Community Integration and Life Satisfaction After Traumatic Brain Injury: Long-Term Findings

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With changing health care trends, the delivery of occupational therapy services will occur more frequently out of the hospital and in the community. For persons with traumatic brain injury (TBI), intervention will need to focus more on the long-term, "real-life" issues as they return home to, recenter, and continue to live in their communities. Consequently, occupational therapy practitioners will need to be able to facilitate the adaptation process of persons with TBI and be knowledgeable about appropriate long-term planning and treatment programs.

TBI is an acquired insult to the brain that may produce temporary or permanent impairments in physical, cognitive, emotional, social, or vocational functioning. TBI can be described as "the silent epidemic" because the injury is not always physically visible (National Head Injury Foundation [NHIF], 1995).

More than 2 million TBIs occur annually (National Institutes of Health [NIH], 1990); 100,000 TBIs occur in the United States alone (Strax, 1994). Each year, 75,000 to 100,000 Americans will die because of TBI (NHIF, 1995). Although a small proportion of those who survive may continue in a persistent vegetative state or coma, a large number will return to the community with some residual cognitive, psychosocial, behavioral, or physical impairments.

Annually, 50,000 to 75,000 persons with TBI in the United States require some form of life-long care and community-based, supported living services (Schaaf,
1992). Although it is understood that outcomes must be evaluated in the community after discharge from rehabilitation hospitals, it remains unclear how well persons with TBI manage their home and community living activities and whether they are satisfied with their lives and ability to engage in these activities (Johnston & Hall, 1994). Only about half of all persons with moderate brain injury will return to school, work, and independent living within 1 year of injury (NHIF, 1995). Persons with severe disability may require as much as 5 to 10 years of rehabilitation services, with life-time costs exceeding $4 million (Max, MacKenzie, & Rice, 1991).

Home and community integration are frequently rehabilitation goals and priorities in treatment, especially for young adults who were establishing careers, families, and community-based activities at the time of injury (Willer, Ottenbacher, & Coad, 1994). A person's achievements in home, school, work, and community after TBI are often how we define successful rehabilitation outcomes (Whiteneck, 1994).

A basic assumption of occupational therapy is that the environment is explored and mastered through the performance of meaningful occupational roles (Reilly, 1969). The involvement of occupational therapy practitioners with a client's life roles and activities of daily living (ADL) enables them to understand the client's experience of illness and how it affects his or her satisfaction with life (Mattingly, 1991). Because role acquisition and development of community-living skills are primary goals of occupational therapy intervention, the relationship between community integration and life satisfaction is an important concern to practitioners.

Community integration and social role performance are rarely measured or quantified (Whiteneck, 1994). Willer, Rosenthal, Kreutzer, Gordon, and Rempel (1993) defined community integration as "effective role performance in community settings" (p. 76) and empirically identified community integration and its components, including home, social, and productivity (work, school, volunteer) integration. They developed the Community Integration Questionnaire (CIQ) as a measure of "reduced handicap," as conceptualized by the World Health Organization (WHO, 1980). This definition of handicap examines the "disadvantage" for persons with impairment or disability that interferes with the fulfillment of normal life roles. More recently, the Advisory Board of the National Center for Medical Rehabilitation Research (NCMRR) has conceptualized a classification of disability-related categories to include (a) pathophysiology, (b) impairment, (c) functional limitation, (d) disability, and (e) societal limitation (NIH, 1993). The NCMRR proposed the societal limitation category as a "legitimate and separate aspect of functional problems of disability" (NIH, 1993, p. 31). This category includes the attitudinal and structural obstacles to actualizing life roles or accessing services that would allow full social participation. It is possible that the extent of the person's integration into the community can be seen as the reduction of handicap as defined by WHO or the decrease in societal limitation as defined by NCMRR. If the degree of societal limitations or community integration can be adequately evaluated and measured, more effective interventions to reintegrate persons with disabilities into their communities as active, independent, and productive members of society can follow (Whiteneck, 1994).

Community Integration and TBI

Community integration as it relates to TBI has had relatively limited exposure in the literature. Community integration is a relatively new concept that has been emerging in rehabilitation over the past 10 to 15 years. In the past, persons with TBI were institutionalized, and their unique disabilities were not understood (Jackson, 1994). Much of the earlier literature on TBI focused on the acute stages of illness, used the medical model, and addressed recovery in terms of survival and residual neurological impairments (physical, cognitive, emotional) up to 1 year after injury (Krefting, 1989). Other studies focused on taking this information and predicting (with limited success) long-term functional outcomes (Jennett, Teasdale, & Braakman, 1976; Vogenthaler, Smith, & Goldfader, 1989).

Functional scales were developed to describe outcomes such as self-care and work performance (Krefting, 1989). These scales were not comprehensive, often addressing only one indicator of social recovery, such as work, despite other aspects of life that may be equally or more important to the person (Krefting, 1989; Oddy, Humphrey, & Uttley, 1978).

Today, as an understanding of persons with TBI grows, rehabilitation services are beginning to identify return to home and the community as the primary goals of treatment, but, unfortunately, these goals are not adequately addressed in many rehabilitation programs (Willer et al., 1994). The functional assessment and treatment approaches typical in inpatient rehabilitation settings rarely include indicators of community integration, and professionals are not adequately trained in how to improve their clients' community integration (Willer, Linn, & Allen, 1993). Emphasis is placed on physical performance and ADL and not on social dimensions (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). Willer, Rosenthal, et al. (1993) found that persons with TBI reported lower levels of integration, especially in social and productivity areas, than in the normal population.

In the occupational therapy literature, Krefting's
(1989) ethnographic study described the loss of identity that results after TBI and how it impedes fulfillment of accepted social roles. In another study, Hallett, Zasler, Maurer, and Cash (1994) concluded that 71% of all role changes after TBI were losses in major roles like worker, hobbyist, and friend. If role gains were reported, they were primarily as home maintainer, family member, and religious participant. Although Hallett et al. did not specifically use the term community integration in their article, many of the roles identified on the instrument they used, the Role Checklist (Oakley, 1982), are similar to those measured by the CIQ. Other studies in the occupational therapy literature identify the need for appropriate community-based and supported living services to address the long-term-care needs of persons with TBI (Jackson, 1994).

Subjective Well-Being and Life Satisfaction

Subjective well-being (SWB), which is considered the synonym of subjective quality of life, is referred to as a person's global judgments of his or her life experiences along a continuum ranging from positive to negative, reflecting the persons own standards rather than objective conditions, and involving cognitive and emotional components (Fuhrer, 1994; Larson, 1974; Okun, Stock, Haring, & Witte, 1984). Many definitions emphasize that SWB is a person's global evaluation of life in general and not his or her momentary mood states or feelings about specific domains of living, such as personal income (Fuhrer, 1994). The concept of SWB includes components of happiness, morale, and life satisfaction and is often used interchangeably with the concept of life satisfaction (Fuhrer, 1994). Life satisfaction is defined as an overall cognitive and global evaluation of the quality of one's life and a component of SWB (Andrews & Whitney, 1976; Campbell, Converse, & Rogers, 1976; Diener, Emmons, Larsen, & Griffin, 1985).

In the limited research that has been conducted on the well-being of persons with TBI, these persons' input is often dismissed and not sought (Condeluci, Ferris, & Bogdan, 1992). DiDonato and Schaffer (1994) explained that many researchers doubt the accuracy of conclusions drawn from life satisfaction scales completed by persons with brain injuries because their perceptions may be skewed due to cognitive impairments in areas such as judgment or self-awareness, or they may not understand the meaning of the questions being asked. However, it is important to get the perspective of persons with brain injury because they may be satisfied with their lives and their daily activities that may be contrary to what society generally believes makes a person happy (DiDonato & Schaffer, 1994). Condeluci et al. (1992) suggested that the survivor's perspective is as valid as other outcome measures and may serve to improve outcome attainment and educate service providers.

Long-term follow-ups of community integration outcomes in persons with TBI would provide information on the amount of support that may be required after injury (Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989). Long-term follow-ups are especially important with regard to TBI because of limiting cognitive impairments, late-onset behavioral problems, and unstable living arrangements that often continue to occur or worsen over time (Johnston & Hall, 1994). In support of the need to address life satisfaction issues and individual subjective assessments, NIH recommends that client perceptions of impairments and perceived health states be considered appropriate outcome measures (Whiteneck, 1994).

This study was conducted to examine the relationship of the following research questions:

1. Is there a relationship between the life satisfaction and long-term total community integration of persons with TBI?
2. Is there a relationship between life satisfaction and home integration, social integration, and productivity integration of persons with TBI?

Method

Participants

Participants were selected from among clients with TBI receiving services in a suburban, postacute, community-reentry rehabilitation program. The program provided outpatient services (individualized levels of supervision with home, community, and clinic-based intervention), supported apartment services (24-hr supervision available with home-based or community-based intervention), and group residential services (24-hr supervision provided on site with home-based or community-based intervention) to persons with TBI living in the community.

Potential participants were reviewed via medical charts and a computer database for the following inclusion criteria: 6 or more hours of coma, 8 or more years after injury, and between 21 and 60 years of age. The 30 participants meeting the criteria (11 women, 19 men) were receiving some rehabilitation services and residing in the community. Thirty-three percent lived in supported apartments, 40% lived in group residential or shared homes, and 27% were outpatients who lived with spouses or alone in homes or apartments.

Participants' ages ranged from 26 to 60 years ($M = 37$ years, $SD = 8.61$). Twenty-three were single, three married, and four divorced or widowed. Time after injury ranged from 8 to 23 years ($M = 13.70$ years, $SD = 4.05$). Participants who had had injuries at an earlier age (before 21 years) tended to have slightly greater average years after
injury. Age at injury ranged from 6 years to 47 years (M = 23.10 years, SD = 9.20). Coma length ranged from 6 hr to 3 years (M = 9.29 months, SD = 9.79).

**Instruments**

The CIQ, a 15-item instrument (Willer, Rosenthal, et al., 1993), was used to document the extent of participants’ community integration. The CIQ assesses home, social, and productivity integration as well as total community integration. It also accommodates some of the cognitive barriers resulting from TBI. The overall community integration score is a summation of the scores from the 15 individual questions and can range from 0, no integration, to 29, maximum community integration. Test–retest reliability was found to be .91 for total community integration, .93 for home integration, .86 for social integration, and .83 for productivity integration (Willer, Rosenthal, et al., 1993). The process of establishing validity has been started. A significant difference was found on the total community integration scores among persons with TBI living independently, living in a supported community situation, and living in an institution (Willer et al., 1994).

The Life Satisfaction Index-A (LSIA-A) (Neugarten, Havighurst, & Tobin, 1961), an 18-item scale, was used to document life satisfaction. This tool was originally developed as a 25-item attitude scale based on life satisfaction ratings (LSR) of (a) zest for life as opposed to apathy; (b) resolution and fortitude as opposed to resignation; (c) congruence between desired and achieved goals; (d) high psychological and social self-concept; and (e) happy, optimistic mood tone. Data analysis of the LSR was interpreted by the tool developers to provide a satisfactory degree of reliability and validity. Further psychometric development of the LSIA-A was completed by Adams (1969). He suggested dropping unreliable items; hence, the 18-item scale was used in the current study.

The LSIA-A measures global versus domain-specific life satisfaction (Fuhrer, 1994). It is one of the most widely used scales of life satisfaction and, according to Fuhrer (1994) and McDowell and Newell (1987), has demonstrated reliability and strong correlation with other indicators of life satisfaction (Lohmann, 1977). Although originally designed for older adults, it has been used recently with persons with disabilities (> 18 years of age). Fuhrer, Rintala, Harr, Clearman, and Young (1992) examined persons with spinal cord injury who were 19 to 77 years of age (M = 37 years) and found that the LSIA-A correlated with self-assessed health, social support, and perceived control. The LSIA-A was also used in examining quality of life of persons after TBI (Webb, Wrigley, Yoels, & Fine, 1995) and life satisfaction of persons with neurotrauma, including TBI (Warren, Wrigley, Yoels, & Fine, 1996).

**Procedure**

Participants were given an explanation about the purpose of the study, the procedures involved, their rights as subjects, and a consent form to sign. They completed the CIQ and the LSIA-A in a quiet room, individually and in small groups, in the presence of the researcher. The researcher assisted a few participants in understanding the questions for accurate responses. Upon completion, the questionnaires were coded to ensure confidentiality. The data were analyzed and summarized for reporting purposes.

**Results**

Preliminary descriptive statistics for the participants’ community integration (total and the three subscales) and life satisfaction appear in Table 1. Spearman rank order correlations used to determine the level of association between total community integration and life satisfaction revealed no significant relationship (rho = -.06, p = .77) (see Table 2). The results did not support the hypothesis that there is a positive relationship between the total community integration and life satisfaction of persons with TBI.

Spearman rank order correlations used to analyze the relationship of life satisfaction to home, social, and productivity integration showed a low, but significant, correlation only between social integration and life satisfaction (rho = .37, p = .047) (see Table 2). Participants with higher social integration reported a greater satisfaction with life. Therefore, the hypothesis that life satisfaction has a positive relationship to social integration was supported.

Additional analyses examined the relationship between years after injury and age at injury with community integration (total and the three subscales) and life satisfaction (see Table 3). Spearman rank order correlations yielded a low, but significant, inverse relationship between years after injury and total community integration (rho = -.38, p = .04) and social integration (rho = -.47, p = .01) specifically. The longer time since injury, the lower the community integration scores and the lower the social integration scores. For life satisfaction, the older the participant was at the time of injury, the higher the life satisfaction scores (rho = .42, p = .02).

Because previous research had differentiated CIQ scores with residential status (Willer et al., 1994), a Kruskal-Wallis one-way analysis was done to examine community integration by residential status. A significant difference (χ² = 7.93, p = .02) was found between the three residential groups on the home integration subscale scores (see Table 4). A post-hoc Mann Whitney U test revealed a significant difference (Z = -2.78, p = .01) between participants living in supported apartments (M
rank = 20.00) and a residential shared home (M rank = 9.60) on home integration subscale scores (see Table 4). The results indicated that participants living in supported apartment settings reported significantly more home integration than did participants living in residential or shared homes. Association between gender and CIQ total and subscale scores were not found.

**Discussion**

Often, emphasis has been placed on short-term rehabilitation outcomes. Little has been known about the quality of life of persons with TBI who have been living in the community for many years. The findings of this study demonstrate a low, but significant, relationship between social integration (a subtype of community integration) and life satisfaction. These results support the findings of studies by Fuhrer et al. (1992) and Heinemann and Whiteneck (1995).

The findings have implications for planning rehabilitation and support services for persons with TBI and their social network. To enhance their quality of life, program planning should focus on maximizing clients' ability for social integration with others in the community. The findings about social integration may be particularly relevant to persons with severe TBI because of possible impairments in judgment, self-awareness, social and sexual disinhibition, egocentricity, anger control, substance abuse, and other problem behaviors. These behaviors are not usually understood or accepted by the general population. Over time, many persons with TBI lose the social network they had before injury. Without the skills to develop new relationships, they may become isolated and dissatisfied with their level of social integration, potentially creating secondary psychosocial disabilities. Krefting (1989) suggested the importance of educating family members, friends, coworkers, and important others about the "fundamentals of head injury" (p. 80) in order to increase acceptance of persons with TBI and assist their adjustment to the community. Our findings would support this approach.

The social integration subscale of the CIQ includes items about visiting friends and relatives, quality of friendships, leisure activities with friends, and banking and shopping in the community. Helping persons with TBI become more independent in these areas is an appropriate treatment objective. The ability to seek and maintain social supports and self-sufficiency in the community beyond the home may be important to the person with brain injury who has lost independence in other areas.

The association found between social integration and life satisfaction is important, although causality cannot be inferred. It is possible that treatment interventions created to assist clients with TBI in developing more successful social integration skills may improve their life satisfaction, and, with higher life satisfaction, clients might be empowered to strengthen and increase their performance in similar or other community-integrated activities.

Future research might examine the influence of psychosocial variables, such as type and amount of social support, self-awareness, marital or family status, perceived control, adjustment before injury, self-perceptions of impairment and function, and acceptance of disability, as well as physiological variables, such as degree of severity and type of brain injury, on community integration and life satisfaction. Also of interest would be the degree to

<table>
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<th>SD</th>
<th>Median</th>
<th>Minimum</th>
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<td>4.50</td>
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<td>6</td>
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<tr>
<td>Life Satisfaction Index-A</td>
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<td>4.48</td>
<td>8.00</td>
<td>2</td>
<td>18</td>
</tr>
</tbody>
</table>

**Note.** N = 30.

**Table 3**

**Correlation of Age at Injury and Years After Injury With Life Satisfaction Index-A and Community Integration Questionnaire and Subscales**

<table>
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<th>Variable</th>
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<th>Years After Injury</th>
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</thead>
<tbody>
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<td>.02</td>
</tr>
<tr>
<td>Community Integration Questionnaire</td>
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<td>.75</td>
</tr>
<tr>
<td>Total community integration</td>
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<td>.75</td>
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<tr>
<td>Home integration</td>
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<td>.29</td>
</tr>
<tr>
<td>Social integration</td>
<td>-.11</td>
<td>.56</td>
</tr>
</tbody>
</table>

**Note.** N = 30.
which premorbid social skills, personality types (i.e., extrovert, introvert), and substance abuse affect postinjury social integration levels.

This study found a positive relationship between age at injury and life satisfaction. This could be an artifact due to the possibility that some of the item content of the LSIA-A may be more relevant to older persons. However, another explanation for this finding may be that the time of injury may have a differential impact on life satisfaction related to the importance of established premorbid social roles and relationships or to limited life experience and maturity level before injury.

In contrast, an inverse relationship between years after injury and both overall community integration and social integration was found. This means that the longer the time since head injury, the less overall community integration and social integration the participant reported. This lessening of community integration could be due to a variety of reasons, including shrinking social supports. Further research should reexamine this lessening of community or social integration as the time from TBI increases to determine the need for rehabilitation services at later points in community adjustment if persons with TBI are to maintain initial gains in community integration.

The negative effect of lessened community and social integration on life satisfaction may have been mediated by age at injury, with the younger participants having been more adversely affected. This suggests that developmentally appropriate programs should be designed for persons with TBI, particularly for those who did not establish themselves as autonomous beings in the community before the injury occurred.

The last finding of the study was that participants who lived in supported apartments scored significantly higher on home integration scores than those who lived in group residences or shared homes. This subscale includes items about active involvement in running a home, such as buying groceries, preparing meals, doing housework, caring for children, and planning social get-togethers, that not all participants could perform. According to Willer, Rosenthal, et al. (1993), if the person does not have an opportunity to participate in these kinds of activities in their own home or aggregate care setting, they are poorly integrated into the home. Thus, the finding may be a result of the level of functioning of the persons placed in either of these two alternative living situations or related to the structure of the living situation. According to Jackson (1994), the "empowerment school of thought" (p. 252) views supported apartments to be preferable to shared homes for persons with TBI because they are most similar to normal living situations. Others within the consumer movement believe that, for economic reasons, a shared home with 24-hr supervision is a viable alternative to a more restrictive life in an institution (Jackson, 1994). Persons in both types of supportive living programs may benefit from occupational therapy services to assist them in maximizing their home, social, and productivity integration. Further research should explore ways to help persons with TBI use their abilities to achieve higher levels of community integration.

Limitations

This study has several limitations. Because the sample received some degree of rehabilitation services, it may not be representative of all persons with TBI who either did not need or did not have the benefit of rehabilitation services. Because of the small size and nonrandom selection of the sample, generalization of the results to other persons with TBI should be done with caution.

Because the LSIA-A was originally designed for older adults, some of its questions (i.e., reviewing one's life) seem more typical for older adults than for younger adults. Future research should examine whether there is a differential content validity of this instrument for younger age groups.

Conclusion

This study explored the life satisfaction and community integration of 30 persons with TBI. A significant relationship was found between life satisfaction and social integration. Subsequent analysis was done to determine relationships between age at injury and years after injury with life satisfaction, community integration, home integration, social integration, and productivity integration. In addition, the relationship of community integration...
to residential status was examined.

The primary finding of this study underscores the importance of the social aspect of community integration to the quality of life of persons with TBI. Implications for occupational therapy practice include the need for rehabilitation programs to provide persons with TBI with more effective strategies to develop social integration skills, educate family members and friends about head injury to facilitate acceptance of the person with TBI into the community, and to provide long-term assistance with community and social integration. Rehabilitation programs will need to take care in assisting persons with TBI to select residential settings that best match their abilities and that provide appropriate levels of support within a real-life milieu in which community integration can be maximized.

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References

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