

Disparities in Disability After Traumatic Brain Injury Among Hispanic Children and Adolescents



WHAT'S KNOWN ON THIS SUBJECT: Previous studies report Hispanic adults have lower access to rehabilitation services, especially among those who only speak Spanish, and higher disability after traumatic brain injury (TBI) compared with non-Hispanic white subjects. No studies have examined disparities in disability after TBI for Hispanic children.



WHAT THIS STUDY ADDS: Hispanic children experience disparities in long-term disability after TBI. Compared with non-Hispanic white children, Hispanic children report significantly larger reductions in health-related quality of life, participation in activities, and ability to communicate and care for themselves 3 years after injury.

abstract



OBJECTIVE: To compare the extent of disability in multiple areas of functioning after mild, moderate, and severe traumatic brain injury (TBI) between Hispanic and non-Hispanic white (NHW) children.

METHODS: This was a prospective cohort study of children aged <18 years treated for a TBI between March 1, 2007, and September 30, 2008. Hispanic ($n = 74$) and NHW ($n = 457$) children were included in the study. Outcome measures were disability in health-related quality of life, adaptive skills, and participation in activities 3, 12, 24, and 36 months after injury compared with preinjury functioning. We compared change in outcome scores between Hispanic and NHW children at each follow-up time. All analyses were adjusted for age, gender, severity and intent of injury, insurance, family function at baseline, parental education, and income.

RESULTS: The health-related quality of life for all children was lower at all follow-up times compared with baseline. Although NHW children showed some improvement during the first 3 years after injury, Hispanic children remained significantly impaired. Significant differences were also observed in the domains of communication and self-care abilities after TBI. Differences between groups in scores for participation in activities were also present but were only significant 3 months after injury.

CONCLUSIONS: Hispanic children with TBI report larger and long-term reductions in their quality of life, participation in activities, communication, and self-care abilities compared with NHW children. The reasons for these differences need to be better understood and interventions implemented to improve the outcomes of these children. *Pediatrics* 2013;131:e1850–e1856

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KEY WORDS

disability, disparities, Hispanic children, traumatic brain injury

ABBREVIATIONS

ABAS-II—Adaptive Behavior Assessment System—Second Edition
AIS—Abbreviated Injury Scale
CASP—Child and Adolescent Scale of Participation
CHAI—Child Health After Injury
CT—computed tomography
GCS—Glasgow Coma Scale
PedsQL—Pediatric Quality of Life Inventory
TBI—traumatic brain injury

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Traumatic brain injury (TBI) is the leading cause of death and disability for children in the United States.^{1,2} Children with moderate to severe TBI may have potentially poor long-term outcomes, with up to 40% suffering significant impaired physical, emotional, social, and cognitive function 2 years after injury.^{3–6} Psychosocial familial factors and underinsurance are associated with poor prognosis and poor functional outcomes in these children.^{3,7} In addition, children of parents with lower levels of education are significantly more likely to have unrecognized needs and less likely to receive post-acute health care services 1 year after sustaining a TBI.⁷

Previous studies demonstrated that Hispanic adults have less access to rehabilitation services, especially among those who only speak Spanish,⁸ and lower functional outcomes⁹ after TBI compared with non-Hispanic white (NHW) subjects, reflecting the higher burden of disability among the Hispanic population. There are no studies regarding disparities in disability after TBI in Hispanic children. Given that Hispanic subjects have the lowest health insurance rates¹⁰ and the lowest education attainment of all racial and ethnic groups in the United States,¹¹ Hispanic children may face similar disparities. Most previous studies evaluating functional outcomes after TBI in children have excluded non-English-speaking participants, limiting information on TBI in Hispanic children.

In 2006, our research group initiated a longitudinal cohort study on long-term disability among children with TBI called the Child Health After Injury (CHAI) study.¹² Unlike previous studies, the CHAI study recruited children of English- and Spanish-speaking families, providing a unique opportunity to evaluate possible disparities in long-term disability after TBI for Hispanic children. Disability was measured by

using health-related quality of life, adaptive skills, and participation in activities data among children and adolescents over a period of 36 months after injury. For the current study, we compared the extent of disability in multiple areas of functioning after a mild, moderate, and severe TBI between Hispanic and NHW children. We hypothesized that disability will be more common among Hispanic children and that it will improve at a slower pace compared with NHW children.

METHODS

Patient Population

Patients included in this study constitute a subsample of the initial CHAI cohort of children treated for TBI or an arm injury between March 1, 2007, and September 30, 2008. A detailed description of this prospective cohort has been published previously.^{5,12} In brief, after approval by the human subjects committees of all participating institutions, we recruited children aged <18 years, discharged alive from the emergency department or as inpatients, treated for TBI or arm injury at 10 study hospitals. Study hospitals included 2 children's hospitals (the Children's Hospital of Philadelphia and Seattle Children's Hospital); Harborview Medical Center, a level 1 trauma center in King County, Washington; and four level 3 and three level 4 trauma centers randomly sampled in King County. Study participants for the initial cohort included children and adolescents, and their parents, randomly selected from a list of eligible patients treated at the 10 participating institutions during the study period. Potential participants were contacted by letter, and follow-up was conducted by telephone or in-person by bilingual interviewers.

Race, ethnicity, and language preference for interviews were obtained from self-report by parents and by children

aged ≥ 14 years. For the purpose of this study, we included children who suffered a TBI and their parents who self-identified as Hispanic of any race or as NHW. We excluded participants of other racial or ethnic backgrounds; we also excluded patients with isolated arm injuries who had served as a comparison group in other analyses.

Definition of Injuries

We used the Centers for Disease Control and Prevention¹³ definition of TBI, described as a blunt or penetrating injury to the head and documented in the medical record as having 1 or more of the following signs or symptoms: observed or reported decreased level of consciousness, amnesia, or objective neurologic or neuropsychological abnormality or diagnosed intracranial lesion.

Mild TBI was defined as follows: (1) any period of transient confusion, disorientation, or impaired consciousness as recorded in the medical record; or (2) any period of amnesia that lasted <24 hours; or (3) signs of other neurologic or other neuropsychological dysfunction; and (4) worst Glasgow Coma Scale (GCS) score of 13 to 15 at the time of the first medical evaluation and a GCS score of 15 at discharge from the emergency department or by 24 hours after injury if hospitalized.^{14,15} Mild TBI was further subdivided into 3 categories: mild I (no abnormalities on computed tomography [CT] or no CT was performed); mild II (skull fracture without intracranial hemorrhage); and mild III (intracranial hemorrhage but case still meet criteria for mild TBI).

Moderate TBI was defined by a best motor GCS score 24 hours after injury of 4 to 5 or a score of 6 for cases that did not meet criteria for mild TBI.¹⁴ Severe TBI was defined as best motor GCS score 24 hours after injury of 1 to 3. In addition, coding of head injuries was performed by using the Abbreviated

Injury Scale (AIS) by a single investigator (Dr Rivara) using the 2008 AIS.⁵

Measures of Disability

A baseline survey was administered to patients aged ≥ 14 years (if cognitively able) and to a parent/guardian for all children. Baseline surveys were completed as soon as possible after injury (median: 37 days). In the baseline survey, parents were specifically asked about their child's functioning in the period before injury. Follow-up surveys were administered at 3, 12, 24, and 36 months after injury to cognitively able patients aged ≥ 14 years and their parents.

Three measures of disability were used in our study. The Pediatric Quality of Life Inventory (PedsQL)¹⁶ is a measure of health-related quality of life, previously used in children with trauma and TBI,^{3,17–19} based on the assessment of physical, emotional, social, and school functioning of children aged ≥ 24 months. Total PedsQL scores range from 0 to 100, with lower scores indicating lower quality of life; a 4.5-point change from baseline is considered to be clinically meaningful.¹⁶ The PedsQL uses separate forms to be administered to parents of children aged 24 months to 4 years and ≥ 5 years. The Adaptive Behavior Assessment System—Second Edition (ABAS-II) was a norm-referenced measure of adaptive skills²⁰ specifically designed to evaluate patients with neurologic disorders, including TBI. Of the 9 subscales of the ABAS-II, we used the communication and self-care subscales. For both subscales, the mean \pm SD value for healthy individuals is 10 ± 3 ; higher scores indicate better functioning, and scores < 8 indicate below-average functioning. The third measure of disability was the Child and Adolescent Scale of Participation (CASP), a 20-item measure of involvement of children in various activities at home, school, and the community.²¹ This scale is designed for children aged ≥ 5 years. It assesses

participation in structured and educational activities, interaction with friends and play; scores range from 0 to 100, with higher scores indicating better participation. The PedsQL²² and ABAS-II²³ Spanish scales have been translated to Spanish and previously validated among Hispanic patients. The CASP scale is available in Spanish, but no validation studies are yet available.²⁴

Other Measures

Preinjury family functioning is a known predictor²⁵ of functional outcomes after TBI. We measured family functioning and emotional relationships within the family, using the 12-item, self-report McMaster Family Assessment Device.²⁶ For this scale, scores range from 11 to 41; higher scores indicate worse family function.

Statistical Analysis

Baseline family functioning and demographic and injury characteristics were compared between Hispanic and NHW children by using the χ^2 and *t* test statistics for categorical and continuous variables, respectively. Within each ethnic group, mixed models were used to assess the change of outcome scores from baseline to 3, 12, 24, and 36 months after injury. Mixed models were then used to assess the change in functional outcome scores from baseline to 3, 12, 24, and 36 months after injury of Hispanic children compared with NHW children by using interaction of ethnic group and survey time points adjusting for patients' age, gender, severity and intention of injury, insurance status, household income, respondent education, and baseline family assessment device. Analyses were conducted by using SAS version 9.3 (SAS Institute Inc, Cary, NC) data analytic software.

RESULTS

Study Patients

Of the 729 children with TBI included in the initial cohort, we excluded 198

children of other races and ethnicities (35 black, 16 Asian, 144 other or multiple races and ethnicities, and 3 unknown). A total of 531 children were included in this study; 74 were Hispanic and 457 NHW. Hispanic children were significantly younger at the time of injury; 41.9% of Hispanic children were aged < 4 years compared with only 25.2% of NHW children ($P = .02$). Hispanic children were less likely to have private insurance (10.8% vs 79.4% for NHW; $P < .0001$), more likely to have parents with < 12 years of education (56.8% vs 2.0% for NHW; $P < .0001$), more likely to be poor, and to have lower levels of family function (Table 1). There were no differences in gender distribution or hospital to which they were admitted. Additionally within the Hispanic group, 71% of Hispanic parents were interviewed in Spanish. Comparisons between the Spanish-versus English-speaking Hispanic families demonstrated no differences in demographic or injury characteristics except for parental levels of education. Parents who interviewed in Spanish were significantly ($P = .004$) more likely to have < 12 years of education (70%) compared with Hispanic parents who interviewed in English (23%).

Injury Characteristics

There were significant differences in the distribution of TBI severity between groups. Hispanic children were more likely than NHW children to sustain moderate to severe TBI (24.4% vs 11.2%; $P = .02$) and to have higher head AIS and lower GCS scores (Table 2). Although there were no differences in the mechanisms of injury, there were significant differences in the intent of injury. Intentional injuries were 3 times higher among Hispanic children compared with their NHW counterparts (13.4% vs 3.6%; $P = .002$). No differences were found in the proportion of isolated TBIs, the emergency medical services level, or the proportion of

TABLE 1 Characteristics of the Study Population (*N* = 531)

Characteristic	No. of Children	NHW (<i>n</i> = 457)	Hispanic (<i>n</i> = 74)	<i>P</i>
Age at injury, y				.02
0–4	146	25.2	41.9	
5–9	121	23.2	20.3	
10–14	147	29.3	17.6	
15–17	117	22.3	20.3	
Child gender				.25
Male	347	66.3	59.5	
Female	184	33.7	40.5	
Index hospital				.44
HMC	197	35.9	44.6	
Seattle Children's	215	40.7	39.2	
Other King County hospitals	103	20.3	13.5	
CHOP	16	3.1	2.7	
Health insurance				<.0001
None	24	3.5	10.8	
Other	136	17.1	78.4	
Private	371	79.4	10.8	
Household income, \$				<.0001
<30,000	109	12.7	68.9	
30,000–60,000	97	19.0	13.5	
>60,000	303	64.8	9.5	
Unknown	22	3.5	8.1	
Respondent education				<.0001
<High school	51	2.0	56.8	
High school, GED	79	13.4	24.3	
>High school	401	84.7	18.9	
Language of interview				<.0001
English	478	100	28.4	
Spanish	53	0	71.6	
Family assessment device, baseline score	531	17.6 ± 4.8	20.5 ± 4.1	<.0001

Data are presented as % or mean ± SD. CHOP, Children's Hospital of Philadelphia; GED, General Educational Development; HMC, Harborview Medical Center.

patients who received a CT scan. The number of preinjury comorbidities was significantly lower among Hispanic children (*P* = .004).

Disability Measures

Health-Related Quality of Life

For Hispanic and NHW children, PedsQL scores were significantly lower at 3, 12, 24, and 36 months after injury than at baseline. There was improvement over time in both groups (Table 3).

Comparing ethnic groups, PedsQL scores at baseline were higher for Hispanic children than their NHW counterparts. After injury, PedsQL scores were significantly lower for Hispanic children compared with NHW children at 3, 12, 24, and 36 months; change scores between baseline and follow-up were 2 to 3 times lower for

Hispanic children at every measured interval.

Adaptive Behavior and CASP Scales

A similar pattern to the one described for the PedsQL scores was found for the ABAS-II communication and self-care assessments. After injury, both ethnic groups presented lower scores compared with baseline (Table 3). Change scores for Hispanic children compared with NHW children were significantly lower at every follow-up visit after injury.

CASP assessments were conducted only in patients aged ≥60 months, corresponding to 74.8% of NHW and 58.2% of Hispanic children. Differences in CASP scores between baseline and follow-up were also more pronounced among the Hispanic group; however, statistically

significant differences were documented only at 3 months after injury.

DISCUSSION

Our study, conducted among a cohort of NHW and Hispanic children with TBI, documented significant disparities in disability for children of Hispanic ethnic background. Hispanic children compared with NHW children showed reductions in health-related quality of life, activities, and adaptive skills that were significantly lower and persistent over time.

These findings echo literature identifying disparities in functional outcomes after TBI in adult Hispanic patients.^{9,27,28} Adult Hispanic patients exhibit higher levels of disability measured according to lower levels of integration into the community,²⁹ lower standard of living, lower engagement in leisure activities, and return to work.⁹ In our study, Hispanic children compared with NHW children had lower scores in participation in social activities in the community and at school. This finding is consistent with the significantly lower scores of Hispanic children compared with NHW children on adaptive communication and self-care skills, both necessary for daily living. Other important findings of our study are the significant differences in the demographic characteristics of Hispanic children and their families as well as differences in the characteristics of injuries. Hispanic children were younger at the time of injury, which is probably a reflection of the age distribution of the 2 studied populations. In addition, Hispanic children were rated healthier based on the parents' report of baseline comorbidities. We question the latter, based on previous literature showing that other conditions such as asthma³⁰ and visual problems³¹ are frequently underdiagnosed among Hispanic children, especially those of parents not fluent in English.

TABLE 2 Injury Characteristics (N = 517)

Characteristic	No. of Children	NHW (n = 449)	Hispanic (n = 68)	P
TBI severity				.02
Mild TBI, I	355	68.3	58.1	
Mild TBI, II	27	5.5	2.7	
Mild TBI, III	80	15.1	14.9	
Moderate TBI	62	10.3	20.3	
Severe TBI	7	0.9	4.1	
Mechanism of injury				.06
Motor vehicle occupant	64	12.1	15.2	
Pedestrian or bicycle	44	7.9	13.6	
Fall	269	53.0	50.0	
Struck by/against	130	26.5	18.2	
Other	4	0.5	3.0	
Intent				.002
Intentional	25	3.6	13.4	
Unintentional	490	96.4	86.6	
EMS level				.87
ALS	110	22.0	24.6	
BLS	61	12.3	13.1	
Not transported by EMS	322	65.7	62.3	
Isolated TBI	296	58.6	48.5	.12
ISS	517	6.8 ± 9.3	10.2 ± 10.9	.01
MAXAIS				.03
1	240	47.9	36.8	
2	144	28.3	25.0	
3	65	12.5	13.2	
4	19	3.3	5.9	
5	49	8.0	19.1	
Head MAXAIS				.01
1	252	50.1	39.7	
2	158	31.2	26.5	
3	45	8.7	8.8	
4	14	2.2	5.9	
5	48	7.8	19.1	
Lowest motor GCS in ED				.26
6	447	87.5	82.4	
4–5	25	4.0	10.3	
2–3	2	0.5	0	
1, not pharmacologically paralyzed	9	1.8	1.5	
1, pharmacologically paralyzed	32	6.3	5.9	
Had CT	343	65.3	75.0	.11
Preinjury comorbidities				.004
None	206	35.9	56.8	
1	116	22.1	20.3	
2	77	15.8	6.7	
≥3	132	26.3	16.2	

Medical records were not available for 14 patients. Data are presented as % or mean ± SD. ALS, advanced life support; BLS, basic life support; ED, emergency department; EMS, emergency medical services; ISS, injury severity score; MAXAIS, maximum AIS.

Parents of Hispanic children were less educated, less likely to speak English, and more likely to be poor and uninsured, findings supported by our result of lower levels of family functioning at baseline. Each of these factors is associated with poor outcomes after TBI and may contribute to increased disability among Hispanic children. Lastly, injuries among Hispanic children tended to be more severe and were

more likely to be intentional. These differences underscore the importance of tailoring prevention strategies to the specific needs of the Hispanic population, especially now that states have passed new immigration reinforcement laws that will result in lesser access to care for Hispanic children of undocumented immigrants.^{32,33}

Studies in adult patients with TBI have documented an association between

access to rehabilitation services and better outcomes.^{8,9,29} We do not have specific information on the intensity, type, and time of rehabilitation services for these patients, and it is therefore unknown if the Hispanic children in our study faced barriers in accessing rehabilitation services. Previous studies have linked limited English proficiency, lower education levels, and underinsurance to lower access to rehabilitation services.^{8,9} Future research is needed to determine patterns of rehabilitation services among Hispanic children with TBI and its association with long-term outcomes.

Our study has a number of limitations. Baseline measurements were obtained at some point after injury (median: 37 days), and thus the possibility exists for recall bias. However, follow-up times were similar for both groups. Measurement of functional outcomes was reported by parents and may differ from the child's perception of his or her limitations. Nonetheless, previous studies have used parental reports and have shown their reliability.³⁴ Likewise, there could be differences in the reports of Hispanic and non-Hispanic parents. Based on previous studies^{30,31} indicating that Hispanic parents tend to underreport symptoms, it can be hypothesized that if in our study, there were differences in parental report, the disparities in outcomes are likely to be worse. Like all cohort studies, there is the possibility for unmeasured confounding accounting for differences between groups. We have controlled for severity and intention of injury and other known sources of confounding in each analysis. Equally important is the recognition in this study that the impact of poverty, language barriers, and poor insurance status all fall more heavily on the group of Hispanic children and families, a fact which is often missed when controlling for each of these factors separately.

TABLE 3 Functional Outcomes 3, 12, 24, and 36 Months After Injury According to Ethnic Group

Outcome	Mean at Month 0	Change 0–36 mo			
		Change 0–3 mo	Change 0–12 mo	Change 0–24 mo	Change 0–36 mo
		Adjusted Δ (95% CI)	Adjusted Δ (95% CI)	Adjusted Δ (95% CI)	Adjusted Δ (95% CI)
PedsQL ^a	(n = 450)	(n = 443)	(n = 444)	(n = 461)	(n = 445)
NHW	86.3	-5.4 (-6.8 to -4.1)	-5.0 (-6.3 to -3.7)	-4.7 (-6.0 to -3.4)	-4.7 (-6.1 to -3.2)
Hispanic	89.9	-15.6 (-20.4 to -10.8)	-12.9 (-17.8 to -8.0)	-12.5 (-18.0 to -7.0)	-16.4 (-21.7 to -11.2)
Difference (Hispanic – NHW)		-10.1 (-15.1 to -5.2)	-7.9 (-13.0 to -2.8)	-7.8 (-13.5 to -2.2)	-11.8 (-17.2 to -6.4)
ABAS-II communication	(n = 530)	(n = 521)	(n = 491)	(n = 466)	(n = 443)
NHW	10.6	-0.01 (-0.2 to 0.2)	0.2 (-0.04 to 0.5)	0.2 (-0.1 to 0.5)	0.3 (0.01 to 0.6)
Hispanic	10.2	-1.4 (-2.2 to -0.6)	-1.4 (-2.2 to -0.6)	-1.8 (-2.8 to -0.8)	-2.0 (-2.8 to -0.9)
Difference (Hispanic – NHW)		-1.4 (-2.3 to -0.6)	-1.6 (-2.5 to -0.8)	-2.0 (-3.0 to -0.9)	-2.3 (-3.0 to -1.9)
ABAS-II self-care	(n = 530)	(n = 521)	(n = 491)	(n = 466)	(n = 443)
NHW	9.2	0.3 (0.04 to 0.6)	0.4 (0.1 to 0.7)	0.6 (0.3 to 0.9)	0.7 (0.4 to 1.1)
Hispanic	9.9	-1.1 (-2.0 to 0.2)	-1.2 (-2.2 to -0.3)	-0.9 (-1.9 to 0.1)	-1.2 (-2.3 to -0.1)
Difference (Hispanic – NHW)		-1.3 (-2.3 to -0.4)	-1.6 (-2.6 to -0.6)	-1.5 (-2.5 to -0.4)	-1.9 (-3.1 to -0.8)
CASP ^b	(n = 385)	(n = 377)	(n = 370)	(n = 374)	(n = 378)
NHW	94.9	-0.7 (-1.7 to 0.3)	0.1 (-0.8 to 1.1)	0.1 (-1.0 to 1.2)	1.1 (0.1 to 2.0)
Hispanic	93.0	-6.8 (-10.7 to -2.9)	-0.9 (-3.7 to 1.9)	-1.3 (-5.4 to 2.7)	-1.7 (-6.3 to 2.8)
Difference (Hispanic – NHW)		-6.1 (-10.1 to -2.0)	-1.1 (-4.0 to 1.9)	-1.4 (-5.6 to 2.8)	-2.8 (-7.5 to 1.9)

Analyses adjusted for age, child gender, injury intention and severity, insurance and parent income, education, and family function at baseline.

^a Only measured in children aged ≥ 24 months.

^b Only measured in children aged ≥ 60 months.

CONCLUSIONS

Our study is the first to document disparities in long-term disability after TBI in Hispanic children. This study highlights differences in demographic and injury characteristics that deserve further study to adequately design prevention measures and rehabilitation

services for Hispanic children and families. Research evaluating discharge practices, continuity of rehabilitation therapies in community settings, and use of school education resources are warranted. We hypothesized possible explanations for these disparities, such as inadequate access

to rehabilitation services, underinsurance, and language and cultural barriers. There is a demonstrated need for further studies and intervention programs to explore and remedy causal factors to reduce the burden of TBI and improve outcomes for vulnerable populations.

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