Role Change After Traumatic Brain Injury in Adults

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Key Words: disability evaluation • social adjustment

Objectives. The purpose of this study was to gather information regarding changes in adult life roles following severe traumatic brain injury.

Method. The Role Checklist and a semistructured interview were administered to 28 adults with traumatic brain injury who had been in the community for at least 8 months prior to the study. All 28 subjects reported role changes in their lives.

Results. The majority of the role changes were losses (71%). More than 64% percent of the subjects reported three or four role losses. The losses were in major organizing roles such as worker, homemaker, and friend. Most role gains were seen in the roles of home maintainer, family member, and religious participant. Almost 40% of all roles were reported as changed (loss or gain), while more than 60% of roles were reported as unchanged (continuous or absent). The participants' subjective impressions concerning the role changes and why they occurred were elicited.

Conclusion. With a better understanding of possible role change after traumatic brain injury, rehabilitation professionals can target the development of specific skills necessary for the continuation of valued roles.

The National Head Injury Foundation (NHIF) estimates that 70,000 to 90,000 persons each year survive a traumatic brain injury (TBI) severe enough to cause life-long debilitating loss of function (E. Savader, personal communication, November 30, 1993). Traumatic brain injury affects each person differently because of the nature of occurrence, specific types of neurologic injury, premorbid health, and premorbid functional and social status (Jennett, 1984). Tyerman and Humphrey (1984), in a study of changes of self-concept after TBI, found that 72% of their 25 subjects said they had changed "as a person" as a result of their injuries. The injury appears to influence many areas of life activity and performance.

Consequences of severe TBI include physical, cognitive, and psychosocial impairments. For many, physical deficits are not the most serious long-term effects of severe TBI. Brooks, Campsie, Symington, Beattie, and McKinlay (1987) concluded that most of their 134 subjects with TBI had made a good physical recovery, but deficits in cognition and social functioning remained. Lezak (1978) classified the psychological deficits of the person with brain injury in five different areas: (a) self-centered behavior, (b) impaired capacity for control, (c) difficulty in planning and organizing activities or projects, (d) emotional alterations, and (e) rigidity. She described these deficits as the patient's greatest barriers in social, community, and occupational reintegration. Problems in these areas may affect performance of the skills associated with role participation (Bermann, 1988).

A role may be defined as the expected pattern of behavior associated with occupancy of a distinctive position in society (Heard, 1977). Adult occupational, family, avocational, and social roles allow persons to participate in society and satisfy human needs. Roles encompass many complex behaviors reflecting personal, sexual, social, and vocational identity (Oakley, 1982). Role changes are almost inevitable when a person sustains a traumatic injury. Disability resulting from a TBI may adversely affect personal role function in ways that range from minor changes to obliteration of all major life roles, such as losing a job (worker role), divorce (family role), or social isolation (friend role).

The World Health Statistics Annual 1990 defined handicap as "a disadvantage, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal for that individual" (World Health Organization, 1991, p. 40). Role performance is a vital component of productive independent living.

Some persons with TBI underestimate the severity and functional effects of cognitive and other deficits when compared to assessment by relatives (McKinlay & Brooks, 1984). Krefting (1989) found that persons with TBI and their families may conceal, ignore, or redefine their situation to "cope with the loss of self-identity" (p. 77). Although Tyerman and Humphrey (1984) acknowledged
this lack of insight, they decried the lack of studies of the personal perspective of persons with TBI. In their study, 25 persons with severe TBI completed a semantic differential scale with respect to present self, past self, and future self. There was a significant difference between past and present on all but 3 of the 20 adjective pairs. Oddy, Humphrey, and Utley (1978) found that their subjects acknowledged changes and deficits rather than underestimating them. Persons with TBI may have greater insight than has been previously reported, and their perspectives should be included in future research (Willer, Allen, Liss, & Zicht, 1991). Research that categorizes areas of life activity (roles) and evaluates them is important to determine a common definition of the construct of recovery.

Role performance and balance are important factors in the quality of life experienced by the person with TBI. It is clear that the person with TBI experiences role changes, but how do these affect the person? The study is intended to be a preliminary examination of role changes from the perspective of persons who have sustained a TBI. This information may help rehabilitation professionals to anticipate problems associated with role change as a consequence of TBI and offer a more holistic approach to preparation for community living.

Method

Subjects

Subjects were selected for this study from a population receiving periodic medical follow-up by a physiatrist at the brain injury clinic at the Medical College of Virginia Hospitals, Richmond, Virginia. The population sampled included men and women who had experienced severe TBI (with a Glasgow Coma Scale score of < 8) and had been in the community at least 8 months before the study. This time criterion was established to assure the beginning of community reintegration, when possible role changes may become apparent.

There were 28 subjects (5 women and 23 men), whose ages ranged from 18 to 52 years. The average age of subjects was 28.4 years (median = 26, SD = 8.5). More than 57% of the subjects were injured as a consequence of a motor vehicle accident (see Table 1). The mean Glasgow Coma Scale (GCS) score at time of injury was 6 (Teasdale & Jennett, 1974). The frequency and percentage of scores of brain injury severity as expressed by the initial GCS score are shown in Table 2. Time in community ranged from less that 1 year to nearly 6 years with a mean of 29.2 months (median = 25 months, SD = 16.8).

At time of interview, 39.3% of the subjects lived with parent or parents, 28.7% with spouse or significant other, 10.7% with extended family, 7.0% alone, and 14.3% in other settings (including a state hospital and group homes).

<p>| Table 1 |
| Etiology of Traumatic Brain Injury for 28 Subjects |</p>
<table>
<thead>
<tr>
<th>Etiology</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor vehicle accident</td>
<td>16</td>
<td>57.1</td>
</tr>
<tr>
<td>Pedestrian hit by vehicle</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>Fall</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>Gunshot</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>7.1</td>
</tr>
</tbody>
</table>

Instrumentation

The Role Checklist self-report assessment was used to elicit information on role participation, balance, and change (Oakley, 1982). Kappa and weighted kappa values reveal moderate or better reliability with normal adults (Oakley, Kielhofner, Barris, & Reichler, 1986) and fair to moderate reliability with depressed adolescents (Pezzuli, 1988). There is no data on the reliability of this test with persons with TBI. The checklist has no normative data, although it appears to have content validity. For this study, the heading of past was changed to before injury, while the heading of present was changed to after injury (now). The nine roles listed on the checklist are as follows: worker, family member, hobbyist, friend, caregiver, home maintainer, religious participant, volunteer, and student. Though the instrument was designed as a self-report, in this study the questions were read to all subjects because of some subjects' inability to read.

The questions asked during the semistructured interview were based on the Occupational History interview format (Moorhead, 1969). Questions were based on responses gained from the Role Checklist. Only the changed roles were the subject of questions during the interview. Participants were asked how they felt about the role loss or gain and why they thought it took place. The interview concluded with the question, “How do you spend a typical day?” The first author developed familiarity with the interview format by rehearsing with five persons with TBI before beginning data collection.

The Disability Rating Scale (DRS) is a sensitive, reliable means of monitoring patients from time of injury to time of community reintegration (Rappaport, Hall, Hopp...
kins, Belleza, & Cope, 1982). The DRS score is often used to track the course of improvement in functional status in task performance over time. All DRS scores were assigned by the subjects' clinic physiatrist (see Table 3). This score was used as a concurrent validity measure with the number of role changes reported on the Role Checklist.

**Data Collection**

The subjects were approached by the examiner before or after their appointment in the clinic, the purpose of the study was briefly described, and a letter of consent was presented. If the person agreed to participate in the study, the letter of informed consent was signed and the Role Checklist and interview were completed in an examination room or waiting room.

**Definition of Variables**

A role change was noted where there was a difference between reported preinjury and postinjury role participation. Role change included both loss and gain role patterns. A role loss was defined as a role reported as present before injury and absent after TBI. A role gain was defined as a role reported as absent before injury and present after TBI. An absent role was defined as a role that lacked participation before and after injury. A continuous role was defined as a role that was reported as present before and after injury.

**Data Analysis**

Percentages were used to describe role patterns, and the most common responses from the semistructured interview were selected to characterize the answers of subjects who had reported changes in each role. Spearman's rank correlation was used to determine the degree of relationship between two dependent variables, the scores on the DRS, and number of role changes reported on the Role Checklist.

### Table 3

**Functional Status as Shown by the Disability Rating Scale**

<table>
<thead>
<tr>
<th>Disability Rating Scale Score</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>32.1</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>7.1</td>
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<tr>
<td>3</td>
<td>5</td>
<td>17.9</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>17.9</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>17.9</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>7.1</td>
</tr>
<tr>
<td>7</td>
<td>9</td>
<td>3.6</td>
</tr>
</tbody>
</table>

*Note: The Disability Rating Scale scores were assigned at the time of the interview.

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### Table 4

**Number of Role Patterns According to Individual Roles**

<table>
<thead>
<tr>
<th>Role Patterns</th>
<th>Worker</th>
<th>Hobbyist</th>
<th>Friend</th>
<th>Family member</th>
<th>Home maintainer</th>
<th>Religious participant</th>
<th>Caregiver</th>
<th>Volunteer</th>
<th>Student</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss</td>
<td>24</td>
<td>17</td>
<td>13</td>
<td>9</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gain</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>9</td>
<td>6</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Continuous</td>
<td>3</td>
<td>4</td>
<td>11</td>
<td>9</td>
<td>11</td>
<td>6</td>
<td>12</td>
<td>21</td>
<td>27</td>
</tr>
<tr>
<td>Absent</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>13</td>
<td>0</td>
<td>21</td>
<td>28</td>
</tr>
</tbody>
</table>

| Total         | 71     | 29       | 48     | 104          |

*Change patterns:* 71.0% loss, 29.0% gain

*Role patterns:* 28.2% loss, 11.5% gain, 19.0% continuous, 41.3% absent

**Results**

**Role Change**

Role patterns (loss, gain, continuous, absent) reported on the Role Checklist are presented in Table 4. The roles are ranked according to total number of losses. The worker role showed the most losses, the home maintainer role showed the most gains, and the home maintainer and friend roles showed the greatest number of continuous role patterns. The roles that demonstrated the least participation were the student and volunteer roles. The worker, hobbyist, friend, and family member roles displayed more losses than gains, whereas those of home maintainer, religious participant, caregiver, and volunteer displayed more gains than losses. All 28 subjects reported at least one role change, and 64.3% reported three or four role losses. More than 48% of the subjects reported no role gains; 46.4% reported one role gain.

**Worker**: More than 85% of the subjects reported a worker role loss. Feelings mentioned by the subjects concerning the loss of the worker role included anger, frustration, apprehension, confusion, boredom, and fear. One subject said "It put me down," and another said "I can't get adjusted." Many stated that they hated not working and wished they had a job. Almost 80% of the subjects who reported role change stated that the worker role was very valuable to them.

When asked why they thought the change occurred, subjects' statements included the following: "I forget," "Haven't seen my brain," "Mind not stable enough," and "Can't keep my mind on one thing." Others mentioned physical problems such as poor balance, incoordination, seizures, and headaches. A few subjects mentioned their low frustration tolerance and stated "I can't handle the pressure," and "I blow up."

Only two subjects who reported a worker role loss said that the role was not very valuable to them. They both mentioned that they had financial settlements from the accidents that produced their injuries.

**Hobbyist**: More than 60% of the subjects reported a
hobbyist role loss. The feelings mentioned by subjects who experienced a hobbyist role loss included frustration, depression, and uselessness. Comments included, "I'm not good enough for anything," and "I feel like an outcast." Approximately half of the subjects reporting a hobbyist role change stated that this role was very valuable to them. Other subjects said that having a hobby was not important to them: "It's not on my mind."

Reasons for the role change included the following: "I haven't been able to get out," and "I can't focus on anything." Other reasons cited by subjects included physical problems with their hands, such as not being able to shoot pool, draw and paint, or play the guitar. Others mentioned lack of funds and transportation. Those few subjects who reported a role gain stated that hobbies gave them something to do and were often good exercise (swimming, basketball).

Friend. Approximately half of the subjects reported a friend role loss, while almost 40% reported a continuous role pattern. The emotions relayed concerning the role change included feeling lonely, crazy, defensive, angry, confused, terribl, embarrassed, and hurt. One subject said he just closed himself up. Another stated, "It makes me feel like shooting myself or getting a gun and shooting other people." Of the subjects who reported a role change, the majority (more than 90%) stated that the role of being a friend was very valuable to them.

Reasons cited for the role change included not feeling like "going out" anymore with old friends, and staying away from the drug scene. Quotes include "They don't think I'm OK," "I'm too quick to get angry," and "I can't do much anymore." One subject stated "I scare people, they call me a crazy and a psycho." One subject reported a friend role gain and stated that he had more time to spend with other people because he was not working.

Family member. For the family member role, equal numbers (32%) reported a role loss and continuous role, while 21% of the subjects reported a role gain. When the subjects who reported the loss of the family member role were asked how they felt, most stated that they were unhappy and angry. More than 90% of the subjects stated that this role was very valuable to them.

Asked why this role loss took place, subjects responded with "Wife left me," "Rest of family working," and "Family gets tired of me." One subject stated that he was too lazy to be involved with his family.

Subjects who reported a role gain of family member were asked how they felt about the change. Statements included: "Have to have someone to hold on to," "Family are the only true friends," "I didn't care before now," and "They are there when you need them."

When asked why this role gain took place, subjects stated that they were home more than before because of spending less time with friends. A few subjects mentioned that the accident had made them closer and that their families were very supportive.

Home maintainer. For the home maintainer role, almost 40% of the subjects reported a continuous role, while more than 32% reported a role gain. The few subjects who reported loss of the home maintainer role appeared apathetic; they stated that because they were living with other people they did not need to do chores or that there was nothing to do around the house. Only half of the subjects who reported a role loss said that the role was very valuable to them.

The feelings that were relayed regarding a role gain include enjoyment and satisfaction: "It's something I can do to help myself and my family." "It helps the day go by faster." One reason cited for the role gain included wanting to help out because the subjects were home more and other family members were there less.

Religious participant. For the religious participant role, almost half of the subjects reported an absent role, while equal numbers (21.4%) reported a role gain and continuous role. The feelings associated with the loss of religious participant role included depression and fear. When asked why the change took place, one subject cited laziness and being tired all of the time. Other reasons included loss of interest, no transportation, and "I do what I want to do now." Of the subjects who reported a role change, 75% reported that the role was very valuable to them.

The feelings associated with the role gain were happiness and belonging. When asked why the change took place, one subject stated that "I almost died and saw God." Another reason cited was "The people in the church like me; before I felt like an outcast."

Caregiver. For the caregiver role, 76% reported an absent role pattern. Enjoyment was the major feeling cited concerning the caregiver role gain. Reasons given by subjects included wanting to be a good parent and spending more time at home.

Volunteer. More than 96% of the subjects reported an absent volunteer role. The only subject who reported a role gain had volunteered to spend time with a person with severe TBI whom he knew through church.

Student. All 28 subjects reported an absent role.

Typical Day

Watching television was the most frequently cited activity, followed by doing chores, participating in hobbies, sleeping, and eating. Other activities included calling friends, playing cards, listening to music, and taking walks. A few subjects commented that they could not remember what they did but that they were bored.

Statistical Analysis

The correlation between the number of role changes and the subject's score on the DRS was significant at the \( p = .01 \) level \( (r = .957) \) using the nonparametric Spearman
rank correlation coefficient. This significant correlation suggests that the more severe the disability, the more changes will be evident in life roles.

Discussion

Relatives of the person with TBI were the source of data in the majority of research on deficits seen after injury (Brooks et al., 1987; Lezak, 1978; Oddly & Humphrey, 1980). Effective intervention requires a balanced approach with the person with TBI and his or her family. This study employed the opinions, thoughts, and feelings of the TBI person through simple, direct questioning with the Role Checklist and interview. Major organizing roles, such as worker and hobbyist, displayed a high percentage of loss. The feelings and thoughts engendered by the role losses ranged from worthlessness to confusion to anger, while role gains were associated with enjoyment and satisfaction. Although a few subjects displayed some apathy regarding the changes in their lives, the majority responded to the questions with strong emotion. The deficits seen after TBI that were reported in the literature (Brooks et al., 1987; Lezak, 1978) were often supported by the subjects, though stated in lay terms. For example, a subject stated "I blow up" instead of "I have low frustration tolerance," and "I can't keep my mind on one thing" rather than "I have a decreased attention span."

Lezak (1987) stated that persons with TBI often have significant residual impairments in filling unstructured time satisfactorily. Comments to the typical day question reflect some problems with thinking of activities, although this difficulty could reflect communication or memory deficits rather than deficits in time management. Further research is needed on this concern.

The DRS score reflects awareness, level of cognitive and physical ability to complete self-feeding and hygiene, and adaptive psychosocial functioning. These factors provide an index of the overall functional outcome of patients (Rappaport et al., 1982). The significant correlation between DRS score and number of role changes suggests a similarity between the physician's assessment and patient's assessment of individual disability.

Many persons with TBI experience important role changes in their lives that cause a decrease in feelings of self-esteem and quality of life experienced. Rehabilitation professionals will find themselves working with increasing numbers of persons with TBI (Gloag, 1985) secondary to advances in medical science. This study provides a preliminary examination of life changes, insights, and feelings of persons who sustained a severe TBI. Some persons have a wide range of long-term needs that may be neglected after rehabilitation services cease. Community services are limited and are often designed for those with chronic mental illness or developmental disabilities. There is a need for community programs specifically designed for persons with TBI (Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989).

Occupational therapy involvement in community programs for the survivor of TBI will likely focus on defining previous life roles and interests and the skills involved in each. Treatment goals could concentrate on the development of these identified skills.

Some aspects of previous roles are essential for a person's sense of worth and self-concept (Bermann, 1988). Specific occupational therapy activities include structuring programs to enhance individual productivity and participation in a valued role or roles (Gloag, 1985) and assisting in reestablishing a client's identity by facilitating new role development (Krefting, 1989). Through accurate assessment of life role changes, professionals can identify and structure programs that target skills needed to fulfill role requirements. Because the worker, hobbyist, and friend roles appear at highest risk for loss, basic job skills and habits, socialization skills, and leisure tasks may require the focus of rehabilitation programs. Encouraging home maintenance skills and incorporating family participation into programs will reinforce those roles that show the greatest gains. The feelings of worth and satisfaction that come from role performance and productivity may increase the quality of life experience.

Study Limitations

Limitations of this study include the use of a convenience sample. Though all patients with TBI who entered the hospital system were followed in the outpatient clinic, patients who were nonverbal were not interviewed and were thereby excluded from the study. Thus, the sample may have been biased toward persons with a better outcome. Changing the headings of the Role Checklist and altering the administration procedure probably did not affect the instrument's reliability, although no testing was done to determine this possibility.

Conclusion

TBI can result in specific types of role change. Roles with the highest risk of loss and roles with the most opportunity for gain were identified by this study. The significant correlation of the number of role changes with DRS scores suggests that persons with TBI do acknowledge deficits and changes in their lives. The results of the study also support the literature related to specific problems seen after injury and what is observed months and years after TBI. Further studies might examine and compare role changes of persons who have experienced mild, moderate, or severe TBI. Further studies could also compare the person's self-rating and relatives' rating of performance, rather than just participation, in major life roles.
Acknowledgments

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References


