ORIGINAL ARTICLE

Relationship of Preinjury Caregiver and Family Functioning to Community Integration in Adults With Traumatic Brain Injury

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ABSTRACT. Sady MD, Sander AM, Clark AN, Sherer M, Nakase-Richardson R, Malec JF. Relationship of preinjury caregiver and family functioning to community integration in adults with traumatic brain injury. Arch Phys Med Rehabil 2010;91: 1542-50.

Objective: To investigate the relationship of preinjury caregiver and family functioning to community integration outcomes in persons with traumatic brain injury (TBI).

Design: Inception cohort.

Setting: Three TBI Model Systems inpatient rehabilitation facilities.

Participants: Persons with TBI (N=141) and their caregivers admitted to inpatient rehabilitation and followed up at 1 to 2 years after injury.

Interventions: Not applicable.

Main Outcome Measures: Community Integration Questionnaire and the Social and Occupation scales of the Craig Handicap Assessment and Reporting Technique.

Results: There were significant interactions of several preinjury caregiver and family variables with injury severity. For persons with complicated mild/moderate injury, better family functioning was associated with greater home integration, and less caregiver distress was associated with better social integration. For persons with severe injuries, greater caregiver perceived social support was associated with better outcomes in productivity and social integration.

Conclusions: Preinjury caregiver and family characteristics interact with injury severity to affect outcomes in persons with injury. Research on outcomes should include measures of caregiver and family functioning. Early interventions targeted toward decreasing caregiver distress, increasing support, and improving family functioning may have a positive impact on later outcomes.

Key Words: Brain injuries, traumatic; Family; Caregivers; Rehabilitation.

RESEARCHERS HAVE documented that persons with TBI show decreased community integration or participation in a variety of areas, including employment,[1-3] ability to live independently,[4-6] household activities,[7,8] parenting,[9] and leisure activities.[6,7,10] Social isolation also is common, with social interactions and activities often restricted to those with immediate family members.[4,6,7]

Although TBI results in decreased participation for many persons, there is variability in outcome for individual patients. Variability in outcomes may be related in part to differences in injury severity. Measures of injury severity, including duration of coma and posttraumatic amnesia, have been inversely related to employment outcomes,[1,11-14] as well as to independent living and social interaction.[11] Other factors that have been related to community integration outcomes include age,[1,15-17] sex,[17] length of hospitalization,[2,16,18] scores on functional rehabilitation scales at rehabilitation admission and discharge,[14,16,19,20] performance on neuropsychologic and neurobehavioral measures,[12,15,21] level of impaired awareness,[22] preinjury employment status,[12,14,23] and history of substance abuse.[14,23] However, these variables account only partially for the variance in participation outcomes after TBI.

The potential contribution of environmental variables to outcome has been receiving increased emphasis.[24-26] One such environmental variable is family functioning. Studies of pediatric patients with TBI emphasize the importance of the family environment in determining outcome after injury. In children with TBI, preinjury family functioning has been predictive of global adaptive functioning, social competence, behavior prob-

List of Abbreviations

BSI	Brief Symptom Inventory
CHART	Craig Handicap Assessment and Reporting Technique
CHocc	CHART Occupation scale
CHsi	CHART Social Integration scale
CIQ	Community Integration Questionnaire
CIQhi	CIQ Home Integration scale
CIQprod	CIQ Productivity scale
CIQsi	CIQ Social Integration scale
DRS	Disability Rating Scale
FAD	Family Assessment Device
GCS	Glasgow Coma Scale
GSI	Global Severity Index
MSPSS	Multidimensional Scale of Perceived Social Support
TBI	traumatic brain injury

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lems, academic performance, and cognitive functioning at 1 year after injury.[27-29] Specifically, children from families with greater cohesion, more positive relationships, and greater flexibility showed better outcomes. Family functioning showed a stronger relationship to children's behavioral outcomes than to academic or cognitive outcomes. Although injury severity was most predictive of the rate of children's recovery during the first year after injury, the family environment was more predictive of their absolute level of outcome.

The role of the family environment in determining outcomes for adults with TBI has received less emphasis. Research has documented that family members experience significant distress after injury.[30,31] Family functioning certainly has the potential to affect the outcome of adults with TBI because family members often bear primary responsibility for assisting persons with injury to reintegrate into their homes and communities.[4] Poor family cohesiveness and support have been suggested as important contributors to difficulty maintaining employment after TBI.[32,33] Using semistructured interviews, a qualitative study of social integration showed that persons with TBI cited family members as having key roles in community reintegration after rehabilitation services ended.[34] Persons with TBI consistently indicated that among other things, family caregivers provided daily assistance with relearning appropriate social behavior and acted as a built-in social network.

Only 1 study to date has investigated the contribution of family functioning to community integration outcomes after adult TBI. Sander et al[35] found that persons with TBI with family environments characterized by unhealthy family functioning, assessed by using the General Functioning Scale of the FAD,[36] showed less improvement on the DRS[37] from the time of admission to 1 month postdischarge from a post–acute TBI rehabilitation program. Family functioning accounted for significant additional variance after accounting for injury severity, admission DRS scores, and time from admission to follow-up. Although this study was a first step in documenting the impact of the family environment on outcomes, it was limited by small sample size and inclusion of only a single site. Furthermore, the study took place in a postacute setting, with participants' average time since injury of 607 days, and family functioning was assessed at the time of postacute admission. In a prior study, Sander et al[38] found that 37% of caregivers of persons with TBI admitted to inpatient rehabilitation reported a high level of emotional distress during the month before injury. Between 25% and 33% of caregivers reported unhealthy family functioning in 1 or more areas during the month before injury. Because studies in the pediatric brain injury literature have indicated a relationship between preinjury family environment and outcomes, investigation of this relationship for adults with TBI seems warranted.

The purpose of the present study was to determine the contribution of preinjury caregiver and family functioning to community integration outcomes at 1 to 2 years after injury. Multidimensional assessments of preinjury caregiver and family functioning and community integration outcomes were used. The hypothesis was that healthier preinjury caregiver and family functioning would be associated with better community integration outcomes for the person with injury. Interactions of injury severity with caregiver and family variables also were investigated.

METHODS

Participants

For this prospective study, participants were recruited from among consecutive admissions to the comprehensive inpatient rehabilitation programs at The Institute for Rehabilitation and Research, Methodist Rehabilitation Center in Mississippi, or the Mayo Clinic between February 1999 and June 2002. Caregivers of persons admitted to 1 of the units with a diagnosis of TBI were approached for participation if they met the following criteria for participation in the TBI Model Systems database: medically documented TBI, treatment at the emergency department of a level I trauma center within 24 hours of injury, receipt of inpatient rehabilitation within the TBI Model Systems, age at least 16 years at the time of injury, and provision of informed consent by the person with injury or a legal proxy. In addition to TBI Model Systems criteria, caregivers included in the study had to be at least 18 years old and identify themselves as the primary person responsible for the care of the person with injury. Measures of preinjury caregiver and family functioning were completed by the caregivers within 2 weeks of admission to the rehabilitation unit, and outcomes of the person with injury were assessed at 1 to 2 years after injury.

Persons with TBI (N=289) and their caregivers were enrolled and completed assessments within 2 weeks of admission to the rehabilitation unit. Of these, 96 were excluded for absence of outcome data at 1 to 2 years after injury. An additional 52 were excluded because of a change in caregiver between the time of initial assessment and follow-up. The final sample consisted of 141 dyads of caregivers and persons with TBI.

Most persons with injury were white men with a high school education or higher. Almost two-thirds of participants had sustained a severe TBI, defined as a GCS score of 8 or less at emergency department admission.[39] Although some participants had mild TBI based on emergency department GCS scores, their cognitive impairments were significant enough for them to be admitted to the inpatient brain injury unit of a TBI Model Systems rehabilitation facility. Caregivers of the person with injury were primarily parents (50%) or spouses (40%). Although half the participants with mild to moderate injury were cared for by spouses, more than half of those with severe injury were cared for by parents. The mild/moderate injury group was significantly older at the time of injury, and there was a longer period between injury and caregiver assessment in the severe injury group. The latter finding is not unexpected because patients with more severe injuries are more likely to stay in the hospital longer and enter rehabilitation later. Demographic characteristics of the sample, categorized by injury severity, are listed in table 1.

Table 2 lists scores for patients included (n=141) compared with those who were excluded (n=148) on the preinjury caregiver and family variables. Those included had significantly better preinjury family functioning (lower mean FAD scores, $t=-2.66$; $P<.01$) and greater preinjury perceived social support (higher mean MSPSS scores, $t=2.60$; $P<.01$) than patients who were not included. Included patients did not differ from those excluded on preinjury BSI scores. As listed in table 2, the 2 groups also did not differ with regard to relationships between the caregiver and person with TBI, sex of the caregiver, or sex, age at injury, or injury severity of the person with TBI.

Measures

Injury severity. Injury severity was coded as complicated mild/moderate (n=47) or severe (n=89) based on GCS scores on admission to the emergency department, with mild/moderate injuries corresponding to GCS scores of 9 or higher, and severe injuries, to GCS scores of 8 or lower. Complicated mild injuries and moderate injuries were grouped together for analysis because research has shown that outcomes of persons with