Community Participation and Quality of Life Outcomes After Adult Traumatic Brain Injury

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OBJECTIVE. This study examined outcomes after traumatic brain injury in adults salient to occupational therapy.

METHOD. Demographic data and Functional Independence Measure (FIM) scores from the inpatient rehabilitation stay were first gathered from a retrospective chart review. At follow-up, 25 adults, on average 21 months post-injury, completed measures of disability, community participation, quality of life, and satisfaction with occupational therapy during a telephone interview. Analysis of covariance was used to test the differences between pretest and posttest scores on the FIM; regression analysis and correlations were used to analyze predictions and relationships.

RESULTS. Statistically significant improvements in FIM scores during rehabilitation were predictive of the level of long-term disability and community participation among participants. At follow-up, participants were often unemployed, depressed and withdrawn, and experienced limitations in decision making, hand use, bladder control, and community integration. Less disability and more community participation were related to higher quality of life. Satisfaction with occupational therapy, although high, was unrelated to most outcomes.

CONCLUSION. Results support the premise that participation is associated with a high quality of life, yet persons with brain injury have significant needs for long-term occupational therapy.

E ach year an estimated 44,000 Americans sustain a moderate to severely disabling traumatic brain injury (TBI); an estimated 5.3 million Americans live with a TBI-related disability (Whyte, Hart, Laborde, & Rosenthal, 1998). The purpose of this study was to examine the outcomes for adults after brain injuries that are particularly salient for occupational therapy. Expected outcomes of occupational therapy intervention are participation and occupational engagement (Youngstrom et al., 2000) with the vision of promoting health, productivity, and quality of life for individuals with disabilities (Fisher, 1998). These outcomes are also consistent with the enablement models of rehabilitation (Brandt & Pope, 1997; World Health Organization [WHO], 1999). Thus, limited disability that permits performance of the activities of life, reintegration into the community and participation in life roles, and a quality of life comparable to someone without a disability are particularly salient outcomes of occupational therapy.

Comprehensive rehabilitation programs for persons with brain injury include occupational therapy as a standard component (Whyte et al., 1998) with demonstrated benefits. For example, Mackay, Bernstein, Chapman, Morgan, and Milazzo (1992) compared carefully matched (on severity of injury and demographics) groups of individuals with severe brain injury. One group (N = 21) received care at hospitals without formalized TBI programs; the other group (N = 17) received...
comprehensive TBI programs that included occupational therapy. Patients who received occupational therapy as part of a comprehensive program had a 33% shorter coma, a shorter rehabilitation stay, higher cognitive levels at discharge, and were more likely to be discharged to home than patients in other programs.

Individuals with brain injury may benefit from occupational therapy as part of comprehensive rehabilitation long after their injury. In a study by Willer, Button, and Rempel (1999), persons with severe long-standing brain injury (n = 23) who received comprehensive residential rehabilitation including occupational therapy, when compared to a matched group who received limited services at home, showed significantly greater gains in motor and cognitive abilities that were retained at 1-year follow-up. In another study, with occupational therapy as one component of a comprehensive program, persons with brain injury (N = 349) achieved significant functional recovery and community reintegration years after their injury (Gray & Burnham, 2000). Panikoff (1983) demonstrated that over a 2-year period, adults with brain injury improved in the skills of shopping, using money, homemaking, and hand coordination when provided with comprehensive rehabilitation. These studies demonstrate the benefits of long-term rehabilitation that includes occupational therapy.

Several studies have attempted to isolate the effects of occupational therapy on long-term outcomes. Five years after a brain injury, a client who received only occupational therapy for 5 months improved in organization, attention to detail, and resumed her education (Nelson & Lenhart, 1996). In a study by Schwartz (1995), two out of three individuals with TBI learned and retained specific routines using compensations such as tape-recorded messages after several months of home-based occupational therapy. These studies used descriptive comparisons, rather than rigorous single-case design, to test the effects of occupational therapy. In another study, after receiving an average of 12.3 weeks of outpatient occupational therapy, 16 participants with TBI (M = 22 months post injury) showed significant achievement of self-identified goals, independence, and satisfaction with their tasks performance (Trombly, Radomski, & Davis, 1998). Trombly et al. argued that the improvements made by clients were associated with occupational therapy because only occupational therapy worked on these goals. All these studies demonstrate that rehabilitation potential exceeds the acute care period, but none describes the specific needs of persons with brain injury, nor examines the prediction of outcomes relevant to occupational therapy expertise.

Outcome measures that demonstrate the benefits of rehabilitation for people with brain injury justify rehabilita-

tion costs and inform management systems (Johnston & Hall, 1994), and they could also be used to describe the needs of adults after brain injury. If occupational therapy is to anticipate needs, design, and promote community-based programs after brain injury, then it is necessary to examine the prediction of needs and to describe the long-term needs of individuals with brain injury, using measures salient to occupational therapy practice. This study examined these research questions: (1) What acute rehabilitation outcomes predict long-term outcomes? (2) What level of activity, participation, and quality of life exist among a typical cohort of persons with brain injury after acute rehabilitation?

Methodology

This study was conducted in two phases. Data from acute rehabilitation were gathered from a retrospective chart review. At follow-up, 25 adults, on average 21 months post-injury, provided data on long-term outcomes relevant to occupational therapy practice during a telephone interview.

Participants

A cohort of clients admitted to an inpatient rehabilitation center between January 1, 1996, and June 30, 1997, was chosen for the study because data were complete on a standard set of measures and they had experienced an adjustment period following acute rehabilitation. All participants had received comprehensive inpatient rehabilitation services, including occupational therapy, for at least 7 days on the brain injury unit. Participants were persons with traumatic brain injury (excluding stroke, tumor, infections, and other causes of brain injury) who were at least 18 years old at admission. Thirty-six individuals were eligible to participate; 25 completed the follow-up study. In 10 cases, the person with brain injury could not be located; one person declined participation.

Follow-up was conducted on average 21 months post-brain injury (range, 16 months to 29 months). Fourteen participants responded for themselves; 11 follow-up interviews were with family members. The phone interview was designed to last 30–45 minutes, but often lasted longer because participants were eager to talk.

Procedures

The research was implemented at a 95-bed rehabilitation center with a range of inpatient and outpatient services. Research review boards at the rehabilitation center and the university approved procedures used in this study. Data on demographics, pre-injury and injury status, and changes in
functional state during rehabilitation were collected retrospectively from a medical chart review.

After the chart review, the individual or the family was contacted first by letter and then by telephone to invite their participation in the follow-up study. The university-based researchers conducted follow-up telephone interviews that included self-reported measures of disability, participation, quality of life, and satisfaction with occupational therapy.

**Retrospective Chart Review Measures**

A data collection tool was designed for this study using suggested standards in brain injury rehabilitation (Hall & Johnston, 1994). Demographic data on pre-injury and discharge status were collected in categories using the traumatic brain injury model system criteria (Harrison-Felix, Newton, Hall, & Kreutzer, 1996).

**Injury Status**

Scores on the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974), an internationally accepted standard for rating depth of coma, were recorded for all participants at the time of initial injury. The lowest GCS score was used to classify the severity of injury as follows: scores of 3–8 defined severe injury, 9–12 defined moderate injury, and 13–15 defined mild brain injury. The type of injury (closed or open head injury), cause of injury, other injuries, and any evidence of alcohol use at the time of injury were recorded from the chart records.

**Admission and Discharge Status**

Rehabilitation team members rated the Functional Independence Measure (FIM) (Uniform Data System for Medical Rehabilitation, 1996) at admission and at discharge. The FIM contains 13 items that address self-care and motor functions, and five items that measure cognitive functions. Each item is rated on a scale ranging from 1 (total assistance) to 7 (complete independence). The Total FIM Score has an interrater reliability of .95 and a test–retest reliability of .95 (Ottenbacher, Hsu, Granger, & Fiedler, 1996); numerous studies support its validity (see Cohen & Marino, 2000 for a review).

**Follow-Up Measures**

**Disability**

The Activity Limitations Survey (ALS) (Willer et al., 1999) was chosen because it measures the concept of disability or activity restriction (ICIDH-2) (WHO, 1999). The ALS is a composite of the Health Activities Limitations Survey (Statistics Canada, 1989) and three scales adapted by Willer et al. The ALS includes 41 items that are scored dichotomously as “yes” or “no” to indicate difficulty or no difficulty on each item. Summary scores are generated for seven subscales: Motor (6 items), Sensory and Communication (6 items), Activities of Daily Living (6 items), Emotional (4 items), Cognitive (8 items), Social Behavioral (8 items), and Medical Complications (3 items). The Total Score ranges from 0 to 82; higher scores suggest more activity limitations. An Adjusted Score is calculated by dividing the mean of each subscale by the number of items in the subscale, depicting the relative extent of disability between subscales. Willer et al. found a Cronbach’s alpha of .89 for the Total Score and above .78 for all subscales except the Sensory (.63), and Emotional (.56) subscales; test–retest reliability at 1-year intervals was .84 for the Total Score. In this study, the Cronbach’s alpha coefficient of internal consistency for the Total Score was .90.

**Community Participation**

The Community Integration Questionnaire (CIQ) (Willer, Linn, & Allen, 1993) was chosen because it is a standard indicator of participation outcomes for traumatic brain injury (Hall & Johnston, 1994). The CIQ is a 15-item measure that yields scores on three dimensions: Home Integration, Social Integration, Productivity, and a Total Score. Twelve items are scored on a three-point scale rating “with whom” or “how often” an item is performed; three items on employment, school, and volunteer activities are rated on a 6-point scale. The Total Score ranges from 0–29; higher scores indicate more community integration. The CIQ has a test–retest reliability of .91 (Willer, Ottenbacher, & Coad, 1994) and multiple studies supporting its validity (see review in Dijkers, Whitenack, & El-Jaroudi, 2000). In this study, the Cronbach’s alpha coefficient of internal consistency for the Total CIQ score was .80.

**Quality of Life**

The Quality of Life Rating (QOLR) (Gust, 1982) was chosen because it measures subjective evaluation of present life circumstances and is appropriate for all persons regardless of disability status. The QOLR is a 20-item self-report measure with a 5-point rating scale; the higher the score the higher the perceived quality of life. Factor analysis of the scale (Huebner, Allen, Inman, Gust, & Turpin, 1998) identified five subscales: Self-Esteem and Well-Being, Interpersonal Attachment, Economics, Recreation/Leisure, and Spirituality. A test–retest reliability coefficient of .74, Cronbach’s alpha test of internal consistency of .87, and concurrent validity with the life satisfaction of .69 were
found (Huebner et al., 1998). Cronbach’s alpha test of internal consistency for the QOLR in this study was .91.

**Satisfaction With Occupational Therapy**

Whiteneck (1994) and Keith (1998) recommend including questions about satisfaction with each service in rehabilitation outcome measurement, in part to differentiate the effects of any single discipline. Satisfaction is also important because high client satisfaction is associated with greater compliance and improved outcomes in rehabilitation (Keith). We reasoned that if we measured outcomes that were salient to occupational therapy, then greater achievement of these outcomes would be associated with higher satisfaction with occupational therapy.

An eight-item measure was adapted from the Client Satisfaction Questionnaire (Larsen, Attkisson, Hargreaves, & Nguyen, 1979) by changing the wording to specify occupational therapy. Corcoran and Fisher (1987) reported the internal consistency of the original measure between .86–.94, use of the questionnaire with thousands of clients, and adequate concurrent validity with treatment gain. Each of the eight items is rated using a four-point scale with item-specific rating anchors. For example, three items used anchor ratings of “no, definitely not” to “yes, definitely” to rate items such as willingness to recommend occupational therapy to a friend in need. Ratings are summed for a Total Score between 8 and 32 points; higher scores reflect higher satisfaction. The Cronbach’s alpha coefficient of internal consistency for the Satisfaction With Occupational Therapy Questionnaire used in this study was .89. An additional question asked participants to tell a story about their experience in occupational therapy.

**Data Analysis**

Data were analyzed using statistical SPSS® software, version 10.0 (2001). Descriptive statistics were calculated on all measures and examined for trends. Pretest and posttest scores on the FIM were analyzed using analysis of covariance (ANCOVA) with the pretest score entered as the covariate and the posttest scores entered as the dependent variable. According to Pedhazur and Schmelkin (1991) “the appropriate analysis for this design is the ANCOVA, where the pretest is treated as the covariate” (p. 270) to compensate for the correlation between pretest and posttest scores that may bias the analysis of treatment gains. Regression analysis was used to test the prediction of follow-up outcomes by FIM scores. The relationship between outcome measures was tested using a correlation matrix and correlation coefficient.

**Results**

**Demographic and Descriptive Results**

The group completing the follow-up (n = 25) and the group unavailable for follow-up (n = 11) were examined for differences using either chi-square tests of distribution or one-way analysis of variance (ANOVA) procedures. There were no significant differences between the groups in age at injury, severity of injury, education, gender, employment status at injury, or diagnosis. Subsequent results are reported here for the group of 25 who completed the follow-up study.

At the time of injury, participants ranged in age from 19.75 years to 81.33 years (mean = 41.99, SD = 17.94). At follow-up, ages ranged from 21.83 years to 83.42 years (mean = 43.79, SD = 18.02). Eight participants were female (32%) and 17 were male (68%). Seventeen (68%) had been injured in a motor vehicle accident, three in bicycle accidents, two from falls, and three from assaults. Seven (28%) were reported to have used alcohol at the time of injury. Twenty-three (92%) sustained a closed head injury, and two (8%) an open-head injury. All participants had additional fractures and multiple medical complications. Based on Glasgow Coma Scale scores, 19 participants were classified as having severe injuries, three were moderate, and three sustained mild head injuries.

Demographic data on pre-injury status were compared to data from the national sample published by Harrison-Felix et al. (1996) using chi-square goodness of fit tests. There were no significant differences between the participants on the basis of gender, education (84% had a high school diploma or better with 16% educated beyond four years of college), or living arrangement at the time of injury. Participants in this study tended to be in older categories (less in the 26–35 year category and more in the 46–55 year category) at the time of injury, X² (7, N = 25) = 18.01, p < .05, and more often retired at injury (24% in this study vs. 10% in the national sample), X² (3, N = 25) = 10.79, p < .05.

The intent of this study was to describe outcomes for a typical cohort of persons with brain injury, rather than demonstrate the worth of any treatment or length of treatment. Information about treatment, nonetheless, provides the context for understanding the experiences of this cohort. The average length of stay in the inpatient rehabilitation hospital was 37.52 days [range = 7–175 days; SD = 36.62, 23 (of 25) clients stayed between 7 and 74 days]. Participants received an average of 28.68 days of occupational therapy [range = 6–100 days; SD = 22.56 but only 2 clients received more than 55 days of occupational therapy].
After discharge from the acute hospital, only six clients received additional occupational therapy through home health or the outpatient programs of the rehabilitation center. All clients reported ongoing medical care, but only a few received community-based services such as vocational rehabilitation.

FIM scores on the Motor subscale were available for 25 participants at both admission and discharge, but Cognitive and hence Total Scores were available for only 22 participants at discharge. Differences between admission and discharge FIM scores were tested for significance using ANCOVA; all differences were statistically significant and are displayed in Table 1.

**Follow-Up Results**

At follow-up, only 5 (16 at injury) participants were competitively employed and 13 (2 at injury) were unemployed. There were no statistically significant differences in where the person with brain injury lived at follow-up compared to admission; 44% vs. 40% lived with a spouse, 12% vs. 8% lived alone, 16% vs. 24% lived with a parent, and 12% lived with an adult child (over age 21) at both times. Over 92% lived in a private residence before and after their injury; one person was in prison and one lived in a nursing home at follow-up.

The mean number of activity limitations was 13.88 ($SD = 8.40$); all participants had at least one limitation in an activity on the scale. Table 2 displays the relative level of disability. The most cognitive limitations reported by participants were in memory and making decisions. They most often reported depression and withdrawal (Emotional Subscale), difficulty with reading and learning new tasks (Sensory Subscale), and limitations in bowel and bladder control and using the hands to handle objects (Activities of Daily Living Subscale).

Mean scores on the Community Integration Questionnaire of 13.43 ($SD = 3.34$) were nearly identical to those obtained by Willer et al. (1994) (mean = 13.02, $SD = 6.02$). Although the mean scores on the CIQ are informative, they do not highlight the restrictions in community participation that might be the focus of occupational therapy. The CIQ is designed to measure restrictions rather than variations in typical performance. To illustrate needs, the percent of participants with the lowest scores on community integration is displayed in Table 3. Because 17 participants in this study were male, we wondered if differences in gender expectations might account for a portion of these limitations in community integration. The effects of gender on community integration were tested using chi-square analysis of distribution. There were no differences based on gender for any of the items on the community integration scale except for completing normal housework. Men with brain injury did less housework than women with brain injury, $X^2 (2, N = 25) = 7.13, p = .03$.

Three (12%) participants reported rarely leaving the home on the CIQ; we questioned what functional limitations hinder community participation. On the Activity Limitations Scale, all three reported feeling tired easily and having limitations in dressing independence. Two out of these three reported difficulty with bowel and bladder control, walking up stairs, using their hands and reaching, and learning and remembering. Less travel outside of the home was associated with multiple activity limitation especially in

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**Table 1. Functional Independence Measure (FIM) Scores, Mean and Standard Deviation: ANCOVA**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Admission Mean ($SD$)</th>
<th>Discharge Mean ($SD$)</th>
<th>Change Score Mean ($SD$)</th>
<th>$F$ Ratio</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Subtotal ($n = 25$)</td>
<td>39.56 (17.39)</td>
<td>66.72 (23.19)</td>
<td>27.16 (18.57)</td>
<td>13.94</td>
<td>.001</td>
</tr>
<tr>
<td>Cognitive Subtotal ($n = 22$)</td>
<td>19.00 (7.57)</td>
<td>25.27 (7.05)</td>
<td>6.27 (5.50)</td>
<td>21.38</td>
<td>.000</td>
</tr>
<tr>
<td>Total Score ($n = 22$)</td>
<td>57.68 (22.20)</td>
<td>93.00 (28.28)</td>
<td>35.32 (22.44)</td>
<td>13.05</td>
<td>.002</td>
</tr>
</tbody>
</table>

*Note.* Higher scores on the FIM are associated with higher function. $SD$ = standard deviation. $p$ = statistical significance.

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**Table 2. Disability or Activity Restrictions Ordered by Adjusted Disability Score ($N = 25$)**

<table>
<thead>
<tr>
<th>Activity Limitation Subscale</th>
<th>Mean</th>
<th>$SD$</th>
<th>Number of Items</th>
<th>Adjusted Disability*</th>
<th>Percent with Limitations**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>3.48</td>
<td>2.43</td>
<td>8</td>
<td>.44</td>
<td>84%</td>
</tr>
<tr>
<td>Emotional</td>
<td>1.78</td>
<td>1.54</td>
<td>4</td>
<td>.44</td>
<td>72%</td>
</tr>
<tr>
<td>Sensory and Communication</td>
<td>2.08</td>
<td>1.66</td>
<td>6</td>
<td>.35</td>
<td>80%</td>
</tr>
<tr>
<td>Medical Complications</td>
<td>1.04</td>
<td>.84</td>
<td>3</td>
<td>.35</td>
<td>72%</td>
</tr>
<tr>
<td>Motor</td>
<td>1.88</td>
<td>2.13</td>
<td>6</td>
<td>.31</td>
<td>68%</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>1.64</td>
<td>2.29</td>
<td>6</td>
<td>.27</td>
<td>40%</td>
</tr>
<tr>
<td>Social Behavioral</td>
<td>2.00</td>
<td>2.02</td>
<td>8</td>
<td>.25</td>
<td>76%</td>
</tr>
<tr>
<td>Limitations Total</td>
<td>13.88</td>
<td>8.40</td>
<td>41</td>
<td>.34</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note.* Scores generated from the Activities Limitation Scale (Willer et al., 1999). $SD$ = Standard Deviation. Items are scored dichotomously as limited or not limited.

*The Adjusted Disability Score is calculated by dividing the mean for each subscale by the number of items for that scale to permit comparisons of disability across subscales.

**Displays the percent of participants who had at least one limitation on any item in the subscale.*
Table 3. Community Participation of Persons with Brain Injury (N = 25)

<table>
<thead>
<tr>
<th>CIQ Item</th>
<th>Response</th>
<th>Percent^*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>Done by someone else</td>
<td>52%</td>
</tr>
<tr>
<td>Finances</td>
<td>Done by someone else</td>
<td>52%</td>
</tr>
<tr>
<td>Normal housework</td>
<td>Done by someone else</td>
<td>48%</td>
</tr>
<tr>
<td>Have a best friend to confide in</td>
<td>No</td>
<td>44%</td>
</tr>
<tr>
<td>Plan social events</td>
<td>Done by someone else</td>
<td>44%</td>
</tr>
<tr>
<td>Care for children</td>
<td>Done by someone else</td>
<td>36%</td>
</tr>
<tr>
<td>Preparing meals</td>
<td>Done by someone else</td>
<td>36%</td>
</tr>
<tr>
<td>Go shopping</td>
<td>Never</td>
<td>24%</td>
</tr>
<tr>
<td>Go out for leisure activities</td>
<td>Never</td>
<td>20%</td>
</tr>
<tr>
<td>Go out for visiting friends/relatives</td>
<td>Never</td>
<td>20%</td>
</tr>
<tr>
<td>Travel outside the home</td>
<td>Seldom/Neaver</td>
<td>12%</td>
</tr>
<tr>
<td>Travel outside the home</td>
<td>Almost daily</td>
<td>56%</td>
</tr>
</tbody>
</table>

Note. Scores generated from the Community Integration Questionnaire (Willer et al., 1993).

^Percent of participants who gave this response on the item.

Table 4. Means From the Quality of Life Rating: Comparison With Typical Population

<table>
<thead>
<tr>
<th>CIQ Item</th>
<th>This study (N = 25)</th>
<th>Typical study* (N = 384)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Family Involvement</td>
<td>4.16</td>
<td>1.03</td>
</tr>
<tr>
<td>Housing and Living Conditions</td>
<td>4.04</td>
<td>1.06</td>
</tr>
<tr>
<td>Transportation Availability</td>
<td>3.80</td>
<td>1.18</td>
</tr>
<tr>
<td>Receiving Affection</td>
<td>3.80</td>
<td>1.15</td>
</tr>
<tr>
<td>Spirituality</td>
<td>3.72</td>
<td>1.31</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>3.28</td>
<td>1.37</td>
</tr>
<tr>
<td>Overall Quality of Life</td>
<td>3.20</td>
<td>1.12</td>
</tr>
<tr>
<td>Financial Conditions</td>
<td>3.08</td>
<td>1.15</td>
</tr>
<tr>
<td>Recreational Activities</td>
<td>3.04</td>
<td>1.21</td>
</tr>
<tr>
<td>Amount of Stress</td>
<td>3.00</td>
<td>1.26</td>
</tr>
<tr>
<td>Liking Myself</td>
<td>2.92</td>
<td>1.38</td>
</tr>
<tr>
<td>Intimate Relationships</td>
<td>2.84</td>
<td>1.49</td>
</tr>
<tr>
<td>Emotional Balance</td>
<td>2.76</td>
<td>1.30</td>
</tr>
<tr>
<td>Hobbies</td>
<td>2.76</td>
<td>1.27</td>
</tr>
<tr>
<td>Sexual Adjustment</td>
<td>2.72</td>
<td>1.21</td>
</tr>
<tr>
<td>Control of Life and Future</td>
<td>2.68</td>
<td>1.31</td>
</tr>
<tr>
<td>Physical/Bodyly Condition</td>
<td>2.68</td>
<td>1.25</td>
</tr>
<tr>
<td>Learning or Educational Activities</td>
<td>2.68</td>
<td>0.69</td>
</tr>
<tr>
<td>Work/Career Activities</td>
<td>2.60</td>
<td>1.19</td>
</tr>
<tr>
<td>Volunteer Activities</td>
<td>2.32</td>
<td>1.03</td>
</tr>
</tbody>
</table>

Note. SD = Standard deviation. Means below 3.0 are aspects of quality of life that are perceived as being below expectations.

^Huebner et al. (1998). Bolded items are more than one SD below the mean of college participants.

The average rating of satisfaction with occupational therapy was 25.21 of a total possible 32 points (SD = 4.72; range = 12–31 points). Overall, 87% of clients were satisfied to very satisfied with occupational therapy, 91.7% would recommend occupational therapy to a friend or family member in need of similar help. When asked, participants recalled stories about cooking, learning to dress, practicing shopping and paying for groceries, and doing puzzles in occupational therapy.

Nearly every participant was eager to talk during the telephone interview. Most respondents spontaneously expressed a desire to have more rehabilitation including occupational therapy, often stating that they were more ready to engage in therapy now. Even those who were working and doing well frequently wondered about events during the coma and posttraumatic amnesia, and worried about the effects of brain injury on their present skills and performance.

Predictive and Relational Results

To determine if FIM scores were predictive of long-term outcomes at follow-up, Admission, Discharge, and Change Total Scores were entered into a linear regression analysis with the Total Score on each outcome measure as the dependent variable. There was no statistically significant relationship between FIM scores and satisfaction with occupational therapy or quality of life. However, Total FIM Change and FIM Discharge Scores were significantly and positively predictive of activity limitation or disability [F(2, 19) = 5.73; p = .011] and community participation [F(2, 19) = 6.15; p = .009].

To test relationships among subscale and total scores on all outcomes measures a correlation matrix was generated. Statistically significant correlations are displayed in Table 5. The presence of fewer activity limitations correlated with more home integration and productivity and overall community integration, but not with social integration. Fewer activity limitations and higher social integration were associated with higher self-esteem, spirituality, economic, and recreation aspects of quality of life. Satisfaction with occupational therapy was negatively correlated with home integration. Quality of life was highly related to all aspects of community integration.

Discussion

The participants in this study were similar to those in other studies on pre-injury demographics (Harrison-Felix et al., 1996) and community integration at follow-up (Willer et al., 1994), increasing the credibility and generalizability of the
results. Participants made significant progress in functional independence during an average 1-month rehabilitation stay, consistent with the findings of Whitlock and Hamilton (1995). Similar to the findings of Felmingham, Baguley, and Crooks (2001), FIM change and discharge scores were more predictive of long-term activity limitations and community integration than initial FIM scores. Higher community integration and fewer activity limitations, in turn, were associated with a higher quality of life. These findings support claims that rehabilitation efforts, including occupational therapy, are associated with long-term outcomes that are considered meaningful to people with brain injury.

Despite significant progress during acute rehabilitation, real disability as measured by activity limitations and diminished community integration, and perceived disability as measured by aspects of quality of life such as work, learning, body conditions, and control of life were found among all participants. Few participants, despite a high incidence of severe injury, received additional rehabilitation after discharge; participants frequently expressed a desire for additional rehabilitation. These findings are disquieting and beg for additional rehabilitation services. Occupational therapy is needed for increased use of technology and environmental accommodations to bypass activity limitations (e.g., bladder control problems) or facilitate community integration, cognitive and behavioral interventions, training in tasks of daily living, and advocacy for social policy that increases inclusion and job opportunities for people with disabilities.

Paradoxically there is mounting evidence demonstrating the benefits of rehabilitation service including occupational therapy, long after injury, coupled with limited availability or funding for such programs (Evans, 1997). Results of this study demonstrate the need for occupational therapy long after injury to increase employment and opportunities for learning. Learning activities, often in post-secondary institutions, and employment opportunities may need to be individually designed to accommodate the activity limitations of persons with brain injury; occupational therapists might initiate the design of such programs. Similar to the findings of McLean, Dikmen, and Temkin (1993), limitations in emotional control, decreased liking of self, problems in intimate relationships dominated at follow-up, suggesting that occupational therapy practitioners should address and anticipate these psychosocial needs during acute rehabilitation.

According to the enablement/disablement model of rehabilitation science (Brandt & Pope, 1997), functional limitations may result in decreased participation and quality of life, but that relationship is neither direct nor deterministic because many factors influence participation and quality of life. The results of this study support this enablement/disablement model. The correlation coefficients between activity limitations and measures of participation and quality of life, although statistically significant, accounted for a maximum of 40% of the variance between variables, suggesting that multiple other factors contribute to quality of life and full participation in the community.

Another influence on quality of life and community participation may be social support and compassion; both are well-documented correlates of adjustment (Halstead, 2001). In this study, family involvement, receiving affection, and social relationships were rated as high, about the same as typical college students, yet the Attachment sub-scale of the QOLR that includes these scores was unrelated to other outcomes. This is a surprising finding that suggests that variables related to interpersonal attachment may be unaccounted for in standard functional outcome measures and warrant further study. The implications of these combined observations suggest that occupational therapists should continue to engage family and friends in problem solving efforts during rehabilitation. Family members might keep a diary, for example, about events during coma and posttraumatic amnesia to later inform and reassure the person with brain injury.

Satisfaction with occupational therapy was generally high, but unrelated to most functional outcomes suggesting that other factors influenced satisfaction. Keith (1998) found that the degree of satisfaction with a health care service was highly related to the perceived warmth, friendliness, and sense of caring in the patient–provider relation-
ship, more than the demonstration of professional competence. In the follow-up interview, participants often commended specific occupational therapists and appreciated the genuine concern of these therapists. It is likely, as Halstead (2001) wrote, that the dynamics of a healing environment, including the occupational therapist’s empathy, compassion, affirmation, and teaching produce a sense of satisfaction, independent of functional gain.

The rather surprising finding that satisfaction with occupational therapy was inversely related to home integration activities, such as housework and cooking, is difficult to explain. It could be that home integration is not enough, that clients desire additional independence in the community including work activities. It could be that completing household tasks is generally perceived as undesirable. Clients who recalled experiences in occupational therapy remembered cooking activities most often and some commented that cooking was outside of their interests or being watched felt demeaning. These experiences and feelings could be reflected in this finding.

A basic tenet of occupational therapy is that improved occupational performance in typical life roles is associated with an improved quality of life. Burleigh, Farber, and Gillard (1998) tested this relationship among 30 clients with TBI and found a single statistically significant correlation between life satisfaction and social integration. Webb, Wrigley, Yoels, and Fine (1995) found higher quality of life associated with increased employment and participation in the community. The results of this study found a significant relationship between many aspects of quality of life, disability, and community participation, supporting the premise that mastery and occupational performance are associated with improved well-being (Youngstrom et al., 2000).

In this study, outcomes of rehabilitation that included occupational therapy were studied; however, we had no access to information about the process of occupational therapy that was associated with these results. The study of process variables is particularly important to understanding what interventions produce what outcomes; future research should include measures of the occupational therapy intervention process (Holm, 2000; Watts & Clement, 2000).

The results of this study are limited by several key factors and should be interpreted cautiously. Data regarding pre-injury status, injury, and acute hospitalization had been collected from the charts from many emergency rooms, making this information subject to rater error. Follow-up information was provided by care providers in 44% of the cases. The ratings of care providers and clients may differ, with clients providing a higher rating of their abilities than therapists or others (see Abreu et al., 2001 for a recent review). Although the Community Integration Questionnaire and Activities Limitations Survey are designed for telephone administration, a telephone interview may be associated with fatigue, inaccuracies in rating items, and distractibility that may have affected the results of this study. Despite these limitations, this study included follow-up on a typical cohort of persons with brain injury that was comparable to other national samples (except on age and retirement status), using multiple measures of outcomes that are salient to occupational therapy. The results document the needs of individuals with brain injury for long-term rehabilitation that includes occupational therapy.

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References


