Health-Related Quality of Life During the First Year After Traumatic Brain Injury

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Objectives: To document health-related quality of life (HRQOL) of children with traumatic brain injury (TBI) and to examine the relationship between TBI severity and HRQOL during the first year after injury.

Design: Prospective cohort study.

Setting: Four pediatric level I trauma centers.

Patients: Children with TBI (n=330).

Main Exposure: Traumatic brain injury.

Main Outcome Measures: A primary caregiver completed telephone interviews at baseline, 3 months, and 12 months to measure the child’s HRQOL using the Pediatric Quality of Life Inventory. The HRQOL outcomes were modeled as a function of injury, patient characteristics, and family characteristics using longitudinal, multivariable regression.

Results: A considerable proportion of children had impaired HRQOL at 3 months (42% of children) and 12 months (40% of children) after injury. Multiple dimensions of HRQOL were negatively affected among children with moderate or severe TBI (decrease of 3.7 to 17.6) (P<.05) and did not improve significantly over time. Concomitant lower extremity fractures and spinal injuries resulted in large declines in overall HRQOL, particularly at 3 months after injury (decrease of 12.9 and 8.1, respectively) (P<.05). The HRQOL scores were also reduced by preexisting psychosocial conditions (decrease of 2.9 to 12.3), impaired family functioning (decrease of 5.1 to 6.8), having Medicaid coverage or being uninsured (decrease of 3.1 to 5.5), and single-parent households (decrease of 3.2 to 3.4) (P<.05).

Conclusions: Moderate or severe TBI resulted in measurable declines in children’s HRQOL after injury. Injury-related factors impacted HRQOL more compared with patient and family characteristics during the first year after injury.

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measured neuropsychological and behavioral outcomes among children with moderate to severe TBI has noted significant and persistent deficits in this patient population long after the acute injury. It could be that the HRQOL instruments used in the studies by Stancin and colleagues and Coster and colleagues were not sensitive enough to discriminate among different levels of TBI severity, or it could be that HRQOL is more affected by premorbid and family characteristics than injury-related factors.

The purpose of this article is to document HRQOL among children hospitalized with TBI during the first year after injury and to examine the relationship between severity of injury and HRQOL after adjusting for premorbid, socioeconomic, and family characteristics. To do this, we compared the outcomes of children hospitalized with TBI of varying severity using the Pediatric Quality of Life Inventory (PedsQL), an instrument that we previously demonstrated to be a reliable and valid measure of HRQOL among children with TBI.

STUDY POPULATION

Children aged 5 to 15 years who were discharged alive after being hospitalized 1 or more nights at 1 of 4 level I pediatric trauma center hospitals (Johns Hopkins Hospital, Baltimore, Md; Children's Hospital of Philadelphia, Philadelphia, Pa; Harborview Medical Center, Seattle, Wash; and Arkansas Children's Hospital, Little Rock) for treatment of TBI with an Abbreviated Injury Scale (AIS) severity score of 2 or greater were eligible for the study.

Children were excluded for the following reasons: (1) they or their parents were non-English speaking; (2) they had a preexisting medical condition that seriously impacted preinjury physical (eg, amputation), psychological (eg, schizophrenia or bipolar disorder), or cognitive (eg, mental retardation or prior TBI-related hospitalization) function; or (3) they were part of a suspected child abuse case. To increase the generalizability of the study and to evaluate the effects of premorbid risk factors on HRQOL, children with premorbid learning disabilities or behavioral problems were eligible.

The sample was stratified by AIS severity to enroll adequate numbers of children with more severe TBI. Consecutive children within each study group were enrolled until there were approximately 95 children with head injuries with AIS scores of 2, 3, and 4. The target number for children with head injuries with AIS scores of 5 was 50 because they are less frequent.

PROCEDURES

The institutional review boards of all of the 4 participating sites approved the study. Between January 15, 2002, and July 31, 2003, the study coordinators identified 536 children with an eligible injury. However, 98 (18%) of the children were deemed ineligible on full review of all of the demographic and injury characteristics. The study coordinators approached all of the eligible children and their families. Those who consented agreed to complete 3 telephone interviews over a 1-year period and to allow pertinent injury and treatment information to be abstracted from the child's medical record.

All of the interviews were conducted by a professional survey research firm with a primary caregiver of the injured child. The first, or baseline, interview conducted within 3 weeks of the initial hospitalization (median, 16 days) was designed to measure the child's preinjury HRQOL and to obtain background information on the child and his or her family. During the baseline interview, the respondent was instructed to think of the child 1 month prior to the injury when answering the HRQOL questions. During the follow-up interviews, the respondent was asked to rate the child's HRQOL during the previous month.

MEASUREMENT

Health-related quality of life was measured with the PedsQL. The PedsQL was selected over other pediatric HRQOL instruments primarily because it advocates a modular assessment strategy that allows for the integration of generic and disease-specific scales. For this study, the PedsQL generic instrument was supplemented with a cognitive function scale since cognitive dysfunction is a common and serious impairment following TBI. Numerous studies have confirmed the PedsQL to be a reliable and valid instrument for measuring HRQOL among children with different types of illnesses or injuries, including TBI.

The PedsQL generic core comprises 23 items that measure 4 health domains: (1) physical functioning, (2) emotional functioning, (3) social functioning, and (4) school functioning. The scales can be aggregated into summary scales of physical health (same as the physical functioning scale), psychosocial health (emotional, social, and school functioning scales), and total health (all of the 4 scales). The PedsQL cognitive function scale comprises 6 items. All of the PedsQL scales have a possible range from 0 (poor health) to 100 (excellent health). Scale scores more than 1 SD below the healthy sample mean are considered impaired.

The child's age, race, health insurance coverage, and the presence of preexisting physical or psychosocial health conditions were obtained from the respondent during the baseline interview. The most prevalent preexisting physical conditions were asthma (18%) and allergies (17%) whereas the most common psychosocial conditions were an attentional problem (12%), a learning disability (11%), and a behavioral problem (7%). The respondent was also queried about his or her age, race, marital status, highest grade in school completed, total annual income of the household, and relationship to the child. Finally, the general functioning scale of the Family Assessment Device was administered to the respondents. This 12-item scale is a self-reported measure of overall family functioning. The scale has a possible range of 1 to 4, and scores of 2 and higher are considered unhealthy family functioning.

The nature and severity of all of the injuries sustained were characterized according to the AIS. This scale classifies more than 2000 injuries according to the body region of injury (eg, head, chest, lower extremity), type of structure involved (eg, nerve, vessel, bone), location of injury within the body region (eg, femur, tibia), and nature of injury (eg, abrasion, crush). The AIS grades each injury according to its associated threat to life on an ordinal scale from 1 (minor) to 6 (unsurvivable). Typical head injuries sustained by the study sample included a closed vault fracture (AIS score=2), comminuted vault fracture or subarachnoid hemorrhage (AIS score=3), epidural or subdural hematoma (AIS score=4), or a diffuse axonal injury (AIS score=5). To reflect overall injury severity, the New Injury Severity Scale score was computed. The New Injury Severity Scale score is the sum of the squares of the 3 most severe injuries sustained. The New Injury Severity Scale score ranges from 0 to 75, and higher scores reflect greater severity. Finally, the mechanism of injury, hospital length of stay, and disposition were recorded for all of the subjects.
DATA ANALYSIS

First, we compared those who enrolled with those who did not by different patient and injury characteristics using a χ² test of homogeneity. We also compared the distribution of subjects with HRQOL outcomes that were 1 and 2 SDs lower than general population norms. Because the PedsQL scale was statistically significant at .05. In addition, children who did not enroll were more likely to be male (69%), white (69%), and part of a single-parent household compared with those who were followed up (P < .05) (Table 1). Of the 330 who enrolled, 302 (92%) completed the interview at 3 months and 288 (87%) completed the interview at 12 months. Seventeen subjects (5%) did not complete either follow-up interview. Those who were not followed up were more likely to be younger, nonwhite, and part of a single-parent household compared with those who were followed up (P < .05) (data not shown).

Table 1 and Table 2 display the patient, respondent, and family characteristics of the sample by the severity of TBI sustained. The mean age of all of the enrolled subjects was 10.4 years (range, 5.1-15.9 years). Subjects were more likely to be male (69%), white (69%), and in good health prior to the injury (89%). There were no significant differences in patient characteristics by the severity of TBI sustained (all P > .10). The respondents for children with severe TBI were more likely to be the father (31%) compared with respondents for children with mild (12%) or moderate (13%) TBI (P < .05). A greater proportion of respondents for children with mild TBI had not completed high school (24%) than respondents for children with moderate (11%) or severe (10%) TBI (P = .001). Finally, the respondents for children with moderate and severe TBI reported better preinjury family functioning (94% and 93%, respectively) than respondents for children with mild TBI (79%) (P < .05) (Table 2).

Traffic-related injuries (39%) and falls (36%) were the most common injuries (Table 3). The mean New Injury Severity Score was 21 (range, 4-66). Subjects with severe TBI were significantly more likely to sustain a thoracic (33%), abdominal (17%), spinal (17%), or upper extremity (26%) fracture than subjects with mild TBI (AIS score = 2) (4%, 3%, 3%, and 9%, respectively) (P < .01).

Children with severe TBI had significantly poorer HRQOL scores after injury (P < .05) than children with mild TBI, except for social functioning (not significantly different at 3 months only [P = .15]) and emotional functioning (not significantly different at 3 or 12 months [P = .51 and P = .15, respectively]) (Table 4).

Table 1. Percentage Distribution of Patient Characteristics of Subjects by Traumatic Brain Injury Severity

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>Overall, % (n = 330)</th>
<th>Mild TBI, % (n = 185)</th>
<th>Moderate TBI, % (n = 103)</th>
<th>Severe TBI, % (n = 42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>5-7</td>
<td>28.4</td>
<td>27.0</td>
<td>35.9</td>
</tr>
<tr>
<td></td>
<td>8-10</td>
<td>26.4</td>
<td>28.7</td>
<td>26.2</td>
</tr>
<tr>
<td></td>
<td>11-12</td>
<td>20.3</td>
<td>20.5</td>
<td>15.5</td>
</tr>
<tr>
<td></td>
<td>13-15</td>
<td>24.9</td>
<td>23.8</td>
<td>22.4</td>
</tr>
<tr>
<td>Sex, male</td>
<td>69.4</td>
<td>69.2</td>
<td>68.9</td>
<td>71.4</td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>68.5</td>
<td>65.4</td>
<td>68.9</td>
</tr>
<tr>
<td></td>
<td>Nonwhite</td>
<td>31.5</td>
<td>34.6</td>
<td>31.1</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uninsured</td>
<td>0.3</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td></td>
<td>Commercial</td>
<td>73.3</td>
<td>71.9</td>
<td>77.7</td>
</tr>
<tr>
<td></td>
<td>Medicaid</td>
<td>26.4</td>
<td>27.6</td>
<td>22.3</td>
</tr>
<tr>
<td>Preexisting physical condition</td>
<td>37.9</td>
<td>35.1</td>
<td>41.7</td>
<td>40.5</td>
</tr>
<tr>
<td>Preexisting psychosocial condition</td>
<td>25.1</td>
<td>22.7</td>
<td>27.2</td>
<td>30.9</td>
</tr>
<tr>
<td>Normal total PedsQL score at baseline</td>
<td>89.1</td>
<td>88.1</td>
<td>89.3</td>
<td>92.9</td>
</tr>
</tbody>
</table>

Abbreviations: PedsQL, Pediatric Quality of Life Inventory; TBI, traumatic brain injury.

RESULTS

Of the 438 children eligible for the study, 381 (87%) consented and 330 (75%) enrolled. Children who did not enroll were more likely to lack health insurance (10%) than those who enrolled (<1%) (P < .05). In addition, children who did not enroll were hospital-
When comparing children with severe TBI with those with moderate TBI, physical functioning was the only significant difference at both 3 and 12 months after injury \((P < .05)\).

Using the total PedsQL score as an overall measure of HRQOL, Figure 1 displays the proportion of children with impaired HRQOL by TBI severity. Overall, a considerable proportion of children had impaired HRQOL at 3 months...
and severity of injuries sustained are associated with the greatest reductions in HRQOL at 3 and 12 months after injury. Children with moderate or severe TBI had significantly poorer physical, cognitive, psychosocial, and overall HRQOL scores compared with children with mild TBI (all \( P < .10 \)). Furthermore, there is a significant interaction effect between type and severity of injury and time. At 3 and 12 months after injury, the presence of a concomitant lower extremity fracture (decrease of 24.1 and 7.3, respectively), upper extremity fracture (decrease of 8.9 and 7.8, respectively), concomitant spinal injury (decrease of 13.2 and 7.7, respectively), or severe TBI (decrease of 11.7 and 9.6, respectively) \( (P < .05) \) was associated with the largest decrements in physical function. Although the impact of a concomitant lower extremity fracture and a concomitant spinal injury (ie, spinal fracture or dislocation) on physical function lessened over time, the impact of a concomitant upper extremity fracture or severe TBI did not. A similar pattern was noted for psychosocial function and overall HRQOL; however, the magnitude of the impact was not as strong (except for TBI), and only the impact of the concomitant lower extremity fracture lessened over time. None of the associated injuries to other body regions significantly influenced HRQOL (all \( P > .10 \)). There was also a strong dose-response relationship noted between the severity of TBI and cognitive function (Figure 3).

The only patient characteristic to demonstrate a significant relationship to HRQOL was the presence of a pre-existing psychosocial condition, which was associated with a significant reduction in all of the dimensions of HRQOL \( (P < .05) \). Although none of the respondent characteristics significantly influenced HRQOL, several family character-

### Table 4. Mean Pediatric Quality of Life Inventory Scores by Traumatic Brain Injury Severity

<table>
<thead>
<tr>
<th>PedsQL Score</th>
<th>Overall, Mean (n = 330)</th>
<th>PedsQL Score for Mild TBI, Mean (n = 185)</th>
<th>PedsQL Score for Moderate TBI, Mean (n = 103)</th>
<th>PedsQL Score for Severe TBI, Mean (n = 42)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical function</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At baseline</td>
<td>88.9</td>
<td>88.3</td>
<td>89.1</td>
<td>90.8</td>
</tr>
<tr>
<td>At 3 mo†</td>
<td>74.8</td>
<td>77.4</td>
<td>73.4</td>
<td>67.4</td>
</tr>
<tr>
<td>At 12 mo‡</td>
<td>77.7</td>
<td>80.0</td>
<td>76.4</td>
<td>70.3</td>
</tr>
<tr>
<td><strong>Emotional function</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At baseline</td>
<td>95.0</td>
<td>94.3</td>
<td>95.4</td>
<td>96.7</td>
</tr>
<tr>
<td>At 3 mo†</td>
<td>78.1</td>
<td>81.5</td>
<td>77.8</td>
<td>65.2</td>
</tr>
<tr>
<td>At 12 mo‡</td>
<td>84.7</td>
<td>87.3</td>
<td>83.4</td>
<td>75.5</td>
</tr>
<tr>
<td><strong>School function</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At baseline</td>
<td>86.0</td>
<td>85.4</td>
<td>86.7</td>
<td>87.0</td>
</tr>
<tr>
<td>At 3 mo</td>
<td>71.0</td>
<td>72.0</td>
<td>69.8</td>
<td>69.6</td>
</tr>
<tr>
<td>At 12 mo</td>
<td>73.1</td>
<td>74.9</td>
<td>70.9</td>
<td>70.1</td>
</tr>
<tr>
<td><strong>Social function</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At baseline</td>
<td>90.4</td>
<td>90.0</td>
<td>90.0</td>
<td>93.6</td>
</tr>
<tr>
<td>At 3 mo</td>
<td>78.7</td>
<td>80.3</td>
<td>77.5</td>
<td>75.4</td>
</tr>
<tr>
<td>At 12 mo</td>
<td>80.9</td>
<td>83.2</td>
<td>79.1</td>
<td>75.1</td>
</tr>
<tr>
<td><strong>Psychosocial function</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At baseline</td>
<td>84.1</td>
<td>83.6</td>
<td>84.1</td>
<td>86.0</td>
</tr>
<tr>
<td>At 3 mo</td>
<td>71.2</td>
<td>75.4</td>
<td>68.7</td>
<td>59.1</td>
</tr>
<tr>
<td>At 12 mo</td>
<td>72.2</td>
<td>74.2</td>
<td>72.3</td>
<td>62.9</td>
</tr>
<tr>
<td><strong>Cognitive function</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>At baseline</td>
<td>86.8</td>
<td>86.3</td>
<td>87.0</td>
<td>88.9</td>
</tr>
<tr>
<td>At 3 mo</td>
<td>73.7</td>
<td>76.0</td>
<td>72.0</td>
<td>68.2</td>
</tr>
<tr>
<td>At 12 mo</td>
<td>75.3</td>
<td>77.4</td>
<td>74.1</td>
<td>68.8</td>
</tr>
</tbody>
</table>

Abbreviations: PedsQL, Pediatric Quality of Life Inventory; TBI, traumatic brain injury.

*There were 433 subjects at baseline, 391 at 3 months after injury, and 377 at 12 months after injury.
†Difference is significant between at least 2 of the study groups \((P < .05)\).
‡Difference is borderline significant between at least 2 of the study groups \((.05 < P < .10)\).
istics did. The HRQOL scores of children who came from single-parent households were significantly lower than those of children who lived with both parents or 1 parent and a partner (range of decrease, 3.2-3.4) (P < 0.05). Similarly, unhealthy family functioning was associated with a significant reduction in HRQOL (range of decrease, 5.1-6.8) (P < 0.05). Finally, children who were covered by Medicaid or were uninsured had poorer HRQOL outcomes compared with children with private health insurance (range of decrease, 3.1-5.5) (P < 0.05). Family income was significantly related to HRQOL when examined alone (subjects with lower family income had poorer HRQOL outcomes compared with subjects from higher income households), but because of its strong correlation to health insurance coverage and marital status, it did not remain significant in the multivariable model (all P > .10; data not shown).

**COMMENT**

This is the first study to our knowledge to document the HRQOL outcomes during the first year after injury of a cohort of children who sustained TBI severe enough to warrant hospitalization, and we found that the severity of injury significantly impacted HRQOL. Our findings are consistent with other studies that have examined neuropsychological and behavioral outcomes following TBI. All of the dimensions of HRQOL measurably declined among children who sustained severe TBI and did not improve over time. With the exception of physical function, multiple dimensions of HRQOL were also negatively impacted among children who sustained moderate TBI.

Our results suggest that there is a strong relationship between the severity of TBI and HRQOL during the first year after injury. Coster et al may not have found a significant association between TBI severity and HRQOL during the first 6 months after injury because the majority of their patients sustained mild TBI. In a multivariable analysis, Stancin et al also did not find a relationship between TBI severity and HRQOL as measured by the Child Health Questionnaire. Although it could be that the Child Health Questionnaire is not sufficiently sensitive for children with TBI, it seems more likely that the relationship between TBI severity and HRQOL weakens over time. Since numerous studies have demonstrated that children with severe TBI have persistent long-term deficits that should negatively impact HRQOL, it will be important in future research to measure HRQOL outcomes multiple times over a long follow-up period to determine how HRQOL and the factors that influence it change over time.

The results of this study demonstrate the importance of measuring the impact of associated injuries on children’s health. The poorest HRQOL outcomes were among children who sustained TBI and an associated extremity fracture or spinal injury (ie, spinal fractures or dislocations). These results concur with earlier studies that noted that a significant proportion of children who sustained an extremity injury had physical and role limitations 1 year later. We also found that a small but significant proportion of children with extremity fractures, particularly lower extremity fractures, had impaired HRQOL at 1 year after injury. MacKenzie et al also found that among adult trauma patients, injuries to the head, spine, or extremities (particularly lower extremities) were more frequently associated with functional limitations after injury compared with injuries to other body regions.

Children with moderate or severe TBI had worse physical and psychosocial functioning during the first year after injury compared with children with mild TBI. Evidence that children who sustain severe to moderate TBI are at higher risk of developing a psychiatric disorder after injury is beginning to accumulate. Other researchers have also found that children who sustain moderate to severe TBI exhibit more depressive symptoms, behavioral problems, and difficulties at school compared with children with an orthopedic injury.
With increasing TBI severity, parents reported more cognitive dysfunction. Moreover, the cognitive dysfunction persisted over time. Our results concur with numerous other studies that have described cognitive deficits at 1 year after injury among children who sustain moderate to severe TBI.

The presence of a preexisting psychosocial condition was associated with a reduction in many domains of HRQOL, even after adjusting for preinjury function. Other studies involving trauma patients have also noted the importance of controlling for the presence of comorbidities when examining the impact of an injury on HRQOL.

During the first year after injury, unhealthy family functioning, single-parent households, and being uninsured or covered by Medicaid all had a small but negative impact on children’s HRQOL. These results are consistent with those of other studies that have also found that preinjury family functioning influences different health outcomes after TBI. It could be that single-parent households have fewer resources (ie, financial and/or social) available to devote to a child’s recovery compared with 2-parent households. Similarly, financial resources could also explain why the HRQOL outcomes were poorer among children covered by Medicaid or who were uninsured.

The results of this study must be considered in the context of several limitations. First, preinjury HRQOL scores were obtained shortly after injury, which could have bias...
as the respondent’s perceptions. Although the preinjury HRQOL scores were not significantly different among the study groups when examined alone, the multivariable regression results showed that the parents of children with severe TBI reported better preinjury HRQOL compared with that which the parents of the children with an extremity fracture reported. While this may reflect a small overestimation of preinjury function, an estimate is important to have when evaluating injury sequelae.\(^3\) Second, HRQOL was based on a primary caregiver’s perspective; future research should incorporate the child’s perceptions of his or her HRQOL. Finally, we may have underestimated the reduction in HRQOL as a result of severe TBI or a lack of health insurance since children with either of these characteristics were less likely to participate.

Despite these limitations, this study illustrates that it is possible to use a brief instrument to assess a child’s physical and psychosocial health following TBI. While it is not feasible to conduct in-depth follow-up assessments on all children who sustain TBI severe enough to warrant hospitalization, it may be that an instrument such as the PedsQL can help clinicians to monitor the recovery of children following different types of injuries and to systematically identify those in need of further evaluation and services.

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Figure 3. Adjusted mean cognitive score by traumatic brain injury (TBI) severity.

Scores were adjusted for associated injury, mechanism of injury, patient characteristics, and family characteristics.

REFERENCES


