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Persistence of Disability 24 to 36 Months after Pediatric Traumatic Brain Injury: A Cohort Study

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Abstract

This study examined the outcome of 0- to 17-year-old children 36 months after traumatic brain injury (TBI), and ascertained if there was any improvement in function between 24 and 36 months. Controls were children treated in the emergency department for an arm injury. Functional outcome 36 months after injury was measured by the Pediatric Quality of Life Inventory (PedsQL), the self-care and communication subscales of the Adaptive Behavior Assessment Scale-2nd edition (ABAS-II), and the Child and Adolescent Scale of Participation (CASP). At 36 months after TBI, those with moderate or severe TBI continued to have PedsQL scores that were 16.1 and 17.9 points, respectively, lower than at baseline, compared to the change seen among arm injury controls. Compared to the baseline assessment, children with moderate or severe TBI had significantly poorer functioning on the ABAS-II and poorer participation in activities (CASP). There was no significant improvement in any group on any outcomes between 24 and 36 months. Post-injury interventions that decrease the impact of these deficits on function and quality of life, as well as preventive interventions that reduce the likelihood of TBI, should be developed and tested.

Key words: children and adolescents; disability; functional outcome; traumatic brain injury

Introduction

Increasing attention has been given in recent years to the effect of traumatic brain injury (TBI), including mild TBI, on children's short- and long-term functioning.[1–3] Prior studies have demonstrated improvement in functioning during the first year after injury,[4] although many injured children, including some with mild TBI, have persistent disability.[5] Information about the persistence of disability beyond 1 year is important for parents, health care providers, and community resources such as schools.

A number of studies have evaluated children more than 12 months after their TBI. These have included studies at 2 years,[6] 3 years,[7] 5 years,[8] 10 years,[9,10] and longer after injury.[11] Some studies have shown a plateauing of improvement after 1 year,[6,7] while others have shown continued improvement in functioning and quality of life. These evaluations have been mostly based on small samples of TBI cases seen at a single facility, with limited ability to disaggregate injuries with different levels of severity, especially for mild TBI. Others have not provided consistent follow-up with high retention rates, or examined outcomes other than performance on neuropsychological tests.

We have previously reported the 3-, 12-, and 24-month outcomes following TBI in a large cohort of children across the range of injury severity.[5] We found that children with moderate or severe TBI, and some children with mild TBI, had persistent deficits which improved between 3 and 12 months after injury, and with improvement in some areas of functioning between 12 and 24 months. Herein we extend this to report their functioning 36 months after injury.

Methods

Child Health After Injury is a prospective study of children who sustained a traumatic brain injury at ages 0–17 years, received medical care in an emergency department, and were subsequently either discharged or were hospitalized for further treatment. Details of study procedures have been described in prior reports,[5,12–14] and will be briefly summarized here. Children with TBI seeking care and admitted to one of 10 hospitals in King County, Washington, or Philadelphia, Pennsylvania, between March 1, 2007 and September 30, 2008 were sampled. TBI was defined using the 2002 definition from the Centers for Disease Control and Prevention (CDC).[15] The injuries were classified as mild, moderate, or severe, based on CDC[16] and World Health Organization (WHO)[17] definitions and

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functioning at 24 h after injury. Because mild TBI patients are a heterogeneous group,[18,19] we subdivided these children into three subgroups: the Mild I group were children who had a normal initial head CT scan or had no scan, the Mild II group were children who had a skull fracture but no intracranial hemorrhage on CT scan, and the Mild III group had intracranial hemorrhage on CT.

We also selected a group of children with isolated arm injury treated in the same King County hospitals concurrently with the TBI patients as a comparison group, as recommended by the CDC Expert Working Group on TBI.[20] We sought to recruit 50 such children in each of the 4 study age groups: 0–4 years, 5–9 years, 10–14 years, and 15–17 years.

Assessments

As described previously, standardized assessments were conducted as soon as possible after injury and sought to determine pre-injury functioning, and were repeated 3, 12, 24, and 36 months following trauma. These assessments were done by phone or on the web by a parent, usually the same parent for all assessments. Health-related quality of life was measured in children 2 years and older with the Pediatric Quality of Life Inventory (PedsQL).[21] Six additional items from the cognitive functioning scale[22] that assess memory, attention, and information processing speed were added. The PedsQL scores range from 0–100, with higher scores indicating better functioning. Changes of 4–5 points on the PedsQL total score have previously been judged to be clinically meaningful.[21]

We used the communication and self-care subscales of the Adaptive Behavior Assessment Scale-2nd edition (ABAS-II) to assess adaptive skills in these two domains.[23] These have a mean score of 10 (standard deviation [SD] 3) in healthy people; scores below 8 represent below-average functioning. Another important area of functioning for children is participation in activities; this was measured with the Child and Adolescent Scale of Participation (CASP).[24] Total scores range from 0–100, with higher scores indicating better participation.

Family functioning was assessed at baseline with the 12-item general functioning scale of the McMaster Family Assessment Device (FAD), which measures overall health of the family system.[25] Higher scores indicate worse functioning.

Data analysis

Among children who were reassessed at 36 months, data were missing for $<5\%$ of patients for most variables. Multiple imputation, using 10 replications, was used to account for missing data. Linear mixed models were developed to assess the change of outcome scores from baseline to 36 months, and the change between 24 and 36 months, in TBI patients compared to controls. This model was adjusted for patient age (linear continuous variable), gender, race/ethnicity, insurance, household income (categorical variable), and respondent education. Time was treated as a categorical variable. Significance was set at $p<0.05$, and no adjustments were made for multiple comparisons. We used robust standard errors to account for clustering within a hospital.

Results

There were 769 children who were followed up at 36 months. This represents 83.0% of the TBI cases and 91.4% of the arm injury controls. The majority of children had mild TBI, with 82 having moderate or severe injury (Table 1). Those with moderate or severe injury were more likely to be older, to be non-white, and to come from families with lower household incomes and lower educational achievement of parents than were those with mild TBI or the arm injury controls. They were also more likely to have been in motor vehicle crashes, have other injuries in addition to the TBI, and have higher injury severity scores.

Compared to pre-injury functioning assessed at the first interview soon after injury, children with moderate or severe TBI had significantly poorer functioning on the communication and self-care subscales of the ABAS-II, and poorer participation in activities (CASP), adjusted for age, gender, race, insurance status, household income, and respondent education, and accounting for the change in scores of the arm injury controls (Table 2). Compared to those with an arm injury, children in the Mild TBI groups II and III had modestly but significantly lower scores for self-care at 36 months than at baseline. There was no significant change in function on the two ABAS subscales, or in participation in activities on the CASP, between 24 and 36 months for any of the TBI subgroups.

At 36 months after TBI, those with moderate or severe TBI continued to have adjusted PedsQL scores that were 16.1 and 17.9 points, respectively, lower than at baseline, compared to the change among arm injury controls (Table 3). While children in the Mild TBI I and III groups had lower scores than at baseline, these differences, as well as those for the Mild TBI II group, disappeared after accounting for the change among the arm injury controls. Scores worsened between 24 and 36 months for three groups, the Mild III, moderate and severe TBI patients, although the difference was statistically significant only for those with moderate TBI.

Discussion

Our study of TBI in children 0–17 years of age at the time of injury found that those with moderate or severe TBI continued to have statistically and clinically significant deficits in function 36 months after injury, with no statistically significant improvement seen between 24 and 36 months.

Certain limitations of this study should be kept in mind when considering the results. The outcomes measurements as well as the baseline assessment were based on parent self-reports, albeit with well-standardized and validated instruments. Responses by the children themselves may differ from those of their parents. At the time the study began, the PedsQL scale was not available for children under 24 months of age, so baseline data are not available on this measure for children less than this age at the time of injury. It is also unclear why children with arm injuries had a 4-point lower score on the PedsQL at 36 months compared with baseline. Varni and associates reported lower scores for school-aged children than for pre-school children, potentially accounting for some of the differences seen as children aged during the 36-month follow-up period.[26] In addition, other studies have shown that problems accessing health care are associated with a decrease of 4.4 points in PedsQL scores.[27]

While there appeared to be some improvement between 12 and 24 months after injury,[5] there was essentially no improvement on our measures between 24 and 36 months. This is in agreement with some prior studies,[6,7,28] but not all.[29] It is important to note that improvement over time in children with TBI has been noted on psychometric measures,[30,31] but that this performance on standardized assessments in controlled settings does not necessarily translate into functional improvements in daily settings. Clinicians and researchers should focus more on functional daily skills, participation in activities, and quality of life such as that measured in this study, as these factors have significantly greater bearing on long-term outcome and functioning in adulthood than individual test performance. Prior research has also found that behavioral problems may actually increase with time post-TBI, and emotional and behavioral symptoms may become more prominent.[32] Adaptive functioning in particular seems to be persistently impaired

Table 1. Characteristics of the Study Population (n = 769)

	TBI						
	Mild I n = 405	*Mild II n = 23*	*Mild III n = 85*	*Mild all n = 513*	*Moderate n = 69*	*Severe n = 13*	*Arm injury n = 174*
	%	%	%	%	%	%	%
Age at injury							
0–4 years	27.7	13.0	29.4	27.3	36.2	30.8	32.7
5–9 years	24.7	34.9	21.2	24.6	8.7	15.4	21.3
10–14 years	28.3	30.4	21.2	27.3	26.1	30.8	28.2
15–17 years	19.3	21.7	28.2	20.8	29.0	23.0	17.8
Gender							
Male	63.5	78.3	75.3	66.1	66.7	76.9	61.5
Female	36.5	21.7	24.7	33.9	33.3	23.1	38.5
Race/ethnicity							
White, non-Hispanic	69.6	82.5	72.9	70.9	53.6	23.1	69.0
Black, non-Hispanic	1.5	0.0	5.9	2.1	8.7	23.1	2.3
Hispanic	6.4	4.4	5.9	6.2	14.5	7.7	10.9
Asian	2.0	0.0	2.4	1.9	2.9	7.7	3.5
Other or multiple	20.0	8.7	12.9	18.3	20.3	38.4	14.3
Unknown	0.5	4.4	0.0	0.6	0.0	0.0	0.0
Household income							
< $30 k	15.8	17.4	17.7	16.2	24.6	38.5	13.2
$30–60 k	17.0	8.7	21.2	17.3	33.4	46.1	16.1
$60–100 k	20.8	34.8	30.5	23.0	21.7	0.0	26.4
Over $100 k	42.0	30.4	29.4	39.4	17.4	0.0	39.7
Unknown	4.4	8.7	1.2	4.1	2.9	15.4	4.6
Respondent parent's education							
Less than high school	5.4	4.4	7.1	5.7	13.0	23.1	6.9
High school	9.1	17.4	17.7	10.9	30.5	30.7	10.3
Some college	27.7	30.4	35.2	29.0	29.0	38.5	25.3
College graduate	31.8	39.1	20.0	30.2	18.8	0.0	34.5
Post-college	25.7	8.7	20.0	24.0	8.7	7.7	22.4
Unknown	0.3	0.0	0.0	0.2	0.0	0.0	0.6
Mechanism of injury							
Motor vehicle occupant	6.4	17.4	17.9	8.8	35.8	40.0	3.6
Pedestrian or bicycle	6.4	17.4	7.1	7.0	13.4	0.0	2.4
Fall	57.3	47.8	54.8	56.5	34.3	30.0	82.7
Struck by/against	29.9	17.4	20.2	27.7	10.5	20.0	10.7
Other	0.0	0.0	0.0	0.0	6.0	10.0	0.6
Isolated TBI[a]	64.9	47.8	49.4	61.5	23.2	15.4	0.0
ISS, mean (SD)[a]	2.9 (4.0)	6.9 (2.7)	11.4 (7.5)	4.8 (5.7)	24.1 (11.8)	34.1 (9.3)	4.6 (3.1)
Head MAXAIS[a]							
0	0.0	0.0	0.0	0.0	0.0	0.0	100
1	75.1	0.0	0.0	58.9	0.0	0.0	0.0
2	24.4	73.9	51.7	31.3	15.9	0.0	0.0
3	0.5	26.1	29.4	6.6	18.8	0.0	0.0
4	0.0	0.0	7.1	1.2	5.8	0.0	0.0
5	0.0	0.0	11.8	2.0	59.5	100	0.0
Lowest motor GCS score in emergency department[a]							
6	98.7	100	76.5	95.0	23.2	0.0	99.4
4 or 5	0.5	0.0	12.9	2.6	30.4	0.0	0.0
2 or 3	0.0	0.0	0.0	0.0	1.5	18.2	0.0
1, not paralyzed	0.0	0.0	0.0	0.0	14.5	36.4	0.0
1, paralyzed	0.8	0.0	10.6	2.4	30.4	45.4	0.6

[a]Medical records were not available on 14 patients.

MAXAIS, Maximum Abbreviated Injury Scale Score; GCS, Glasgow Coma Scale; ISS < Injury Severity Score; TBI, traumatic brain injury; SD, standard deviation

across all studies of children with moderate to severe TBI. Rehabilitative or school services may be less available that long after TBI. The lack of significant change between 24 and 36 months in our patients does not imply that therapy should not be given; indeed, the results could be interpreted as evidence of continuing need.

One potential reason for a lack of improvement after 24 months may be inadequate provision of services for children with need. We have previously reported that the proportion of children who received new special services among those who scored one standard deviation or more below the norms on the ABAS, CASP, or

Table 2. Adaptive Skills and Activities 36 Months After Injury

	Mean at month[a]					*Change 0–36 months*				*Change 24–36 months*			
	0	*3*	*12*	*24*	*36*	Δ	*95% CI*	*Adjusted net difference*[b]	*95% CI*	Δ	*95% CI*	*Adjusted net difference*[b]	*95% CI*
ABAS Communication													
Total no.	**887**	**864**	**812**	**777**	**769**								
Arm injury	10.7	10.9	10.9	10.8	10.9	0.3	−0.1,0.7	ref		0.1	−0.2,0.5	ref	
Mild TBI													
I	10.3	10.4	10.7	10.6	10.6	0.3	−0.01,0.6	−0.03	−0.6,0.5	0.1	−0.2,0.3	−0.1	−0.5, .3
II	11.1	11.3	10.9	11.0	11.6	0.2	−0.8,1.1	−0.1	−1.4,1.1	0.2	−0.3,0.8	0.03	−1.0,1.0
III	10.6	10.4	10.5	10.9	10.7	−0.1	−0.8,0.5	−0.4	−1.2,0.4	0.0	−0.4,0.4	−0.2	−0.8,0.4
Moderate TBI	10.5	9.4	9.1	9.0	9.0	**−1.7**	**−2.4,−0.9**	**−2.0**	**−2.8,−1.2**	−0.1	−0.6,0.4	−0.3	−0.9,0.4
Severe TBI	10.7	7.4	7.5	6.7	6.8	**−4.5**	**−7.1,−1.9**	**−4.9**	**−6.5,−3.2**	−0.2	−2.5,2.1	−0.4	−1.7,0.9
ABAS self-care													
Total no.	**887**	**864**	**812**	**777**	**769**								
Arm injury	9.1	9.2	9.9	10.2	10.4	**1.3**	**0.8,1.8**	ref		0.2	−0.1,0.6	ref	
Mild TBI													
I	8.8	9.1	9.3	9.4	9.7	**0.9**	**0.6,1.2**	−0.4	−1.0,0.2	**0.3**	**0.1,0.6**	0.1	−0.4,0.5
II	10.2	10.3	10.0	10.6	10.0	−0.4	−1.6,0.8	**−1.5**	**−2.9,−0.2**	−0.8	−2.0,0.3	−0.9	−2.0,0.1
III	9.9	10.3	10.1	10.7	10.0	−0.1	−0.7,0.5	**−1.4**	**−2.3,−0.6**	−0.3	−0.8,0.2	−0.5	−1.2,0.1
Moderate TBI	10.2	8.4	8.8	8.9	9.0	**−1.0**	**−1.8,−0.2**	**−2.4**	**−3.3,−1.5**	0.4	−0.2,1.0	0.1	−0.6,0.8
Severe TBI	10.1	6.3	6.1	6.4	5.9	**−4.6**	**−7.6,−1.7**	**−5.8**	**−7.6,−4.0**	−0.3	−1.8,1.1	−0.1	−1.6,1.3
CASP[c]													
Total no.	**629**	**615**	**612**	**625**	**659**								
Arm injury	95.6	95.4	96.8	96.6	96.5	1.2	−0.1,2.6	ref		0.5	−0.4,1.4	ref	
Mild TBI													
I	94.0	93.3	94.8	94.5	94.9	0.9	−0.1,1.8	−0.5	−2.3,1.3	**0.8**	**0.1,1.5**	0.3	−1.0,1.5
II	94.9	96.5	96.7	96.2	99.2	**3.6**	**0.8,6.4**	2.1	−1.8,6.0	2.7	−0.3,5.6	2.1	−0.8,5.0
III	95.9	94.5	94.5	96.7	94.9	−1.0	−3.3,1.3	−2.4	−5.0,0.2	−1.0	−2.9,1.0	−1.2	−3.1,0.7
Moderate TBI	95.9	90.8	92.1	93.2	92.5	**−3.2**	**−6.1,−0.3**	**−4.2**	**−7.0,−1.4**	0.8	−0.4,2.0	0.01	−2.1,2.1
Severe TBI	91.9	70.4	79.4	82.3	82.7	−11.3	−24.9,2.4	**−13.2**	**−18.9,−7.5**	−3.1	−11.5,5.4	−3.9	−8.0,0.3

[a]Mean values for the measure at the time indicated in the heading. The means in month 0 are of the parent's assessment of pre-injury functioning collected soon after the injury.
[b]Adjusted for arm injury controls, age, child gender, child race, insurance, and household income.
[c]Only measured in children ≥60 months old.
Changes that are significantly different from 0 are shown in boldface.
CASP, Child and Adolescent Scale of Participation; TBI, traumatic brain injury; ABAS, Adaptive Behavior Assessment Scale; CI, confidence interval.

Table 3. Scores on the Pediatric Quality of Life Scale for Children 60 Months or Older at the Time of Assessment

	Mean at month[a]					*Change 0–36 months*				*Change 24–36 months*			
	0	*3*	*12*	*24*	*36*	Δ	*95% CI*	*Adjusted net difference*[b]	*95% CI*	Δ	*95% CI*	*Adjusted net difference*[b]	*95% CI*
No.[c]	**767**	**747**	**746**	**770**	**766**								
Arm injury	89.3	86.1	86.7	86.0	85.5	**−4.0**	**−5.7,−2.2**	ref		−0.5	−1.8,0.9	ref	
Mild TBI													
I	85.6	81.1	82.1	82.0	82.0	**−4.1**	**−5.5,−2.7**	−0.2	−2.8,2.3	0.4	−0.7,1.6	0.8	−1.1,2.8
II	87.6	83.1	82.7	83.9	86.3	−1.8	−5.9,2.3	1.5	−4.4,7.4	0.9	−3.9,5.6	0.6	−4.2,5.4
III	85.9	79.8	81.5	84.5	83.5	**−4.4**	**−7.3,−1.5**	−0.7	−4.4,3.1	−1.2	−3.4,0.9	−0.9	−3.7,2.0
Moderate TBI	90.9	73.6	75.8	75.4	71.3	**−20.3**	**−25.1,−15.6**	**−16.1**	**−20.0,−12.2**	**−4.1**	**−7.1,−1.1**	**−3.7**	**−6.8,−0.6**
Severe TBI	87.5	54.4	61.1	68.1	67.2	**−21.9**	**−32.1,−11.7**	**−17.9**	**−26.2,−9.7**	−2.3	−9.1,4.5	−2.1	−8.6,4.3

[a]Mean values for the measure at the time indicated in the heading. The means in Month 0 are of the parent's assessment of pre-injury functioning collected soon after the injury.
[b]Adjusted for the change in scores of arm injury controls, age (continuous), gender, race, insurance, respondent education, and household income.
[c]Only measured in children ≥24 months of age.
Changes that are significantly different from 0 are shown in boldface.
TBI, traumatic brain injury; CI, confidence interval.

PedsQL was never more than 38.5%, suggesting unmet need for at least some children.[33] Similarly, Slomine and associates[34] reported that 31% of children 12 months after TBI were viewed by their parents as having unmet health care needs, the most frequent of which was the need for cognitive services. In another study, 45% of parents reported that their child did not receive all the services needed during the mean of 4 years after their TBI.[35] An important limitation of the study is that we did not collect detailed data on therapy that patients received after discharge from the inpatient setting. In addition, there is a lack of national standards on the rehabilitation interventions children with TBI should receive, and wide variations both within and across institutions in the nature of care delivered.[36] There has also been a relative dearth of randomized controlled trials in the rehabilitation of children with TBI, especially trials on patients beyond the first year after injury. Finally, confounding by indication makes it difficult to determine whether the lack of improvement seen between 24 and 36 months was due to the lack of a particular intervention in those who did not improve.

Quality of life, as measured by the PedsQL, provides an overall assessment of functioning. Differences of 4–5 points on this scale represent clinically meaningful differences in function. Children with moderate-to-severe TBI had differences from baseline that were 3- to fourfold higher. In adults after childhood TBI, quality of life correlated closely with the individual's self-perceived level of independence.[37] We also found a slightly lower quality of life in children in the Mild TBI III group. Moran and colleagues have shown that lower quality of life in children with mild TBI correlates with more post-concussive symptoms at initial assessment.[3]

There are a number of implications of our study for future research. The reasons for the variability in outcomes are unknown, and efforts to better detail the location and nature of the injury, as well as to assess the genetic contributions to recovery are needed; such information can provide more accuracy in prognostic discussions for families and patients. Controlled trials of interventions at different time points after injury would help to determine if the types of interventions that are needed and effective change during the pathway of recovery.

In summary, recovery after TBI appeared to plateau between 24 and 36 months. In this study, children with moderate and severe TBI had substantial deficits that persisted over time. Interventions are needed to decrease the impact of these deficits on function and quality of life.

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Author Disclosure Statement

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