likely to report "no need" as a barrier (see Table 4). Caregivers with annual household income between \$50 000 and \$99 999 were more likely to report "no need" than those who earned less than \$50 000 (adjusted odds ratio [AOR] = 2.8; 95% confidence interval [CI], 1.4-5.9). The barrier "schedule conflicts" was not

TABLE 1 Comparison of patients whose caregivers completed the survey and those who did not

Patient characteristics	Survey participation						P
	No		Yes		Total		
	n	Row %	n	Row %	N	Row %	
Total	235	59.6	159	40.4	394	100.0	
Sex							.95
Male	153	59.5	104	40.5	257	65.2	
Female	82	59.8	55	40.1	137	34.8	
Age, y							.37
2-4	51	64.6	28	35.4	79	20.1	
5-7	35	58.3	25	41.7	60	15.2	
8-10	70	63.6	40	36.4	110	27.9	
13-18	79	54.5	66	45.5	145	36.8	
Race							.46
White	190	58.6	134	41.4	324	82.2	
Black	34	66.7	17	33.3	51	12.9	
Hispanic	4	80.0	1	20.0	5	1.3	
Others	7	50.0	7	50.0	14	3.6	
Insurance							<.0001
Commercial insurance	79	47.3	88	52.7	167	42.4	
Medicaid	110	66.3	56	33.7	166	42.1	
No insurance	46	75.4	15	24.6	61	15.5	
Glasgow Coma Scale ^a							.92
Severe (3-8)	31	62.0	19	38.0	50	12.7	
Moderate (9-12)	13	61.9	8	38.1	21	5.3	
Mild (13-15)	188	59.3	129	40.7	317	80.5	
Injury Severity Score							.39
Minor (0-15)	176	58.5	125	41.5	301	76.4	
Major (16-75)	59	63.4	34	36.6	93	23.6	
Head AIS ^a							.98
Mild/moderate (1-2)	128	59.8	86	40.2	214	54.3	
Severe (3-4)	95	60.5	62	39.5	157	39.8	
Critical (5-6)	10	58.8	7	41.2	17	4.3	
Chronic condition							.17
Without chronic condition	155	62.2	94	37.8	249	63.2	
With chronic conditions	80	55.2	65	44.8	145	36.8	
Multiple injury							.34
Single injury	29	53.7	25	46.3	54	13.7	
Multiple injuries	206	60.6	134	39.4	340	86.3	
Length of stay, d							.22
0-1	122	63.9	69	36.1	191	48.5	
2-3	63	57.3	47	42.7	110	27.9	
4+	50	53.8	43	46.2	93	23.6	
Cause of injury							.83
Motor vehicle collision/motorcycle	93	58.5	66	41.5	159	40.4	
Fall	60	58.8	42	41.2	102	25.9	
Bike/sports	40	60.6	26	39.4	66	16.8	
Pedestrian	19	70.4	8	29.6	27	6.9	
Other causes of injury ^b	23	85.2	17	42.5	40	10.2	

Values in bold are significant at $P < .05$.

^aMissing less than 2%.

^bOther causes of injury: animal, assault, gunshot, hit by, pedestrian, sports, etc.

TABLE 2 Characteristics of caregivers who completed the survey

	Sample <i>n</i>	Weighted	
		<i>N</i>	Column %
Total	159	394	100.0
What is your relationship with the patient? ^a			
Parent	154	383	97.2
Grandparent	2	6	1.5
Family relative	1	3	0.8
Self	1	2	0.5
Sex ^a			
Male	15	37	9.4
Female	143	357	90.6
Age, mean (SE)	40.7 (0.65)	40.3 (0.54)	
Race			
Nonwhite	25	69	17.5
White	134	325	82.5
Insurance			
Commercial insurance	88	167	42.4
Medicaid	56	166	42.1
Self-pay	15	61	15.5
Education level ^a			
High school graduate or less	47	127	32.2
Some college or associate's degree	74	192	48.6
Bachelor's degree or above	36	75	19.2
Household income in the past year ^a			
<\$50 000	70	204	51.7
\$50 000-\$99 999	48	109	27.8
≥\$100 000	35	81	20.6
Does your child (patient) have chronic health problems (eg, asthma, ADHD)?			
Yes	45	106	26.9
No	114	288	73.1
After discharge from our hospital, does your child see doctors for brain injury symptoms at hospitals or clinics other than our hospital?			
Yes	22	53	13.5
No	135	341	86.5
How many children do you have? ^a			
1	13	30	7.7
≥2	145	364	92.3
Do you have someone help take care of other children when you take the patient to appointments? ^a			
Yes	110	299	75.9
No	34	92	23.3
N/A	15	3	0.8
Do you think follow-up visits are important for children with TBIs? ^a			
Yes, every child with TBI should have follow-up visits, even when they have no symptoms.	121	302	76.6
Follow-up visits are needed only for those who have TBI symptoms (eg, sleep problems, memory loss)	31	78	19.9
No, not needed at all.	5	14	3.5

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; TBI, traumatic brain injury.

^aMissing less than 0.1%—Not all caregivers answered all questions.

TABLE 3 Caregiver-perceived barriers and facilitators to return for follow-up care after pediatric TBI^a

	Total			Missed appointments			Never missed appointments		
	Sample n	Weighted		Sample n	Weighted		Sample n	Weighted	
		N	%		N	%		N	%
Total surveyed	159	394	100.0	61	162	100.0	98	232	100.0
Barriers									
No need (eg, my child is doing well)	63	152	38.5	31	81	50.2	32	70	.04
Schedule conflicts (eg, I had to work or finish other tasks)	22	56	14.1	12	30	18.7	10	25	.052
Lack of resources (eg, no insurance, no transportation, no childcare support)	14	41	10.3	11	33	20.2	3	8	.001
Bad appointment scheduling system (eg, no reminders, multiple appointments are scheduled on different weekdays)	11	29	7.5	7	19	11.5	4	11	.03
I forgot about the appointment	9	24	6.0	6	18	11.0	3	6	.077
Long drive distance	6	15	3.7	2	5	3.0	4	10	.507
Lack of counseling and support services (eg, no services to help relieve parental stress)	4	11	2.7	1	3	1.8	3	8	.707
Bad weather	2	8	2.1	1	4	2.5	1	4	.625
Bad hospital experience (eg, long waiting time)	0	0	0.0	0	0	0.0	0	0	...
None, never missed appointments	24	58	14.8	3	7	4.2	21	52	.016
Facilitators									
Good hospital experience	108	270	68.6	36	98	60.7	72	172	.151
Need	61	149	37.8	24	59	36.7	37	90	.977
Sufficient resources	58	141	35.8	14	34	21.0	44	107	.006
Well-coordinated appointments	51	122	31.1	17	41	25.2	34	82	.411
Provision of counseling and support	46	109	27.6	12	29	18.0	34	80	.112
Parental responsibility	19	49	12.4	8	24	14.7	11	25	.889
Appointment scheduled at discharge	9	18	4.6	4	8	4.7	5	11	.819

Values in bold are significant at $P < .05$.

Abbreviation: TBI, traumatic brain injury.

^aCaregivers could choose as many barriers and facilitators as they felt applied.

TABLE 4 Caregiver characteristics associated with reporting of “no need (Y/N)” as a barrier

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.0	(0.9-1.0)	.130	1.0	(0.9-1.0)	.155	1.0	(0.9-1.0)	.227
Sex									
Male (ref)									
Female	0.2	(0.1-0.5)	.001	0.2	(0.1-0.5)	.001	0.2	(0.1-0.5)	.001
Race									
White (ref)									
Nonwhite	1.2	(0.5-2.5)	.690	1.0	(0.5-2.1)	.910	1.5	(0.6-3.3)	.364
Child head AIS									
Mild/moderate (1-2) (ref)									
Severe (3-4)	0.8	(0.5-1.5)	.518	0.9	(0.5-1.5)	.624	0.9	(0.5-1.7)	.796
Critical (5-6)	0.4	(0.1-1.4)	.143	0.4	(0.1-1.2)	.099	0.2	(0.0-1.3)	.094
Insurance									
Commercial insurance (ref)									
Medicaid	0.6	(0.3-1.3)	.204						
Self-pay	0.7	(0.3-1.8)	.437						
Education level									
High school graduate or less (ref)									
Some college or associate's degree				0.8	(0.4-1.5)	.467			
Bachelor's degree or above				1.7	(0.8-3.6)	.201			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							2.8	(1.4-5.9)	.005
≥\$100 000							2.0	(0.9-4.5)	.107

Abbreviations: AIS, Abbreviated Injury Scale; AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and *P*-values are shown in bold text.

associated with any of the variables in the logistic models (see Table 5). Nonwhite caregivers were more likely to report “lack of resources” (see Table 6). Caregivers of patients without insurance were also more likely to report “lack of resources” (AOR = 4.91; 95% CI, 1.05-22.91), as were caregivers of patients with Medicaid (AOR = 3.29; 95% CI, 1.13-9.55). Caregivers with some college education were less likely to report “lack of resources” than those with high school education or below (AOR = 0.27; 95% CI, 0.10-0.74).

Facilitators

Tables 7 to 11 show caregiver characteristics associated with reporting the top 5 facilitators. Female caregivers were more likely to report “good hospital experience” as a facilitator (see Table 7). Caregivers with annual household income \$100 000 or above also were more likely to report “good hospital experience” than those who earned less than \$50 000 (AOR = 2.30; 95% CI, 1.08-4.92). Nonwhite caregivers were more likely to report “need” in all 3 models (see Table 8) but less likely to report “sufficient resources” (see Table 9). Females were more likely to report “sufficient resources” (model

1 AOR = 3.12; 95% CI, 1.09-8.88; model 2 AOR = 2.89; 95% CI, 1.03-8.05). Caregivers with some college education (AOR = 2.03; 95% CI, 1.03-4.03) or a bachelor's degree or above (AOR = 2.35; 95% CI, 1.01-5.49) were more likely to report “sufficient resources” than those with a high school education. Caregivers with a household income level between \$50 000 and \$99 999 were also more likely to report “sufficient resources” (AOR = 1.97; 95% CI, 1.00-3.88). Caregivers with a bachelor's degree or above were less likely to report “well-coordinated appointments” (AOR = 0.4; 95% CI, 0.2-1.0), whereas those who had an annual income of \$50 000 to \$99 999 were more likely to do so (AOR = 2.2; 95% CI, 1.1-4.3) (see Table 10). Females were more likely to report “provision of counseling and support” (see Table 11). Caregivers with some college or an associate's degree were less likely than those who had a high school education to report “provision of counseling and support” (AOR = 0.4; 95% CI, 0.2-0.8).

DISCUSSION

In this study, the most common caregiver-reported barrier to return for pTBI follow-up appointments was

TABLE 5 Caregiver characteristics associated with reporting “schedule conflicts (Y/N)” as a barrier

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.0	(0.95-1.04)	.8	1.0	(0.94-1.04)	.7	1.0	(0.94-1.05)	.8
Sex									
Male (ref)									
Female	1.9	(0.43-8.46)	.4	1.9	(0.39-9.49)	.4	1.6	(0.32-8.18)	.6
Race									
White (ref)									
Nonwhite	1.1	(0.37-3.13)	.9	1.1	(0.45-2.82)	.8	1.5	(0.48-4.49)	.5
Insurance									
Commercial insurance (ref)									
Medicaid	1.4	(0.60-3.45)	.4						
Self-pay	1.2	(0.34-3.95)	.8						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				0.6	(0.28-1.45)	.3			
Bachelor’s degree or above				0.7	(0.28-1.81)	.5			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							1.00	(0.37-2.71)	1.0
≥\$100 000							1.5	(0.47-4.60)	.5

Abbreviation: AOR, adjusted odds ratio.

TABLE 6 Caregiver characteristics associated with reporting of “lack of resources (Y/N)” as a barrier

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.00	(0.94-1.05)	.89	0.99	(0.93-1.05)	.77	0.99	(0.93-1.06)	.80
Sex									
Male (ref)									
Female	1.44	(0.20-10.23)	.71	1.53	(0.20-11.83)	.68	1.13	(0.17-7.46)	.90
Race									
White (ref)									
Nonwhite	4.10	(1.40-12.02)	.01	3.70	(1.50-9.12)	.01	3.58	(1.21-10.56)	.02
Insurance									
Commercial insurance (ref)									
Medicaid	3.29	(1.13-9.55)	.03						
Self-pay	4.91	(1.05-22.91)	.04						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				0.27	(0.10-0.74)	.01			
Bachelor’s degree or above				0.30	(0.06-1.56)	.15			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							0.48	(0.12-1.90)	.29
≥\$100 000							0.31	(0.05-1.84)	.19

Abbreviation: AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and P-values are shown in bold text.

TABLE 7 Caregiver characteristics associated with reporting “good hospital experience (Y/N)” as a facilitator

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	0.99	(0.96-1.02)	.55	0.99	(0.96-1.02)	.54	0.98	(0.95-1.02)	.27
Sex									
Male (ref)									
Female	2.87	(1.12-7.32)	.03	2.85	(1.19-6.84)	.02	3.52	(1.43-8.68)	.01
Race									
White (ref)									
Nonwhite	1.10	(0.48-2.50)	.82	1.03	(0.46-2.32)	.94	0.96	(0.43-2.16)	.93
Insurance									
Commercial insurance (ref)									
Medicaid	0.85	(0.46-1.57)	.61						
Self-pay	1.84	(0.67-5.05)	.24						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				1.72	(0.91-3.27)	.10			
Bachelor’s degree or above				1.55	(0.73-3.29)	.25			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							1.52	(0.78-2.98)	.22
≥\$100 000							2.30	(1.08-4.92)	.03

Abbreviation: AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and *P*-values are shown in bold text.

“no need.” Caregivers may not be fully aware of the symptoms to watch for or of the importance of follow-up care after hospital discharge. In one study, parents of children with TBI reported confusion about the language that physicians used to define a TBI, and the study recommended that physicians use more understandable language and verify parental understanding of the provided information.³¹ Timing of physician-parent communication may also affect parents’ understanding of TBI. Because parents are often under tremendous stress during their child’s hospitalization, it is difficult for them to process information given about their child’s condition, symptoms to watch for after discharge, or the value of follow-up care. Finally, the method used in providing education to families might also contribute to the breakdown in communication. In studies conducted on recall of discharge instructions after their child’s concussion, parents were unable to recognize symptoms 2 to 5 days later and had the most difficulty recalling the often more “invisible” cognitive, sleep, or emotional symptoms.^{32,33} Offering education at a later, less stressful time and using additional, more innovative methods such as verbal reinforcement, illustrations, video instructions, and checklists may improve parental recall of TBI symptoms.^{32,33} The “invisible” nature and delayed development of many TBI symptoms indicate that caregiver education about TBI is critical.^{5,7} If care-

giver education about pTBI is provided using understandable language, multiple education sessions, and a variety of communication methods, caregivers may be more adept at recognizing the need for follow-up care upon their return to the home environment and into the future.

Among caregivers in this study, women were significantly less likely to report “no need” as a barrier. Following pTBI, mothers and fathers have been found to have different coping strategies.³⁴ Mothers were more likely to use strategies that involve acceptance, whereas fathers use strategies that involve denial. This supports our findings that the fathers were more likely to report “no need,” perhaps in denial of the true needs of their children. However, our number of male respondents was small, so further work should be done to explore the role of maternal versus paternal influence on the recognition of need for follow-up care after pTBI. Caregivers with an annual income between \$50 000 and \$100 000 a year were also more likely to report “no need” as a barrier. The possible social factors influencing this barrier in pTBI patients and their families in this income bracket need to be further explored.

The second most common barrier to follow-up attendance reported by caregivers in this study was “schedule conflicts.” This finding is consistent with past studies examining follow-up care in other pediatric specialty

TABLE 3 Caregiver characteristics associated with reporting “need (Y/N)” as a facilitator

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.0	(0.9-1.0)	.359	1.0	(1.0-1.0)	.433	1.0	(1.0-1.0)	.523
Sex									
Male (ref)									
Female	2.5	(0.9-7.0)	.094	2.4	(0.9-6.6)	.084	1.9	(0.7-5.2)	.234
Race									
White (ref)									
Nonwhite	2.3	(1.0-5.2)	.046	2.2	(1.0-4.8)	.047	3.0	(1.3-6.8)	.011
Child head AIS									
Mild/moderate (1-2) (ref)									
Severe (3-4)	0.7	(0.4-1.2)	.184	0.6	(0.4-1.1)	.137	0.8	(0.4-1.4)	.400
Critical (5-6)	1.0	(0.2-4.8)	.964	0.9	(0.2-4.0)	.887	1.2	(0.2-6.4)	.816
Insurance									
Commercial insurance (ref)									
Medicaid	0.7	(0.4-1.4)	.352						
Self-pay	0.6	(0.2-1.6)	.325						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				1.3	(0.7-2.4)	.453			
Bachelor’s degree or above				1.0	(0.5-2.1)	.985			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							2.0	(1.0-4.0)	.054
≥\$100 000							0.7	(0.3-1.6)	.460

Abbreviations: AIS, Abbreviated Injury Scale; AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and *P*-values are shown in bold text.

areas.^{28,35-37} In one study, following admission to a pediatric intensive care unit, patients were 5.8 times more likely to be noncompliant for each additional appointment they had scheduled.³⁷ Thus, the number of follow-up appointments a family is asked to attend may result in scheduling conflicts and increase the rates of missed appointments. Scheduling multiple appointments on the same day might decrease the scheduling burden placed on caregivers. In addition, having appointments available during evening and weekend hours, as suggested by our parent focus groups, may help eliminate work schedule conflicts. “Schedule conflicts” as a barrier was not associated with any of the evaluated caregiver characteristics. This could be because it is a barrier that is equally faced by all groups or the group sizes were too small to find a difference. Flexibility and thoughtful planning and scheduling of appointments may help lessen the barrier of “schedule conflicts.”

“Lack of resources” was the third most commonly reported barrier to follow-up care. Transportation, job, insurance issues, and childcare problems have all been noted barriers in studies of appointment adherence for other pediatric conditions.^{28,36,38} After emergency department visits, follow-up compliance to aftercare (physician follow-up appointment and/or the use of prescribed medication) was found to exist along a socioe-

conomic continuum: those who had the most financial resources had the best attendance at follow-up appointments and correct use of medication.³⁹ Similarly, in a previous study at our institution, TBI inpatients were found to have higher odds of attending all scheduled follow-up appointments when the patient had private insurance versus Medicare or Medicaid.²⁵ In our current study, both nonwhite participants and those without commercial insurance were significantly more likely to report “lack of resources” as a barrier. Previous studies have shown that socioeconomic status (SES) and health disparities exist on a gradient—whether this is measured by income, education, or insurance type—in that resources increase as SES increases and hardships increase as SES decreases.⁴⁰ Identifying families in need and connecting them to support agencies might help alleviate some of these concerns. Supporting families who have limited resources is necessary to ensure accessibility and equity in care and may promote better outcomes following pediatric TBI.

The most frequently reported facilitator in our study was having a “good hospital experience.” Female caregivers were more likely to report a good hospital experience as a facilitator, as were those with an annual income above \$100 000. These results are consistent with previous findings that both gender and income contribute to

TABLE 9 Caregiver characteristics associated with reporting “sufficient resources (Y/N)” as a facilitator

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	0.97	(0.94-1.01)	.11	0.97	(0.93-1.00)	.08	0.97	(0.94-1.01)	.13
Sex									
Male (ref)									
Female	3.12	(1.09-8.88)	.03	2.89	(1.03-8.05)	.04	2.89	(0.95-8.79)	.06
Race									
White (ref)									
Nonwhite	0.14	(0.05-0.43)	.00	0.16	(0.06-0.45)	.00	0.17	(0.06-0.50)	.00
Insurance									
Commercial insurance (ref)									
Medicaid	0.90	(0.46-1.76)	.76						
Self-pay	0.85	(0.36-2.03)	.72						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				2.03	(1.03-4.03)	.04			
Bachelor’s degree or above				2.35	(1.01-5.49)	.05			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							1.97	(1.00-3.88)	.05
≥\$100 000							1.11	(0.50-2.46)	.80

Abbreviation: AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and P-values are shown in bold text.

TABLE 10 Caregiver characteristics associated with reporting “well-coordinated appointments (Y/N)” as a facilitator

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.0	(1.0-1.1)	.235	1.0	(1.0-1.1)	.153	1.0	(1.0-1.1)	.191
Sex									
Male (ref)									
Female	1.3	(0.5-3.3)	.569	1.3	(0.5-3.6)	.572	1.1	(0.4-2.8)	.908
Race									
White (ref)									
Nonwhite	0.7	(0.3-1.6)	.366	0.7	(0.3-1.6)	.451	1.1	(0.5-2.7)	.761
Insurance									
Commercial insurance (ref)									
Medicaid	1.1	(0.6-2.2)	.688						
Self-pay	0.5	(0.2-1.4)	.166						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				0.9	(0.5-1.7)	.836			
Bachelor’s degree or above				0.4	(0.2-1.0)	.042			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							2.2	(1.1-4.3)	.030
≥\$100 000							1.2	(0.5-2.6)	.728

Abbreviation: AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and P-values are shown in bold text.

TABLE 11 Caregiver characteristics associated with reporting “provision of counseling and support (Y/N)” as a facilitator

Caregiver characteristics	Model 1			Model 2			Model 3		
	AOR	95% CI	P	AOR	95% CI	P	AOR	95% CI	P
Age	1.0	(1.0-1.0)	.934	1.0	(1.0-1.0)	.843	1.0	(1.0-1.0)	.696
Sex									
Male (ref)									
Female	8.4	(1.7-42.3)	.010	8.9	(1.7-46.6)	.010	7.5	(1.3-43.0)	.024
Race									
White (ref)									
Nonwhite	1.0	(0.4-2.5)	.934	0.8	(0.4-1.8)	.674	1.0	(0.4-2.3)	.996
Insurance									
Commercial insurance (ref)									
Medicaid	0.7	(0.3-1.4)	.302						
Self-pay	0.5	(0.2-1.4)	.171						
Education level									
High school graduate or less (ref)									
Some college or associate’s degree				0.4	(0.2-0.8)	.009			
Bachelor’s degree or above				0.9	(0.4-1.9)	.709			
Household income level									
<\$50 000 (ref)									
\$50 000-\$99 999							1.3	(0.6-2.6)	.517
≥\$100 000							0.6	(0.2-1.4)	.235

Abbreviation: AOR, adjusted odds ratio.

Statistically significant odds ratios and the associated 95% CIs and *P*-values are shown in bold text.

patient satisfaction.^{41,42} Another reported facilitator related to patient satisfaction was “provision of counseling and support.” Females were more likely to report “provision of counseling and support” as a facilitator. This is supported by the fact that that in previous studies, mothers of children with head injuries benefitted more from the provision of information, the ability to talk about their experience, and social support during their child’s hospital stay than did fathers.^{43,44} Those with some college or an associate’s degree were less likely to report “provision of counseling and support” as a facilitator, suggesting that they had the best level of access to social support and counseling services from elsewhere. This U-shaped distribution of support has been found in a previous study looking at education level that suggested lower educated families had less effective social networks and barriers to professional support whereas higher educated families had less accessible networks of informal support and had to rely more on formal childcare due to full-time employment.⁴⁵ Addressing caregiver satisfaction, specifically by targeting counseling and support offered to different genders and education levels, might improve follow-up adherence after pTBI.

The remaining facilitators can be studied together to highlight areas in which future studies might attempt to improve follow-up attendance. “Need,” the second most commonly reported facilitator, could be assumed

to be related to the physical condition of the child, but it was not associated with the severity of the TBI. “Need” was, however, associated with the race of the caregiver. Nonwhite caregivers were more likely to report “need” as a facilitator than white caregivers. A previous study has shown that minority races have different expectations of healthcare, which may also alter their interpretation of “need.”⁴⁶ In addition, nonwhite caregivers were less likely to report “sufficient resources” as a facilitator. The association between race, availability of resources, and awareness of need warrants further research. Caregivers with higher income and education levels were generally more likely to report the facilitator “sufficient resources.” Those with higher income were also more likely to report “well-coordinated appointments” as a facilitator, whereas those with higher education were less likely to do so. This suggests that the desire for or the type of flexible appointments might differ on the basis of family income and education levels.

Together, the barriers and facilitators identified in this study point to the need for better care coordination to help manage the long-term follow-up needs of children with TBI. Care coordination involves the patients and families, the care team and providers, and the healthcare system working together to ensure patients receive the services they need.⁴⁷ Studies have suggested the need for, and shown the benefits of, care

coordination in pediatric populations with other chronic healthcare needs.^{48–50} Care coordination's role in improving parent/patient education, provider-parent communication, and parent/patient satisfaction, which were all identified in this study as influencing follow-up attendance, has been highlighted in previous studies.^{51–53} Specifically, there is evidence that care coordination improved parent-reported perception of knowledge, access to services, patient-provider trust, and communication in families who have children with asthma.⁵² Hospitals could assign care coordinators to help families navigate their child's TBI care from hospital arrival to postdischarge follow-up to help eliminate many of the barriers identified in this study.

Limitations

This study has several limitations. One limitation is potential selection bias, a problem that cannot be overcome in a survey study. Our 40.4% response rate is similar to rates of other studies,^{3,54} and we have acknowledged that responders were more likely to have commercial insurance, often an indication of higher SES. This responder bias is consistent with previous studies that show participation in research is influenced by social and economic factors.^{55,56} The participants in our study were more likely to have had better adherence to follow-up, another difficult to overcome survey bias. Because of these limitations, unique barriers that affect lower SES families and those who do not attend follow-up appointments may not have been elucidated. In addition, because only 15 male caregivers completed

our survey, our findings may be influenced by gender. Nonwhite participants were a small proportion of our respondents, making this less generalizable to more diverse settings. Additional misclassified data leading to bias in our results might also come from lack of accuracy in responses, intentional misreporting, or other respondent biases or behaviors not accounted for that are common in survey studies.⁵⁷ While our results represent responses from only one large pediatric institution, it would be helpful to expand this study to a more representative national sample to improve generalizability.

CONCLUSION

Caregivers in our study reported that no identified needs, schedule conflicts, and a lack of resources were the top 3 barriers they faced in returning for follow-up care after pTBI. Good hospital experience, need, sufficient resources, well-coordinated appointments, and the provision of counseling and support were the top reported facilitators leading them to return for follow-up care. Care coordination for pTBI shows great promise in improving communication about the need for follow-up care, addressing appointment scheduling, helping with resource allocation, and improving the hospital experiences. All of these factors were identified in this study as facilitators that improved adherence to follow-up appointments. As we focus on improving the long-term care of children with TBI, future work to advance follow-up care for these children will contribute to better equality in care for all injured children and may lead to better long-term outcomes.

REFERENCES

1. Faul M, Xu L, Wald MM, VG C. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Death 2002–2006*. Atlanta, GA: Centers for Disease Control and Prevention; 2010.
2. Hawley CA. Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK. *Brain Inj*. 2003;17(2):105–129.
3. Hooper SR, Alexander J, Moore D, et al. Caregiver reports of common symptoms in children following a traumatic brain injury. *NeuroRehabilitation*. 2004;19(3):175–189.
4. Yeates KO. Closed-head injury. In: Yeates KO, Ris DM, Taylor HG, eds. *Pediatric Neuropsychology: Research Theory and Practice*. New York, NY: Guilford; 2000:92–116.
5. Haarbauer-Krupa J, Ciccio A, Dodd J, et al. Service delivery in the healthcare and educational systems for children following traumatic brain injury: gaps in care. *J Head Trauma Rehabil*. 2017;32(6):367–377.
6. Di Battista A, Godfrey C, Soo C, Catroppa C, Anderson V. Does what we measure matter? Quality of life defined by adolescents with brain injury. *Brain Inj*. 2015;29(5):573–582.
7. Laatsch L, Harrington D, Hotz G, et al. An evidence-based review of cognitive and behavioral rehabilitation treatment studies in children with acquired brain injury. *J Head Trauma Rehabil*. 2007;22(4):248–256.
8. Barlow KM, Crawford S, Stevenson A, Sandhu SS, Belanger F, Dewey D. Epidemiology of postconcussion syndrome in pediatric mild traumatic brain injury. *Pediatrics*. 2010;126(2):e374–e381.
9. Taylor HG, Orchinik LJ, Minich N, et al. Symptoms of persistent behavior problems in children with mild traumatic brain injury. *J Head Trauma Rehabil*. 2015;30(5):302–310.
10. Yeates KO, Luria J, Bartkowski H, Rusin J, Martin L, Bigler ED. Postconcussive symptoms in children with mild closed-head injuries. *J Head Trauma Rehabil*. 1999;14(4):337–350.
11. 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):728–725.
12. Corrigan JD, Hammond FM. Traumatic brain injury as a chronic health condition. *Arch Phys Med Rehabil*. 2013;94(6):1199–1201.
13. Johnson VE, Stewart W, Smith DH. Widespread tau and amyloid-beta pathology many years after a single traumatic brain injury in humans. *Brain Pathol*. 2012;22(2):142–149.
14. Masel BE, DeWitt DS. Traumatic brain injury: a disease process, not an event. *J Neurotrauma*. 2010;27(8):1529–1540.
15. Coelho CA. Management of discourse deficits following traumatic brain injury: progress, caveats, and needs. *Semin Speech Lang*. 2007;28(2):122–135.

16. Greenspan AI, MacKenzie EJ. Use and need for post-acute services following paediatric head injury. *Brain Inj.* 2000;14(5):417–429.
17. Slomine BS, McCarthy ML, Ding R, et al. Health care utilization and needs after pediatric traumatic brain injury. *Pediatrics.* 2006;117(4):e663–e674.
18. Walz NC, Yeates KO, Taylor HG, Stancin T, Wade SL. Emerging narrative discourse skills 18 months after traumatic brain injury in early childhood. *J Neuropsychol.* 2012;6(2):143–160.
19. Chard SE. Community neurorehabilitation: a synthesis of current evidence and future research directions. *NeuroRx.* 2006;3(4):525–534.
20. Cope DN. The effectiveness of traumatic brain injury rehabilitation: a review. *Brain Inj.* 1995;9(7):649–670.
21. Irdesel J, Aydiner SB, Akgoz S. Rehabilitation outcome after traumatic brain injury. *Neurocirugia.* 2007;18(1):5–15.
22. Tepas JJ III, Leaphart CL, Pieper P, et al. The effect of delay in rehabilitation on outcome of severe traumatic brain injury. *J Pediatr Surg.* 2009;44(2):368–372.
23. Fuentes MM, Wang J, Haarbauer-Krupa J, et al. Unmet rehabilitation needs after hospitalization for traumatic brain injury. *Pediatrics.* 2018;141(5). doi:10.1542/peds.2017-2859.
24. Blinman TA, Houseknecht E, Snyder C, Wiebe DJ, Nance ML. Postconcussive symptoms in hospitalized pediatric patients after mild traumatic brain injury. *J Pediatr Surg.* 2009;44(6):1223–1228.
25. Spaw AJ, Lundine JP, Johnson SA, et al. Follow-up care adherence after hospital discharge in children with traumatic brain injury. *J Head Trauma Rehabil.* 2018;33(3):E1–E10.
26. Gordon M, Antshel KM, Lewandowski L, Seigers D. Economic grand rounds: predictors of missed appointments over the course of child mental health treatment. *Psychiatr Serv.* 2010;61(7):657–659.
27. Irwin CE Jr, Millstein SG, Ellen JM. Appointment-keeping behavior in adolescents: factors associated with follow-up appointment-keeping. *Pediatrics.* 1993;92(1):20–23.
28. Jhanjee I, Saxena D, Arora J, Gjerdingen DK. Parents' health and demographic characteristics predict noncompliance with well-child visits. *J Am Board Fam Pract.* 2004;17(5):324–331.
29. McKay MM, Pennington J, Lynn CJ, McCadam K. Understanding urban child mental health service use: two studies of child, family, and environmental correlates. *J Behav Health Serv Res.* 2001;28(4):475–483.
30. Willis, GB. Cognitive interviewing: a “how to” guide. In: *From the Short Course “Reducing Survey Error Through Research on the Cognitive and Decision Processes in Surveys.”* Meeting of American Statistical Association. Research Triangle Park, NC: Research Triangle Institute International; 1999.
31. Roscigno CI, Swanson KM. Parents' experiences following children's moderate to severe traumatic brain injury: a clash of cultures. *Qual Health Res.* 2011;21(10):1413–1426.
32. Stevens PK, Penprase B, Kepros JP, Dunneback J. Parental recognition of postconcussive symptoms in children. *J Trauma Nurs.* 2010;17(4):178–182.
33. Thomas DG, Bradley L, Servi A, et al. Parental knowledge and recall of concussion discharge instructions. *J Emerg Nurs.* 2018;44(1):52–56.
34. Wade SL, Walz NC, Cassidy A, Taylor HG, Stancin T, Yeates KO. Caregiver functioning following early childhood TBI: do moms and dads respond differently? *NeuroRehabilitation.* 2010;27(1):63–72.
35. Harmon SL, Conaway M, Sinkin RA, Blackman JA. Factors associated with neonatal intensive care follow-up appointment compliance. *Clin Pediatr.* 2013;52(5):389–396.
36. Izadi N, Tam JS. Benefits of subspecialty adherence after asthma hospitalization and patient perceived barriers to care. *Ann Allergy Asthma Immunol.* 2017;118(5):577–581.
37. McPherson ML, Lairson DR, Smith EO, Brody BA, Jefferson LS. Noncompliance with medical follow-up after pediatric intensive care. *Pediatrics.* 2002;109(6):e94.
38. Siegal MD, Marx ML, Cole SL. Parent or caregiver, staff, and dentist perspectives on access to dental care issues for head start children in Ohio. *Am J Public Health.* 2005;95(8):1352–1359.
39. Wang NE, Kiernan M, Golzari M, Gisondi MA. Characteristics of pediatric patients at risk of poor emergency department aftercare. *Acad Emerg Med.* 2006;13(8):840–847.
40. Adler NE, Stewart J. Health disparities across the lifespan: meaning, methods, and mechanisms. *Ann N Y Acad Sci.* 2010;1186:5–23.
41. Otani K, Buchanan PR, Desai SP, Herrmann PA. Different combining process between male and female patients to reach their overall satisfaction. *J Patient Exp.* 2016;3(4):145–150.
42. Tajeu GS, Cherrington AL, Andreae L, Prince C, Holt CL, Halanych JH. “We’ll get to you when we get to you”: exploring potential contributions of health care staff behaviors to patient perceptions of discrimination and satisfaction. *Am J Public Health.* 2015;105(10):2076–2082.
43. Youngblut JM, Brooten D. Pediatric head trauma: parent, parent-child, and family functioning 2 weeks after hospital discharge. *J Pediatr Psychol.* 2006;31(6):608–618.
44. Youngblut JM, Brooten D, Kuluz J. Parents' reactions at 24-48 hrs after a preschool child's head injury. *Pediatr Crit Care Med.* 2005;6(5):550–556.
45. Parkes A, Sweeting H, Wight D. Parenting stress and parent support among mothers with high and low education. *J Fam Psychol.* 2015;29(6):907–918.
46. Figueroa JF, Zheng J, Orav EJ, Jha AK. Across US hospitals, black patients report comparable or better experiences than white patients. *Health Aff (Millwood).* 2016;35(8):1391–1398.
47. Schultz EM, McDonald KM. What is care coordination? *Int J Care Coordination.* 2014;17(1/2):5–24.
48. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics.* 2005;116(5):1238–1244.
49. Antonelli RC, Stille CJ, Antonelli DM. Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics.* 2008;122(1):2007–2254.
50. Weier RC, Gardner W, Conkol K, Pajer K, Kelleher KJ. Partners for kids care coordination: lessons from the field. *Pediatrics.* 2017;139(suppl 2):S109–S116.
51. Howitt MJ. The family care coordinator: paving the way to seamless care. *J Pediatr Oncol Nurs.* 2011;28(2):107–113.
52. Janevic MR, Baptist AP, Bryant-Stephens T, et al. Effects of pediatric asthma care coordination in underserved communities on parent perceptions of care and asthma-management confidence. *J Asthma.* 2017;54(5):514–519.
53. Lyles AA, Overgaard PM, Caputo GL, Reifsnider E. Stakeholders' perceptions of care coordination: a participatory process. *J Pediatr Health Care.* 2017;31(5):555–559.
54. McNally KA, Bangert B, Dietrich A, et al. Injury versus noninjury factors as predictors of postconcussive symptoms following mild traumatic brain injury in children. *Neuropsychology.* 2013;27(1):1–12.
55. Blaha RZ, Arnett AB, Kirkwood MW, et al. Factors influencing attrition in a multisite, randomized, clinical trial following traumatic brain injury in adolescence. *J Head Trauma Rehabil.* 2015;30(3):E33–E40.
56. Wade SL, Zhang N, Yeates KO, Stancin T, Taylor HG. Social environmental moderators of long-term functional outcomes of early childhood brain injury. *JAMA Pediatr.* 2016;170(4):343–349.
57. Glasow P. *Fundamentals of Survey Research Methodology.* McLean, VA: The MITRE Corporation; 2005.