

# A Survey of Very-Long-Term Outcomes after Traumatic Brain Injury among Members of a Population-Based Incident Cohort

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## Abstract

To assess quality of life and barriers to participation in vocational and community life for persons with traumatic brain injury (TBI) over the very-long term, a population-based cohort was identified in Olmsted County, Minnesota; 1623 individuals were identified as having experienced a confirmed TBI while a resident of Olmsted County, Minnesota, during the period from 1935–2000. A survey was sent to eligible individuals that included elements of standardized instruments addressing health status and disability, and questions that assessed issues important to successful social reintegration after TBI. Of 1623 eligible participants sent surveys, 605 responded (37% response rate). Thirty-nine percent of respondents were female and 79% had mild injuries. Mean age at injury was 30.8 years, and mean years since injury was 28.8. Overall, respondents reported living in the community; the majority were married and had achieved education beyond high school. Problems with memory, thinking, and physical and emotional health were most often reported. Respondents reported low levels of depression and anxiety, and high levels of satisfaction with life. Seventy-three percent of respondents reported no problems that they attributed to their TBI. Increasing injury severity was associated with a significant risk of reporting injury-related problems at survey completion. Respondents with a longer time since injury were less likely to report any TBI-related problems. These results indicate that self-reported outcomes and adaptation to impairment-related limitations improve as the time since injury increases. These findings highlight the importance of providing coordinated medical rehabilitation and community-based support services to promote positive outcomes over the life span after TBI.

**Key words:** data collection; rehabilitation; time factors

## Introduction

**T**RAUMATIC BRAIN INJURY (TBI) is associated with significant mortality in the acute period (Brown et al., 2004; Kraus et al., 1984; Masson et al., 1997; Thurman et al., 1999; Vazquez-Barquero et al., 1992). However, the life expectancy for those surviving beyond this early phase appears to be similar to that of other persons of the same age and sex (Brown et al., 2004; Chamberlain, 1995; Wiederholt et al., 1989), except among the most severely injured (Baguley et al., 2000; Shavelle et al., 2001; Strauss et al., 1998). Aging of the U.S. population will not only put increasing numbers of people at risk for fall-related TBI, but preserved life expectancy for those

surviving TBI has created a growing population of individuals aging with TBI-related activity limitations, and potential restrictions to participation in social roles.

Recent interest and investigation related to outcomes after TBI over the very-long term has indicated that individuals and families may adapt better than expected in the decades following serious injury (Wood, 2008). Studies using self-reported population-based data concerning psychosocial outcome and quality of life with data obtained by mailed survey in Copenhagen up to 15 years after injury ( $n = 257$ ) have shown that only 2% of responders lived in nursing homes at follow-up; 63–84% were in expected educational or vocational situations; and 95% found their life as a whole at follow-up

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good or at least acceptable (Engberg and Teasdale, 2004). Lasting cognitive problems were more limiting than physical problems in these respondents. It was also found that a longer duration of follow-up was associated with fewer reports of diminished quality of family and social relationships. However, the scores for general well-being in the subgroup of responders with cerebral lesions showed substantial levels of dysfunction (Teasdale and Engberg, 2005).

Outcome studies beyond 10 years are dominated by samples of individuals with moderate to severe or severe injuries, who are interviewed and have some form of psychometric assessment. Some investigators have found relatively good outcomes in the long term using these more objective measures. However, problem areas—most commonly in the cognitive and behavioral realms—are more prominent than in self-reported samples. Wood and Rutterford reported outcomes a mean of 17 years after severe injury in 56 patients, assessed both by a rating scale and by responses to mailed-in questionnaire. Seventy-two percent required no supervision; 41% were employed, and none were in residential care. Only slight decreases in functional competency and life satisfaction ratings were reported, with mild levels of anxiety and normal ratings for mood compared to those reported by non-disabled patients (Wood and Rutterford, 2006b). Lewin and associates (Lewin et al., 1979) reported that severe physical or mental disabilities were uncommon in a sample of 291 individuals followed for between 10 and 25 years after severe head injury, using descriptive measures of neurophysical and mental disability, though only 49% were reported to have recovered. Eighteen percent of the sample was either totally or severely disabled. A study of 306 individuals with moderate to severe TBI identified in a retrospective cohort and interviewed on average 14 years after injury showed that 88% were independent in activities of daily living, and that their physical function scores were comparable to non-injured norms (Colantonio et al., 2004). Objective measures of cognitive performance in the study population showed significant impairment that primarily limited instrumental activities of daily living. A smaller sample of 58 patients followed for 10 years in Chile, with no specified injury severity classification, showed that 69% were employed at follow-up, with 87.5% returning to their previous workplace (Franulic et al., 2004). Compared to groups of subjects followed for 2 and 5 years, the group followed for 10 years showed the highest educational level, the highest job re-insertion level, and the highest level of work satisfaction. A recent report of a convenience sample of 60 patients with the spectrum of injury severity studied using the Glasgow Outcome Scale-Extended and psychometric testing, seen an average of 10.58 years after injury, showed that 52% of the sample experienced good recovery, with 5% of the sample rated in poor outcome categories (Ponsford et al., 2008). At follow-up, 62% of the sample was employed or full-time students, and 62% were married. A report of cognitive performance spanning 16 years after moderate to severe injury, while confirming the presence of long-term cognitive impairment, showed no signs of intellectual decline that would be expected to affect psychosocial outcome (Wood and Rutterford, 2006a). A longitudinal study of psychometric performance repeated 30 years after injury in 61 patients representing the spectrum of TBI severity, showed that they performed at a lower level than controls in all areas at follow-up, with 56% of the sample

declining over the 30-year study period (Himanen et al., 2006).

Even for the most severe TBI, there is evidence showing substantial positive changes many years after injury. In a study that included 40 permanently impaired individuals followed 15 years after injury, half of the sample who could not be left alone 2 years or more after injury eventually became independent (Thomsen, 1984). Other investigators have reported small samples of individuals interviewed 10 years after severe injury, and showed that recovery continues and adaptability improves throughout this period (Sbordone et al., 1995), and that despite poor functional outcome, satisfaction with life can be relatively good, with 73% of one sample reporting rather high satisfaction with life in general (Koskinen, 1998).

Studies of outcome after TBI are numerous, yet synthesizing this information into a generally meaningful sense of how individuals fare over time is confounded by highly variable research samples and analytical approaches. Samples often lack representativeness of the entire spectrum of injury severity, sex, and age. Individuals who survive moderate-to-severe TBI can acquire significant neurological and other impairments reported to be associated with high unemployment (Keyser-Marcus et al., 2002; Kreuzer et al., 2003), as well as significant activity limitations, restrictions to participation, and social isolation, during the 5–10 years following injury (Dawson and Chipman, 1995; Hawthorne et al., 2009). Age, sex, and socio-economic factors including education have been reported to affect outcome after TBI in the long term (Farace and Alves, 2000; Keyser-Marcus et al., 2002; Marquez de la Plata et al., 2008). A significant minority of individuals who experience less severe TBI can also acquire long-term impairment (Hessen et al., 2007).

Given the wide variation of samples and sample characteristics that currently exist in the literature, the goal of this study was to survey a population-based cohort of individuals with TBI, whose injuries occurred during the period from 1935–2000 in Olmsted County, Minnesota, to understand their quality of life, and the barriers they experienced to participation in the workforce and community life. This is the first population-based study of this type conducted in the United States; the only similar prior study was conducted in Denmark. This provided the first opportunity to study outcome after TBI over the very-long term, in a large population-based cohort that includes uniquely large numbers of people over age 55 years and women, representing the spectrum of injury severity, and for whom the date of first TBI and injury severity were objectively documented.

## Methods

### Study setting

Olmsted County, Minnesota (2000 census population, 124,277), provides a unique opportunity for investigating the natural history of TBI (Annegers and Coan, 2000; Annegers et al., 1980a, 1980b, 1998; Brown et al., 2004; Chandra et al., 1989; Flaada et al., 2007; Grabow et al., 1984; Malec et al., 2007; Nelson et al., 1984; Nemetz et al., 1999; Wiederholt et al., 1989; Williams et al., 1991). Rochester, the county seat, is approximately 80 miles from the nearest major metropolitan area, and is home to one of the world's largest private medical centers, the Mayo Clinic. The Mayo Clinic and its two affiliated hos-

pitals together with Olmsted Medical Center (OMC), a second group practice and its affiliated hospital, provide nearly all of the medical care delivered to local residents. Since 1907, every Mayo Clinic patient has been assigned a unique identifier, and all information from every contact (including office, emergency department, nursing home visits, and hospital inpatient or outpatient admissions) is contained within a single dossier for each patient. The detailed information includes medical history, all clinical assessments, consultation reports, surgical procedures, dismissal summaries, laboratory and radiology results, correspondence, death certificates, and autopsy reports. The diagnoses assigned at each visit are coded and entered into continuously updated computer files (Melton, 1996). Under the auspices of the Rochester Epidemiology Project (REP), the diagnostic index and the medical records linkage were expanded to include the few other providers of medical care to local residents, including OMC and the few private practitioners in the area, thereby linking the medical records for community residents. The REP provides the capability for population-based studies of disease risk factors, incidence, and outcomes that is unique in the United States (Melton, 1996).

#### Study sample

These REP resources were previously used to construct a population-based cohort consisting of Olmsted County residents with confirmed TBI that occurred during the years 1935 through 1984 (Annegers and Coan, 2000; Annegers et al., 1980a). The original cohort was expanded and extended from 1985 to 2000 (Brown et al., 2004; Flaada et al., 2007; Malec et al., 2007). The original cohort (1935–1984) was limited to persons for whom there was documented evidence of loss of consciousness (LOC), post-traumatic amnesia (PTA), brain contusion, intracranial hematoma, or skull fracture. In the original cohort, injuries were divided into three levels of severity. “Severe” included persons with documented brain contusion (as diagnosed by computed tomography, observation during surgery, or focal neurological symptoms), intracranial hematoma, or 24 h or more of documented LOC or PTA. “Moderate” included persons who did not meet these criteria, but for whom there was documented LOC of 30 min to 24 h or a skull fracture. “Mild” included persons without skull fracture who had LOC or PTA from momentary to less than 30 min. Individuals for whom their clinical diagnosis was based on history alone (i.e., who did not present for medical care for either the event or for sequelae) were excluded. With the most recent update (1985–2000), the definition of TBI was expanded to include persons with possible brain injury (i.e., those without documented LOC or PTA, but who exhibited neurological or neuropsychological signs and symptoms consistent with brain dysfunction following head injury). This process led to the development of a new classification system for TBI injury severity (Malec et al., 2007). Criteria for the Mayo Classification System for TBI Injury Severity are listed in Table 1. After the survey process was complete, injury severity was determined for all responders and non-responders using the Mayo System. For the purposes of this study, injury severity for all cases was classified as either moderate to severe (definite), or mild (probable). No cases classified as symptomatic (possible) were included in this analysis.

TABLE 1. MAYO CLASSIFICATION SYSTEM FOR TBI INJURY SEVERITY

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- A. Classify as moderate to severe (definite) TBI if one or more of the following criteria apply:
1. Death due to this TBI
  2. Loss of consciousness of 30 min or more
  3. Post-traumatic anterograde amnesia of 24 h or more
  4. Worst Glasgow Coma Scale full score in first 24 h < 13 (unless invalidated upon review, e.g., attributable to intoxication, sedation, or systemic shock)
  5. One or more of the following is present:
    - Intracerebral hematoma
    - Subdural hematoma
    - Epidural hematoma
    - Cerebral contusion
    - Hemorrhagic contusion
    - Penetrating TBI (dura penetrated)
    - Subarachnoid hemorrhage
    - Brainstem injury
- B. If none of criteria A apply, classify as mild (probable) TBI, if one or more of the following criteria apply:
1. Loss of consciousness of momentary to less than 30 min
  2. Post-traumatic anterograde amnesia of momentary to less than 24 h
  3. Depressed, basilar, or linear skull fracture (dura intact)
- C. If none of criteria A or B apply, classify as symptomatic (possible) TBI, if one or more of the following symptoms are present:
1. Blurred vision
  2. Confusion (mental state changes)
  3. Dazed
  4. Dizziness
  5. Focal neurological symptoms
  6. Headache
  7. Nausea
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TBI, traumatic brain injury.

#### Data collection and measurement

Assessment by questionnaire is a common method to gather information about health status and quality of life from large populations for medical and epidemiological research, and has been shown to be a valid tool to assess outcomes for people with TBI and their significant others (Bohnen et al., 1994; Dombrovsky and Olek, 1997; Hellawell et al., 2000; Martin et al., 2001; Masson et al., 1997; Stancin et al., 2002). The survey used in this study was developed in consultation with the Mayo Clinic Survey Research Center, the Injury and Violence Prevention Unit of the Minnesota Department of Health, and the members of the Mayo Clinic TBI Regional Advisory Council. It incorporates elements of the pilot Minnesota Traumatic Brain Injury questionnaire used by the Minnesota Department of Health, the first Injury Control and Risk Survey (ICARIS) conducted by the Centers for Disease Control and Prevention in 1994, the disability module from the Behavioral Risk Factor Surveillance System instrument (Centers for Disease Control and Prevention, 2001), the Satisfaction With Life Scale (Diener et al., 1985), and items culled from responses by members of the Mayo Clinic TBI Regional Advisory Council.

The mailed survey included 22 questions, beginning with whether the responder—as a result of their injury—experienced problems or difficulties in the areas of school,

employment, marital status, personal relations, living arrangements, memory/thinking, physical health, and emotional health. Respondents were asked to rate problems as mild, moderate, or severe. Additional questions addressed whether responders were limited by injury-related impairments, needed help from others, or used special equipment because of their injury. The survey requested information about the individual's current living situation, marital status, and whether it had changed since injury, and the highest level of education achieved. Work status both at the time of injury and at the time of survey response was requested, as well as current wage for those employed, and whether the responder felt they had ever lost their job because of their injury. The survey contained detailed questions about current mood, and whether responders had noticed a change in their use of chemicals.

In this way, the survey incorporated elements of standardized instruments that address health status and disability, including questions that address issues important to successful social reintegration after TBI in the long term, that were identified as meaningful by persons with TBI in our community, and persons who provide community services.

#### Procedure

This research was approved by the Mayo Clinic Institutional Review Board. Individuals who had declined authorization of the use of their medical records for research were excluded from review (Melton, 1997). In order to be eligible for the present study, we required that individuals had a Mayo Clinic identifier; of REP TBI cases from 1935–2000 with moderate to severe (definite) or mild (probable) TBI, more than 95% had such an identifier. The survey, letter of explanation, consent form, and postage-paid return envelope were mailed to all eligible subjects who were not identified as deceased following review. If no response was received in 1 month, another packet was mailed. If no response was received within the following month, a third and final packet was sent.

#### Statistical analysis

Descriptive summaries are reported as mean  $\pm$  standard deviation (SD) for continuous variables such as age at injury

and time since injury. Categorical variables such as gender, cause of TBI, and patient characteristics reported in the survey instrument were summarized as frequencies and percentages. Demographic and injury severity characteristics between survey responders and non-responders were compared at baseline using Wilcoxon's rank-sum test, chi-square test, or Fisher's exact test, as appropriate. Among the responders, comparisons between mild versus moderate-to-severe groups for responses to various items in the survey instrument were made in a similar manner.

Further analysis using logistic regression models and adjusting for gender and age at injury was performed. The number of TBI-related problems (none versus any) was used as an outcome of interest in this analysis. TBI injury severity (mild versus moderate to severe) and years since injury were included as potential predictor variables. Interaction effects between TBI injury severity and years since injury were also assessed. The magnitude of associations was reported as odds ratio (OR) and 95% confidence interval (CI).

#### Results

Of 1717 surveys mailed, 94 were returned because we were previously unaware that the subject had died, or because the address was incorrect and no forwarding address was available. Of the 1623 potentially eligible subjects 605 individuals responded (37% response rate). Demographic and injury characteristics of responders and non-responders are listed in Table 2. Female respondents represented 39% of the sample. The mean age at injury was 30.8 years and mean years since injury was 28.8. Mild injury represented 79% of the cases. Motor vehicle and motorcycle collisions were the most common injury cause. For each comparison in Table 2, the differences between responders and non-responders reached statistical significance; however, with the exception of distribution by injury severity, the numeric differences appear relatively minor.

Of the 605 responders, 93% completed the survey by themselves. The responder characteristics at the time of injury were compared between mild and moderate-to-severe cases. There were no significant differences in either sex or age at injury (data not shown). However, a significant difference

TABLE 2. DEMOGRAPHIC AND INJURY CHARACTERISTICS OF RESPONDERS COMPARED TO NON-RESPONDERS.

	Responders	Non-responders	p Value
Number (%)	605 (37)	1018 (63)	
Sex: Male, no. (%)	370 (61)	685 (67)	0.013
Age at injury, years, mean ( $\pm$ SD)	30.8 ( $\pm$ 12.9)	28.1 ( $\pm$ 11.1)	<0.001
Time since injury, years, mean ( $\pm$ SD)	28.8 ( $\pm$ 10.8)	27.2 ( $\pm$ 10.3)	0.003
Injury severity, no. (%)			<0.001
Mild	479 (79)	875 (86)	
Moderate to severe	126 (21)	143 (14)	
Cause of TBI, no. (%)			<0.001
Fall	91 (15)	143 (14)	
MVC and motorcycle	333 (55)	567 (56)	
Recreational <sup>a</sup>	115 (19)	125 (12)	
Other <sup>b</sup>	66 (11)	183 (18)	

<sup>a</sup>Bicycle, snowmobile, or other recreation.

<sup>b</sup>Occupational, assault, gunshot, or other.

MVC, motor vehicle collision; TBI, traumatic brain injury.

was detected for injury cause ( $p=0.002$ ). Among the four cause of injury categories, the 333 injuries due to MVC and motorcycle accidents accounted for 52% of mild and 67% of moderate-to-severe injury; the 115 injuries due to recreational causes accounted for 22% of mild and 10% of moderate-to-severe injuries (data not shown).

Table 3 summarizes the characteristics of the responders at the time of injury with respect to level of productive activity. The comparison between mild and moderate-to-severe cases was limited to a comparison between full-time/part-time employed, full-time/part-time student, volunteer/homemaker, and unemployed. The categories "retired" and "retired/disability" were not included in the comparison. In this analysis, there was no difference between mild and moderate-to-severe injuries ( $p=0.72$ ).

Tables 4, 5, 6, and 7 summarize responder characteristics at the time of survey completion. A significant difference was detected for time since injury when comparing respondents with mild versus moderate-to-severe injuries (Table 4). Though statistically significant, this difference may lack clinical relevance. Overall, 97% of respondents reported living in the community (outside of institutional settings such as assisted-living or skilled care), the majority were married, and more than 70% of respondents reporting having achieved education beyond high school.

Table 5 shows that 61% of the sample was currently employed. When compared with Table 3, the percentage of respondents reporting they were unemployed was 2% at the time of injury and 3% at the time of survey completion. Comparing responders who experienced mild injuries to those who experienced moderate-to-severe injuries, comparable percentages reported working exclusively full time at the time of injury (60.8% mild and 65.9% moderate to severe), and at the time of survey (44.1% mild and 38.9% moderate to severe). At the time of survey completion, over 60% of the sample reported earnings greater than \$30,000 annually. No difference was detected in productive activity or current annual wage when comparing mild versus moderate-to-severe cases.

Table 6 summarizes responses about current problems related to injury and chemical use. Problems with memory and thinking were most often reported (22% of the sample), followed by physical and emotional health (both 12%). Problems with physical and emotional health were reported significantly more often in respondents who experienced moderate-to-severe injuries compared to mild injuries. Other than prescription medicines, less than 10% of respondents reported increasing their use of chemicals since their injury.

TABLE 3. PRODUCTIVE ACTIVITY OF RESPONDERS AT THE TIME OF INJURY

Number (mild, moderate to severe)	605 (479, 126)
Type of activity, no. (% of 600 responding)	
Full-time/part-time employed, no. (%)	453 (76)
Full-time/part-time student	91 (15)
Retired	13 (2)
Retired due to disability	1 (<1)
Unemployed	12 (2)
Volunteer/homemaker	30 (5)

Survey responses to questions concerning mood and quality of life are summarized in Table 7, showing generally low levels of self-reported depression and anxiety, and generally high levels of satisfaction with life.

Table 8 summarizes respondent's reports of problems and limitations, and whether they attributed them to their TBI. Sixteen percent of respondents reported that their activity was limited at survey completion, with just over half of those respondents attributing these limits to their injury. Less than 10% of the sample reported yes to either currently needing help, using special equipment, or ever losing a job because of their injury. Compared to individuals with mild injury, individuals with moderate-to-severe injury responded significantly more often that they currently had limitations or needed help. However, this difference by injury severity did not reach statistical significance when respondents were asked whether these limitations and need for help were attributed to TBI. Seventy-three percent of respondents

TABLE 4. NUMBER AND CHARACTERISTICS OF RESPONDERS AT THE TIME OF SURVEY: TIME SINCE INJURY AND CURRENT LIVING ARRANGEMENT, MARITAL STATUS, AND EDUCATION

Number (mild, moderate to severe)	605 (479, 126)
*Time since injury, years, mean ( $\pm$ standard deviation)	28.8 ( $\pm$ 10.8)
Current living arrangement, no. (% of 603 responding)	
Alone	101 (17)
Alone with caregiver visits	3 (<1)
Spouse/partner/roommate	452 (75)
Family members	33 (5)
Assisted living	8 (1)
Nursing home	3 (<1)
Other	3 (<1)
Current living arrangement meets needs, no. (% of 560 responding)	
Yes	537 (96)
Current marital status, no. (% of 563 responding)	
Single	36 (6)
Married	391 (69)
Cohabitation	24 (4)
Separated	6 (1)
Divorced	69 (12)
Widowed	36 (6)
Other	1 (<1)
Highest level of school completed, no. (% of 603 responding)	
$\leq$ 8 years	13 (2)
9-11 years	24 (4)
General Educational Development (GED)	8 (1)
High school diploma	132 (22)
Post-high school	239 (40)
Bachelor's degree	124 (21)
Master's degree	43 (7)
Doctoral degree	18 (3)
Other	2 (<1)

\* $p=0.025$  for mild ( $28.4 \pm 10.7$  years) versus moderate to severe ( $30.0 \pm 11.6$  years) using the Wilcoxon rank sum test; no statistically significant differences were found when comparing the mild versus moderate to severe groups for any other responses (data available on request).

TABLE 5. CHARACTERISTICS OF RESPONDERS AT THE TIME OF SURVEY: CURRENT PRODUCTIVE ACTIVITY AND CURRENT ANNUAL WAGE

Number (mild, moderate to severe)	605 (479, 126)
Current productive activity, no. (% of 601 responding)	
Full-time or part-time employed	366 (61)
Full-time or part-time student	4 (1)
Retired	168 (28)
Retired due to disability	26 (4)
Unemployed	20 (3)
Volunteer/homemaker	17 (3)
Current annual wage, no. (% of 306 responding)	
0\$-<\$10K	32 (10)
\$10-29K	80 (26)
\$30-49K	87 (28)
≥\$50K	107 (35)

No statistically significant differences were found when comparing the mild versus moderate to severe groups for these responses (data available on request).

reported no TBI-related problems, with a significantly higher percentage of respondents with mild injuries reporting no problems compared to respondents who experienced moderate-to-severe injuries.

Additional analysis of factors associated with risk for reporting any problems was completed using multivariable logistic regression modeling, adjusting for age at injury and sex. Characteristics of particular interest were injury severity and time since injury. There was no significant interaction between injury severity and time since injury. Patients with moderate-to-severe injuries were 2.2 times more likely to report at least one TBI-related problem. An odds ratio of 0.97 for the variable “years since injury” suggests that respondents who had a longer time interval from injury to survey completion were less likely to report any TBI-related problems.

**Discussion**

Results of this survey represent the spectrum of self-reported TBI-related experiences over the long term among eligible residents of Olmsted County who first experienced a confirmed moderate-to-severe or mild TBI during the years 1935 to 2000. The findings indicate that most respondents report generally faring well 29 years, on average, after their injury. While it is likely that many respondents are aging with acquired impairments related to their injury, this impairment does not appear to limit activities or restrict participation in personal or social roles for the majority of the sample. However, these data do identify substantial differences in responders with moderate-to-severe injury compared to those with mild injury, in the realms of activity limitations, the need for help from others, the use of special equipment, cognitive limitations, physical and emotional health, and experiencing any TBI-related problems. No substantial difference between injury severity groups was reported in the realms of living arrangements, marital status, education, productive activity, income, mood, or quality of life.

These findings confirm previously reported population-based survey data indicating very low levels of need for skilled care living, high percentages of expected educational

TABLE 6. CHARACTERISTICS OF RESPONDERS AT THE TIME OF SURVEY: PROBLEMS OR DIFFICULTIES RELATED TO INJURY, CURRENT CHEMICAL USE, AND CHANGE SINCE INJURY

Number (mild, moderate to severe)	605 (479, 126)
Ever experienced problems or difficulties with:	
School, yes, no. (% of 472 responding)	36 (8)
Employment, yes, no. (% of 568 responding)	53 (9)
Marital status, yes, no. (% of 557 responding)	27 (5)
Personal relations, yes, no. (% of 581 responding)	54 (9)
Living arrangements, yes, no (% of 575 responding)	24 (4)
Memory/thinking, yes, no.* (% of 583 responding)	128 (22)
Physical health, yes, no.** (% of 581 responding)	68 (12)
Emotional health, yes, no.*** (% of 582 responding)	71 (12)
Current use of chemicals, change since injury	
Alcohol, no. (% of 592 responding)	
Never used	106 (18)
Less	179 (30)
Same	258 (44)
More	49 (8)
Tobacco, no. (% of 591 responding)	
Never used	263 (45)
Less	175 (30)
Same	110 (19)
More	43 (7)
Prescription medications, no. (% of 588 responding)	
Never used	157 (27)
Less	35 (6)
Same	205 (35)
More	191 (32)
Drugs of abuse, no. (% of 584 responding)	
Never used	497 (85)
Less	41 (7)
Same	30 (5)
More	16 (3)

\*p = 0.013 for mild 91 (20) versus moderate to severe 37 (31).

\*\*p = 0.001 for mild 43 (9) versus moderate to severe 25 (21).

\*\*\*p = 0.011 for mild 48 (10) versus moderate to severe 23 (19).

and vocational activity, and high levels of life satisfaction over a decade after TBI (Engberg and Teasdale, 2004; Teasdale and Engberg, 2005). The results indicating an inverse relationship between time since injury and reporting TBI-related problems in this analysis (Table 9) also provide further evidence that recovery after TBI is a dynamic process, and that outcomes continue to improve for the majority of individuals the longer they survive (Engberg and Teasdale, 2004; Franulic et al., 2004; Sbordone et al., 1995; Teasdale and Engberg, 2005; Thomsen, 1984; Wood, 2008). These findings are also consistent with numerous reports indicating that cognitive impairment and emotional health are more commonly reported than is physical impairment in the long term after TBI (Hoofien et al., 2001; Powell et al., 2001; Wood, 2008).

TABLE 7. CHARACTERISTICS OF RESPONDERS AT THE TIME OF SURVEY: MOOD AND QUALITY OF LIFE

Number (mild, moderate to severe)	605 (479, 126)
Mood in preceding 2 weeks	
Sad, blue, or depressed, no. (% of 595 responding)	
Not at all or a little bit	465 (78)
Moderately	81 (14)
Quite a bit or extremely	49 (8)
Worried, tense, or anxious, no. (% of 591 responding)	
Not at all or a little bit	446 (76)
Moderately	86 (15)
Quite a bit or extremely	59 (10)
Trouble with getting enough sleep, no. (% of 589 responding)	
Not at all or a little bit	432 (73)
Moderately	79 (13)
Quite a bit or extremely	78 (13)
Healthy and full of energy, no. (% of 591 responding)	
Not at all or a little bit	177 (30)
Moderately	176 (30)
Quite a bit or extremely	238 (40)
Current quality of life	
In most ways, my life is close to ideal, no. (% of 593 responding)	
Slightly to strongly agree	414 (70)
The conditions of my life are excellent, no. (% of 597 responding)	
Slightly to strongly agree	412 (69)
I am satisfied with my life, no. (% of 596 responding)	
Slightly to strongly agree	447 (75)
I've gotten important things I want in life, no. (% of 593 responding)	
Slightly to strongly agree	477 (80)
If I could live life over, I'd change nothing, no. (% of 593 responding)	
Slightly to strongly agree	357 (60)

No statistically significant differences were found when comparing mild versus moderate-to-severe injury severity for these responses. The analyses between mild and moderate-to-severe cases were conducted using five categories for mood (not at all, a little bit, moderately, quite a bit, and extremely), and three categories for quality of life (strongly to slightly disagree, neither agree nor disagree, strongly to slightly agree).

These study results differ in some respects from other reports of long-term outcome after TBI. Compared to our findings, a greater degree of diminished well-being was reported by Teasdale and Engberg; this difference could reflect the more detailed, sensitive, and specific quality-of-life measure used (European Brain Injury Questionnaire; Teasdale and Engberg, 2005). A lower percentage of subjects employed at follow-up has been reported by others (40% versus 61% reported here; Colantonio et al., 2004); however, 73% of that sample (mean age at injury 30 years, mean years to follow-up 14) reported that their job met their income needs. Difficulties related to anxiety, depression, and quality of life have been reported to be less commonly favorable compared to the self-reported results detailed here (Franulic et al., 2004). A recent cross-sectional follow-up telephone survey study of aging in individuals hospitalized for rehabilitation after TBI showed

that increasing years post-injury predicted declines in physical and cognitive function, as well as declines in societal participation (Sendroy-Terrill et al., 2010). This contrasts with our finding that the longer the time since injury, the less likely individuals are to report any TBI-related problems. This may relate to different sample characteristics, as the telephone survey was limited to those individuals who received inpatient rehabilitation. However, the relationship between injury severity and self-reported outcome reported here is consistent with the findings of the telephone survey, and we believe that the impact of problems related to aging with TBI may not be as dramatic as anticipated.

Significant psychiatric symptomatology has also been reported in a convenience sample of 76 individuals followed an average of 14 years after severe injury with standardized measures of psychiatric symptomatology, and physical and social functioning (Hoofien et al., 2001). Though the sample is described at follow-up as experiencing permanent difficulties in all realms, long-term psychiatric problems, loneliness, and social withdrawal were most prominent. Physical independence and daily functioning were reported to be largely normal at follow-up, with 60% of the sample employed. These differences in self-reported psychological and psychiatric symptoms compared to those described in the present study are likely due to the difference between a convenience sample of severe cases and a population-based cohort.

Other investigators have reported distinctly unfavorable long-term outcomes after TBI. Using Canadian national health and activity survey data from self-identified cases of TBI, and personal interviews a mean of 13 years after injury ( $n = 454$ ), Dawson and Chipman reported that 66% of the sample required some form of assistance for activities of daily living, 75% were unemployed, and 90% reported dissatisfaction with social integration (Dawson and Chipman, 1995). Isolated single males with limited income represented the sample profile. Differences between the Canadian study findings and those presented here likely relate to the differences in sample characteristics and survey methods. In the report by Dawson and Chipman, subjects were self-identified, lacking classification of injury severity or other confirmatory data from their medical records. The survey was comprehensive, including 552 variables, with 12% of the interviews conducted by proxy, and the survey response rate was much higher (90%) than the 37% reported here.

A limitation of the present study is that the modest response rate of 37% may have biased the survey sample. We observed statistically significant (but generally numerically small) differences between responders and non-responders. Responders were more likely female, were older at injury, had a longer time since injury, and were more severely injured compared to non-responders. However, these differences were unlikely to affect our overall conclusion of generally positive outcomes. Comparison between respondents and non-respondents revealed that a significantly greater percentage of respondents experienced moderate-to-severe than mild injuries. And among respondents, those who experienced moderate-to-severe injuries were more likely to report any TBI-related problems than those who experienced mild injuries. These factors may indicate that the results of reported problems overestimate their actual occurrence in the population. Further, studying self-reported outcomes over decades after an incident TBI adds recall bias to survey responses that

TABLE 8. CHARACTERISTICS OF RESPONDERS AT THE TIME OF SURVEY: ACTIVITY LIMITATIONS, NEED FOR HELP, USE OF SPECIAL EQUIPMENT, LOSS OF JOB, PROBLEMS, AND WHETHER THE CHARACTERISTIC WAS RELATED TO TRAUMATIC BRAIN INJURY (TBI)

	Total	Mild	Moderate to severe	p Value for comparing mild versus moderate to severe
Current activity limitations: <sup>a</sup> no. responding "yes," no. responding (%)	97, 602 (16)	62, 477 (13)	35, 125 (28)	<0.001
For subjects responding "yes," are limitations related to TBI?	52, 89 (58)	28, 55 (51)	24, 34 (71)	0.080
No. responding "yes," no. responding of those responding "yes" to above (%)				
Current need for help: <sup>b</sup> not needed before injury: no. responding "yes," no. responding (%)	53, 600 (9)	34, 474 (7)	19, 126 (15)	0.005
For subjects responding "yes," is need for help related to TBI?	28, 53 (53)	16, 34 (47)	12, 19 (63)	0.44
No. responding "yes," no. responding of those responding "yes" to above (%)				
Ever had to use special equipment <sup>c</sup> because of injury: No. responding "yes," no. responding (%)	31, 599 (5)	16, 473 (3)	15, 126 (12)	<0.001*
Ever lost job due to injury: no. responding "yes," total no. responding (%)	21, 575 (4)	13, 458 (3)	8, 117 (7)	0.053**
Number of TBI-related problems				0.001***
No problems: no., total no. responding (%)	434, 593 (73)	360, 471 (76)	74, 122 (61)	
Any problem: no., total no. responding with 1–8 problems (%)	159 (27)	111 (24)	48 (39)	
1–2 problems, no. (% of no. responding with problems)	92 (58)	66 (59)	26 (54)	
3–4 problems, no. (% of no. responding with problems)	26 (16)	15 (14)	11 (23)	
5–6 problems, no. (% of no. responding with problems)	25 (16)	16 (14)	9 (19)	
7–8 problems, no. (% of no. responding with problems)	16 (10)	14 (13)	2 (4)	

<sup>a</sup>Activity limitations because of physical, mental, or emotional problems.

<sup>b</sup>Help from another person.

<sup>c</sup>Cane, wheelchair, special bed, or telephone.

\*p-value: for responding yes versus no (eliminating "not sure" responses, which were 3% of total responses).

\*\*p-value: for responding yes versus no (eliminating "not sure" responses, which were 6% of total responses).

\*\*\*p-value: calculated comparing no problems versus any (1–8 problems).

may have affected the accuracy of the results. Persistent injury-related or otherwise acquired cognitive impairments during the interval since injury, including limited self-awareness at the time of survey completion, may also have limited response validity. The cross-sectional sample used in this study did not contain a control group, so the survey results cannot be compared to a non-injured population.

The socio-demographic characteristics of the community from which this sample was surveyed may also limit how the findings relate to other communities. In 2000, residents in Olmsted County were 90.3% white, compared to 75.1% for the total U.S. population. The demographics of Olmsted County are otherwise similar to those for the state of Minnesota, the upper Midwest, and the U.S. white population. However, compared to the demographic characteristics of the total U.S. population, Olmsted County has a higher median per capita income (\$24,939 versus \$21,587 total U.S.), and a lower percentage of residents below the poverty line (6.4% versus 9.2%). A higher percentage of Olmsted County residents have high school or greater educations (91.1% versus 80.4% total U.S.), and bachelor's or graduate degrees (34.7% versus 24.4%). In addition, Olmsted County has a large tertiary multi-specialty medical center with a coordinated system of care, serving individuals with all medical diagnoses and

conditions, including acquired disorders of brain function due to injury or disease. Although no single community can ever completely represent the entire U.S. population, these factors may limit how these results can be generalized to communities with a different demographic profile and community-based services. Higher levels of income and education, as well as better access to health care, suggest that the outcomes reported here may be optimal and not representative of less-advantaged populations. The moderate-to-severe group of respondents includes survivors who experienced TBI an average of almost 29 years previously. This may be a remarkably

TABLE 9. FINAL MULTI-VARIABLE MODEL OF RISK FACTORS FOR EXPERIENCING ANY TBI-RELATED PROBLEMS

Parameter	Odds ratio	95% Lower CI	95% Upper CI	p Value
Moderate to severe	2.21	1.44	3.41	<0.001
Years since injury	0.97	0.95	0.99	<0.001
Age at injury	1.00	0.98	1.01	0.51
Male	0.95	0.65	1.40	0.81

TBI, traumatic brain injury.

resilient group, many of whom survived very serious injuries prior to the development of rapid and advanced emergency medical care systems.

These results represent the overall self-reported outcomes over multiple decades following TBI for mild and moderate-to-severe cases, uniquely contributing to outcome reporting of the spectrum of experiences after TBI within a community. They confirm that the most common self-reported persistent problems in the long term after moderate-to-severe TBI relate to cognitive function and associated limitations, and physical and emotional health. Consistent with the spectrum of TBI severity, a substantial majority of responders experienced a mild injury, had few problems or limitations, little need or use of support services, and had appropriate employment activity. These results contribute to the growing body of evidence indicating that self-reported outcomes and adaptation to impairment-related limitations seem to improve as the time since injury increases. These findings may also inform clinicians who counsel the families and significant others of those surviving injury in the acute phase, that recovery—though often slow—can continue over the lifespan with progressive improvement. This further highlights the importance of providing coordinated medical rehabilitation and community-based support services to promote positive outcomes over the very long term post-TBI.

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