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Behavioral Health Service Utilization and Unmet Need after Traumatic Brain Injury in Childhood

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Abstract

Objective: We examine need for behavioral health services, service utilization, and predictors of utilization in children with moderate-severe traumatic brain injury (TBI) relative to a comparison group of children with orthopedic injury (OI) 6.8 years after injury.

Method: A total of 130 children hospitalized for a moderate-severe TBI (16 severe, 42 moderate) or OI (72) between the ages of three - seven years and completed a long-term follow-up 6.8 years after injury were enrolled at three tertiary care children's hospitals and one general hospital in Ohio.

Results: Adolescents with TBI (moderate [38%] and severe [69%]) had significantly greater rates of need than OI (17%). Behavioral health services were utilized by 10% of the sample with no injury group differences (OI: 6%; Moderate: 17%; Severe: 13%). Early treatment and white race were associated with less service utilization. 77% had an unmet need, with no injury group differences (OI: 75%; Moderate: 75%; Severe: 82%). Rate of unmet need greater among white than non-white children.

Conclusions: Children who sustain a TBI in early childhood experience persistent and clinically significant impairments even years after injury. Rates of unmet need were high for all injury

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groups. Findings underscore the importance of long-term monitoring to identify developing needs and prevent significant complications/deficits.

Keywords

Behavioral Health Service Utilization; Pediatric TBI; Unmet Need

Pediatric traumatic brain injury (TBI) is the leading cause of acquired morbidity and mortality in children,¹ and is estimated to affect more than 500,000 children a year in the United States.² Pediatric TBI is associated with a number of short and long term behavioral,^{3,4} academic,⁵ and psychosocial impairments.^{6,7} Behavioral dysregulation, including secondary attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), and anxiety, are common consequences of pediatric TBI, with younger age at injury associated with greater long term functional impairment.^{8–11} Although the behavioral and psychosocial impairments following TBI are well documented and have been shown to persist many years post injury,^{4,6,11} little is known about the behavioral health services utilized by families. Moreover, as soon as one year post injury, mental health service is one of the most commonly reported unmet needs¹² with 31% of children with TBI failing to receive potentially helpful or critical services.¹³

Environmental factors, such as socioeconomic status (SES) and family functioning, which have been linked with poorer outcomes following injury^{14–19} may be barriers to accessing needed mental health care services.^{17,20,21} Prior research examining the utilization of health care services within the first few years post TBI reveals that children with poorer family functioning, lower SES, or who are non-white have the highest rates of unmet mental health/behavioral health care needs.^{13,22} However, little is known about the utilization of behavioral health care services beyond the first few years after injury. To better understand the risk and resilience factors that contribute to long-term outcomes following pediatric TBI, research is needed to characterize behavioral health needs several years post-injury and the factors associated with un-met long-term behavioral health needs.

The current study aimed to examine need for behavioral health services, parent-reported utilization of behavioral health services, and predictors of utilization in children with moderate to severe TBI relative to a comparison group of children with orthopedic injury (OI) approximately seven-years after injury. Based on existing evidence that TBI increases risk of long-term behavioral and emotional sequelae,^{4,6,11} we hypothesized that children with a history of TBI would have higher rates of need for behavioral health services, compared to those with OI, and that this increased need would be accompanied by higher rates of behavioral health service utilization. Because family functioning and SES may present barriers to receiving behavioral health services,^{17,20,21} we also examined the impact of demographic and family factors associated with behavioral health service utilization and rates of unmet behavioral health need. We hypothesized that greater family dysfunction and lower SES would predict lower rates of service utilization and greater levels of unmet behavioral health needs. Finally, we examined the role of receipt of behavioral health services within the first year of injury. A number of studies have reported the association between early assessment and intervention and improved quality of life and behavior in

children with a history of prematurity^{23,24} and improved mental health following traumatic injuries.²⁵ Based on these findings, we hypothesized that families who received services within the first year following injury would have lower levels of unmet need at the extended follow-up ~6.8 years after injury.

Methods

Participants

The sample for the current study was drawn from a prospective longitudinal cohort study of children who sustained TBI during early childhood. To enroll the original cohort, consecutive admissions of children between three and seven years of age with TBI or OI (that did not involve the central nervous system) were screened at Level One trauma centers at three children's hospitals and one general hospital all of which were located in Ohio. Catchment areas of these institutions covered all of Ohio, as well as parts of West Virginia, Kentucky, and Pennsylvania. Additional inclusion criteria included overnight hospitalization, accidental cause of injury, no history of pre-injury neurological problems or developmental delay, and English as the primary language in the home. Traumatic brain injury severity was classified into two categories, moderate TBI and severe TBI, using the lowest post resuscitation Glasgow Coma Scale (GCS) score. Severe TBI was defined as a GCS to eight. Moderate TBI was defined as GCS score of 9–12 or 13–15, accompanied by TBI-related abnormality on clinical imaging. The OI group consisted of children who sustained a bone fracture (not including the skull), had an overnight hospital stay, and no alterations in consciousness or other signs or symptoms of head trauma or brain injury.

Families were approached to participate in the original study when children were medically stable. After informed consent was obtained baseline assessments were completed in the hospitals in which the children received care for their injuries. In addition, a home visit was conducted to assess the quality of the home environment. Follow-up assessments were completed approximately 6-months, 12-months, and 18-months post-injury, as well as a long-term follow-up (~3.4 years post injury), and an extended follow-up (~6.8 years post-injury). At all occasions, child and caregiver assessments were conducted in tandem, and included parent interviews and parent ratings of child and family functioning, tests of the child's cognitive abilities, and videotaped parent-child interactions. Primary and secondary contact information was collected from all families at all visits to maximize likelihood of being able to successfully contact them for future visits. Family centered scheduling, feedback regarding the child's recovery, and incentives for continued participation were used to facilitate completion of the extended follow-up visit (~6.8 years after injury).

A total of 221 children were enrolled in the study at a baseline assessment an average of 1.32 months post injury. The current sample included 141 children who completed the extended follow-up assessment. The timing of this extended follow-up was designed to coincide with the entrance into middle school/early adolescence, a time of increased demands for self-regulation, organization, and higher-order thinking skills, rather than a specific time since injury. To focus on the behavioral health needs and service utilization of children with more severe injuries, 11 children with uncomplicated mild injuries (GCS >13 with no neuroimaging findings) and were excluded from the current analyses. In addition,

one child in the OI group attended assessment visit and contributed data, but did not have completed rating scales needed to determine potential need for service and was also excluded from the sample. Therefore, the final sample in the present analyses included 129 children: 58 children with TBI (16 severe TBI, 42 moderate TBI) and 71 children with OI. Table 1 presents demographic characteristics of the sample. A composite SES variable was created by using the sample z-scores for family census tract income and level of maternal education. The groups did not differ significantly in any demographic characteristics or level of general family functioning (as reported at the extended follow-up), and children who completed the extended follow-up did not differ significantly from those who did not complete the extended follow-up in injury severity, sex, race, or SES.

Procedure

All procedures were approved by Institutional Review Boards at each of the participating sites, and written informed consent was obtained from the parents/legal guardians of all participants. Demographic and injury-related information, as well as parent report of family functioning and their child's behavioral and psychosocial functioning prior to the injury, was collected at the initial baseline assessment. Utilization of behavioral health services was assessed by asking parents if their child was currently receiving any therapy or counseling. At all visits parents were asked if their child was receiving a number of specialty services including physical therapy, occupational therapy, speech therapy, and counseling/behavior therapy. Their response to "In the past year, has your child received counseling/behavior therapy?" was used to determine current therapy/counseling. Services received within the first year of injury was designated as parent report of receipt of therapy or counseling at either the 6-month or 12-month visit.

Measures

Family Assessment Device (FAD) 26—The FAD is a 60-item self-report questionnaire measuring structural, organizational, and transactional characteristics of families with established reliability and validity.^{26,27} Parents rated their level of agreement ("strongly agree" to "strongly disagree") with statements reflecting family functioning such as "we don't get along well together" and "we confide in each other". Scores range from one to four with higher scores indicative of worse functioning.²⁶ The 12-item FAD-GF scale was used as a summary measure of family functioning, and a score >2.17 was considered clinically elevated. The FAD was collected at all assessment visits, with the ratings from the most recent extended follow-up visit (~6.8 years post injury) used in the models.

Child Behavior Checklist (CBCL) 28—The CBCL is a parent rating scale that measures child emotional and behavioral problems. The measure consists of 112 items, and parents are asked to rate items from 0 ("not true") to 2 ("very true" or "often true"). It has high test-retest reliability and criterion validity and has been shown to be sensitive to behavior problems following TBI.^{29,30} The Total Problems, Internalizing Problems, Externalizing Problems scores and selected DSM oriented scales (Affect, Anxiety, ADHD, and ODD) were used to determine potential need for behavioral health services. Children with elevated ratings would be expected to benefit from counseling or behavioral intervention. Consistent with previous work, significant elevations were defined as T-scores

63,^{4,8,22,30,31} with a clinical need defined as the presence of a significant elevation on one or more of the identified CBCL scales. Achenbach et al 28 recommends a T-score of 63 as an appropriate cut off for classifying patients into clinical vs. non-clinical groups. This corresponds with ratings obtained by <10% of a normative sample, and is consistent with previous research regarding behavior ratings following pediatric TBI.^{4,8,30} To examine if this more liberal cut off was associated with an over identification of potential need, the cut off scores indicated in the rating scale manuals (T-score = 70) were also utilized. Frequencies for both the potential need and high need group are presented in Table 2. An unmet need was defined as a clinical need that was not accompanied by parent-reported current service utilization. The CBCL was collected at all assessment visits, with ratings from the most recent extended follow-up visit (~6.8 years post injury) used for determining potential need.

Statistical Analyses

Chi-square analyses were used to examine injury group differences in rates of clinical need, behavioral health service utilization, and unmet need. Only those identified as having potential need for services were included in analyses examining unmet need. Separate logistic regressions were used to examine factors associated with behavioral health service utilization and unmet need. Factors examined included injury group, receipt of services within the first year of injury, sex, race, SES, age at injury, and family functioning. Interactions of injury group with SES, family functioning, and services within the first year of injury were included to examine the possible moderating effects of the latter factors on group differences in service utilization and unmet need.

Results

Need for Behavioral Health Services

Table 2 presents the proportion of participants within each injury group that met the criteria for potential need at the extended follow-up (~6.8 years after injury). Significant group differences were found for rates of need, with a dose-like response of injury severity, such that a significantly greater proportion of the severe TBI group (69%) met criteria for potential need than the moderate TBI (38%) and OI group (17%). The difference between moderate TBI and OI was also statistically significant.

Specific areas of clinical elevation/need are reported in Table 2. The most commonly reported problems (scale elevations) for adolescents with moderate and severe TBI included the internalizing problems summary scale (e.g., symptoms of depression, anxiety, and somatic complaints; 31% of moderate TBI sample, 38% of severe TBI sample), externalizing problems (e.g., symptoms of inattention, hyperactivity/impulsivity, oppositionality, conduct concerns; 24% moderate TBI sample; 31% severe TBI sample), and the Affect DSM-oriented scale (e.g., symptoms of depression; 21% of moderate TBI sample, 38% of severe TBI sample). Injury group differences were detected on the CBCL Total Behavior Problems scale, Internalizing Problems scale, Externalizing Problems scale, Affective scale, and ODD scale. In most cases (Total Problems, Internalizing, Externalizing, and ODD scales), rates of elevation were greater among the TBI groups (both moderate and severe) compared to the OI group, with rates of impairment similar between the moderate

and severe TBI groups. In terms of the Affective scale, those with severe TBI reported greater rates of elevation than both the moderate TBI and OI groups, and the difference between the moderate TBI and OI group was also statistically significant.

Behavioral Health Service Utilization

Mental health services were utilized by 10% of the total sample at the extended follow-up (~6.8 years after injury), with no significant differences between injury groups (6% of the OI sample, 17% of the moderate TBI sample, and 13% of the severe TBI sample; Table 2). Similarly, of those who met criteria for potential need at the extended follow-up (i.e., clinically elevated scores on the CBCL), 23% were receiving services, with no injury group differences noted (Table 2).

Logistic regression analysis revealed that services with the first year of injury ($X^2(1) = 4.78, p = .03$) and child race ($X^2(1) = 6.03, p = .01$) were each associated with service utilization at the extended follow-up (See Table 3). Interestingly, children who received behavioral health services within the first year of their injury ($n = 9$) were less likely than children who did not receive services within the first year of injury to be receiving services at the extended follow-up. Specifically, of those receiving treatment at the extended follow-up ($n=13$), only 23% had received services within the first year of their injury. Additionally, a greater proportion of the non-white sample reported receiving behavioral health services than the white sample. Main effects of injury group, child sex, SES, age at injury, and family functioning were not significant. Analyses also failed to find significant early services*injury group, SES*injury group, or family functioning*injury group interactions on service utilization.

Unmet Need for Behavioral Health Services

Seventy-seven percent of those with an identified need for service met criteria for unmet need. While group differences in unmet need were not significant, the majority of children in each group with potential need for mental health services were not receiving these service at the extended follow-up (75% of OI group, 75% of moderate TBI group, and 82% of severe TBI group. see Table 2). This reflects a high rate of unmet need for behavioral health services within this middle school aged population, regardless of injury type or severity.

In examining potential predictors of unmet need, child race was identified as a significant predictor of unmet need ($X^2(1) = 4.50, p = .03$; See Table 4). Rates of unmet need were significantly higher among white children ($24/28 = 86\%$) compared to non-white children ($6/11 = 55\%$; $X^2(1) = 4.32, p = .04$). Main effects of injury group, services within the first year of injury, child sex, age at injury, and family functioning were not significant. Analyses also failed to find significant early service*injury group, SES*injury group or family functioning*injury group interactions on unmet need. Further, the receipt of services within the first year of injury did not significantly predict unmet need at the extended follow up. However, among children with an unmet behavioral health need at follow-up, only 18% had received services within the first year after their injury.

Discussion

The purpose of this study was to describe the potential need for and utilization of behavioral health services of children and adolescents seven years after TBI. At an extended follow-up, children with a history of TBI had higher rates of potential clinical need than children with OI, but the groups did not differ in rates of service utilization. The rate of service utilization at the extended follow-up was greater for non-white adolescents compared to white adolescents, and lower for those who had received services within the first year of their injury compared to those who did not receive services within the first year post-injury. Finally, 75–82% of children had unmet need for behavioral health services at the extended follow up, with rates of unmet need greater for white children than non-white children.

Overall, the findings suggest that adolescents who sustain a TBI in early childhood experience persistent and clinically significant social, emotional, and behavioral deficits even many years after injury.^{4,6,11} We failed to identify injury group differences in service utilization or unmet need among patients with potential need for service. However, consistent with previous reports of utilization within this population,²² as well as the general population³² rates of unmet need were high for all injury groups. Our findings that white adolescents have greater rates of unmet need than non-white adolescents was surprising. While some studies have reported that race and ethnicity is not a consistent predictor of mental health service utilization,³³ most studies report significant racial and ethnic disparity in service utilization.^{20, 32} It is not believed that results suggest that white adolescents have poorer access to mental health services, rather it is possible that racial minorities did not have poorer access to care in our cohort; however, a number of factors should be considered when interpreting these findings. First, in order to complete this final assessment we had to be able to get in touch with and schedule visits with the family, therefore it is possible that they had more stable living situations or still receiving services as the institutions, both of which may impact access to care. Additionally, the non-white sample in this study is quite small, and one needs to be cautious when making conclusions about these findings.

There are many potential downstream consequences of inadequate behavioral health services in childhood and adolescence, especially for children with TBI. Managing behavioral and emotional difficulties is critical for children's success in the home, school, and community settings.³⁴ A lack of access to services may exacerbate emotional and behavioral problems and lead to impaired functioning in a variety of domains including home, school, and the community, perhaps increasing risk for unemployment and poorer quality of life.³⁵ Early mental health treatment may also be preventative, as suggested by our findings that obtaining mental health services within the first year post-injury may be associated with less utilization of services at the seven-year follow-up. Other studies, with adult populations, have also demonstrated the potential economic benefits of early intervention and prevention of more severe mental health conditions.^{25,36} Given the vast evidence base for the effectiveness of mental health treatment for children and adolescents, with effect sizes ranging from small to moderate (.15-.61),³⁷ the potential benefits of pursuing mental health treatment are apparent.

Our findings suggest that patients with a history of pediatric TBI may benefit from being managed through a chronic care model including long-term monitoring to identify developing needs and prevent significant complications/deficits.³⁸ The complex interaction of injury and development may result in latent cognitive and behavioral impairments that may not develop until well after the injury, or during the chronic stage of recovery.³⁹ With continued monitoring, the early identification of emerging deficits can prevent or lessen the impact of these impairments in behavioral, psychosocial, or academic functioning.³⁹

Several study limitations should be noted. First, rates of unmet need were high for all injury groups, which may suggest that unmet behavioral health need is a ubiquitous issue, independent of TBI history. Secondly, we had limited information on the child's pre-injury functioning or current level of disability, and therefore could not take into account premorbid adjustment problems or adjustment to residual disability. Thirdly, our definition of clinical need relied on parent report of elevated internalizing and/or externalizing behavior problems on standardized questionnaires. This approach may be less sensitive to internalizing problems, such as anxiety and depression. Future studies would benefit from more rigorous methods of identifying clinical need through structured interview or multiple informant observations (e.g., self-report, teacher-report). Further, our means of identifying service utilization was limited to parent report of services, and no details on the types or quality of mental health services were obtained, and dose and duration of services was not measured. Future work would benefit from a review of medical records or insurance records to identify patients who have received behavioral health services and the types of services received. Finally, sample size, especially within the severe TBI group, was relatively small which may have limited our power to detect differences.

Conclusion

In conclusion, parents and providers must be aware of the long term behavioral and psychosocial impairments that can result from TBI and the potential benefits of behavioral health services. This knowledge, coupled with increased and routine monitoring, will help ensure that patients and families receive appropriate referrals in a timely manner. Future research might develop and implement effective behavioral health screening measures for children with TBI to address the gap between mental health needs and service utilization. Access to behavioral health care for all individuals with TBI should be encouraged, to work towards a prevention model that heads off more serious psychopathology. Finally, working to limit barriers for families and increase access to needed services is essential, whether this be identifying appropriate clinicians in the community or encouraging telehealth interventions with specialists. Focusing on awareness, accurate detection, and timely treatment of the mental health needs of children with TBI may help maintain a higher quality of life for children with TBI and their families.

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Table 1

Demographics

	OI	Moderate TBI	Severe TBI
Child Sex, N (%) male	38 (53%)	25 (60%)	10 (63%)
Child Race, N (%) non-white	17 (24%)	10 (24%)	6 (38%)
Age at injury, mean (SE)	5.10 (.13)	5.19 (.17)	5.04 (.28)
SES	.09 (.11)	.04 (.14)	-.42 (.23)
Maternal Education	--	--	--
Less than HS	7 (10%)	3 (7%)	1 (6%)
HS/GED	20 (28%)	15 (36%)	9 (56%)
2 yrs of college	15 (21%)	11 (26%)	3 (19%)
Bachelor's degree	20 (28%)	10 (24%)	2 (13%)
Graduate degree	9 (13%)	3 (7%)	1 (6%)
2010 Census tract income	68,329.75 (24,657.98)	68,121.33 (26,739.28)	54,708.88 (21,816.77)
FAD-GF	1.61 (.05)	1.65 (.06)	1.85 (.10)

Note: OI: Orthopedic Injury; TBI: Traumatic brain injury; SES = Socio-Economic Status; FAD-GF = Family Assessment Device – General Functioning.

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Rates of receipt of behavioral/mental health services within the first year post injury (Early Service), potential need for service (at least one CBCL scale elevation), specific CBCL scale elevations, service utilization and unmet need by injury group.

Table 2

	OI (n = 71)	Moderate TBI (n = 42)	Severe TBI (n = 16)	X²/F	Group Differences
Early Service	2 (3%)	3 (7%)	4 (25%)	9.50 **	Sev>OI, Mod=OI, Mod=Sev
Total Potential Need	12 (17%)	16 (38%)	11 (69%)	18.85 ****	OI<Mod<Sev
Total Problems	8 (11%)	11 (26%)	7 (44%)	9.97 **	Mod>OI, Sev>OI, Mod=Sev
Internalizing	3 (4%)	13 (31%)	6 (38%)	18.72 ****	Mod>OI, Sev>OI, Mod=Sev
Externalizing	6 (9%)	10 (24%)	5 (31%)	7.57*	Mod>OI, Sev>OI, Mod=Sev
Affective	3 (4%)	9 (21%)	8 (50%)	22.55 ****	OI<Mod<Sev
Anxiety	5 (7%)	7 (17%)	3 (19%)	3.28	N/A
ADHD	8 (11%)	10 (24%)	4 (25%)	3.75	N/A
ODD	4 (6%)	10 (24%)	5 (31%)	10.91 **	Mod>OI, Sev>OI, Mod=Sev
Total Potential High Need	7 (10%)	13 (31%)	7 (44%)	12.84 **	Mod>OI, Sev>OI, Mod=Sev
Total Problems	1 (1%)	9 (21%)	4 (25%)	14.71 ****	Mod>OI, Sev>OI, Mod=Sev
Internalizing	3 (4%)	3 (7%)	4 (25%)	7.91 *	Sev>OI, Mod=OI, Mod=Sev
Externalizing	2 (3%)	5 (12%)	2 (13%)	4.22	N/A
Affective	2 (3%)	5 (12%)	2 (13%)	4.22	N/A
Anxiety	2 (3%)	3 (7%)	2 (13%)	2.74	N/A
ADHD	2 (3%)	7 (16%)	0 (0%)	6.17*	Mod>OI, Sev=OI, Mod=Sev
ODD	2 (3%)	5 (12%)	2 (13%)	4.22	N/A
Service Utilization					
Total Sample	4 (6%)	7 (17%)	2 (13%)	3.66	N/A
Potential Need Sample	3 (25%)	4 (25%)	2 (18%)	.90	N/A
High Need Sample	3 (43%)	4 (31%)	1 (14%)	1.39	N/A
Unmet Need					
Potential Need Sample	9 (75%)	12 (75%)	9 (82%)	.21	N/A
High Need Sample	4 (57%)	9 (69%)	6 (86%)	1.39	N/A

p < .001.

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*,
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p < .01,
p < .05

Note: OI: Orthopedic Injury; TBI: Traumatic Brain Injury; Early Service: Receipt of behavioral/mental health services with the first year of injury; Total Potential Need: at least one CBCL scale score 63; Total Potential High Need: at least one CBCL scale score 70; Sev: Severe TBI; Mod: Moderate TBI; ADHD: Attention Deficit Hyperactivity Problems Scale, ODD: Oppositional Defiant Disorder Scale.

Table 3

Results of Logistic Regression Analyses Examining Factors Associated with Receipt of Behavioral Health Services at the Extended Follow-up visit ~6.8 years after injury.

Effect	DF	Chi-Square	p
Injury Group	2	3.83	0.15
Early Service	1	4.75	0.03
Child Sex	1	0.10	0.76
Child Race	1	5.45	0.02
SES	1	1.46	0.23
Age at Injury	1	0.05	0.83
FAD-GF	1	0.05	0.83
Injury Group * FAD-GF	2	4.13	0.13
Injury Group * SES	2	1.19	0.55
Injury Group * Early Service	2	2.35	0.31

Note: Early Service = Receipt of behavioral/mental health services with the first year post injury; SES: socioeconomic status; FAD-GF: Family Assessment Device-General Functioning. Bolded items indicate statistically significant effects.

Table 4

Results of Logistic Regression Analyses Examining Factors Associated with Unmet Need for Behavioral Health Services at the Extended Follow-up visit (~6.8 years after injury) within the group with potential need for services.

Effect	DF	Chi-Square	p
Injury Group	2	3.48	0.18
Early Service	1	1.39	0.24
Child Sex	1	2.15	0.14
Child Race	1	4.51	0.03
SES	1	0.02	0.89
Age at Injury	1	1.73	0.19
FAD-GF	1	2.48	0.12
Injury Group * FAD-GF	2	3.76	0.15
Injury Group * SES	2	1.75	0.42
Injury Group * Early Service	2	0.47	0.79

Note: Early Service = Receipt of behavioral/mental health services within the first year after injury; SES: socioeconomic status; FAD-GF: Family Assessment Device-General Functioning. Bolded items indicate statistically significant effects.