Family Burden and Adaptation During the Initial Year After Traumatic Brain Injury in Children

Shari L. Wade, PhD*; H. Gerry Taylor, PhD*; Dennis Drotar, PhD*; Terry Stancin, PhD‡; and Keith Owen Yeates, PhD§

ABSTRACT. Objective. Traumatic brain injury (TBI) often leads to long-term behavioral and cognitive deficits in children. However, little is known about the burden and psychosocial morbidity of pediatric TBI for families. The purpose of this study was to test the hypothesis that moderate and severe TBI in children has more adverse consequences than orthopedic trauma.

Design. The sample was comprised of children between the ages of 6 and 12 recruited from hospital trauma and inpatient units including 53 with severe TBI, 56 with moderate TBI, and 80 with orthopedic injuries not involving central nervous system insult. Measures of injury-related burden, parental distress, and family functioning were administered to the child’s primary caregiver at baseline assessment conducted soon after injury and at 6- and 12-month follow-ups. Multivariate repeated measures analysis of covariance was used to examine group differences in these outcomes over time.

Results. Caregivers in the severe TBI group reported significantly higher levels of family burden, injury-related stress, and parental psychological symptoms than caregivers in the orthopedic injury group (ORTHO). The groups did not differ with respect to marital distress. Caregivers in the severe TBI group were significantly more likely than caregivers in the ORTHO group to exceed the clinical cutoff on the Brief Symptom Inventory and to report clinically significant levels of family dysfunction at follow-up.

Conclusions. The findings suggest that severe TBI is a source of considerable caregiver morbidity, even when compared with other traumatic injuries. Caregivers in the severe TBI group had persistent stress associated with the child’s injury, as well as the reactions of other family members, and a relative risk of clinically significant psychological symptoms nearly twice that of the ORTHO comparison group. These findings underscore the need for interventions that facilitate family adaptation after pediatric TBI. Pediatrics 1998;102:110–116; traumatic brain injury, orthopedic injuries, burden, adaptation, family outcomes.

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raumatic brain injury (TBI) in children is likely to affect families in many important ways, especially given the marked risk of ongoing neuropsychological, behavioral, and academic problems in these children. Caregivers and spouses of adults who have experienced TBI report elevated levels of burden and depression. Caregiver distress, moreover, has been shown to increase as a function of time since the injury. Although a number of investigators have speculated that initial cognitive impairments and behavior changes in the child may disrupt family life and adversely affect parent adjustment and parent-child interactions, few studies have assessed the effects of TBI on the family.

Only two studies of the effects of pediatric TBI on families incorporated both a prospective design and standardized assessments of family functioning. In the Seattle study by Rivara et al., families of children at three levels of TBI severity (mild, moderate, and severe) were followed for 3 years postinjury. Based on interviewer ratings, there was a deterioration in family functioning from preinjury to postinjury in the families of children with severe TBI. The negative family impact of severe TBI was first observed at 1 year postinjury, but was also present at the 3-year follow-up. However, changes in family functioning were not demonstrated on parent self-report measures. Furthermore, important family outcomes, such as parental psychological adjustment, were not assessed.

Preliminary results from the study by Wade et al. revealed significantly greater acute injury-related stress and burden among parents of children who had experienced severe TBI, in comparison to parents of children with moderate TBI or orthopedic injuries requiring hospitalization. Families of children with severe TBI experienced higher levels of injury-related stress associated with concerns for the child’s recovery, whereas group differences in stress associated with sibling behavior and the reactions of spouses and extended family to the injury only approached significance. Parents of children with TBI also reported significantly higher levels of psychological symptoms than parents of children with orthopedic injuries at a baseline assessment conducted...
several weeks after the injury. The long-term outcomes of this investigation are described in the present report.

Research on the family consequences of pediatric TBI underscores the importance of considering various dimensions of family impact. Several investigators, for example, have distinguished between injury-related burden and family functioning and adaptation.\(^1^,16\) Injury-related burden is closely tied to injury severity and encompasses stresses associated with medical management, disruption in family routines, changes in the injured child’s behavior, and concerns over the reactions of other family members.\(^1\) Adaptation, including parental psychological adjustment, marital quality, and family functioning, reflect the family’s ability to respond and cope with the burdens of the injury, as well as with preexisting stresses and strains. The distinction between burden or stress related to injury and the family’s coping ability and adaptation is consistent with current models of stress and coping,\(^17\) and is critical in conceptualizing family response to TBI.

The effects of TBI on the family also need to be considered in relation to the time that has passed since the injury. The tasks and stresses associated with an acute hospitalization of a family member are quite different from those arising from chronic neuropsychological and behavioral deficits.\(^18\) Findings from the literature on TBI in adults\(^2\) indicate that family distress and dysfunction may intensify rather than diminish over time. Furthermore, a family’s ability to successfully cope with the initial demands of the injury may have important implications for longer term family adaptation.\(^12\) Thus, future research must distinguish initial effects of pediatric TBI on families from ongoing and chronic concerns.

The current report represents a continuation of our previous investigation, of families of children with severe TBI, moderate TBI, and orthopedic injuries not involving the central nervous system (CNS).\(^14,15\) In the present study we examined injury-related burden, stress, and family adaptation at 6 and 12 months after the baseline assessment. We also investigated clinically significant problems with parental adjustment and family functioning after pediatric TBI and orthopedic injuries.

The findings from this project extend our earlier work and the work of previous investigators in several respects. This is the first prospective study of family outcomes after TBI to use a comparison group with orthopedic injuries to control for preinjury family status and the effects of acute hospitalization. By comparing family consequences of orthopedic injuries to family consequences of TBI, we were able to measure the impact of TBI with greater precision. We also examined a broad range of family consequences including injury-related burden and stress, caregiver psychological adjustment, marital adjustment, and family functioning.

Our central hypothesis was that TBI would result in greater parental stress and burden, higher levels of parental psychological symptoms, and greater deterioration in marital and family functioning than orthopedic injuries not involving CNS insult. We further hypothesized that burden and stress arising from the injury would be more persistent among families of children with severe or moderate TBI, while diminishing among the parents of children with orthopedic injuries. Finally, we anticipated that the family consequences of TBI would be greater for children with severe TBI than for children with moderate TBI.

METHOD

Sample

The total sample recruited included 53 children with severe TBI, 56 with moderate TBI, and 80 with orthopedic injuries not involving CNS insult. Eligibility criteria for both the TBI and orthopedic injury (ORTHO) groups included: 1) age between 6 to 12 years of age at the time of injury, 2) no evidence of child abuse or previous history of neurologic disease or neurosensory impairment, and 3) English as the primary language spoken at home. Recruitment into the TBI group also required documentation of moderate-to-severe TBI. Consistent with previous investigations, severe TBI was defined as a Glasgow Coma Scale (GCS)\(^9\) score of 8 or less.\(^9,20\) Moderate TBI was defined using GCS score between 9 to 12 or a GCS score >12 accompanied by seizures or other signs of neurologic dysfunction, skull fracture, intracranial mass lesion, diffuse cerebral swelling, or documented loss of consciousness for >15 minutes. The lowest documented GCS score was used for determinations of injury severity. Children with types of TBI other than closed head injuries were excluded. Inclusion in the ORTHO group additionally required a documented bone fracture requiring an overnight hospital stay and the absence of any evidence of loss of consciousness or other findings suggestive of brain injury (eg, symptoms of concussion, severe facial trauma). Families refusing to participate did not differ from participants with respect to injury severity or ethnicity.

Table 1 presents demographic and injury characteristics for the sample as a whole. Although the groups were comparable in most respects, there was a significantly higher proportion of non-white children in the ORTHO group compared with the TBI groups. As anticipated, the groups also differed significantly with respect to indices of injury severity\(^21\) and length of hospitalization.

**Procedures**

All age-appropriate admissions at three regional children’s hospitals and a large county hospital were monitored for potential eligibility. Once the children who met study criteria were medically stable, informed consent was obtained. Baseline assessments were conducted as soon as could be arranged after the injury (\(M = 7\) months; SD = 4) and the groups did not differ in this regard. Information obtained from parents at this time included parent perceptions of the burden of the injury on the family since the child’s discharge from the hospital and concurrent parental psychological distress.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Severe TBI</th>
<th>Moderate TBI</th>
<th>ORTHO</th>
</tr>
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<tbody>
<tr>
<td>(n = 53)</td>
<td>(n = 56)</td>
<td>(n = 80)</td>
<td></td>
</tr>
<tr>
<td>M Age at injury (±SD)</td>
<td>9.4 (2.1)</td>
<td>10.0 (1.9)</td>
<td>9.3 (1.9)</td>
</tr>
<tr>
<td>M Highest non-head AIS Score (± SD)*</td>
<td>2.0 (1.38)</td>
<td>1.1 (0.88)</td>
<td>2.5 (0.55)</td>
</tr>
<tr>
<td>M Days in hospital (±SD)*</td>
<td>13.4 (10.0)</td>
<td>7.0 (7.5)</td>
<td>13.8 (13.7)</td>
</tr>
<tr>
<td>Gender of child</td>
<td>74% Male</td>
<td>73% Male</td>
<td>59% Male</td>
</tr>
<tr>
<td>Race</td>
<td>75% White</td>
<td>77% White</td>
<td>57% White</td>
</tr>
<tr>
<td>Proportion two-parent families</td>
<td>55%</td>
<td>71%</td>
<td>62%</td>
</tr>
<tr>
<td>Hollingshead Four Factor Index</td>
<td>33.2 (15.4)</td>
<td>33.9 (14.9)</td>
<td>33.2 (15.2)</td>
</tr>
<tr>
<td>Percent receiving public assistance</td>
<td>34%</td>
<td>23%</td>
<td>32%</td>
</tr>
</tbody>
</table>

Abbreviation: AIS, Abbreviated Injury Scale.\(^21\) * Group differences significant, \(P < .05\).


Measures of injury-related burden, parental distress, and family functioning were readministered at 6 and 12 months after baseline. The child’s biological mother served as the primary informant in 90% of the TBI cases and 93% of the orthopedic cases.

**Measures**

Based on existing conceptual models, we considered two broad classes of outcomes: 1) burdens and stress arising from the injury; and 2) family adaptation and functioning. We conceptualized family adaptation as occurring at the individual (parental psychological adjustment), dyadic (marital adjustment), and family levels (family functioning). We used this multilevel approach to increase our sensitivity to the various aspects of family adaptation that might be affected by TBI and its sequelae.

**Measures of Injury-related Stress and Burden**

The Family Burden of Injury Interview (FBII)\(^1\) was developed to assess the unique burdens and challenges of pediatric TBI for families. The FBII generates individual scales representing injury-related stress in each of three areas: 1) concerns with the child’s recovery and adjustment; 2) the reactions of extended family and friends; and 3) spouse’s reactions. Factor analyses of the FBII reveal that these three subscales measure similar constructs in the TBI and orthopedic groups. The mean of the three subscales, or total score, provides a summary of overall injury-related stress.

The McMaster Family Assessment Device (FAD)\(^2\,^3\,^4\) was used to assess global family functioning. The FAD is a 53-item self-report measure with demonstrated reliability and validity.\(^2\,^3\,^4\) Parents were asked to complete the FAD at baseline in reference to the family’s functioning before the injury. The 12-item General Functioning scale was used as a summary measure of family functioning.

The Brief Symptom Inventory (BSI)\(^5\,^6\) was selected to assess parent psychological adjustment because of its brevity and sensitivity to change. The BSI is a widely-used 53-item, self-report questionnaire of psychiatric symptoms with well-documented reliability and validity.\(^5\,^6\) Based on the recommendations of Derogatis and Spencer,\(^5\) clinically severe symptoms (ie, symptom levels likely to warrant clinical attention) were defined as a Global Severity Index T-score \(\geq 63\) or T-scores on two or more subscales \(\geq 63\).

The Dyadic Adjustment Scale (DAS)\(^2\,^8\) was used to assess marital functioning among the 86 participants with spouses. The DAS is a 32-item Likert measure of marital satisfaction with demonstrated reliability and validity. The DAS completed at baseline was completed as a measure of preinjury marital adjustment.

**Measures of Family Functioning and Adaptation**

The McMaster Family Assessment Device (FAD)\(^2\,^3\,^4\) was used to assess global family functioning. The FAD is a 53-item self-report measure with demonstrated reliability and validity.\(^2\,^3\,^4\) Parents were asked to complete the FAD at baseline in reference to the family’s functioning before the injury. The 12-item General Functioning scale was used as a summary measure of family functioning.

The Impact on Family (IOF) Scale, Version G\(^2\) provided a previously validated measure of the impact of pediatric disability on the family. For each item, parents indicate the extent to which they agree with a statement regarding the impact of the child on the family, and then report whether they feel that their rating is related to the child’s health condition (in this case, injury). The Total Negative Impact score served as a summary measure of family burden in the current analyses.

**Measures of Sociodemographic Status**

Sociodemographic status was assessed in terms of race and the Socioeconomic Composite Index (SCI). The SCI was defined as the mean of the sample z scores for the Duncan Socioeconomic Index,\(^9\) maternal educational level, and family income level as assessed by the Life Stressors and Social Resource Inventory.\(^10\) Because of the higher correlation of the SCI to child outcomes in the ORTHO group, this measure was used in place of the Hollingshead Four Factor Index of Social Status.\(^11\)

**Analyses**

Multivariate repeated measures analysis of covariance (MANCOVA) was used to examine group differences over time in injury-related caregiver burden and caregiver and family functioning.\(^2\,^1\) In these analyses, the main effect for group was tested by comparing groups on the average score across the baseline, 6-month, and 12-month assessments. Subsequent MANCOVAs examined the effects of time and group by time interactions. In these analyses, contrasts representing linear and quadratic trends over time served as the dependent variables. As noted previously, race and the SCI were included as covariates in these analyses. For measures for which the baseline assessment evaluated preinjury functioning (FAD General Functioning scale; Dyadic Adjustment Scale), the 6-month and 12-month assessments were examined using repeated-measures MANCOVA. In these cases, the baseline score was included as a covariate.

Logistic regression analysis was used to examine group differences in rates of clinically elevated symptoms on the BSI, clinically significant family dysfunction on the FAD as defined by the FAD General Functioning Index > 2.17,\(^2\,^3\) and marital dysfunction as defined by DAS < 100.\(^2\) Race and SCI were also included as covariates in the logistic regressions. Odds ratios (ORs) were computed by comparing the rates of family difficulties in each of the TBI groups to rates in the orthopedic group.

Because of attrition and missed appointments, sample size was reduced for the repeated measures MANCOVAs. The current findings are based on the information gathered from the families at all three assessments that included 40 children with severe TBI, 51 with moderate TBI, and 55 children with orthopedic injuries who served as a comparison group. Only 86 respondents completed the DAS because a substantial number of participants who were single or divorced. The subsample of families seen at all three assessments were similar to the total sample with respect to gender distribution and age. However, there was a greater proportion of non-whites in the excluded families. In addition, socioeconomic status, as measured by the Hollingshead Four Factor Index of Social Status,\(^11\) scores were lower for the excluded families. Although social status and race were taken into account as covariates in the data analysis, the final sample may thus be underrepresentative of families that are non-white or of lower socioeconomic status.

**RESULTS**

### Bivariate Relationships Among Outcome Measures

Intercorrelations of the subscales of the FBII at 6 months ranged from .47 to .56. Injury-related stress on the FBII was also significantly correlated with Total Negative Impact scores from the IOF (r = .50; \(P < .001\)). Correlations between measures of injury-related stress and family adaptation ranged from .36 (P < .001) for the relationship between average stress and FAD General Functioning to .40 (P < .001) for the relationship between average stress and the BSI Global Severity Index. Further, measures of family adaptation were only modestly correlated with one another, with a correlation of .42 (P < .001) between BSI Global Severity Index and FAD General Functioning scale. This pattern of intercorrelations among the measures at 6 months postinjury suggests that the outcomes represent distinct, yet related, domains of family burden and adaptation.

### Injury-related Burden

As hypothesized, the groups differed significantly with respect to average family burden, as assessed by the IOF Total Negative Impact score, over the 12 months after injury, even after controlling for race and the SCI (\(F = 4.39, P < .05\); see Table 2). There was also a significant linear interaction between group membership and time for this measure (\(F = 4.11; P < .05\)). Specifically, although the Total Negative Impact scores declined linearly over time in the sample as a whole (\(F = 11.15; P < .001\)), the differences between the TBI and ORTHO groups increased over time (see Fig 1). According to follow-up analyses, the ORTHO group had a significantly greater
reduction in burden between baseline and 6 months and baseline and 12 months than the moderate TBI group (see Fig 1). A similar, but nonsignificant, trend is seen in comparing the changes over time in the severe TBI and ORTHO groups. Posthoc analysis of the change in burden over time in each group indicated that the ORTHO group showed both linear and quadratic decline in total negative impact scores over the three assessment periods. In contrast, posthoc tests of changes in Total Negative Impact scores over time in the two TBI groups were nonsignificant.

Injury-related Stress

The groups differed significantly with respect to the average level of injury-related stress on the FBII across the three assessments, with the severe TBI group reporting significantly higher levels of injury-related stress than the moderate TBI and ORTHO groups (see Table 3). Although average injury-related stress diminished linearly over time in all three groups ($F = 10.85; P < .001$), changes in injury-related stress over time did not differ significantly among the groups.

Analysis of the three individual FBII scales revealed significant group differences in the average levels of injury-related stress arising from the child’s problems and behavior ($F = 22.5; P < .0001$), the reaction of the spouse ($F = 5.65; P < .01$), and the reaction of other family members ($F = 12.83; P < .0001$) (see Table 3). Stress levels related to the child’s condition and the spouse’s reaction declined significantly over time ($F = 11.12; P < .001$ for child condition, and $F = 6.59; P < .05$ for spouse’s reaction). However, stress associated with the family members’ reactions did not decline significantly over time, nor was the group by time interaction significant for any of the dimensions of the FBII.

Aspects of Family Functioning and Adaptation

Parental Psychological Symptoms

Consistent with initial hypotheses, parents in the severe TBI group experienced a significantly greater number of psychological symptoms than parents in the ORTHO group ($F = 4.34; P < .05$) (see Table 4). There was also a significant linear decline in parent psychological symptoms across the three assessments ($F = 4.74; P < .01$). Parental psychological symptoms declined significantly between both baseline and 6 months ($F = 7.53, P < .01$) and baseline and 12 months postinjury ($F = 8.59; P < .01$). However, analyses failed to reveal a significant interaction between group membership and the degree of reduction of symptoms over time.

Logistic regression analyses indicated that there was a significantly higher rate of clinically severe
symptoms on the BSI at 6 months for the severe TBI group compared with the ORTHO group (OR = 3.27; confidence interval [CI] = 1.22, 8.77, P < .05). At 12 months, the severe TBI group continued to have significantly higher rates of clinically severe symptoms on the BSI than the ORTHO group (OR = 2.85; CI = 1.04, 7.83, P < .05). Forty percent of the severe TBI group, compared with 29% of the moderate TBI group and 22% of the ORTHO group, continued to report psychological symptoms of clinical magnitude a full year after the injury. These rates are substantially higher than the 10% rates noted in normative samples. 

Marital Adjustment

Contrary to our hypothesis, there were no overall differences between the groups with respect to scores on the DAS (see Table 5). Analyses also failed to reveal a significant interaction between group membership and changes in marital adjustment over time. However, the power to detect group differences was limited because of the reduced number of participants with spouses.

Logistic regressions were used to compare the proportion of couples in each group exceeding the clinical cutoff on the DAS at 6 and 12 months postinjury. The groups did not differ significantly in rates of marital difficulties at either assessment.

Family Functioning

The groups did not differ significantly in terms of the average FAD General Functioning score across the postinjury follow-up period (see Table 5). Additionally, no interaction between group membership and changes in family functioning over time was observed.

Rates of family dysfunction were significantly higher in the severe TBI group compared with ORTHO group at the 6 month follow-up (OR = 5.55; CI = 1.37, 22.43, P < .05). According to the criteria given above, 25% of the severe TBI group, 11% of the moderate TBI group, and 7% of the ORTHO group were identified as having significant family dysfunction at 6 months. Group differences in rates of family dysfunction were not significant at the 12-month follow-up.

DISCUSSION

The incidence of TBI in children each year is approximately 180 per 100,000, making it a major source of morbidity and mortality among children. Our findings support the hypothesis that severe TBI in children results in greater and more persistent injury-related burden and stress for families than does orthopedic trauma. Burden was greatest for the families of children in all three injury groups at the time of discharge from the hospital (baseline). However, burden diminished markedly by 6 months postinjury for families of children with orthopedic injuries, whereas burden declined less sharply for families of children with TBI. Interestingly, by the 12-month follow-up, families of children in both the moderate and severe TBI groups reported more stress related to concerns about the injured child than did families of children in the ORTHO group. The latter finding supports the notion that stress arising from cognitive and behavioral changes may persist for families of children with either moderate or severe TBI. Further, group differences in stress associated with the reactions of spouses and extended family members, which approached significance at baseline, became more pronounced when considering the initial year after injury.

The current investigation was among the few prospective studies of pediatric TBI to examine parent outcomes of TBI using a standardized measure of parental psychological symptoms. As hypothesized, parents of children with severe TBI reported more psychological symptoms than parents of children with orthopedic injuries. With respect to symptom levels of clinical magnitude, fully 41% of the parents in the severe TBI group continued to exceed the clinical cutoff on the BSI at 12 months postinjury, a relative risk that is four times that reported in normative samples. These findings are consistent with reports regarding psychological distress among caregivers of adults with TBI. However, the current data does not allow us to determine if traumatic injuries lead to an increased risk of parental distress or if parents of children who are injured have higher rates of clinical distress before the injury.
case, there is a clear need for intervention services for parents to reduce this level of psychological distress.

The findings regarding marital and family outcomes were less consistent with previous research findings. 2,6 Although the groups did not differ overall on the DAS and FAD, we did find group differences in the rates of family dysfunction. At 6 months, rates of family dysfunction were 3.5 times higher in the severe TBI group compared with the ORTHO group. By 12 months, the rates of family dysfunction were comparable in all three injury groups and approached rates reported in normative samples. These data are contrary to the findings regarding family outcomes after TBI in adults, which indicate continued deterioration in family functioning over time, up to 5 years after the injury. 6 In their study of pediatric TBI, Rivara et al 12 also noted a greater deterioration in family functioning during the initial 12 months postinjury among families of children with severe TBI when compared with those with less severe injuries. The differences between our findings and those of Rivara may be because of differences in the comparison group and measures of family outcome (self-report vs interviewer ratings). It is also possible that longer term follow-up of our sample will reveal increases in marital and family problems over time, particularly as families encounter developmental and life transitions.

Several limitations of this study should be noted. First, our understanding of family burden, stress, and adaptation was based on self-report, primarily by mothers. Thus, our data shed no light on paternal or sibling distress, nor does it inform us about other family members’ perceptions of postinjury family function. Distressed caregivers may perceive family functioning differently from other family members. Reports from other family members, as well as direct observational methods, would provide a more thorough picture of the effects of TBI on families. The length of follow-up and the fact that attrition was higher for non-whites and for families of lower socioeconomic status also limit study conclusions. It is possible that overall group differences in family outcomes may vary according to sample composition, or that longer term follow-up may reveal more pronounced differences among the groups. For example, Rivara et al 12 found somewhat poorer family functioning at 3 years postinjury than they had observed at 12 months postinjury.

The current findings have important implications for the clinical management of families after TBI. Families may benefit from anticipatory guidance as well as specific informational and emotional support around identified areas of injury-related burden. On-going contact with families after discharge from rehabilitation services could facilitate appropriate referrals, particularly because family dysfunction appears to intensify at 6 months postinjury.

CONCLUSION

These results highlight the potential for significant morbidity among caregivers after pediatric TBI when compared with those of children with other traumatic injuries. After severe TBI, families differed from the ORTHO comparison group with respect to injury-related burden, caregiver distress, and family dysfunction. The high levels of family burden and parental distress after severe TBI suggest that families may benefit from anticipatory guidance and stress management. To the extent that the family environment contributes to child outcomes, family interventions may also be useful in reducing injury-related morbidity more generally. 2,7 Subsequent analyses will help identify those families in the severe TBI group at greatest risk for longer term difficulties.

ACKNOWLEDGMENTS

This work was supported by Grant MCJ-390611 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

We thank Nori Mercuri Minich, Elizabeth Shaver, Madeline Polonia, Barbara Shapero, and Matt Diamond for their contributions. We also wish to acknowledge the participation of the Children’s Hospital Medical Center of Akron and the collaboration of Drs Duane Bishop, Timothy Magstan, Scott Maxwell, George Thompson, G. Dean Timmons, and Dennis Weiner. We thank Ruth E. K. Stein, MD, for use of the Impact on Family Scale.

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