Long-term Parental and Family Adaptation Following Pediatric Brain Injury

Shari L. Wade,1 PHD, H. Gerry Taylor,2 PHD, Keith Owen Yeates,3 PHD, Dennis Drotar,3 PHD, Terry Stancin,4 PHD, Nori M. Minich,2 BA, and Mark Schluchter1 PHD
1Department of Pediatrics, Cincinnati Children’s Hospital Medical Center, University of Cincinnati College of Medicine, 2Department of Pediatrics, Rainbow Babies and Children’s Hospital, Case Western Reserve University School of Medicine, 3Department of Pediatrics, Columbus Children’s Hospital, The Ohio State University, and 4Department of Pediatrics, MetroHealth Medical Center, Case Western Reserve University School of Medicine

Objective To determine whether parents of children with traumatic brain injuries (TBI) report increased injury-related burden, distress, and family dysfunction and to examine the effects of attrition on the results. Methods Children with severe TBI, moderate TBI, and orthopedic injuries were followed at six time points from baseline to 6 years after injury. Parents completed measures of injury-related burden, psychological distress, and family functioning at each assessment. Mixed model analysis was used to examine long-term changes. Results Attrition was higher among families in the severe TBI group with lower burden thereby amplifying group differences. The severe TBI group reported higher injury-related burden over time after injury than the other groups. Family functioning was moderated by social resources. Families of children with severe TBI and low resources reporting deteriorating functioning over the follow-up interval. Conclusions Although environmental advantages moderate long-term effects on family functioning, families of children with severe TBI experience long-standing injury-related burden.

Key words brain injury; family adaptation; stressors; support.

Pediatric Brain Injury and Its Impact on Families

More than 100,000 children sustain traumatic brain injuries (TBI) each year in the United States (Kraus, 1995), with sequelae ranging from transient cognitive impairment to lifelong physical, cognitive, and behavioral disabilities. Among the 10–15% of children with severe TBI, there is a high risk of academic difficulties, behavioral problems, and deficits in adaptive functioning (Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Max, Castillo, & Robin, 1998). Longer-term follow-up suggests that behavioral changes and behavior problems represent the most persistent sequelae of TBI in children, with 62–71% of children with severe TBI developing a new psychiatric disorder (Fay et al., 1994; Fletcher et al., 1990; Schwartz et al., 2003).

A growing number of investigations have documented increased injury-related stress and burden, parental anxiety and depression, and family dysfunction during the initial year following a child’s injury (Rivara et al., 1992; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Although a significant minority of parents experience persistent burden and distress, many families adapt successfully to the increased demands of the injury. Factors such as socioeconomic status (SES), preinjury family functioning, resources and stresses, and initial response to the injury appear to moderate the impact of pediatric TBI on caregivers, placing some families at greater risk for
long-term difficulties (Rivara et al., 1996; Wade, Wolfe, Brown, & Pestian, 2005; Wade et al., 2002).

Findings from longer-term follow-up studies have yielded inconsistent results regarding family adaptation (Rivara et al., 1996; Wade et al., 2002). Rivara et al. (1996) prospectively followed children with mild, moderate, and severe TBI at 3, 12, and 36 months after injury. They reported deterioration in family relationships and functioning between 3 and 36 months after injury among the families of children with severe TBI. However, group differences were found only on interviewer ratings and not on standardized self-report measures. Additionally, although their analytic strategy did not include analysis of change between 12 and 36 months after injury, examination of group means at each assessment suggests that deterioration in parent/family functioning primarily occurred during the initial year with relatively little subsequent change. Therefore, depending on one’s interpretation of the data, the conclusion that family functioning continued to worsen may not be warranted.

In the other prospective investigation of longer-term family outcomes, our research team (Wade et al., 2002) followed children with severe TBI, moderate TBI, and orthopedic injuries not involving the central nervous system (CNS) at a follow-up conducted an average of 4 years after injury. Unlike Rivara et al. (1996), we found no differences between the severe TBI, moderate TBI, and orthopedic injury (ORTHO) groups on parental psychological symptoms and family functioning at this follow-up. Injury-related stress and burden declined significantly over time in all three groups. However, we continued to find elevated levels of injury-related stress and burden among the severe TBI group relative to the moderate TBI and ORTHO groups at this assessment. Given the failure to find group differences in psychological distress and family functioning and the relatively low levels of stress and burden even among the severe TBI group, we concluded that injury stresses diminished after longer periods following injury and that most families, even those of children with severe injuries, adapted favorably.

Likewise, the literature on caregiver adaptation following adult TBI contains several long-term follow-up studies with conflicting conclusions. In one of the first investigations of caregiver adaptation following brain injury, Brooks and colleagues (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986) followed caregivers of 42 adults with severe TBI from 12 months to 5 years after injury and found increasing levels of injury-related strain over time. However, a comparison group was lacking, and strain was assessed by a single question regarding stress associated with changes in the injured individual. Studies employing standardized measures have failed to find increasing caregiver stress over time (Hall et al., 1994; Oddy, Humphrey, & Uttley, 1978; Sanders, High, Hannay, & Sherer, 1997). To the contrary, these investigations have documented declining stress and caregiver psychological symptoms after the acute recovery phase. Thus, patterns of long-term caregiver adaptation remain unclear even in the more extensive adult TBI literature.

From a transactional stress and coping framework, stress results from a perceived imbalance between the demands of the situation and the resources available to meet these demands (Lazarus & Folkman, 1984). Within this framework, pediatric TBI poses many unique, ongoing stressors that might contribute to greater long-term parental burden and distress than other injuries not involving the CNS, including emerging behavior problems and concerns about the child’s ability to function independently (Fletcher et al., 1990; Schwartz et al., 2003). These stressors may tax parental coping and deplete family resources thereby contributing to deteriorating functioning over time.

**Aims and Hypotheses**

This study is a continuation of the work of Wade et al. (2002) examining the longer-term parent and family outcomes of pediatric TBI. To control for the social and demographic background characteristics that may predispose some children to injury, we compared families of children with TBI to those of children with orthopedic injuries not involving the CNS. The ORTHO comparison group also at least partially controlled for the effects of traumatic injury and acute hospitalization on parents, thereby allowing us to identify family consequences unique to childhood TBI. To determine whether the effects of TBI on family outcomes varied with injury severity, we divided the TBI cohort into a moderate and severe TBI groups. We sought to determine whether parents of children with TBI continued to report increased burden at periods longer than our previous follow-up at the mean of 4 years after injury. An additional objective was to determine whether background and environmental factors, such as race, SES, and family stressors and resources, moderated group differences in these outcomes over time. We hypothesized that TBI would continue to be associated with higher levels of injury-related burden but not psychological distress or family dysfunction across the long-term follow-up interval. We further hypothesized that group differences in long-term outcomes would be moderated by...
stressors and resources. More specifically, we anticipated that burden and distress in the severe TBI group, relative to the ORTHO group, would be greater in parents with higher stressors and/or lower resources compared with those with more favorable life circumstances.

This investigation extended previous research on family outcomes in many respects. It is one of the longest prospective studies of pediatric TBI, following children from the time of injury across multiple assessments extending to an average of 6 years after injury. Additionally, we employed growth-modeling analysis, which allows inclusions of participants without data from all time points (Singer, 1998). We further sought to examine whether attrition and missing data biased the findings of the study using pattern mixture analyses (Hedeker & Rose, 2000). This type of analysis is employed to determine whether the dependent or outcome measure is related to the participant’s choice to remain in a study or drop out. Such analyses are particularly critical in longitudinal studies in which attrition is substantial and where interest in continuing participation may diminish over time. Thus, our goals were threefold: (a) to compare family outcomes of pediatric TBI with outcomes of pediatric orthopedic injuries across an interval from the end of the first postinjury year to an average of 6 years after injury, (b) to investigate the possibility that attrition from the sample over time biased the results, and (c) to examine whether demographic and social environmental factors moderated group differences in family outcomes over time.

Method
Sample Recruitment and Follow-up

All families were recruited shortly after the child’s injury by monitoring hospital admissions at four hospitals in north-central Ohio for school-age children with traumatic injuries. Inclusion criteria for the severe TBI, moderate TBI, and ORTHO groups included: (a) age between 6 and 12 years at the time of injury, (b) no evidence of child abuse or previous history of neurological disease or neurosensory impairment, (c) an overnight stay in the hospital for their injury, and (d) English as the primary language spoken at home. Consistent with previous investigations (Fletcher et al., 1990), severe TBI was defined as a Glasgow Coma Scale (GCS) (Jennett & Bond, 1975) score of 8 or less. Moderate TBI was defined from a GCS score of 9–12, or a GCS score greater than 12 accompanied by seizures or other signs of neurological dysfunction, skull fracture, intracranial mass lesion, diffuse cerebral swelling, or documented loss of consciousness for more than 15 min. Support for distinguishing moderate from severe TBI as defined above was provided by group differences in length of hospitalization and duration of impaired consciousness (Table I). Inclusion of children in the moderate group who had skull fractures that were not accompanied by evidence for intracranial lesion or sustained alteration in consciousness was justified by our interest in examining effects of a broad range of injury severity. In addition to meeting the criteria specified above, children in the ORTHO group had documented bone fracture in the absence of any evidence of loss of consciousness or other findings suggestive of brain injury (e.g., symptoms of concussion).

Once the children meeting study criteria were medically stable, informed consent was obtained from their parents. Baseline assessments were conducted as soon as could be arranged following the injury ($M = 0.7$ months, $SD = 0.4$), and the groups did not differ in this regard. Information obtained from parents at this time included retrospective reports of preinjury parent stressors and resources and preinjury family functioning (Wade et al., 1998, 2002, 2004). Measures of postinjury parental

| Table I. Sample Characteristics at the 1-Year Follow-up Assessment |
|------------------|------------------|------------------|
| Variable         | Severe TBI ($N = 46$) | Moderate TBI ($N = 54$) | ORTHO ($N = 68$) |
| Age at injury (years) | $9.5 (2.1)$ | $9.9 (1.9)$ | $9.3 (1.9)$ |
| Number/% boys | $–$ | $35 (76)$ | $39 (72)$ | $41 (60)$ |
| Number/% Whites | $–$ | $36 (78)$ | $42 (78)$ | $41 (60)$ |
| Hollingshead score | $33.2 (15.0)$ | $34.4 (14.6)$ | $33.9 (15.5)$ |
| Days hospitalized** | $13.1 (9.0)$ | $7.1 (7.6)$ | $13.3 (14.1)$ |
| MISS** | $20.8 (12.0)$ | $12.7 (5.9)$ | $7.6 (3.2)$ |

ORTHO, orthopedic injury; TBI, traumatic brain injury.

Modified Injury Severity Scores (MISS) were defined as the sum of the squared scored for the three most affected body regions, including the head (Mayer, Matlak, Johnson, & Walker, 1980).

$p < .05$. **$p < .01$. 

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psychological distress and injury-related family burden were also administered at baseline. These measures were re-administered to participants remaining in the study 6 months later and then again at a mean of 1.10 years after injury (range = 0.99–1.51, SD = 0.07). Additional follow-up visits took place at mean postinjury intervals of 4.10 years (range = 2.37–5.85, SD = 0.91), 5.13 years (range = 3.34–6.92, SD = 0.93), and 6.09 years (range = 4.34–8.14, SD = 0.97). Interviewers were centrally trained and supervised by the principal investigator at each site. Consistency across sites was monitored during regular telephone calls between investigators and at quarterly meetings. The child's biological mother served as the primary informant in 90% of the TBI cases and 93% of the ORTHO cases.

The sample originally enrolled in the study included 52 children with severe TBI, 56 children with moderate TBI, and 80 children with orthopedic injuries (Taylor et al., 2002). Owing to missed recruitment opportunities (e.g., short stays on the weekends) and parent refusals, we were able to recruit only 42% of children with TBI and 32% of children with orthopedic injuries who were eligible based on review of the medical records from the two largest sites. Comparisons of participants and nonparticipants indicated that the participants had more severe injuries and longer hospitalizations. Although some nonparticipants may not have met inclusion criteria after parent interview, available data suggest that the sample is not representative of all admissions of children meeting our enrollment criteria at participating hospitals.

For this study, we considered only families of the children who continued in follow-up at or after the 1-year postinjury assessment. Characteristics of the long-term follow-up sample are summarized in Table I. The reason for including only these families was our focus on changes in long-term family outcomes. By this assessment, 168 families remained in the study (89% of the initial sample), including 46 (89%) from the severe TBI group, 54 (96%) from the moderate TBI group, and 68 (85%) from the ORTHO group. Comparisons of families that participated in the 1-year assessment with those that had dropped out failed to reveal differences in age at injury or gender but did indicate a higher proportion of African Americans and lower SES for the subset of families that dropped out. African Americans and families of lower SES were thus under-represented in the sample of participants who entered the long-term follow-up phase of the study.

By the 4-year follow-up, 134 families remained in the study (71% of initial sample). Because of further attrition, 107 families (57%) remained at the 5-year follow-up, and 96 families (51%) completed the study. According to comparisons of the families that were initially enrolled but subsequently dropped out (non-completers) with families that participated in the final assessment (completers), higher proportions of the non-completers were from the ORTHO group and were African American. Because the proportion of African American families that dropped out was not significantly greater within the ORTHO or TBI groups, the race difference in the drop out likely reflected the somewhat greater percentage of African Americans in the ORTHO group. Noncompleters did not differ from completers on SES, age at injury, or gender.

**Measures**

**Predictors**

**Family Background Characteristics.** Sociodemographic status was assessed by race and the Socioeconomic Composite Index (SCI), defined as the mean of the sample z scores for the Duncan Socioeconomic Index (Stevens & Featherman, 1981), maternal educational level, and family income level as assessed by the Life Stressors and Social Resource Inventory, Adult Form (LISRES-A; Moos & Moos, 1994).

**Stressors and Resources.** The LISRES-A was also used to assess concurrent social resources and stressors. The stressors index consisted of an average of the health, work, spouse, friend, and extended family subscales, whereas the resources index included an average of the work, spouse, friend, and extended family subscales. On the stressor subscales, parents reported on health problems affecting them or their relatives, and they also indicated the extent to which their interactions with coworkers, friends, extended family, and spouses were negative or conflictual, as defined for criticism, irritation, anger, and unreasonable expectations. On the resource subscales, parents indicated the degree to which they perceived coworkers, friends, extended family, and spouses as positive sources of support, as defined for being understanding, respectful, reliable, and encouraging. The LISRES-A was re-administered at each follow-up assessment to obtain concurrent measures of social resources and stressors.

**Caregiver Outcomes**

**Injury-Related Burden.** The Family Burden of Injury Interview (FBII; Burgess et al., 1999) is a structured interview developed to assess the unique burdens associated with pediatric TBI. The FBII generates scaled scores representing injury-related burden in three areas: (a) concerns with the child's recovery and...
adjustment, (b) the reactions of extended family and friends, and (c) spouse’s reactions. The FBII possesses high internal consistency (Cronbach’s $\alpha = .90$) and has concurrent and predictive validity relative to family and child outcomes (Burgess et al., 1999). The mean of the three subscales, or total score, provides a summary of overall injury-related burden, with scores ranging from 0 (not at all stressful) to 4 (extremely stressful). Families with high injury-related burden were identified by having assigned a rating of 3 or 4 to at least one FBII item.

**Parental Psychological Distress.** The Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) was selected to assess parent psychological adjustment because of its brevity and sensitivity to change. The BSI is a widely used self-report questionnaire of psychiatric symptoms with well-documented reliability and validity (Derogatis & Spencer, 1982). The summary measure considered for this study was the BSI–General Severity Index (BSI-GSI), which considers ratings of distress across all scales. Parents displaying clinically severe symptoms were identified using the criteria established by Derogatis and Melisaratos (1983), which include a BSI-GSI $T$ score $>63$ or at least two dimensional $T$ scores $>63$.

**Family Functioning.** The Family Assessment Device (FAD) was administered to assess global family functioning. The FAD is a self-report measure with demonstrated reliability and validity (Miller, Bishop, Epstein, & Keitner, 1985). The 12-item FAD–General Functioning scale (FAD-GF) was used to provide a summary measure of family functioning. High family dysfunction was identified by a FAD-GF score $>2.17$ (Byles, Byrne, Boyle, & Oxford, 1988).

Controlling for group effects and measures of the family environment, associations between the three family outcomes were only modest. At the 1-year assessment, partial correlations between the FBII and BSI-GSI, FBII and FAD-GF, and BSI-GSI and FAD-GF were $.27$, $.17$, and $.28$, respectively (all $p < .05$).

**Analyses**

General linear mixed-model analysis, also known as hierarchical linear or growth modeling, was used to examine long-term changes in three parental outcomes (FBII, BSI-GSI, and FAD-GF). The advantages of the mixed-model approach are that it utilizes data from all participants, even those not seen at every assessment, and does not require equal intervals between assessments. A further virtue of this method is that both continuous and categorical variables can be included as predictors.

Mixed-model analysis was conducted using SAS Proc Mixed (SAS Institute, 1990), with group (severe TBI, moderate TBI, and ORTHO) as the primary predictor and with race and 1-year measures of the three environmental factors (i.e., SCI, stressors, and resources) as covariates. The basic model assumed that family outcomes for each family followed a quadratic curve over time after injury, with random family-specific intercept and linear and quadratic terms. This analysis used the actual times between 1-year and subsequent follow-up, which varied from subject to subject. The analysis examined the effects of group and the covariates on the intercepts and on linear and quadratic trends. The combined effects of the latter two trends defined change in family outcome across the postinjury follow-up interval. The Satterthwaite option in Proc Mixed was used to estimate the denominator degrees of freedom in determining the significance of model effects (Littell, Milliken, Stroup, & Wofinger, 1996). To enhance precision in examining group effects on the FAD-GF, we included the preinjury FAD-GF as an additional covariate in analysis of this measure. Because the FBII was a measure of parent response to the injury and because parents were not asked to rate their preinjury distress on the BSI, these two outcomes were assessed only after injury. Nevertheless, the groups did not differ significantly on the preinjury FAD-GF, preinjury stressors or resources, or the baseline SCI.

Model predictors included main effects and interactions of group with linear and quadratic effects of time (i.e., time and time squared, respectively), and the three-way interactions of 1-year environmental factors $\times$ group $\times$ linear time and environmental factors $\times$ group $\times$ quadratic time. Main effects of group and the covariates represented the effects of these factors on model intercepts. The double interactions were included to examine group differences in postinjury change, and the triple interactions to examine moderating effects of environmental factors on these group differences. To adjust family outcomes at each point for the three concurrent measures of the family environment, the model also included these factors as time-varying covariates. Because the injured child’s age and gender did not differ by group or predict any of the family outcomes, these factors were not considered in analysis.

Models were trimmed by eliminating nonsignificant higher- and then lower-level interactions, with alpha level set at $p < .017$ ($.05$/number of outcomes) to adjust for multiple comparisons. Given this correction in alpha, significance levels are reported to three decimals. To preserve statistical power, the SCI was the only environmental
factor included in initial models. Once models that included the SCI were trimmed, stressors and interactions of stressors with group and time after injury change were added to examine their effects. These models, in turn, were trimmed, and the influences of resources were then examined in a similar manner. The main effects of SCI were included in all models, but main effects for stressors and resources were retained only if they or interactions involving these factors were related to outcomes independently of the SCI.

To investigate group differences in rates of adverse family outcomes, we analyzed the three dichotomous family outcome variables (high injury-related family burden on the FBII, clinically significant parental distress on the BSI-GSI, and high family dysfunction on the FAD-GF) in a logistic regression model by using generalized estimating equation (GEE; Diggle, Liang, & Zeger, 1994). With advantages similar to those of mixed-model analysis and employing the same factors and procedures, this method tested covariate-adjusted group differences in the proportions (i.e., percentages) of adverse outcomes. By using clinical cutoffs for the outcome measures, we could examine whether there were long-term group differences in clinically significant outcomes (e.g., family dysfunction). The results from the mixed-model analyses of the continuous outcomes are reported first, followed by the GEE analyses of the dichotomous data.

Because factors related to drop out (race, group, and the SCI) were included in the mixed model, estimates of model effects were unbiased, and incomplete data related to these factors are considered ignorably missing (Schafer, 1997). It was nevertheless conceivable that other unmeasured factors were associated with drop out and that these factors were also related to the family outcomes. In this case, missing data would be nonignorable. For example, failure to return for follow-up may be related to greater (or lesser) injury-related family burden or dysfunction, thereby biasing findings in favor of more positive (or negative) family outcomes. Although we had no means for directly evaluating such possibilities, a potential bias of this sort was examined using pattern-mixture analysis (Hedeker & Gibbons, 1997; Hedecker & Rose, 2000). Specifically, a “completer” factor representing complete versus incomplete longitudinal data was added to the final models for each family outcome. Interactions of the completer factor with group and the time after injury factors were also included. With the exception of one analysis described below, neither the completer main effect nor interactions involving this factor predicted the outcomes, and results were similar with and without the inclusion of this factor in analyses.

Results
Findings from Mixed-Model Analysis of Family Outcomes

Consistent with our initial hypothesis, mixed-model analysis of the FBII scores revealed a significant main effect for group, $F(2, 168) = 25.79, p < .001$. The severe TBI group had higher injury-related burden than the moderate and ORTHO groups (for both comparisons, $p \leq .001$), and the moderate TBI group had higher burden than the ORTHO group ($p = .002$). Effect sizes (which are differences in adjusted means divided by root mean square error) for the severe TBI versus ORTHO groups and the moderate TBI versus ORTHO groups were 1.20 and 0.52, respectively. A main effect for time after injury, $F(1, 108) = 37.43, p < .001$, reflected a decline in burden across the follow-up interval in all groups. Figure 1 graphs model estimates of this decline, with constant group differences over time after injury. Significant main effects for the SCI, $F(1, 234) = 16.00, p < .001$, and stressors, $F(1, 470) = 19.29, p < .001$, indicated associations of lower SCI and higher stressors with higher burden.

When the completer factor and its interactions were considered, analysis of the FBII revealed a marginally significant group-completer interaction, $F(2, 188) = 3.65, p = .028$. However, completer status did not interact significantly with main effects or interactions involving time. Follow-up of the group-completer interaction indicated that completers in the severe TBI group had more burden than noncompleters, $t(194) = 2.35, p = .020$, but that this difference was not evident for the other two groups. Further follow-up tests demonstrated that group differences were significant only for the completers, $F(2, 141) = 26.87, p < .001$. Attrition was thus

![Figure 1. Model estimates of scores on the Family Burden of Injury Interview (FBII) by group from mixed-model analysis.](https://academic.oup.com/jpepsy/article-abstract/31/10/1072/2952458/1077)
selectively higher among families in the severe TBI group with lower burden, and the impact of this attrition was to amplify group differences. The reasons for this bias are unknown, but may represent a tendency for families with lesser burden to be less inclined to continue their participation. Pattern mixture-modeling methods that differentially weight-model estimates according to completer status were used to determine whether group differences would remain after adjustments for the effects of this bias (Hedeker & Gibbons, 1997). The results of this analysis confirmed a group main effect and gave results very similar to the analysis that did not adjust for completer status. Follow-up tests again indicated higher burden in the severe TBI than in the other two groups and higher burden in the moderate TBI group than in the ORTHO group.

Although the group main effect on the BSI-GSI was not significant, results revealed a trend in this direction, $F(2, 163) = 3.18, p = .044$. As shown in Fig. 2, the group effect reflected higher parental distress in the moderate TBI group than in the ORTHO group $t(169) = 2.52, p = .013$. Distress was also higher in the severe TBI group compared with the ORTHO group, but this difference was not significant, $t(164) = 1.14, p = .257$. Higher parental distress was also associated with a lower SCI, $F(1, 229) = 13.11, p < .001$, lower resources, $F(1, 466) = 14.65, p < .001$, and higher stressors, $F(1, 467) = 17.41, p < .001$. Figure 2 also depicts a trend of increasing BSI-GSI scores over time, $F(1, 132) = 4.64, p = .033$.

Analysis of the FAD-GF revealed a three-way interaction of group $\times$ time after injury $\times$ resources, $F(4, 126) = 3.98, p = .004$. In support of our second hypothesis, the latter interaction suggests that group differences in change across the follow-up interval were moderated by resources. As evident in Fig. 3, the severe TBI group reported significantly worse family functioning than the ORTHO group, but only in families with low levels of resources and only at the 4- and 5-year follow-up assessments, $t(126) = 3.16, p = .002$; $t(139) = 3.06, p = .003$, respectively. Effects sizes for these two group comparisons were .91 and .89, respectively. Inspection of Fig. 3 suggests that the failure to find continued group differences at the last assessment may have reflected increasing family dysfunction for the ORTHO families with low resources. For families with high resources, group differences were not significant at any of the long-term follow-up assessments.

### Findings from GEE Analysis of Rates of Adverse Family Outcomes

As depicted in Fig. 4, GEE analyses of the presence/absence of high injury-related burden revealed a significant group by time-after-injury interaction, $\chi^2(2) = 9.90, p = .007$, indicating increasing group differences over time. In this case, the proportion of moderate TBI and ORTHO participants reporting a severe burden declined significantly over time (moderate TBI $\chi^2 = 5.52, p = .019$; ORTHO $\chi^2 = 9.63, p = .002$), whereas the proportion of severe TBI families with severe burden remained relatively stable across follow-up. Consistent with findings from the mixed-model analysis and hypothesis 1, simple effect tests indicated higher rates of severe burden in the severe TBI group than in the ORTHO group at all four follow-ups. The odds of having high burden in the severe TBI group relative to ORTHO group at the 1-, 4-, 5-, and 6-year follow-up assessments were $2.32 (CI = 1.04–5.19, p = .041)$, $7.65 (CI = 3.32–17.66, p < .001)$, $11.39 (CI = 4.23–30.71, p < .001)$, and $16.96 (CI = 5.19–55.42, p < .001)$, respectively. The moderate TBI group also reported higher rates of severe burden than the ORTHO group at all but one of the 1-year follow-up. The odds of having high burden in the moderate TBI group relative to the ORTHO group at the 1-, 4-, 5-, and 6-year follow-up assessments were $3.00 (CI = 1.39–6.52, p = .005)$, $3.56 (CI = 1.36–9.31, p = .010)$, and $4.22 (CI = 1.29–13.75, p = .017)$, respectively.

GEE analyses for the BSI-GSI failed to reveal group differences or interactions of group with stressors, resources, or SCI. Despite an absence of group differences, 36% of the severe TBI group, 37% of the moderate TBI group, and 24% of the ORTHO group exceeded the clinical cutoff at time 6, indicating a somewhat elevated level of psychological distress in the sample as a whole. There was a significant main effect for both SCI and resources with higher SCI and social resources associated with a
lower likelihood of clinically significant distress ($p < .001$ and $= .003$, respectively).

GEE analyses of the FAD-GF also failed to reveal group differences or interactions of group with stressors or resources. At the final assessment, 23% of the severe TBI, 21% of the moderate TBI, and 21% of the ORTHO group exceeded the cutoff on the FAD. There were significant main effects for time since the injury, $\chi^2(1) = 6.87, p = .009$, and social resources, $\chi^2(1) = 11.19, p < .001$. Greater time since injury and lower levels of social resources were associated with a greater likelihood of family dysfunction.

**Discussion**

**Long-Term Family Sequelae of Pediatric TBI**

These findings support our hypothesis that moderate to severe TBI is associated with greater injury-related burden than orthopedic injuries not involving insult to the CNS for many years following the acute injury. These findings are consistent with our previous work (Wade et al., 2002), as well as that of other investigators (Rivara et al., 1992, 1996), suggesting that the burdens arising from TBI are chronic. Although TBI continued to be associated with more burden than non-CNS injuries, overall burden levels declined across follow-up, indicating that some problems or issues may resolve themselves over time. However, group differences in the proportion of parents reporting an area of burden that was quite or extremely stressful became more pronounced over time after injury. This pattern of findings suggests that some families of children with severe TBI may continue to face some element of severe burden arising from the child’s injury many years later, despite reductions in burden in most families. In particular, these parents may experience persistent worries regarding their child’s future. By the later follow-ups, most children in this sample were entering adolescence and young adulthood. As implied by the increasing parental distress and family dysfunction in the sample as a whole, the development transition from childhood to adolescence and its attendant
challenges can contribute to greater parental stress and family conflict (Silverberg, 1996). For parents of adolescents with severe TBI, the strains of adolescence may be coupled with emerging concerns regarding the child’s ability to function autonomously as an adult. These findings suggest that a subset of families of children with severe TBI may benefit from professional guidance in negotiating life transitions with their injured child even though the injury occurred many years earlier.

The effects of TBI on parent psychological distress and family functioning were also generally consistent with our hypotheses and previous results suggesting an absence of such effects. One exception to this pattern was discovery of higher levels of parent psychological distress, as measured by the BSI-GSI, in the moderate TBI group compared with the ORTHO group. The reason for finding greater distress in the moderate TBI but not in the severe TBI group is unclear. One possibility is that the greater parental concerns for the child evident in the severe TBI group may have been accompanied by a reluctance to endorse their own problems, thereby dampening parental self-reports of distress in this group. The tendency for parents to deny their own needs reported in an earlier follow-up is consistent with this possibility (Wade, Taylor, Drotar, Stancin, & Yeates, 1996). An alternative interpretation is that sequelae of injury may be more “unexpected” in children with moderate compared with severe TBI and that the child’s difficulties meeting expectations may contribute to more prominent parental adjustment problems.

In support of the moderating or buffering hypothesis, families in the severe TBI group only reported worse family functioning than families in the ORTHO group, when social resources or supports were lacking. The latter evidence for moderating effects of resources on family outcomes is consistent with previous investigations (Rivara et al., 1996; Wade et al., 2004) and underscores the importance of considering the family impact of pediatric TBI in the broader context of the social environment. These findings suggest that support from spouse, family, friends, and coworkers may protect families from the additional adversity arising from severe TBI.

Although conventional wisdom suggests that group differences in family functioning arising from the injury should diminish over time, these findings revealed a more complicated scenario, in which group differences were greatest at the 4- and 5-year follow-ups. The absence of group differences at 1-year after injury may indicate that much of the significant long-term burden (e.g., concerns for the child’s ability to function independently) and accompanying family distress had not emerged by this time. Thus, longer-term concerns arising as children with severe TBI approach their adolescence or young adulthood may contribute to increased family dysfunction. Although supportive relationships with one’s spouse, family, friends, and coworkers may enable parents to cope more effectively with these long-term challenges, families lacking such supports may become increasingly dysfunctional. Group differences in family dysfunction were no longer significant at the final assessment. However, inspection of that pattern of changes over the follow-up interval (Fig. 3) suggests that this may have been because of increasing levels of dysfunction among parents in the ORTHO group with few resources rather than to improved functioning among parents in the severe TBI group. It is possible that the increased family difficulties reported at the final assessment by ORTHO parents lacking resources is reflective of difficulties coping with the strains of adolescence (Duncan & Brooks-Gunn, 2000).

Taken together, these findings suggest that some of the discrepancies among the conclusions of previous investigations may be attributable to differences in the timing of follow-up, how outcomes were assessed (continuously or categorically), and which outcomes (e.g., burden versus psychological distress) were considered. Although approximately 2/3 of parents in the severe TBI group reported an area of severe injury-related burden across the extended follow-up period, far fewer were experiencing significant parental distress or family dysfunction. As we consider outcomes more distal to the injury (e.g., parental psychological distress), other factors such as SES and interpersonal stressors and resources exert a stronger influence on outcome than the nature or severity of the injury. Thus, in accordance with the framework of risk and resistance factors described by Wallander, Varni, and others (Wallander & Varni, 1998), intervention models must address the intra- and interpersonal risks such as maladaptive coping or inadequate supports (Wade et al., 2001, 2004) that contribute to the heightened adversity experienced by some individuals and families following pediatric brain injury.

Several limitations of this study should be noted. First, families that chose to participate had more severe injuries and longer hospitalizations than nonparticipants. Additionally, many families dropped out of the study across the four follow-ups, with greater attrition in the ORTHO group than in the TBI groups and among African American participants. Additionally, pattern mixture-model analysis revealed a higher rate of drop out from the severe TBI group for families reporting lower
levels of burden. We took completer status and the factors we found related to attrition into account in our analyses as covariates. We also used pattern-mixture modeling to adjust for the effects of drop out on the FBII. Despite these efforts, recruitment and attrition biases may have influenced the findings in ways that were not controlled. Caution is thus advised in generalizing our findings to the broader population of children with TBI, and replication would be advisable in view of our relatively small sample size. Future research would benefit from closer examination of the factors that may contribute to differential attrition among minority families and implementation of strategies to enhance retention among these individuals. For example, motivational interviewing techniques could potentially be adapted to address underlying ambivalence toward research among nonwhite participants (Miller & Rollnick, 2002).

Other factors may have limited our ability to detect the true long-term burden and distress arising from severe TBI including the use of an admittedly crude measure of TBI severity (i.e., the GCS score) and recruitment of children with orthopedic injuries as a comparison group. Although the GCS score is commonly used to define TBI severity, other measures of brain insult not available in this study, such as high-resolution magnetic resonance imaging (Tong et al., 2004), may have enabled us to identify a subsample of children with more extensive damage for whom family distress and burden was especially high. The use of an orthopedic comparison group allowed us to control for the experience of a severe injury requiring hospitalization and, in this way, to more rigorously assess the effects of TBI per se. However, orthopedic injuries may themselves contribute to burden, parental psychological distress, and family dysfunction. For this reason, and because many of the children with TBI sustained accompanying orthopedic injuries, our group comparison may have underestimated the total impact of TBI on families. Our reliance on self-report measures of injury-related stress and burden and caregiver distress from a single informant is a further limitation. Associations between social resources and parent outcomes may be attributable, in part, to shared method variance.

In conclusion, this study sheds light on the degree of long-term caregiver and family burden and distress arising from pediatric TBI based on data from one of the longest prospective follow-up studies to date. The findings suggest that, although severe TBI is associated with some level of long-term burden, families of children with severe TBI with adequate interpersonal resources are not at greater risk for significant psychological disorder or family dysfunction over the long term. Conversely, families lacking social supports may benefit from interventions that provide support and facilitate coping (Wade et al., 2005). This study also illustrates methods for examining attrition biases and their effects in longitudinal investigations. Future research exploring parent and family outcomes of TBI from the perspectives of multiple family members (e.g., father, sibling) and observer ratings will help to shed further light on the complex process of family adaptation over time.

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