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Longitudinal Follow-up of Families and Young Children With Traumatic Brain Injury

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ABSTRACT

OBJECTIVES. To examine the stability of functional outcomes 2 years after injury among children who sustained a traumatic brain injury (TBI) before 2 years of age and to examine the characteristics of the families caring for these children.

METHODS. All North Carolina-resident children who were hospitalized between January 2000 and December 2001 in any of the state's 9 PICUs and survived a TBI that occurred on or before their second birthday were eligible to participate in the prospective cohort study. Child health status, use of ancillary medical resources, and family characteristics were assessed through maternal caregiver interviews ~2 years after injury. Comparisons were made among injury types (inflicted versus noninflicted).

RESULTS. There were 112 children who survived a TBI during the 2-year study period. Fifty-seven (79%) of the 72 maternal caregivers who had completed an interview 1 year after the child's injury participated in the year 2 interview. Most children (67%) had an outcome of mild disability or better at year 2, with 45% functioning at an age-appropriate level. Children's outcomes did not differ significantly at year 2 according to the mechanism of injury. The majority (67%) of children retained their Pediatric Overall Performance Category scores from year 1 to year 2. Children who changed were as likely to show improvement as deterioration. Children differed very little across time, as measured with the Stein-Jessup Functional Status II (Revised) scale. Families tended to have multiple environmental factors that could put their children at risk for poor developmental outcomes, including living below the poverty level (22%) and low social capital (39%).

CONCLUSIONS. The children in this cohort had relatively stable functional outcomes from year 1 to year 2 after injury. This population of children remains very vulnerable to poor developmental outcomes secondary to the effects of their TBI and environmental factors.

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Key Words

traumatic brain injury, outcomes, child abuse, shaken baby syndrome

Abbreviations

CI—confidence interval
 FSII(R)—Functional Status II (Revised)
 GCS—Glasgow Coma Scale
 IQR—interquartile range
 POPC—Pediatric Overall Performance Category
 RR—relative risk
 TBI—traumatic brain injury

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THE PERIOD FROM infancy to the toddler stage is a time of rapid social, cognitive, and behavioral development. As a result, parents of young children look forward to watching the developmental stages of their infants as they become toddlers. Children who sustain a traumatic brain injury (TBI) may not follow the normal developmental trajectory, although they may make developmental gains.¹ How children develop over time after early brain injury is not well studied, although it is thought that rapid gains in development plateau 6 months after injury.²

We monitored, for 2 years after the injury event, a cohort of children who sustained either inflicted or non-inflicted TBI. In this report, we examine the functional outcomes of children at 2 years after discharge from the hospital and assess any changes in the children's functional outcomes from 1 to 2 years after discharge from the hospital. We hypothesized that deficits might become more apparent to maternal caregivers at 2 years after injury than at 1 year after injury if children failed to follow a normal developmental trajectory. We characterized the ongoing need for services that children demonstrated between the first and second years after hospital discharge, as well as family characteristics that might affect the meeting of those needs.

METHODS

Study Cohort and Follow-up Monitoring

This study was reviewed and approved by the institutional review boards at the University of North Carolina at Chapel Hill and the University of Utah. All North Carolina-resident children <2 years of age who were injured between January 2000 and December 2001, suffered a TBI severe enough to require hospitalization in an ICU, and had pathologic or radiographic evidence of a brain injury were eligible for inclusion in the study. This study population has been described previously.³ Briefly, each ICU was called 3 times per week by study personnel, who inquired whether any child meeting the study criteria had been admitted to the unit. In addition, a medical records review was performed every 6 months, to ensure that no qualifying patient was missed. The 3 closest out-of-state hospitals also performed record reviews, to ensure that no North Carolina resident injured in North Carolina had been transported to an out-of-state hospital. The maternal caregiver (either the biological or foster mother) or the Department of Social Services worker for each surviving child was asked for permission to enroll the child in a follow-up study of child health outcomes. Postcards were sent quarterly to all enrolled families, to track families who moved and to provide them with a toll-free telephone number with which they could contact the investigators with their changed address and telephone number. Maternal caregivers were interviewed 1 and 2 years after their child's

hospital discharge. Year 1 and 2 interviews included information on the child's functional status, use of ancillary medical resources, and family characteristics. In addition, year 2 interviews included direct questions about the family's socioeconomic status. Each interview lasted ~45 minutes.

Children's Outcomes

Children's outcomes were assessed with 3 separate instruments. The first was the Pediatric Overall Performance Category (POPC) scale, which was used at hospital discharge, posttrauma year 1, and posttrauma year 2. This scale is a composite measure of functional morbidity and cognitive outcome.⁴ The POPC scale has been related significantly to the Bayley Psychomotor Development Index and the Vineland Adaptive Behavior Scales.⁵ Children's outcomes are ranked from 1 to 6. A score of 1 indicates that the child is healthy, alert, and capable of age-appropriate activities. A score of 6 indicates death. Because of the difficulty in detecting mild delays among very young children, for some analyses we categorized the POPC results into good and poor outcomes. Children were considered to have good outcomes if they scored 1 or 2 on the POPC scale, consistent with mild disability at most. Children were considered to have poor outcomes if they scored 3 or 4 on the POPC scale, consistent with moderate to severe disability. There were no survivors in a vegetative state (POPC score of 5). The POPC score was obtained through direct questions about the child's ability to perform age-appropriate activities, use of rehabilitative services, and physical disabilities.

The second outcome measure used was the short-form (14-item) Stein-Jessup Functional Status II (Revised) [FSII(R)] scale.⁶ This scale is designed to measure the health status of children who have ongoing health conditions. It measures behavioral inventories associated with the child's condition that interfere with the child's age-appropriate activities. This scale was compared previously with population normative values for ages 1 through 17 years. The short form has validity equal to that of the long form. Among well children, the mean score is 96.1 ± 8.2 ; among children who are ill, the mean score is 86.8 ± 15.7 .⁶

The third measure was the Global Health Index.⁷ This measure is used to assess the respondent's perception of 5 areas of their child's development, including the child's general health, physical well-being, role functioning, psychological distress, and social functioning. Each area is measured with a 4-point Likert scale, with higher numbers indicating better performance.

Family Characteristics

Family characteristics, including whether the child was in the home of origin, the age, educational status, and marital status of the maternal caregiver, and whether the maternal caregiver was employed, were assessed.

Data on paternal caregivers' educational status and employment status were collected during the maternal interview. A paternal caregiver was defined as a male partner identified by the mother, regardless of marital status. The maternal caregiver's social capital was also assessed. Social capital is a measure of a person's social relationships in his or her community and family.⁸ The social capital index used for this study was composed of questions about maternal social support, neighborhood support, church attendance, the number of children in the home, and whether the maternal caregiver had a partner. This instrument was used previously in a set of longitudinal studies of preschool-aged children at high risk for poor developmental outcomes because of adverse social or economic conditions. The social capital index was associated strongly with the child's well-being; scores of ≥ 4 were associated with children faring well, and scores of < 4 were associated with children faring poorly.⁹

In addition, in the year 2 interviews, information was collected on the families' socioeconomic status with the Hollingshead 4-Factor Index of Social Status.¹⁰ The Hollingshead Index has a range from 8 to 66, with higher numbers indicating higher social status. Social status is determined by factors such as gender, marital status, education, and occupation. Each family's financial capital was assessed through direct questions about all sources of the family's pretax income. The maternal caregiver was asked in which income bracket (in \$5000 increments up to \$50 000) her family resided. Family income was compared with the North Carolina poverty level for the year 2000.¹¹ This information was not collected in the year 1 interviews.

Statistical Analyses

Child and family characteristics were examined with frequencies and percentages. Comparisons were made between children and families with inflicted versus non-inflicted injuries with χ^2 analysis. Means with SDs were calculated for normally distributed data, and medians with interquartile ranges (IQRs) were calculated for nonnormally distributed data. The change in POPC scores was examined from the hospital discharge to posttrauma year 1 and from posttrauma year 1 to posttrauma year 2. Continuous scales were compared from year 1 to year 2 with the *t* test if normally distributed and the Mann-Whitney *U* test if nonnormally distributed. A cumulative logarithmic regression model using the generalized estimating equation to account for the correlation between measures obtained for a patient over time was used to assess whether there were changes in POPC scores over all 3 time periods and to assess interactions between time and mechanism of injury.

A logistic regression analysis was used to examine hospital predictors of year 2 outcomes, dichotomized as good (POPC scores of 1 or 2) or poor (POPC scores of 3

or 4). Covariates that were associated significantly with outcomes at hospital discharge or year 1 or were significant at the .05 level in bivariate analyses were placed in the model. Covariates that did not change the estimate by $\geq 10\%$ were then removed in a stepwise manner.

Poverty level was calculated by using the highest number of the self-identified income bracket, divided by the number of people that income supported. This value was then compared with the North Carolina state poverty level.

Medical Resources

Children's use of ancillary medical resources was evaluated through maternal report. Items included whether the child had a primary pediatrician, medication use, use of home health services, and use of occupational, physical, and speech therapies. Children who used ≥ 2 therapies > 1 time per week were categorized as "high users" of resources. Children were compared between assessments performed at year 1 and year 2.

RESULTS

A total of 112 children with TBI were admitted to any of the 9 ICUs in the state during the 2-year study period and were discharged alive from the hospital. There were 72 children and families (64.3%) who completed the year 1 evaluation and were eligible for the year 2 evaluation. Of the 72 children eligible, 57 (79%) completed evaluations at posttrauma years 1 and 2 (50.9% of all children injured during the 2-year study period). Reasons for not completing the year 2 interview included inability to contact the family ($n = 11$), return of the child to the custody of the biological parent and inability to obtain consent ($n = 2$), inability to schedule the evaluation ($n = 1$), and withdrawal from the study ($n = 1$). The median age of the child at the time of injury in this cohort was 0.4 years (IQR: 0.2–0.8 years). Children in the inflicted-TBI group were substantively younger at the time of injury than were those in the noninflicted-TBI group (0.3 years [IQR: 0.2–0.5 years] vs 0.7 years [IQR: 0.1–1.6]; $P = .03$). The child and injury characteristics of children who completed both evaluations and children from the initial group of all injured children who survived their injuries are presented in Table 1. Child and injury characteristics were similar for all 3 groups, except that children who were neither black nor white were less likely to be represented in year 2 interviews. Family characteristics at year 1 and year 2 were similar; however, maternal caregivers interviewed at year 2 were more likely to be married than those interviewed at year 1 (Table 2). In addition, 7 children had adoptive parents by 2 years after injury.

The year 2 evaluations showed that 37 children (64.9%) had good outcomes (POPC scores of 1 or 2) and 20 (35.1%) had poor outcomes (POPC scores of 3 or 4). There was no statistical difference in outcomes (POPC

TABLE 1 Characteristics of Children and Families Who Participated in Year 1 (*n* = 72) and Year 2 (*n* = 57) Evaluations and Those From the Initial Study Population Who Did Not Participate in Year 2 Evaluations (*n* = 55)

	Year 1	Year 2	Nonparticipant
Child age at interview, median (IQR), y	1.5 (1.3–2.0)	2.6 (2.4–3.0)	0.5 (0.25–0.75)
Gender, <i>n</i> (%)			
Male	42 (58.3)	34 (59.6)	33 (60.0)
Female	30 (41.7)	23 (40.4)	22 (40.0)
Injury type, <i>n</i> (%)			
Inflicted	41 (56.9)	33 (57.9)	29 (52.7)
Noninflicted	31 (41.7)	24 (42.1)	26 (47.3)
GCS score category, <i>n</i> (%)			
13–15	40 (55.5)	33 (57.9)	27 (49.1)
9–12	14 (19.4)	10 (17.5)	12 (21.8)
3–8	17 (23.6)	14 (24.6)	14 (25.5)
Missing	1 (1.4)	0 (0)	2 (3.6)
Race/ethnicity, <i>n</i> (%)			
White	33 (45.8)	27 (47.4)	26 (47.3)
Black	28 (38.9)	26 (45.6)	17 (30.9)
Other minority	4 (5.6)	4 (7.0)	12 (21.8)
Refused/missing	7 (9.7)		

scores) 2 years after injury according to the mechanism of injury (relative risk [RR] of moderate to severe disability among children with inflicted TBI: 1.6; 95% confidence interval [CI]: 0.8–3.4).

POPC outcomes were examined for 3 times, ie, discharge from the hospital, year 1 interview, and year 2 interview (Table 3). The hospital discharge POPC score was generally reflective of the year 2 POPC score. Of the 19 children with normal outcomes (POPC score of 1) at hospital discharge, the majority (73.6%) seemed to have no deficits at the time of the year 2 interview. However, 4 children had mild deficits recognized, and 1 child had a moderate deficit recognized. Sixteen children had mild deficits at hospital discharge (POPC score of 2). Of these 16, 11 were thought to have no deficits by year 2. However, 3 children were recognized to have moderate deficits by 2 years after discharge from the hospital. Therefore, of the 35 children with good outcomes (POPC scores of 1 or 2) at discharge, 31 (89%) still had good outcomes 2 years later. However, 8 children (22.8%) had additional deficits recognized.

Of the 22 children with poor hospital discharge POPC results (POPC scores of 3 or 4), 4 of the 10 children with moderate deficits (POPC scores of 3) improved to the mild category by year 2, whereas 3 had additional deficits recognized. Among the most severely impaired children (POPC scores of 4), 2 improved to the mild/no deficit category and 4 improved to the moderate category by 2 years after discharge from the hospital. Therefore, 6 (27.3%) children had improved to the good category, whereas the remainder continued to have poor outcomes.

The majority of children (66.7%) did not change their

TABLE 2 Family Characteristics of Children Who Participated in Year 1 and Year 2 Interviews

	Year 1	Year 2
Family characteristics		
Maternal caregiver age, median (IQR), y	29 (24–41)	31 (27–41)
Marital status, <i>n</i> (%)		
Yes	33 (45.8)	41 (71.9)
No	39 (54.2)	16 (28.1)
Maternal education, <i>n</i> (%)		
Less than high school	18 (25.0)	14 (24.6)
At least high school	54 (75.0)	43 (75.4)
Paternal education, ^a <i>n</i> (%)		
Less than high school	7 (22.6)	10 (24.4)
At least high school	15 (48.4)	30 (73.2)
Missing	9 (29.0)	1 (2.4)
Relationship of maternal caregiver to child, <i>n</i> (%)		
Biological parent	50 (69.4)	41 (71.9)
Adoptive parent	0 (0)	7 (12.3)
Foster parent (relative)	12 (16.7)	6 (10.5)
Foster parent (unrelated)	10 (13.9)	3 (5.3)
Social capital index, <i>n</i> (%)		
≥4	41 (56.9)	32 (56.1)
<4	31 (43.1)	22 (38.6)
Missing		3 (5.3)
Financial capital		
Maternal caregiver employed, <i>n</i> (%)		
Yes	46 (63.9)	39 (68.4)
No	26 (36.1)	18 (31.6)
Paternal caregiver employed, <i>n</i> (%) ^a		
Yes	27 (87.1)	36 (87.8)
No	2 (6.5)	5 (12.2)
Missing	2 (6.5)	
Family employment (in 2-parent households), <i>n</i> (%)		
Dual employment	17 (54.8)	26 (63.4)
One parent employed	11 (35.5)	13 (31.7)
Both parents unemployed	1 (3.2)	2 (4.9)
Missing	2 (6.4)	

^a Paternal caregivers were adult men identified by the maternal caregiver as a partner.

POPC scores between the year 1 and year 2 evaluations. Of the 31% who exhibited changes, children were as likely to show improvement (17.5%) as deterioration (14.0%). No child changed by >1 POPC point between year 1 and 2, with only 2 children changing from a poor to good outcome. When POPC scores for assessments at all 3 time points were placed in a cumulative logarithmic regression model, there was no significant change in POPC scores overall (*P* = .1); however, when mechanism of injury was added to the model, there was a significant interaction between time of assessment and injury type (*P* = .02). Children with noninflicted injuries tended to have increases in their POPC scores over time, compared with children with inflicted injuries.

Overall, children showed no substantive differences between the year 1 and year 2 interviews, as evaluated with the FSII(R) (*P* = .3). In addition, the FSII(R) showed no appreciable differences between the inflicted-TBI and noninflicted-TBI groups at the year 2 evalu-

TABLE 3 Child Outcomes at Hospital Discharge, Year 1, and Year 2 After TBI (n = 57)

	Hospital Discharge	Year 1	Year 2	RR (95% CI) or P
POPC, n (%)				
Good	19 (33.3)	24 (42.1)	26 (45.6)	
Mild	16 (28.1)	12 (21.0)	11 (19.3)	
Moderate	10 (17.5)	11 (19.3)	11 (19.3)	
Severe	12 (21.0)	10 (17.5)	9 (15.8)	
FSII(R) score, median (IQR)				
All children		100 (78.5–100.0)	100 (92.8–100.0)	.3
Inflicted TBI		96.4 (75.0–100.0)	100 (92.8–100.0)	.2
Noninflicted TBI		100 (92.8–100.0)	100 (92.8–100.0)	.8
Global Health Index, median (IQR)		21 (17–23)	22.0 (19–24)	.2
Resource use, n (%)				
High use		19 (33.3)	17 (29.8)	0.9 (0.6–1.4)
Low use		38 (66.7)	40 (70.2)	
Physical therapy, n (%)				
Weekly or more		22 (38.6)	16 (28.1)	0.8 (0.5–1.2)
Less than weekly or none		35 (61.4)	41 (71.9)	
Occupational therapy, n (%)				
Weekly or more		17 (29.8)	13 (22.8)	0.8 (0.5–1.3)
Less than weekly or none		40 (70.2)	44 (77.2)	
Speech therapy, n (%)				
Weekly or more		7 (12.3)	17 (29.8)	1.6 (1.1–2.3)
Less than weekly or none		50 (87.7)	40 (70.2)	

ation ($P = .4$) and no longitudinal differences within the groups across time (inflicted TBI, year 1 to year 2 interviews: $P = .2$; noninflicted TBI, year 1 to year 2 interviews: $P = .8$). There was also no appreciable change in the scores on the Global Health Index between year 1 and year 2 evaluations.

Logistic regression modeling was performed to analyze whether there were hospital covariates associated with outcomes (good versus poor on the POPC scale) at year 2. The only significant predictor was a Glasgow Coma Scale (GCS)¹² score of ≤ 12 . Children with GCS scores of ≤ 12 had adjusted odds of 4.2 (95% CI: 1.1–16.3) of having poor outcomes, compared with children with GCS scores of ≥ 13 , after adjustment for mechanism of injury (inflicted versus noninflicted), presence of seizures, and gender. Whether the child had received cardiopulmonary resuscitation was not included in the model. However, precision was poor because of small numbers in some cells.

A group of children continued to need intensive rehabilitative therapy 2 years after injury (Table 3). More than one fourth (26.3%) of the children remained in formal rehabilitation programs. Sixteen children (28%) had weekly or more physical therapy, 13 (22.8%) required weekly or more occupational therapy, and 17 (29.8%) received weekly or more speech therapy. More children were receiving speech therapy at year 2 than at year 1 (12.3% vs 29.8%). When resource use was categorized into high use (2 of 3 service types at least once weekly) versus low use, one third (29.8%) of children were high resource users. However, this did not vary according to inflicted versus noninflicted injury (RR: 1.3;

95% CI: 0.6–2.6) or race (RR for minority patient having low resource use: 0.8; 95% CI: 0.6–1.1). No child with a good outcome (POPC score) was a high resource user, with the majority of services being focused on children with poor outcomes. Families living below 2 times the poverty level tended to have lower use of ancillary resources (RR of low resource use if below 2 times the poverty level: 0.6; 95% CI: 0.4–1.0), compared with families living above 2 times the poverty level. There were 17 children receiving regular medications. Of the children receiving medications, most (70.5%) were taking anticonvulsants because of ongoing seizure disorders. More children with inflicted injuries required anticonvulsant therapy, compared with children with noninflicted injuries (RR: 1.5; 95% CI: 1.0–2.3). Almost all children (94.7%) had a primary care doctor.

Income and socioeconomic data were collected from the families at the year 2 interview (Table 4). Families tended to be poor, with ~50% of families at less than 2 times the poverty level and 20% of families at less than the poverty level. This reflects a higher prevalence of poverty than the 12.3% of North Carolinians reported to be at or below the poverty level throughout the state in 2000.¹¹ Dual employment was common, with 63.4% of 2-parent households and 26 of all 57 families (45.6%) reporting 2 working adults. The Hollingshead Index reflects a wide range of parental social status, which did not differ according to mechanism of injury (median index: 29 and 27 for inflicted and noninflicted TBI groups, respectively; $P = .8$). When the Hollingshead Index results were divided into groups above and below the median, children's outcomes on the POPC were not

TABLE 4 Socioeconomic Data for Families Participating in the Year 2 Interview

Grouped annual family income (all sources), <i>n</i> (%)	
<\$20 000	21 (36.8)
\$20 000 to <\$30 000	10 (17.5)
\$30 000 to <\$50 000	13 (22.8)
>\$50 000	11 (19.3)
Missing	2 (3.5)
Below poverty level, <i>n</i> (%)	
Yes	12 (21.8)
No	55 (78.2)
Below 2 times poverty level, <i>n</i> (%)	
Yes	29 (52.7)
No	26 (47.3)
Hollingshead Index of Social Status	
Median (IQR)	27.8 (24–42.5)
Range	11–63

associated statistically with the Hollingshead Index results (RR: 0.8; 95% CI: 0.5–1.2).

DISCUSSION

The main finding of this study is that more than one half of the children with severe TBI had good outcomes at evaluation 2 years after hospital discharge and their functional outcomes remained relatively stable from year 1 to year 2 evaluations. The stability seen between the year 1 and year 2 evaluations was maintained regardless of the mechanism of injury. The second important finding from this study is that many families caring for children in this cohort with early TBI faced multiple challenges, including low social and financial capital. These factors may be important in the developmental outcomes of the injured children.

Our study showed that functional outcomes between year 1 and year 2 evaluations did not change substantively, as measured with either the POPC or the FSII(R). Deficits noted in hospital discharge POPC results were maintained in the majority of cases, and POPC scores did not change dramatically between year 1 and year 2. Children with inflicted injuries were less likely to have stability in their POPC scores when examined at 3 time points, including hospital discharge, year 1, and year 2, compared with children with noninflicted injuries; however, year 1 to year 2 POPC scores tended to remain stable in both the inflicted-TBI and noninflicted-TBI groups. This is consistent with results of a previous study of young children with TBI, which showed variable recovery during the first 6 months after recovery from posttraumatic amnesia and then stable persistent deficits.² The need for an increase in speech therapy as the children grow older is also supported by deficits in expressive language noted among children with mild or moderate TBI.² These deficits are more likely to be noticed as children grow older. However, it should be noted that the children in the study of TBI by Ewing-Cobbs et al² had a median age of injury of 41 months and

the study excluded children who were victims of abuse; therefore, the cohorts are not entirely comparable. Longitudinal studies of very young children suffering TBI are sparse; however, studies of older children (5–15 years of age) suggest that the full consequences of brain injury may not be seen in the first several years after injury. Importantly, growth curves of academic achievement among older children declined over time in the youngest cohort of children.¹

Children with inflicted versus noninflicted injuries had similar functional outcomes at the year 1 and year 2 evaluations. No substantive differences were seen across time within groups. The most important predictor of poor outcome (POPC scores of 3 or 4) at 2 years after discharge was a GCS score of ≤ 12 , although precision was poor. This highlights the difficulty in predicting longer-term outcomes for children after TBI. Whether these 2 groups of children will diverge in outcomes eventually or might differ importantly with more precise testing is unknown.

Many more families in this injured cohort were living below the poverty level than would be expected on the basis of state normative values. This is despite the fact that many families had 2 working adults. This cohort also had a low median Hollingshead Index, compared with a brain-injured cohort from Houston¹³ (Hollingshead Index of 46 for the severely injured group), which indicates that many families had a combination of occupations with low social prestige (such as unskilled labor), low educational achievement, and unmarried status. Social capital was low for ~40% of families, which puts children at additional disadvantage.⁹ Children from households with multiple risk factors, including low socioeconomic status, have been shown to have worse developmental and behavioral outcomes.¹⁴ A combination of multiple risk factors puts children at higher risk, compared with a single risk factor, showing a dose-response effect. Sameroff et al¹⁵ found that environmental factors were more predictive of preschool intelligence than were child factors for a group of uninjured children. Environmental factors that were considered included minority group status, maternal education, family social support, family size, and stressful life events, among others. Caring for a brain-injured child has been shown to be more stressful to families than caring for a child with orthopedic injuries.¹⁶ Therefore, this group of children should be considered at high risk for poor development and preschool performance secondary to environmental risk factors, as well as their brain injury.

This study has limitations. There is selection bias, because we were unable to retain all families in the study. It is possible that families with higher levels of coping and organizational skills were more likely to be able to make and keep appointments for telephone interviews, thus biasing our findings toward families with better coping abilities. In addition, it is possible that

families whose children were faring well might think that the developmental evaluations would be of less benefit to their children than families of children who were faring poorly. However, when families that were eligible to participate but chose not to have their children evaluated were compared with those whose children were evaluated at year 2, the groups were similar except for the loss of nonwhite and nonblack subjects. The 2 groups could differ in other ways not measured in this study. It is also possible that our instruments were not fine enough to measure more-subtle distinctions in children's outcomes. Cognitive disabilities may not be reflected adequately by functional testing in this group of children and may be more important predictors of future school performance. It is also possible that parents thought that the child was progressing well and did not report difficulties because the child had made progress since the injury event. Finally, it is unclear whether foster or adoptive parents might rate children's deficits differently than biological parents who knew the child before the injury.

This study also has strengths. It represents 2 years of follow-up monitoring for a cohort of children who were injured at similar ages, from a statewide population. Unlike other studies, it does not exclude children with inflicted injuries, who represent approximately one half of all children <2 years of age with brain injuries. It also allows for comparisons of child outcomes and family characteristics between the inflicted-TBI and noninflicted-TBI groups.

CONCLUSIONS

This cohort of young children showed little change in functional outcomes from the year 1 to year 2 evaluations after discharge from the hospital. It is encouraging that almost one half of the children seemed to have good outcomes 2 years after injury. However, these children remain a vulnerable population. Many of the children are cared for by socially disadvantaged families, which may increase the risk for poor behavioral and health outcomes. In addition, it is not known whether the developmental trajectory of these very young brain-injured children will slow as they grow older or whether they will develop behavioral problems, as a result of their brain injuries, that will interfere with their school performance. The outcome measures used in this study are functional outcomes and may not be predictive of future cognitive performance, especially for the group faring well or showing mild disability. It is not known currently whether any type of early childhood interventions would be useful for this population. It is possible that early cognitive and social interventions designed to support the mother and provide an improved environment for the child, such as the intensive nurse visiting program designed by Olds et al,¹⁷ would be advantageous and improve outcomes for both the family and the child.

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