Health-Related Quality of Life of Children and Adolescents After Traumatic Brain Injury

Terry Stancin, PhD*; Dennis Drotar, PhD‡; H. Gerry Taylor, PhD¶; Keith Owen Yeates, PhD§; Shari L. Wade, PhD‖; and Nori Mercuri Minich, BS‡

ABSTRACT. Objective. Relatively little is known about the longer-term impact of traumatic brain injury (TBI) on children’s daily functioning, especially the broader outcome domain referred to as health-related quality of life (HRQL). The objective of the present study was to examine the nature and predictors of HRQL outcomes in children in moderate to severe TBI an average of 4 years postinjury.

Methods. The study used a concurrent cohort-prospective design involving postinjury assessments of 3 groups of traumatically injured children and their families including 42 with severe TBI, 42 with moderate TBI, and 50 with orthopedic injuries only. Parent and child self-report cysts of HRQL and adaptive behavior measures were obtained along with parent descriptions of the child’s health problems and use of medical and mental health services. Predictors included indices of injury severity, social factors, and ratings of preinjury child behavior problems and school performance.

Results. Based on parent report, adolescents who sustained severe TBI had lower HRQL related to overall psychosocial functioning and in the domains of behavior, mental health, general health, and family impact than adolescents who sustained orthopedic injuries only. Communication skills, daily living skills, and general adaptive functioning also were rated lower in the severe TBI group. In contrast to parent reports, adolescents with severe TBI did not rate their HRQL in most domains differently than did adolescents with orthopedic injuries. There were no group differences in frequency of persistent physical limitations. Sixty-seven percent of families of children with severe TBI used mental health counseling at some point after the injury. Risks for poorer HRQL outcomes were related to family social disadvantage and poorer preinjury child behavior problems and school performance.

Conclusions. Findings underscore the importance of using comprehensive measures of HRQL, along with traditional indicators of functional outcomes, when evaluating the longer-term impact of injuries in children. Identification of predictors suggests the need for close monitoring and intervention of high-risk children.

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Received for publication June 29, 2001; accepted Nov 5, 2001.

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PEDIATRICS (ISSN 0031-4005). Copyright © 2002 by the American Academy of Pediatrics.

pediatrics.org/cgi/content/full/109/2/e34; traumatic brain injury, health-related quality of life, functional outcomes.

ABBREVIATIONS. TBI, traumatic brain injury; HRQL, health-related quality of life; CNS, central nervous system; GCS, Glasgow Coma Scale; MISH, Modified Injury Severity Score; SCL, Socioeconomic Composite Index; FAD, Family Assessment Device; FAD-GF, Family Assessment Device General Functioning Scale; CHQ, Child Health Questionnaire; SD, standard deviation; WHO, World Health Organization; CBCL, Child Behavior Checklist; TRF, (Child Behavior Checklist) Teacher’s Report Form; OR, odds ratio; CI, 95%; confidence interval; SE, standard error.

Study of the functional status of children with traumatic brain injury (TBI) is justified by both the prevalence of the condition and the multifaceted nature of injury sequelae. Annual hospital admissions for TBI range from 180 to 230 cases per 100,000 children under the age of 15 years.1 Sequelae are most prominent in children with severe TBI and include cognitive deficits, poor academic achievement, and behavior problems.2–5 Although some recovery in cognitive abilities has been demonstrated,6 consequences are long lasting.7 TBI also results in long-term family adversity.8–14

Unfortunately, relatively little is known about the impact of TBI on children’s daily functioning. Such data are important for 2 major reasons. First, documentation of effects on children’s functioning would clarify the types and range of impairments and disabilities in this population.7,15 Second, examination of these functional outcomes would provide information relevant to the needs of children for medical, mental health, and educational interventions. For example, recent data indicate that a majority of children with severe TBI receive postinjury special education services.16

Although previous studies have documented the effects of TBI on children’s adaptive behavior skills,4,7,10,17,18 other aspects of children’s functional status have received little attention. Several studies have demonstrated that functional disability is common within the year after a pediatric injury.19–22 Measures of functional outcome often have relied on parent reports of limitations in role activity, physical activity, self-care, and mobility. Although TBI is associated with the most disabling sequelae, children with other traumatic injuries also have a high prevalence of functional limitations.21 Moreover, TBI and persistent physical limitations have been shown to place children at risk for psychosocial morbidity, including behavioral, academic, and family adjust-
ment problems. Resultant family financial burdens are substantial. To our knowledge, the broader outcome domain referred to as health-related quality of life (HRQL) has not been previously examined in children with TBI. Indices of functional outcome, including physical health limitations, adaptive behavior, educational status, and physical and mental health service utilization can be subsumed under this rubric. A major benefit of measures of HRQL is that they provide a comprehensive description of well-being in physical, mental, and social domains as perceived by the child and others in the child’s environment. Previous studies of TBI assessed functional outcomes rather than HRQL, had relatively small samples, used short follow-up intervals, and failed to evaluate children’s self-perceptions of their functioning, an important aspect of quality of life assessments.

To address these limitations and obtain more information on longer-term functional sequelae of pediatric TBI, we examined HRQL in children with moderate to severe TBI at an extended follow-up conducted a mean of 4 years postinjury. Outcomes for children and adolescents with TBI were compared with those for children who were hospitalized for orthopedic injuries only. We also explored predictors of poorer HRQL outcomes in the 2 TBI groups. We hypothesized that children with TBI would have lower HRQL at the extended follow-up than the children in an orthopedic-injury-only comparison group. We further hypothesized that these sequelae would be more pronounced in children with severe TBI than in children with moderate TBI, and that perceptions of HRQL would be associated with adaptive behavior skills, health care utilization, and educational status. Our final hypothesis was that poorer HRQL in children with TBI would be predicted by factors in addition to TBI group (severe versus moderate), including other injury characteristics, greater preinjury problems in behavior and school performance, and environmental disadvantage.

### Methods

**Design**

The study used a concurrent cohort prospective design involving repeated postinjury assessments of 3 groups of traumatically injured children and their families. The groups included children with severe TBI, moderate TBI, and orthopedic injuries not associated with central nervous system (CNS) insult (ORTHO group). The rationale for including the ORTHO group was to permit assessment of outcomes of TBI relative to those of non-CNS-related trauma. Inclusion of the ORTHO group also controlled for background factors associated with prouness to accidental injury and for the experience of hospitalization.

Children and their families were invited to participate in the study at the time of hospitalization for injuries after the children were medically stable and parents gave informed consent. Parents completed measures pertaining to the child’s preinjury behavior and functioning shortly after recruitment. A baseline assessment was completed an average of 3 weeks postinjury. Assessments included collection of family data, parent ratings of child behavior, and child neuropsychologic testing. In addition, schools were contacted for information about children’s academic performance and behavior. The present report focuses on HRQL measures obtained at the extended follow-up.

### Sample Characteristics

Children were recruited by monitoring admissions for school-aged children with traumatic injuries at 4 hospitals in north-central Ohio. Criteria for inclusion in the sample were hospitalization of at least 1 night’s duration either for moderate or severe TBI or for orthopedic trauma not involving brain insult, age at injury between 6 and 12 years, the absence of evidence of child abuse or previous neurologic disorder, and residence in an English-speaking household. Following Fletcher et al. children with TBI were classified into 2 severity groups. Severe TBI was defined on the basis of a lowest Glasgow Coma Scale (GCS) score of 8 or less. Moderate TBI was defined in terms of a lowest GCS score of 9 to 12, or a GCS score >12 accompanied by a skull fracture, intracranial mass, lesion, or contusion, diffuse cerebral swelling, posttraumatic neurologic abnormality, or loss of consciousness for >15 minutes. Children with brain insults that did not fall into the category of closed-head injuries were excluded (e.g., brain injury attributable to near-drowning or toxins, projectile wounds, stroke). Although many children in the TBI group had accompanying orthopedic injuries, the ORTHO group was limited to children without symptoms suggestive of CNS insult (e.g., symptoms of concussion, severe facial trauma).

The severity of traumatic injuries sustained by children in the sample was measured by computing Modified Injury Severity Scale (MISS) ratings. These ratings were defined as the sum of the squares of injury ratings for the 3 most affected body regions, including the head. Partial MISS ratings were also computed to provide an estimate of injury severity to body areas other than the head. The latter ratings were defined as the sum of the squares of the 3 most affected body regions, excluding the head.

Family demographic information was used to compute the Hollingshead Four Factor Index, Duncan-Demographic Index, and Socioeconomic Composite Index (SCI). Although the 3 groups were compared on all 3 indices, the SCI served as our primary measure of socioeconomic status. The SCI was formed by averaging sample z-scores for the Duncan occupational rating, annual family income as coded on the Life Stressors and Social Resources Inventory, and a 7-point maternal education scale. Information on the participating children was supplemented by having parents complete the Family Assessment Device (FAD) as part of the baseline assessment. The FAD is a self-report measure of family functioning with demonstrated reliability and validity. The 12-item Family Assessment Device General Functioning Scale (FAD-GF) was used as a summary measure of family functioning. Parents were asked to base their ratings on family functioning before the child’s injury.

The original sample included 189 injured children, 53 with severe TBI, 56 with moderate TBI, and 80 with orthopedic injuries only (see Taylor et al for description). Table 1 summarizes demographic characteristics of the children who remained in the study at the 4-year follow-up, including 42 with severe TBI, 42 with moderate TBI, and 50 with orthopedic injuries only. Sample attrition was attributable to family moves, unwillingness to continue participation in the study, and multiple missed appointments. Comparison of children participating in the extended follow-up to those who dropped out of the study failed to reveal differences in age of injury, gender or ethnic distribution, measures of preinjury child functioning, or baseline postinjury test results. However, those who dropped out had lower family socioeconomic status than those who remained in the study, and attrition was highest in the ORTHO group. The three groups did not differ in terms of age at injury or family background characteristics, although differences in race approached significance (P = .051).

Overall injury severity as reflected in the MISS was greatest in the severe TBI group and least in the ORTHO group. Although the children with moderate TBI were hospitalized for fewer days and had lower partial MISS ratings than children in the severe TBI and ORTHO groups, the latter 2 groups were similar in both respects. The contrast between the 2 TBI groups in duration of impaired consciousness, defined as the number of days until the child was able to follow simple verbal commands, documents the marked difference between these groups in severity of head injury.

### Resources

- [Fletcher et al.](https://example.com)
- [Hollingshead Four Factor Index](https://example.com)
- [Duncan-Demographic Index](https://example.com)
- [Socioeconomic Composite Index (SCI)](https://example.com)
- [Family Assessment Device (FAD)](https://example.com)
- [Modified Injury Severity Scale (MISS)](https://example.com)
- [Glasgow Coma Scale (GCS)](https://example.com)

### Conclusion

The findings of this study provide further support for the importance of HRQL in the evaluation of children with TBI and orthopedic injuries. The distribution of external causes of injury was more common among severe TBI, whereas sports and recreational accidents were more frequently responsible for moderate TBI and orthopedic injuries.
Injury-related predictors of outcomes in the children with TBI for the 2 TBI groups combined is similar to distributions reported in epidemiologic studies of children with moderate-to-severe TBI and suggests that the present sample was broadly representative of this population.38

Outcome Measures

Parent and child perceptions of HRQL were assessed by the Child Health Questionnaire, Parent Form ([CHQ]-PF50, 50 items) and Child Form ([CHQ]-CF87, 87 items).39,40 These measures were selected because they measure child HRQL in accord with the multidimensional World Health Organization (WHO) definition of health36 and allow comparison of child and parent reports.39,40 The measures survey multiple domains of child HRQL (eg, Physical Functioning, Limitations in Role/Social Functioning due to Physical Health). The CHQ-PF50 also assesses the perceived burden of the injury on parents. Responses yield transformed scores that can range from 0 to 100, 0 indicating the lowest possible level of functioning and 100 indicating the highest possible level of functioning. Ratings on 2 domains of the CHQ-PF50 (Physical and Psychosocial domains) are summarized as T-scores (mean = 50, standard deviation [SD] = 10). The validity of these measures has been established in recent studies of children with chronic health conditions.39–42 To our knowledge, the present study is the first application of the CHQ in assessment of outcomes after TBI or orthopedic injury.

The Vineland Adaptive Behavior Scale43 is a widely used measure of adaptive behavior obtained by semi-structured parent interview. The Vineland assesses multiple domains of children’s adaptive functioning, including Communication, Daily Living Skills, and Socialization, as well as overall of adaptive functioning (Adaptive Behavior Composite). Age standardized scores were considered in analyses of the Vineland.

A structured child health interview designed for this study was administered to parents to obtain their perceptions of the child’s health problems and to assess utilization of health services. Parents were queried as to whether the child had ongoing medical problems or behavioral changes related to the injury. In addition, parents provided information about medical and psychological services the child and family received since the injury. Items pertaining to health-related limitations in activities, mobility, and self-care were taken from parent responses on the CHQ-PF50. Responses indicating physical activities were limited “a little,” “some,” or “a lot” were collapsed as positive endorsements of limitations.

Predictors

Injury-related predictors of outcomes in the children with TBI were TBI severity (severe versus moderate), severity of nonhead injuries as defined by the nonhead injury severity score, lowest GCS score, days of impaired consciousness, and the presence/absence of focal frontal or other abnormalities on the computed tomography scan. Frontal lobe insults have been associated with deficits in executive function and social behavior44 and thus may pose special risks for diminished HRQL. Child predictors were ratings of preinjury behavior and school performance obtained by administering the Child Behavior Checklist (CBCL)45 and Child Behavior Checklist–Teacher’s Report Form (TRF)46 at the baseline assessment. The CBCLs are broad-spectrum, standardized measures of child behavior problems and competence. Parents and teachers completed these ratings based on the child’s preinjury status. The measures considered in predicting HRQL outcomes were the CBCL Behavior Problem scale and TRF School Performance scores. The Behavior Problem scale reflects problem ratings across all items on the CBCL, and TRF School Performance is an average rating of performance in academic subject areas. Environmental predictors were the preinjury SCI and FAD-GF.

Statistical Methods

Comparisons of the injury groups were conducted using analysis of covariance for continuous variables and logistic regression for categorical variables. Logistic regression was conducted to determine if group differences were significant after considering covariates. On the basis of preliminary analysis of correlates of the outcomes, the SCI was controlled in examining differences in health concerns or service and in health-related physical limitations; the SCI and race were controlled in examining differences in mental health service utilization; the SCI, race, and gender were controlled in examining the Vineland; and the SCI, race, gender, and age were controlled in examining for categorical variables. Logistic regression was conducted to examine predictors of child mental health counseling services in the year preceding the assessment. Factors included as covariates in these analyses were the same ones used in the corresponding group comparisons. TBI severity was included as an additional covariate in these analyses.

RESULTS

Mean scores on the CHQ-PF50 for the injury groups are presented in Table 2. Children in the

<table>
<thead>
<tr>
<th>TABLE 1. Sample Demographic Characteristics (N = 134)</th>
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<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>N</td>
</tr>
<tr>
<td>Mean child age in y (SD)</td>
</tr>
<tr>
<td>% Male</td>
</tr>
<tr>
<td>% Nonwhite</td>
</tr>
<tr>
<td>Mean maternal years of education (SD)</td>
</tr>
<tr>
<td>Mean SCI (SD)</td>
</tr>
<tr>
<td>Mean family Hollingshead (SD)</td>
</tr>
<tr>
<td>Mean days hospitalized (SD)‡</td>
</tr>
<tr>
<td>Mean Miss (SD)†</td>
</tr>
<tr>
<td>Mean partial Miss (SD)‡</td>
</tr>
<tr>
<td>Mean days of unconsciousness (SD)‡</td>
</tr>
<tr>
<td>Mean lowest GCS score (SD)‡</td>
</tr>
<tr>
<td>Cause of injury (%)</td>
</tr>
<tr>
<td>Motor vehicle accident</td>
</tr>
<tr>
<td>Falls</td>
</tr>
<tr>
<td>Sports/recreation</td>
</tr>
<tr>
<td>Assault</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

ORTHOT indicates orthopedic injury; Partial MISS excluded the head region. * Severe TBI group significantly different from ORTHO group; P < .05. † Moderate TBI group significantly different from ORTHO group; P < .05. ‡ Severe TBI group significantly different from moderate TBI group; P < .05.
Severe TBI group were rated as functioning more poorly than children the ORTHO group on the Psychosocial Summary Score ($F(1,124) = 5.803; P = .017$) and on several CHQ-PF50 subdomains, including Behavior ($F(1,126) = 7.709; P = .006$), Mental Health ($F(1,126) = 4.669; P = .033$), General Health Perceptions ($F(1,126) = 8.748; P = .004$), and Parent Impact-Time ($F(1,126) = 5.193; P = .024$). The moderate TBI group had a lower mean score than the ORTHO group on the subdomains Parent Impact-Emotional ($F(1,126) = 7.829; P = .006$) and General Health Perceptions ($F(1,126) = 4.080; P = .046$).

Mean scores on the CHQ-CF87 are presented in Table 3. Children’s self-reports revealed poorer functioning in the severe TBI group than in the ORTHO group in Behavior ($F(1,124) = 4.118; P = .045$). Mean scores on the Vineland for the injury groups are listed in Table 4. The severe TBI group scored lower than the ORTHO group on the Communication domain ($F(1,128) = 5.030; P = .027$) and Daily Living Skills domain ($F(1,128) = 4.557; P = .035$) as well as on the Adaptive Behavior Composite ($F(1,128) = 3.977; P = .048$). Logistic regression revealed higher rates of low adaptive behavior (Adaptive Behavior Composite <80) higher in the severe TBI group than in the ORTHO group (odds ratio [OR] = 4.070; 95% confidence interval [CI] = 1.424, 11.633).

Table 5 summarizes rates of ongoing health concerns or medical services used and health-related physical limitations. Although many children in each group had health problems, the severe TBI group had higher rates of several adverse outcomes than the ORTHO group, including continuing medical problems (OR = 2.590; CI = 1.026, 6.542), reported changes since the injury on ability, personality or behavior (OR = 8.398; CI = 3.191, 22.102), continuing medical problems or other changes since the injury (OR = 6.924; CI = 2.544, 18.845), and injury-related medical visits in the year previous to follow-up (OR = 11.007; CI = 2.848, 42.537). The severe TBI group also had a higher rate of placement on psych-
otropic medicine than the other 2 groups ($\chi^2[2,134] = 12.638; P = .002$). The moderate TBI group differed from the ORTHO group only in the rates of reported changes since the accident in ability, personality or behavior (OR = 3.137; CI = 1.225, 8.035). Few children from any of the groups had health-related physical limitations.

Table 6 summarizes information on mental health service utilization for families and children in the injury groups. Rates of counseling at any time since the injury were higher for the severe TBI group than for the ORTHO group when considering counseling for the child (OR = 2.716; CI = 1.066, 6.920) and any family member (OR = 2.543; CI = 1.028, 6.292). Rates of counseling during the year previous to follow-up were also higher for the severe TBI group than for the ORTHO group when considering the child (OR = 4.746; CI = 1.487, 15.150), sibling (OR = 3.102; CI = 1.042, 9.235) and parent (OR = 3.501; CI = 1.251, 9.793). Rates of counseling at follow-up were higher for the severe TBI group than for the ORTHO group when considering the sibling (OR = 5.444; CI = 1.027, 28.858) and any family member (OR = 3.219; CI = 1.008, 10.286).

To determine if a subset of children contributed to the higher rates of concerns, physical limitations, and service utilization in the severe TBI group, we examined group differences in the frequencies of 5 adverse indications of outcome listed from those in Tables 4 and 5: presence of ongoing injury-related medical concerns, changes in behavior, need for injury-related medical visits, child counseling services in the year preceding the assessment, and presence of any physical limitation. Of the total possible of 5 adverse indications, 14/42 children (33%) in the severe TBI group had 3 or more, compared with 8/42 (19%) in the moderate TBI group and 6/50 (12%) in the ORTHO group, $\chi^2(2; N = 134) = 6.411; P < .05$. Thus, whereas more children in the severe TBI group had multiple ongoing injury-related problems, these data suggest that differences were not attributable to a small subset of children with numerous adverse outcomes.

Regression analyses failed to reveal associations between any of the injury-related factors and HQRL outcomes (all $P$’s > .05), whether analyses were conducted with the total TBI sample or with each TBI group separately. However, analyses did identify preinjury child and family risk factors. Specifically, higher rates of preinjury child behavior problems on the CBCL predicted both lower CHQ-PF50 Psychosocial summary scores ($\beta = -.457$; standard error [SE] = .100; $P < .001$) and a lower Vineland Adaptive Behavior Composite ($\beta = -.379$, SE = .152; $P < .05$).
TABLE 6. Mental Health Service Utilization for Families With Children Sustaining a Traumatic Injury 4 Years Earlier

<table>
<thead>
<tr>
<th>Group</th>
<th>Severe TBI</th>
<th>Moderate TBI</th>
<th>ORTHO</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Counseling any time since the injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child*</td>
<td>20 (47.6)</td>
<td>7 (16.7)</td>
<td>13 (26.0)</td>
</tr>
<tr>
<td>Sibling</td>
<td>16 (38.1)</td>
<td>5 (11.9)</td>
<td>9 (18.0)</td>
</tr>
<tr>
<td>Parent(s)</td>
<td>19 (45.2)</td>
<td>13 (31.0)</td>
<td>12 (24.0)</td>
</tr>
<tr>
<td>Any family member*</td>
<td>28 (66.7)</td>
<td>15 (35.7)</td>
<td>21 (42.0)</td>
</tr>
<tr>
<td>Counseling during the year previous to follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child*</td>
<td>15 (35.7)</td>
<td>4 (9.5)</td>
<td>5 (10.0)</td>
</tr>
<tr>
<td>Sibling*</td>
<td>15 (35.7)</td>
<td>4 (9.5)</td>
<td>7 (14.0)</td>
</tr>
<tr>
<td>Parent(s)*</td>
<td>16 (38.1)</td>
<td>10 (23.8)</td>
<td>7 (14.0)</td>
</tr>
<tr>
<td>Any family member*</td>
<td>22 (52.4)</td>
<td>11 (26.2)</td>
<td>14 (28.0)</td>
</tr>
<tr>
<td>Counseling at follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>7 (16.7)</td>
<td>2 (4.8)</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Sibling*</td>
<td>8 (19.0)</td>
<td>3 (7.1)</td>
<td>2 (4.0)</td>
</tr>
<tr>
<td>Parent(s)</td>
<td>7 (16.7)</td>
<td>6 (14.3)</td>
<td>2 (4.0)</td>
</tr>
<tr>
<td>Any family member*</td>
<td>12 (28.6)</td>
<td>6 (14.3)</td>
<td>5 (10.0)</td>
</tr>
</tbody>
</table>

P < .05; P < .01.
Differences between each TBI group to the ORTHO group were examined by logistic regression, controlling for the SCI and race.

More preinjury behavior problems were also associated with higher rates of child counseling during the previous year (OR = 1.072; CI = 1.005, 1.142). Similarly, lower teacher ratings of academic performance on the TRF predicted a lower Vineland Adaptive Behavior Composite ($\beta = .531; SE = .220; P < .05$). Preinjury socioeconomic disadvantage on the SCI predicted poorer outcomes on the CHQ-PF50 Physical ($\beta = -3.098; SE = 1.186; P < .05$) and Psychosocial ($\beta = -6.175; SE = 1.453; P < .001$) Summary Scores and on the Vineland Adaptive Behavior Composite ($\beta = -7.212; SE = 1.932; P < .001$). In addition, preinjury family dysfunction on the FAD predicted a lower Vineland Adaptive Behavior Composite ($\beta = -11.376; SE = 4.447; P < .05$).

To examine the validity of the CHQ-PF50 in relation to functional outcomes, children with and without specific conditions or problems at the follow-up assessment were compared on the CHQ-PF50 Physical and Psychosocial summary scores. Significantly lower ($P < .05$) Physical summary scores were associated with placement on any medication, changes in ability, behavior or personality, ongoing medical problems, and injury-related medical visits. Significantly lower Psychosocial summary scores were associated with grade retention or an individual education plan, counseling, placement on a psychotropic medication, placement on any medication, changes in ability, behavior or personality, ongoing medical problems, injury-related medical visits, and a score <80 on the Vineland Adaptive Behavior Composite.

DISCUSSION

The present findings enhance scientific knowledge of the long-term impact of pediatric TBI on children’s functioning and HRQL in several respects. To our knowledge, this is the first study to assess the effects of TBI on children’s HRQL in a relatively large cohort of children with TBI, to include controls for the traumatic injury and hospitalization, to include comprehensive assessments of functioning via both parent and child report, and to assess postinjury health service utilization. At a follow-up conducted an average of 4 years postinjury, adolescents who experienced severe TBI had lower communication skills, daily living skills, and general adaptive functioning than adolescents who sustained orthopedic injuries only. Lower HRQL in the severe TBI group was demonstrated in the areas of overall psychosocial functioning and in the domains of behavior, mental health, general health, and family impact. Parent perceptions of HRQL, moreover, were related to indicators of functional impairment, including the extent to which the child had ongoing medical problems, changes in behavior, school problems, and adaptive behavior. Given that few children had serious limitations of mobility and ambulation, these findings imply that traditional indicators of functional outcome greatly underestimate the ongoing impact of these injuries.

Consistent with research on the long-term behavioral, neuropsychologic, and family consequences of TBI, our results suggest extensive individual variability in HRQL outcomes, with some children’s HRQL clearly diminished relative to normative expectations but with relatively mild effects for the TBI groups as a whole. Injury variables over and above TBI severity categorization were not related to major HRQL outcomes. This finding may reflect the lack of precision in measurement of neuropsychology using computed tomography scans as well as the overlap of measures of injury severity with the severe versus moderate TBI classification. However, preinjury child and family factors did predict HRQL outcomes in children with TBI. Children with more premorbid behavior problems had poorer psychosocial functioning, poorer adaptive behavior, and were more likely to have been seen in counseling 4 years postinjury. Likewise, children with poorer premorbid school performance had poorer adaptive behavior at follow-up. With regard to family factors, children from families with greater environmental...
disadvantage and poorer family functioning were at highest risk for poorer HRQL. Therefore, our results suggest that HRQL in children with TBI is likely to reflect a combination of the effects of TBI with pre-existing behavioral, social and environmental characteristics.

These findings also indicate that adolescents and their parents had different perceptions of HRQL. Specifically, parents rated their adolescents’ HRQL less favorably than the adolescents themselves. Adolescent ratings, in fact, were comparable in all but 1 domain (Behavior) to scores for the ORTHO group. Previously, we found discrepancies between self- and parent report in examining perceptions of problems attributable to injury, suggesting that adolescents may be more prone to minimize concerns about their own health and functioning and hence, compared with their parents, report higher HRQL. However, adolescents do not always rate their own HRQL better than their parents do, as shown in other follow-up studies of adolescents. An alternative interpretation of our data are that the cognitive and behavioral sequelae of TBI render adolescents less capable of accurate appraisal of problems in social and emotional functioning. Consistent with this interpretation, deficits in self-awareness are common sequelae of severe TBI.

An important clinical implication of the difference between self- and parent reports, and of the discrepancy between adolescent self-report and documented deficits in long-term outcomes is that adolescents are either unaware of their limitations or unwilling to admit to them. Such lack of insight or denial may affect adolescent compliance with recommendations for services that parents or professionals deem necessary. Differences in parents’ and adolescents’ appraisals of the nature and severity of long-standing problems after TBI may also serve to intensify family conflict.

An additional clinical implication is that parents often act on their perceptions of problems in functioning by seeking health services. A large number of families in the present sample, especially those in the severe TBI group, used mental health counseling at some point after the injury. The finding of chronic mental health needs after TBI accords with the continuing problems in behavior noted by parents. In addition to the child’s mental health, our results suggest that it may be important to monitor the impact of TBI on the other members of the family. Not surprisingly, children with premorbid behavior problems were more likely to be receiving mental health services at the extended follow-up. Our results suggest that children at greatest risk for lower psychosocial functioning after TBI are those with premorbid behavioral or school problems and those from more disadvantaged social backgrounds. It may be useful to monitor the outcomes of these at-risk children most carefully, and over longer time periods, to more readily refer them to mental health and social services. Moreover, these at-risk children may be in greater need of assistance for facilitating adaptive behavior skills.

One of the limitations of this study is that we were unable to evaluate the quality, duration, timing, or effectiveness of the mental health services provided for the children and their families. We also failed to examine the accessibility of appropriate care. Despite these shortcomings, group differences in rates of health care underscore the importance of examining the long-term needs of children with TBI.

Two additional limitations are sample attrition and lack of prospective assessment of HRQL. Because dropouts were less socioeconomically advantaged than participants who remained in follow-up, attrition may have yielded biased estimates of functional outcomes. If deficits in functioning are less common in advantaged than disadvantaged adolescents, sample attrition may have underestimated that negative impact of injury on the sample as a whole. However, group differences may have been less subject to this bias, socioeconomic status was taken into account in data analysis, and dropouts did not differ from the participants in most respects. With regard to assessments of HRQL, our findings provide information on long-term sequelae but fail to indicate how HRQL changed over time postinjury. It is unclear, for example, if HRQL in children with severe TBI was better or worse earlier postinjury than was the case at the extended follow-up.

More research is needed to determine if results can be replicated with other samples and to investigate HRQL prospectively. Additional research is also required to further specify injury characteristics that predict HRQL and associated functional impairments. However, injury characteristics alone, or even cognitive skills, may not be sufficient to account for the HRQL consequences of TBI. Jaffe and colleagues found relatively intact functional outcomes in children with severe TBI who had significant deficits in neuro-psychologic and academic competence. Other research suggests that problems in school performance and behavior can emerge even in children free of cognitive impairments. A challenge for future investigations will be to clarify reasons for these disparities. The present findings provide impetus for including measures of HRQL in evaluating TBI outcomes and for assessing children’s ongoing health care needs.

ACKNOWLEDGMENTS

This work was supported by the National Institute of Neurological Disorders and Stroke grant NS36335, National Institutes of Health, and by Grant MCI-390611, Maternal and Child Health Bureau (Title V, Social Security Act, Health Resources and Services Administration, Department of Health and Human Services).

We acknowledge the contributions of Elizabeth Shaver, Nichole Wood, Barbara Shapero, Madeline Polonia, and Matt Diamond in data collection and coding. We also wish to acknowledge the participation of the Children’s Hospital Medical Center of Akron and the collaboration of George Thompson, MD, G. Dean Timmons, MD, and Dennis Weiner, MD the Rainbow Pediatric Trauma Center, Rainbow Babies & Children’s Hospital, Columbus Children’s Hospital Trauma Program, and MetroHealth Center Trauma Registry provided assistance with recruitment. Finally, we acknowledge the assistance of Susan Wood and Anne Bimbaum in processing this manuscript.

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