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Severe Traumatic Brain Injury: Some Effects on Family Caregivers

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Abstract

This study assesses the effects of severe traumatic brain injuries on family members and functioning—a topic of interest for those working with survivors and their families. This issue is receiving increased attention as recent findings suggest that family adjustment influences outcome for brain-injured persons. The Family Environment Scale and the Profile of Mood States were completed by 25 individuals who had a family member with a severe traumatic brain injury. These scales were also completed by a comparison group of 32 individuals who had no brain-injured family member. In terms of family functioning, the findings suggest that, when a family member suffers a severe traumatic brain injury, depression may be elevated, along with a decreased ability to express feelings, decreased time and energy for social and recreational activities, and increased control in comparison to families without a brain-injured member. While this might contribute to family isolation which could last for many years, the overall finding of the present study was that caregiver families were coping adequately.
warning; it can affect individuals of all ages and may require sudden changes in lifestyle. For families of the patients, this can create major problems that may have a profound and lasting influence (DePompei, Zarski, & Hall, 1987; Godfrey & Smith, 1995, 1996; Smith, 1995; Acorn & Offer, 1998). Such injuries are a concern because there are a growing number of victims and other people affected each year (Baker, 1990; Kendall, 1991; Ponsford, Sloan, & Snow, 1995). Most frequently injured are males between 15 and 24 years of age (Fisher, 1985). Often, these individuals will have a normal life expectancy but may be left with continuing disabilities that involve economic, social, and personal costs for 40 to 50 years. While physical problems are initially the most prominent difficulties faced, social, behavioral, and psychological difficulties are the most enduring and may have the greatest effects on the life of the victim and the family (Livingston & Brooks, 1988; Brooks, 1991). With severe traumatic brain injury, relatively few survivors return to work, and those who do often can hold jobs only in supported settings (Lezak, 1995). Aside from persisting physical deficits, sequelae for severe brain injury may include substantial personality changes that often disrupt family relationships (Oddy, Humphrey, & Uttley; 1978; Oddy & Humphrey, 1980; Brooks, 1984; McClelland, 1988). Personality changes may include aggressive outbursts, childish behavior, lack of judgement and consideration of others, irritability, and constant frustration (Blyth, 1981). These behaviors may have been present before the accident to some extent but are more pronounced afterwards. Caring for the injured person places a considerable burden on the family and can result in ongoing psychological dysfunction (Livingston, Brooks, & Bond, 1985). Coping with the effects of brain damage is perhaps one of the most difficult tasks which can confront a family (Florian, Katz, & Lahav, 1989). The family is often more distressed than the injured person, who may be unaware of the changes in self (Lezak, 1978; Brooks, 1991).

Rosenbaum and Najenson (1976) reported that for wives, interpersonal
relationships with the husband, his parents, and friends were particularly stressful. Zeigler (1987) pointed out that the strain in the marriage was due in part to the injured husbands being self-oriented, childish, dependent, and lacking in ability to feel concern for others, especially the caregiver. Further areas of concern include decreased or no participation in child care, decision-making, or sexual function (Florian, et al., 1989).

Zeigler (1987) suggested that family members may experience a sense of loss, both of the person they loved and their own former lives. This may cause the spouse either to leave the marriage or to assume the role of caregiver. According to Zeigler, the reasons for staying include feelings of guilt and fear of social condemnation, a sense of responsibility, or gratitude and fond memories. While research such as that by Livingston, et al. (1985) often indicated heightened stress in family members having to cope with a brain-injured person, this is not always the case (Thomsen, 1974). Maitz (1990) suggested that adjustment is related to family characteristics such as cohesion, adaptability, marital adjustment, and affectional relations among family members. Kaplan (1991) found that social support and family cohesion is associated with psychosocial adjustment of the injured person. Kaplan reported that there is an inverse relationship between family cohesion and irritability, aggressiveness, and indifference expressed by the injured person. He suggested that social support directly buffers the deleterious effects of stress and anxiety and directly contributes to psychological well-being. Also, several factors contributed to family cohesion, including moral and religious beliefs and the provision of high structure in the life of the injured person.

Moore, Stambrock, Peters, and Lubusko (1991) examined the relationship between adjustment and family coping style. They found a small but significant relationship between the use of social support, reframing, seeking spiritual support, mobilising the family, and passive appraisal with marital adjustment in younger families. Peters,
Stambrook, Moore, Zubek, Dubo, and Blumenschein (1992) reported a correlation between severity of the injury and marital relationship. As expected, the wives of seriously injured men experienced more difficulties than did the spouses of patients with moderate injuries—there being less affection, lower satisfaction, and reduced feelings of cohesiveness.

Premorbid personality of the patient partly determines the rehabilitation outcome (Brooks, 1984, Fisher, 1985). A further factor is the quality of service the family receives during the rehabilitation process and how much information and support is given family members (Oddy et al., 1978)

As for the hypotheses, it was predicted (H1) that families with a member who has a closed-head injury will exhibit significantly elevated conflict, control, and communication problems. It was further predicted that the primary caregiver will report significantly higher scores on depression, tension, anxiety, and anger than a comparison group. Changes that can occur in the injured person, such as aggressive outbursts, childish behavior, and lack of judgement or consideration of others may result in difficulties with interpersonal interaction and social isolation. It was also predicted (H2) that these difficulties will result in family members being less willing to participate in recreational, achievement, intellectual, and cultural activities and that scores for cohesion and independence will be lower than in a comparison group.

Method

Participants
Families of people diagnosed with severe traumatic brain injuries were represented by individuals in contact with the Headway associations in Brisbane, the Gold Coast and Bundaberg. Headway provides assistance to people who have survived a serious brain injury and also provides support to their families. Mean age of this caregiver group was 54.5 yr. (SD= 12.5 yr.). The patients were 18 men
and 7 women, having been diagnosed with severe traumatic brain injuries which resulted in long-lasting residual dependency. The most frequent cause of brain injury was motor vehicle accidents.

Survivors had suffered a severe trauma, evidenced by the fact that they were not able to resume their previous normal lifestyles and that they needed someone to care for them. All except one survivor had extended stays in a hospital (at least several months). Not all the injuries resulted in loss of mobility or speech, but all were affected by difficulties such as memory loss, loss of ability to concentrate, plan, and maintain relationships.

Survivors had suffered serious injuries, resulting in an inability to work and concomitant severe reduction in finances; loss of family home; husband/wife relationships changed to caregiver relationships; inability to pursue previous hobbies, sports, and activities; loss of social contact due to unsociable behavior; epilepsy; loss of ability to drive a car; emotional liability; memory loss and concentration difficulties; and problems with organising and planning. Many also sustained other physical injuries or impairments at the time of the severe traumatic brain injury. In these seriously injured cases, either a spouse or parent often has had to give up full-time employment to look after the brain-injured person. Four individuals were so severely injured that they were unable even to speak, dress, feed, or take care of toilet needs themselves.

Caregivers comprised 18 women and 6 men; 10 were mothers while eight were the wives of the brain-injured person. Among the men, four were husbands and two were fathers of the brain-injured person. Mean time since injury was 9.8 years (SD = 9.3). Clearly, family climate may vary by family type, size, socio-economic status, and life stage. A common problem among some caregivers in this sample was their advancing age (some older than 70 years), showing considerable involvement of aging parents as caregivers. Although the brain-
injured persons whom they cared for may have received their injuries many years earlier, they still required constant care and attention. In interviews with the families of brain-injured persons, many caregivers expressed fear and concern about what would happen to their loved ones if they themselves were to become ill, incapacitated, or die. Caregivers were often forced to live a fairly isolated existence given the behavioral and social problems of the severely brain-injured family member.

The criterion for participation was that the respondent was the primary caregiver for the person who had sustained a severe traumatic brain injury. The comparison group comprised 32 adults (21 women, 11 men) from lower socioeconomic backgrounds so both groups had high economic burden and were matched for socioeconomic status. Potential participants were excluded if they presented with prior head trauma, psychiatric illness, or substance abuse. Assessment of effects on mood states and family coping skills was undertaken using two separate psychometric tests which were administered to caregiver participants.

**Tests**

The Profile of Mood States (McNair, Lorr, & Droppleman, 1971), is a 65-adjective check list with a 5-point rating scale. It was designed to provide a quick self-report measure of six emotional states labelled Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment (Peterson & Headen, 1984; Boyle, 1987). KR20 coefficients ranged from .87 for Confusion-Bewilderment to .95 for Depression-Dejection (cf. Boyle, 1988). In the present combined sample, the overall Cronbach coefficient α was .75, suggesting moderate item homogeneity with little item redundancy (Boyle, 1991). Stability estimates ranged from .65 for Vigour to .74 for Depression-
Dejection. Retest at six weeks produced coefficients that ranged from .43 for Vigor to .53 for Anger-Hostility.

The *Family Environment Scale* (Moos & Moos, 1994) is a 90-item true-false self-report scale designed to measure the social environmental attributes of various kinds of families. The scale which distinguishes between normal and distressed families (Caldwell, 1985; Bishop & Miller, 1988) has 10 subscales that assess three underlying dimensions of Relationship, Personal Growth, and System Maintenance.

Cronbach coefficients alpha for the subscales ranged from .61 to .78 (Moos & Moos, 1994): In the present combined sample, the overall Cronbach coefficient alpha was .50 suggesting moderate item homogeneity and little item redundancy and that the items in the scale provided broad measurement (cf. Cattell, 1982). Test-retest reliabilities after two months ranged from .68 for Independence to .86 for Cohesion; at a four month interval, retest coefficients ranged from .54 for Independence to .91 for Moral-Religious Emphasis.

Relationship dimensions are assessed by the Cohesion, Expressiveness, and Conflict scales. The Cohesion subscale assesses the amount of commitment, assistance, and sustenance family members report contributing to one another. The Expressiveness subscale assesses how much family members are encouraged to express their feelings directly and to act overtly. The Conflict subscale assesses the extent to which family members report engaging in aggression, conflict, and overt anger.

Personal Growth dimensions are measured by five subscales of Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis. The Independence subscale appraises how much family members exhibit assertiveness, self-sufficiency, and independent decision-making. Achievement
Orientation is a measure of how such activities as work and school can affect the casting of families into a competitive or achievement-oriented frame of mind. Intellectual-Cultural Orientation assesses the amount of reported interest in cultural, intellectual, political, and social activities. Active-Recreational Orientation assesses the amount of reported participation in recreational and social enterprises. Moral-Religious Emphasis assesses the amount of reported emphasis on religious and ethical values and problems.

Procedure

Headway associations, both in Brisbane and the Gold Coast, were approached for assistance in obtaining individuals who would be willing to participate in this study. The Gold Coast family worker identified and approached families who would fit the criterion of having a family member with a severe traumatic brain injury. The Brisbane office placed an advertisement in the Headway newsletter asking for volunteers to participate in this research. This advertisement resulted in the inclusion of five appropriate respondents from the Bundaberg district. The selected primary caregivers were asked to fill out a general demographic questionnaire, the Family Environment Scale, and the Profile of Mood States. Respondents were asked to read the instructions on the test forms and were also given verbal instructions. Data were analyzed using the SPSS statistical package. Also, multiple analyses of variance were carried out (cf. Huberty & Morris, 1989).

Results

Table 1 presents the means and standard deviations obtained for the Family Environment Scale subscales (see Table 2 for Profile of Mood States data).
As shown in Table 1, for the Family Environment Scale, only the Expressiveness, Active-Recreational Orientation, and Control subscales produced significant between-group effects ($F_{1,53} = 18.14$, $p < .0001$; $F_{1,53} = 4.03$, $p < .05$; and $F_{1,53} = 4.61$, $p < .05$, respectively). For the Profile of Mood States, the only subscale to produce a significant score was Depression-Dejection ($F_{1,53} = 4.09$, $p < .05$). For the Active-Recreational subscale ($M=5.4$, $SD=2.3$ vs. $M=4.1$, $SD=2.4$) the scores suggest that the families with a brain-injured member participated in recreational pursuits less than unafflicted families. On the Control dimension ($M=4.6$, $SD=3.5$ vs. $M=3.5$, $SD=2.2$), families with a brain-injured member appear to rely on established procedures and Regulations in running family life more than unafflicted families. Traumatic brain injury is also associated with higher scores on depression in family members ($M=10.9$, $SD=12.1$ vs. $M=5.5$, $SD=7.6$).
Table 2

Means and Standard Deviations for Profile of Mood States

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Brain-injured Group (n = 23)</th>
<th>Non-brain-injured Group (n = 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Anger-Hostility</td>
<td>8.0</td>
<td>9.4</td>
</tr>
<tr>
<td>Tension-Anxiety</td>
<td>9.6</td>
<td>7.7</td>
</tr>
<tr>
<td>Depression-Dejection</td>
<td>10.9</td>
<td>12.1</td>
</tr>
<tr>
<td>Vigor</td>
<td>14.5</td>
<td>5.9</td>
</tr>
<tr>
<td>Fatigue</td>
<td>10.6</td>
<td>8.2</td>
</tr>
<tr>
<td>Confusion</td>
<td>8.2</td>
<td>6.4</td>
</tr>
</tbody>
</table>

After Bonferroni correction to control for the large number of simultaneous comparisons, however, only the Expressiveness subscale remained significant. For that subscale (M=6.6, SD=2.1 vs. M=4.5, SD=1.3), the families without a brain-injured member appeared more able to express their feelings and more open in their behavior than families with a brain-injured member.

There were several significant intercorrelations between scores on the two self-report tests, the most relevant being Anger-Hostility (r = .48 with Conflict, and -.46 with Independence), Depression (r = -.31 with Organisation), Vigor (r = .48 with Intellectual/Cultural Orientation), Fatigue (r = -.33 with Independence), and Confusion-Bewilderment (r = -.45 with Cohesion, .46 with Conflict, -.47 with Independence, and -.44 with Intellectual/Cultural Orientation).

The present findings suggested that, for the primary caregivers, reduced participation in former activities and a loss of relationships with family and friends were the most common problems reported (75% and 65%, respectively). Reduced participation in the workforce was reported by 56% of respondents. Most (95%) had experienced negative changes in their lives, namely, financial losses,
more stress, lack of understanding by family members, and role changes. Two caregivers reported having good relationships with their partners, one who married after the injury and one male caregiver of a brain-injured wife. For caregivers with a brain-injured family member, 78% reported reduced work participation, and 69% reported reduced participation in former activities, including recreational, achievement, intellectual and cultural activities.

**Discussion**

Caregivers were sampled from a group self-selecting for assistance from Headway associations, presumably because of difficulties in caring for their brain injured family member, making it difficult to generalise the findings to all family caregivers of such patients. Nonetheless, the present study confirmed that traumatic brain injury can produce changes in family life which may result in ongoing difficulties for many such families (cf. Rosenbaum & Najenson, 1976). With a Bonferroni correction, families with a brain-injured member exhibited lower scores on the Expressiveness subscale of the Family Environment Scale than did families without a brain-injured member. Consequently, these families may be avoiding the expression of feelings or acting openly.

Baker (1990) found a significant relationship between the increased expression of negative emotions by the brain-injured person and depression in family members. In the present study also were higher scores for depression in the family members of brain-injured patients than in the comparison group. Depression differed significantly between groups on the Profile of Mood States, suggesting that it is a common emotional response (cf. Rosenbaum & Najenson, 1976).

The significant differences between the two groups on the Active-Recreational subscale suggest that the head-injured family members participated
less in social and recreational activities. As this measure correlated with scores on Vigor and Fatigue, it is likely that they had less time and energy to devote to activities for themselves. A further reason could be that they are more socially isolated given the behavior of the head-injured member, as was suggested by Lezak (1978).

A significant mean difference between groups was found on the Control subscale. This scale was part of the System Maintenance dimension, and the results suggest that families with a brain-injured member require more structure in running the family. As Lezak (1978) pointed out, apathy, self-regulation, and inflexibility are often problems for those with head injury. It may be that more control is a relatively successful coping strategy for those who have been caring for a brain-injured person for some time. Research such as that by Kaplan (1991) suggests that higher control may be needed so the injured person and the family can function more efficiently.

In many instances, the families of brain-injured victims had reduced living standards, either through the patient having lost the ability to work at a previous capacity or due to the caregiver having to give up or reduce time spent working outside the home. Yet, as Peters, et al. (1992) reported, problems are greater for families with a brain-injured member because there are additional neurological deficits. The present study (albeit limited to those caregiver families seeking assistance from supportive associations) examined this family distress using psychometric tests, finding some specific changes in family environment and in depressive mood state, as would be expected.

The results suggest that families with a brain-injured member may have special difficulties in the areas of expressiveness, active recreational, control, and depression or dejection. Therefore, families of the head-injured person may
themselves be in need of assistance after the injury occurs to one of their members, even long after the accident. Specific problems identified in the present study include depression, reduced ability to speak and act openly within the family, and reduced participation in recreation and leisure activities. All of these factors can lead to social isolation and withdrawal from the social support that is potentially available (Kaplan, 1991).

There was also higher control used in the running of the family life in homes where there was a person with closed-head injury. This may have been a coping mechanism used in adapting to the problems posed by the patient. Studies would be improved by incorporating larger sample sizes and by focusing on how to increase social support and family cohesion—important aspects of rehabilitation of the patient and ultimately the continued functioning of the family.

Some caveats in regard to the present study must be taken into account. For example, it seems likely that the effects of caregiving could differ substantially across the two categories of spouses vs. parents, particularly in terms of energy, depressive affect, and involvement in outside activities—all of which are known to covary with age. In addition, the caregiver group was a non-representative sample of caregivers, comprised of that subset of caregivers requesting assistance from Headway (a social assistance association) because of difficulties in caring for their brain-injured family member. Another issue is that the data on the families of the brain-injured individuals were collected after an average interval of more than nine years after the occurrence of the traumatic brain injury. Given that family and caregiver adaptation is likely to vary over time, it is not clear how much the present findings reflect reactions to the brain injury vs. adaptation (or lack of it) to the long-term caregiving process. How adaptation is affected by the severity of the traumatic brain injury, the personality of the patient, the quality of family support, and the type of supportive services the family receives are all questions
requiring further investigation.

Overall, the present findings suggest that caregivers may be (a) avoiding or editing expression of their feelings, (b) struggling with their own dysphoria, (c) less involved outside the home in social and recreational activities, and (d) relying to a greater extent on structure and control within the family to care for their brain-injured family member. These findings are consistent with prior clinical and research findings in the published literature. Recommendations for research might include (a) matching caregiver and non-caregiver samples more closely, (b) examining differences across various caregiver groups, and (c) using more advanced statistical techniques including those that deal with multivariate data and those that permit structural modeling of presumed mediating variables.

In conclusion, the present findings (pertaining to mood states and family coping skills (other cognitive, personality, and functional changes were not measured) are limited to caregiver families seeking outside support or assistance. Although caregiver families exhibited some changes in terms of family dynamics, as would be expected, by and large, these families appeared to be coping despite the presence of a brain-injured person in their midst.

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