

# Longitudinal Follow-Up of Patients with Traumatic Brain Injury: Outcome at Two, Five, and Ten Years Post-Injury

Jennie L. Ponsford,<sup>1–4</sup> Marina G. Downing,<sup>1,2</sup> John Olver,<sup>4,5</sup> Michael Ponsford,<sup>4</sup> Rose Acher,<sup>4</sup>  
Meagan Carty,<sup>2,4</sup> and Gershon Spitz<sup>1,2</sup>

## Abstract

The deleterious consequences of traumatic brain injury (TBI) impair capacity to return to many avenues of pre-morbid life. However, there has been limited longitudinal research examining outcome beyond five years post-injury. The aim of this study was to examine aspects of function, previously shown to be affected following TBI, over a span of 10 years. One hundred and forty one patients with TBI were assessed at two, five, and 10 years post-injury using the Structured Outcome Questionnaire. Fatigue and balance problems were the most common neurological symptoms, with reported rates decreasing only slightly during the 10-year period. Mobility outcomes were good in more than 75% of patients, with few participants requiring aids for mobility. Changes in cognitive, communication, behavioral, and emotional functions were reported by approximately 60% of the sample at all time points. Levels of independence in activities of daily living were high during the 10-year period, and as many as 70% of subjects returned to driving. Nevertheless, approximately 40% of patients required more support than before their injury. Only half the sample returned to previous leisure activities and fewer than half were employed at each assessment time post-injury. Although marital status remained stable over time, approximately 30% of participants reported difficulties in personal relationships. Older age at injury did not substantially alter the pattern of changes over time, except in employment. Overall, problems that were evident at two years post-injury persisted until 10 years post-injury. The importance of these findings is discussed with reference to rehabilitation programs.

**Key words:** functional outcome; structured outcome questionnaire; traumatic brain injury

## Introduction

MANY STUDIES have examined long-term functional outcome following traumatic brain injury (TBI).<sup>1–5</sup> Changes in neurological, physical, cognitive, and behavioral functioning are common, although considerable variability is evident, which is influenced by the severity of the brain injury.<sup>6–12</sup> While some of these changes resolve within the first six months after injury, some have been shown to persist for many years.<sup>10,13,14</sup>

Understanding long-term outcome is important as TBI most commonly occurs in young adults who survive for decades in societies that tend to equate disability with the elderly or developmentally disabled.<sup>15</sup> While most of the research has been cross-sectional or retrospective in design, several prospective longitudinal studies have assessed participants with TBI on two or more occasions, documenting symptoms and/or changes in functional status (see Table 1.<sup>2,3,16–23</sup> Studies of serial cognitive testing

are beyond the scope of this paper and have not been reviewed). The results of these studies indicate that there is gradual improvement in functional outcome in terms of capacity for independent living and functioning in daily activities, work, or leisure activities; however, this is at a lower level than pre-injury functioning.<sup>2,14,17,23</sup> Reporting of some adverse symptoms, including headache, dizziness, and fatigue, generally decreases over time post-injury.<sup>17,18,23</sup> Conversely, other symptoms, such as irritability and being bothered by noise, are reported more often at later time periods.<sup>17</sup> Based on the reporting of changes by relatives, Brooks and colleagues<sup>16</sup> found increased reporting of behavioral problems between one and five years after injury.

Also of relevance in the context of longitudinal outcome studies is the potential impact of age. Although the majority of individuals sustaining moderate to severe TBI are younger than 30, there is a proportion who are older. A number of studies have shown that older age at injury—particularly age older than 50—results in poorer

<sup>1</sup>School of Psychology and Psychiatry and <sup>5</sup>School of Medicine, Monash University, Melbourne, Australia.

<sup>2</sup>Monash-Epworth Rehabilitation Research Centre, Epworth Healthcare, Melbourne, Australia.

<sup>3</sup>National Trauma Research Institute, Melbourne, Australia.

<sup>4</sup>Epworth HealthCare, Melbourne, Australia.

functional outcomes and greater cognitive impairments.<sup>19,21,22,24,25</sup> However, there has been no clear evidence of accelerated decline over time post-injury associated with older age at injury.<sup>24,26</sup>

Two previously published studies from our research group examined changes in function at two<sup>4</sup> and five years<sup>19</sup> following TBI. Even though these cohorts had received rehabilitation, a proportion continued to report various neurological symptoms, decreased mobility, relationship and communication issues, need for supervision or assistance in activities of daily living (ADLs), and the presence of cognitive, behavioral, and emotional changes at each of the follow-up time points.

Although these previous studies have highlighted areas of significant functional disability, as well as areas where gradual improvement might be expected, there has been limited prospective examination of functional outcome over periods of more than five years following injury. Those studies that have examined outcome longitudinally over long periods of time, such as studies by Thomsen<sup>22,30</sup> and Tate and colleagues,<sup>21,31</sup> have tended to focus on severely injured samples. While illuminating, these studies may present a pattern of outcome that does not necessarily generalize to less severe injuries—for example, where post-traumatic amnesia duration is shorter than one month—and which represent the majority of individuals with TBI. Another small study of 20 individuals with severe TBI by Sbordone and colleagues<sup>5</sup> relied on relatives to retrospectively rate the status of their injured family member at two, five and 10 years post-injury, reporting progressive improvements over time across most dimensions. However, the accuracy of recollection of the experience and status of an injured relative over such long periods is likely to be limited. There also may be a tendency to work to demonstrate that progress has been made over time. Some other limitations of previous studies include their focus on only one aspect of functional outcome<sup>14</sup> and inclusion of different numbers of participants completing each follow-up time point.<sup>2</sup>

The aims of the current study were to extend the findings of our research group's two previously published studies<sup>4,19</sup>—based on the reports of those injured—to 10 years post-injury. Using a longitudinal design, functional outcome was examined across a broad range of areas in a cohort of the same individuals followed up at two, five, and 10 years following their injury. Given the extended time frame of follow-up, which introduced the potential for age-related changes, comparison was made of outcomes reported by those older than 50 at the time of injury with those age 50 or younger.

## Methods

### Participants

Individuals with complicated mild-to-severe TBI were recruited from consecutive admissions to a TBI rehabilitation center in the context of a no-fault accident compensation system. Participants were recruited between the years 1985 and 2002. They had all received inpatient rehabilitation, during which they typically received 3–5 h daily of physiotherapy, occupational therapy and speech therapy, neuropsychological assessment, and social work services. This was generally followed by outpatient or community-based rehabilitation, with continuing therapy as needed, as well as support for return to work (with funded work trials) and study (with funding for integration aides or tutoring support). There also was funding for home help and attendant care support for as long as needed. These individuals received therapy services over an average nine-month period, although there was considerable variability according to individual needs. They all had been routinely invited

to attend a follow-up clinic at one year and two, three, five, and 10 years post-injury. There were 141 patients who attended follow-up at two, five and 10 years post-injury. This group was the focus of the current study.

Sixty-one percent of the sample were men, with a mean age at time of injury of 34.91 years (standard deviation [SD], 16.07) and mean education of 11.29 years (SD, 2.43). This group included 28 participants who were older than 50 at time of injury, of whom 16 were 61 years or older with the oldest being 73. Participants had a median GCS of 5 (interquartile range, 5; range, 3–15) and a mean post-traumatic amnesia (PTA) duration of 35.75 days (SD, 38.68; range, 0–182). Classifying injury severity based on duration of PTA resulted in 2.8% of the sample being classified as mild (<24 h), 23.4% as moderate (1–7 days), 29.8% as severe (8–28 days) and 44% as very severe (>28 days). When this was compared between the younger (50 or younger) and older (older than 50) age groups, the younger group had a mean PTA duration of 39.53 days (SD, 40.63) and the older age group had a mean PTA duration of 20.5 days (SD, 24.7). Injury severity based on Glasgow Coma Scale (GCS) scores resulted in 10.2% of the sample being classified as mild, 12.7% as moderate, and 77.1% as severe. Only 1.42% of the sample was classified as having complicated mild TBI, while no one was classified as mild on both PTA and GCS. Prior to injury, 46.8% of participants were single/never married, 42.5% were married or de facto, 6.5% were separated or divorced, and 4.3% were widowed. At the time of injury 61% of participants were employed full-time, 5% were employed part-time, 7.1% were unemployed, 14.9% were not in the labor force, 5.7% were secondary students, and 6.4% were tertiary students.

The current sample of 141 participants was compared to hospital patients with TBI who did not attend follow-up at all of the two-, five-, and 10-year time points ( $n = 1261$ ). They did not differ significantly in terms of gender ( $\chi^2[1, N = 1402] = 5.51; p > 0.05$ ), years of education ( $t[1263] = 1.24; p > 0.05$ ), or duration of PTA ( $t[1373] = 1.21; p > 0.05$ ). However, the patients who did not attend follow-up at all these time points were significantly younger in age (mean, 31.17; SD, 15.31;  $t[1393] = 2.74; p < 0.01$ ), and had higher GCS scores (mean, 7.37; SD, 4.16;  $t[155] = -2.66; p < 0.01$ ).

### Materials

Participants completed the Structured Outcome Questionnaire<sup>4</sup> at each of the follow-up assessments. The responses reported in this paper are based on self-report by the person with TBI.

### Structured Outcome Questionnaire

The Structured Outcome Questionnaire addresses domains of functioning previously shown to undergo change following TBI, including changes to neurological functioning, mobility, cognition, behavior, communication, emotional state, independence in personal, domestic and community activities of daily living, leisure activities, employment, and relationship status.

The neurological complaints section documents presence of increased epilepsy, headaches, dizziness, balance difficulties, physical fatigue, vision, smell, or hearing since the injury. Mobility was rated on an eight-point scale from 1 (confined to bed) to 8 (previous level). The cognitive, behavioral, communication, and emotional domains assessed included changes in memory, planning and problem-solving, concentration, speed of thinking, mental fatigue, initiative, self-centeredness, irritability, impulsivity, socially inappropriate behavior, difficulty making speech understood, following conversation, and thinking of words, as well as levels of depression and anxiety. Responses were rated as change present or absent relative to pre-injury.

Independence in personal (e.g., feeding, dressing, grooming), light domestic, heavy domestic, and community (shopping and financial management) activities of daily living were rated on a six-point

TABLE 1. SUMMARY OF LONGITUDINAL STUDIES EXAMINING FUNCTIONAL OUTCOME FOLLOWING TRAUMATIC BRAIN INJURY

Study	No. of subjects	Time assessed following TBI	Measures	Results
Brooks and colleagues (1986) <sup>16</sup>	Relatives of 42 participants with severe TBI (age range, 16–60 years)	Two: 1 year, 5 years	Structured interview of close other	<ul style="list-style-type: none"> <li>At both 1 year and 5 years, behavior problems most frequently reported by relatives</li> <li>Changes in personality reported by more relatives at 5 years (74%) than at 1 year (60%). Similar increase over time in threats of violence (from 15% to 54%)</li> <li>Number of physical, emotional and subjective difficulties similar at 1 year and 5 years; language disturbance, level of dependence and memory problems increased slightly over time; and disturbed behavior increased greatly over time</li> </ul>
Dikmen and colleagues (1993) <sup>17</sup>	31 participants with moderate-to-severe TBI (age range, 15–60 years), and 102 friend controls (age range not given; mean age, 24 years)	Three: 1 month, 1 year, 2 years	SIP, HISC, FSI, structured interview	<ul style="list-style-type: none"> <li>Ambulation, mobility and self-care as measured by the FSI improved from 1 month to 2 years post-injury</li> <li>Of those living independently pre-injury, only 9% were living independently at 1 month post-injury, 50% at 1 year and 68% at 2 years (significantly fewer than controls)</li> <li>None had returned to work 1 month post-injury, 30% at 1 year and 46% at 2 years (significantly fewer than controls)</li> <li>Self earnings declined post-injury, with 70% of participants reported as financially independent 1 year and 2 years post-injury</li> <li>While 26% reported dysfunction on the SIP at 1 month post-injury, this dropped to 10% at both 1 year and 2 years post-injury</li> <li>Percentage reporting symptoms of headache, fatigue, bothered by light, and difficulty concentrating decreased from 1 month to 1 year and again to 2 years post-injury. Being bothered by noise and irritability were reported more often from 1 month to 1 year to 2 years post-injury</li> </ul>
Dikmen and colleagues (2010) <sup>18</sup>	732 participants with mild-to-severe TBI (age range not given; mean age, 31 years), 120 trauma controls (age range not given; mean age, 31 years)	Two: 1 month, 1 year	Symptom Checklist	<ul style="list-style-type: none"> <li>The rates of symptom reporting decreased from 74% at 1 month post-injury to 53% at 1 year for the TBI group</li> <li>There were between 4–18% of adults with TBI who reported symptoms at 1 year post-injury but not at 1 month post-injury</li> </ul>
Grauwmeijer and colleagues (2012) <sup>2</sup>	113 participants with moderate-to-severe TBI (age range not given; mean age, 33 years)	Seven: Pre-injury, 3 months, 6 months, 12 months, 18 months, 24 months, 36 months	Employment outcome, FIM, BI, FAM used as predictors	<ul style="list-style-type: none"> <li>Employment rate dropped from 80% pre-injury to 15% at 3 months and then increased to 55% at 3 years</li> </ul>
Olver and colleagues (1996) <sup>19</sup>	103 participants with moderate-to-severe TBI (age range, 11–69y)	Two: 2 years, 5 years	SOI	<ul style="list-style-type: none"> <li>Between 2 and 5 years, there was an increase in independence in personal, domestic and community ADL and the use of transport</li> <li>There was a higher incidence of cognitive, behavioral and emotional changes reported at 5 years than at 2 years</li> <li>32% of those employed at 2 years were not employed at 5 years</li> </ul>
Pagulayan and colleagues (2006) <sup>3</sup>	133 participants with mild-to-moderate TBI (age at least 14 years), 111 general trauma patients, 87 healthy friend controls (age range, 15–60 years)	Four: 1 month, 6 months, 12 months, 3–5 years	SIP	<ul style="list-style-type: none"> <li>There was an improvement from 1 month post-injury to 6 months post-injury in the physical domain, with a smaller improvement observed for the psychosocial domain</li> </ul>

TABLE 1. (CONTINUED)

Study	No. of subjects	Time assessed following TBI	Measures	Results
Sigurdardottir and colleagues (2009) <sup>20</sup>	115 participants with mild-to-severe TBI (age range, 16–55 years)	Two: 3 months, 12 months	GOSE, FSS	<ul style="list-style-type: none"> <li>• There was a significant time effect on the GOSE, with higher scores at 12 months, compared with at 3 months</li> <li>• 37% of the sample were employed at 3 months and this significantly increased to 68% at 12 months</li> </ul>
Tate and colleagues (2005) <sup>21</sup>	68 participants with severe TBI (age range at injury, 15–43 years)	Two: 6 years, 23 years	CHART, SPRS-C, semi-structured interview	<ul style="list-style-type: none"> <li>• Mobility: 85.3% were independent at 6 years post injury, but only 75% were independent at 23 years post injury</li> <li>• High rates of independence in self-care (81%) were observed at both time-points</li> <li>• Employability: 45.5% were employed at 6 years, while only 33.8% were employed at 23 years</li> <li>• 36.8% had good relationships at 6 years post-injury, with this increasing to 45.6% at 23 years post-injury</li> <li>• 54.4% had good living skills at 6 years post-injury, with this increasing to 61.8% at 23 years post-injury</li> </ul>
Thomsen (1984) <sup>22</sup>	40 participants with extremely severe TBI (age range, 14–44 years)	Two: 2.5 years, 10–15 years	Questionnaire	<ul style="list-style-type: none"> <li>• Place of living: Many more participants were living alone at 10–15 years post-injury (<math>n=17</math>) than at 2.5 years post-injury (<math>n=2</math>)</li> <li>• 22.5% were married at 2.5 years; 15% were married at 10–15 years</li> <li>• Motor impairment: Motor impairment was initially present in all participants, but 10 had recovered from all symptoms by 2.5 years post-injury. This remained the same at 10–15 years post-injury</li> <li>• Dependence: 24 participants were dependent at 2.5 years post-injury and this decreased to 12 participants at 10–15 years post-injury</li> <li>• Communication: 16 participants had aphasia at 2.5 years post-injury. This decreased to 4 at 10–15 years post-injury. The same number of participants (<math>n=15</math>) had dysarthria at both follow-up time points</li> <li>• Employment: 15% were employed full-or part-time at 2.5 years and 12.5% at 10–15 years; 93% received disablement pension at the 10–15 year time point</li> <li>• Psychosocial sequelae: Major loss of social contact and decline in family relationships. Decline in reporting of some problems from 2.5 years to 10–15 years: poor memory, changes in personality and emotion, childlessness, emotional lability, disturbed behavior, poor concentration, and slowness. For other problems, reporting increased at the second follow-up: irritability, restlessness, loss of social contact, spontaneity, tiredness, sensitivity distress and lack of interests</li> <li>• Work capacity: 9 participants (22.5%) were either in full-time, part-time, or paid sheltered work at 2.5 years post-injury, with slightly more participants (<math>n=12</math>) working at 10–15 years post-injury (30%)</li> </ul>
van der Naalt and colleagues (1999) <sup>23</sup>	67 participants with mild-to-moderate TBI (age range, 15–64 years)	Four: 1 month, 3 months, 6 months, 12 months	HISC, RTW	<ul style="list-style-type: none"> <li>• The percentage of those reporting dizziness, poor concentration and slowness decreased with each follow-up time-point (i.e., over time)</li> <li>• The percentage of those reporting alcohol intolerance increased over time</li> <li>• At 12 months post-injury, 73% had returned to work, though 84% still reported complaints, such as headaches, irritability, forgetfulness, poor concentration, and fatigue</li> </ul>

TBI, traumatic brain injury; SIP, Sickness Impact Profile; HISC, Head Injury Symptom Checklist; FSI, Function Status Index; FIM, Functional Independence Measure; BI, Barthel Index, used to assess independence; FAM, Functional Assessment Measure; SOI, Structured Outcome Interview; ADL, activities of daily living; GOSE, Glasgow Outcome Scale-Extended; FSS, Fatigue Severity Scale; CHART, Craig Handicap and Reporting Technique; SPRS-C, Sydney Psychosocial Reintegration Scale-categorical version; RTW, return to work, as measured on a 4-point scale (0=previous work or study resumed, 1=previous work or study resumed, but with lower demands or part time; 2=previous work or study not resumed, different work or significantly lower level; 3=not working).



scale: 1 = total dependence; 2 = dependence (minimal participation); 3 = dependence (active participation); 4 = minimal assistance only; 5 = supervision only; 6 = independence with or without aids. Driving ability was rated on a four-point scale; specifically, 0 = no, 1 = not eligible (e.g., too young, suspended license), 2 = not driving for other reasons, 3 = able to drive with modifications to car or license conditions, and 4 = able to drive without restrictions. Independence in use of public transport was recorded on a four-point scale: 0 = not applicable (e.g., from country), 1 = not able to use, 2 = limited use of public transport (e.g., assistance required), and 3 = independent use of public transport. Changes in leisure activities was rated on a four-point scale, ranging from 1 = return to no previous leisure activities to 4 = return to all previous leisure activities. Participation in leisure activities after the injury was recorded as yes or no. Current marital status, difficulties in personal relationships, and getting on with friends also were recorded. Level of support from close others, compared with pre-injury, was rated on a three-point scale (more support, same support, or less support). Employment status was recorded as non-vocational (injury too severe or still in rehabilitation), employed (including full-time and part-time work, work trials and work experience), student or not in the labor force (e.g., homemaker, retired, maternity leave).

Scores on the Glasgow Outcome Scale-Extended (GOSE)<sup>32</sup> were recorded at 10 years post-injury. Using a structured questionnaire, the GOSE assesses outcome on an eight-point scale: 1 = dead; 2 = vegetative; 3 = lower severe disability; 4 = upper severe disability; 5 = lower moderate disability; 6 = upper moderate disability; 7 = lower good recovery; and 8 = upper good recovery.

### Procedure

Ethical approval for this study was obtained from the Epworth Hospital Human Research Ethics Committee. Individuals with TBI were invited to participate in the study and provided with a full written explanation of the study at the time of inpatient rehabilitation admission and again at each follow-up. Following consent, participants with TBI completed the Structured Outcome Questionnaire with their consulting doctor or a member of the research team (in person, over the phone, or via mail). Demographic and injury-related information was obtained from interview with participants and, with their permission, from medical records.

### Data Analysis

All analyses were conducted with SPSS v20.0 (IBM Corp., Armonk, NY). Frequency distributions were computed for all the variables at each follow-up assessment. However, frequencies for the GOSE were examined only at 10 years due to incomplete data at the other time points. Where responses were dichotomous, proportions across time were compared using Cochran's Q test analysis. The alpha level was adjusted using Bonferroni correction according to the number of statistical tests conducted for each section (e.g., neurological complaints; eight categories;  $0.05/8 = 0.01$ , etc.). In addition, all of the results were stratified by duration of PTA into mild, moderate, severe, and very severe injury severity groups. PTA, rather than GCS, was used to stratify individuals as 77% of the cohort had GCS of 3 to 8, and some studies have suggested that PTA is more strongly related to longer-term outcomes<sup>32,33</sup>

## Results

### Neurological complaints

The percentage of participants reporting neurological complaints is shown in Figure 1. Approximately 7% of the sample developed epilepsy over the 10-year follow-up period. About a third experienced persistent dizziness, headaches, visual disturbance and re-

duced sense of smell, with a non-significant trend towards a decline in dizziness and visual disturbance over time. Balance problems were reported by more than 60% of the sample at two years post-injury, which was significantly different over the 10-year period, (40.4% at five years and 55% at 10 years;  $\chi^2 = [2] = 9.19$ ;  $p = 0.01$ ). Fatigue was the most common complaint, reported by over 70% of the sample; however, the percentage reporting fatigue tended to decrease from two to five years and then again from five to 10 years. Neurological complaints by individuals with mild TBI tended to decrease over time. Dizziness and problems with smell were not reported beyond two years post-injury. Headaches and difficulties with balance were not reported beyond five years post-injury. However, those with moderate-to-very-severe TBI continued to report neurological complaints up to 10-years following injury. Participants age 50 or younger at injury were more likely to report headaches overall but there were no other significant age-related differences in symptom reporting. Participants who were older than 50 at the time of injury did not report more neurological complaints over time than those who were younger than 50.

### Mobility

There was little change in the level of mobility for participants across time post-injury (Fig. 2). More than 55% of participants had high mobility at two, five, and 10 years post-injury, with no significant differences between the younger and older age groups. Only a small proportion (0.8%) had low mobility at two years post-injury, which increased slightly but not significantly to 6.1% at 10 years post-injury. Those individuals moving into the low mobility category included five participants age 50 or younger and three participants older than 50 at time of injury. Those moving into low mobility also tended to have severe or very severe TBI. All individuals with mild TBI reported high mobility throughout the 10 years.

### Cognition, behavior, emotion, and communication

A high proportion of the sample reported the presence of changes in cognition, communication, behavior, and emotional state. More than 60% of participants reported memory problems and more than 50% reported difficulty concentrating, slowed thinking, cognitive fatigue, and word-finding difficulties. There were no significant differences in the percentage of participants who reported these changes over time (see Fig. 3). Problems with planning, initiative, self-centeredness, and impulsivity were reported by 25–45% of the sample. However, there was an increase in the percentage of participants reporting problems with planning from two to five years and from five years to 10 years post-injury (predominantly from the group age 50 or younger at the time of injury), as well as with inappropriate social behavior, having their speech understood by others, and following conversation. The increase in reporting largely stemmed from individuals who had severe and very severe TBI. Irritability was a common problem, reported by more than two thirds of the sample, although the frequency of reported irritability declined somewhat over the 10-year period. Those who were age 50 or younger were more likely to report injury-related changes in speed of thinking, cognitive fatigue, self-centeredness, irritability, impulsivity, and inappropriate social behavior than those older than 50. Those older than 50 did not report more cognitive changes over time relative to those who were younger, apart from a trend to report increased cognitive fatigue. Almost half of the group reported being more anxious and/or more depressed, compared with before their injury. This

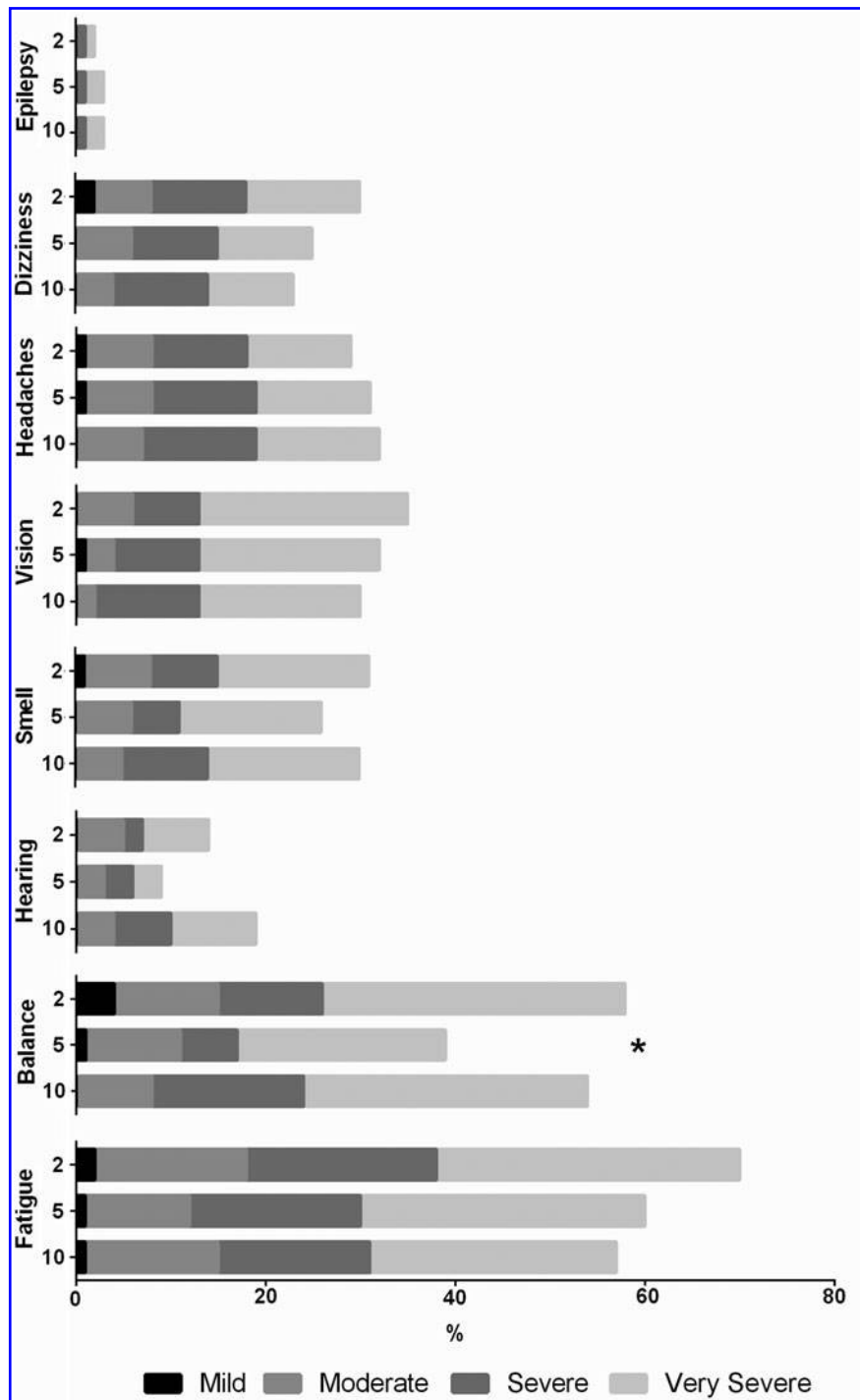


FIG. 1. Neurological complaints at each year post-injury.

proportion declined only slightly over time and did not differ significantly according to age.

Daily functioning

The vast majority (more than 95%) were independent in personal activities. There was an increase in the percentage of participants who reported independence in light domestic activities over time post-injury, predominantly in individuals with moderate severity of injury (see Fig. 4). Approximately 30% of the sample required

some assistance in heavy domestic activities, and approximately 20% required assistance with shopping. Independence in financial activities increased from 77.8% at two years to 85.1% at five years, but then decreased to 70.2% at 10 years post-injury. This decline was evident in both younger and older participants. There were no overall differences in younger versus older participants in independence in personal, domestic, or community ADLs.

With regard to use of transport, more than 50% of participants reported returning to driving without restrictions at two years post-injury, with this increasing to approximately 70% at the five year

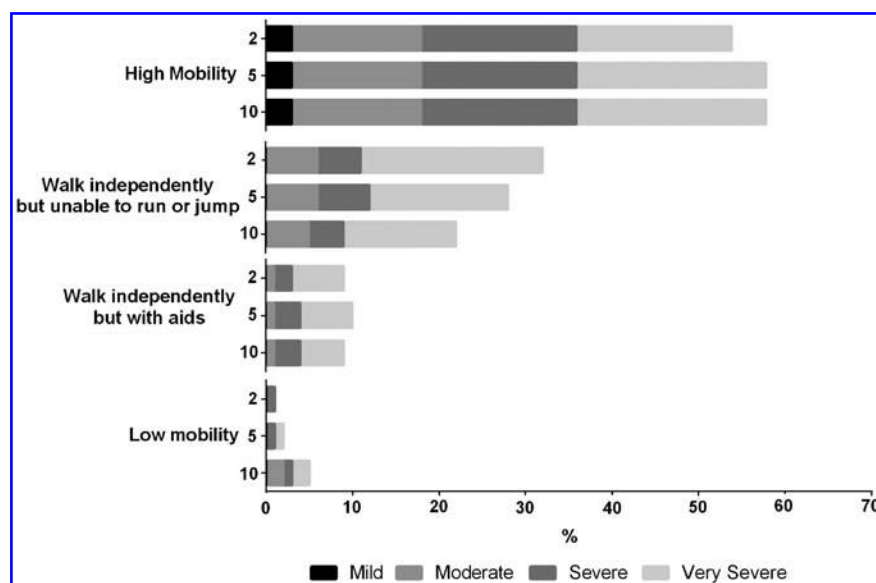


FIG. 2. Mobility at each time point post-injury.

and 10 year post-injury time points. The proportion of participants older than 50 at the time of injury who returned to driving was lower (50.7%) than that of the younger age group (69.6%). Approximately 80% of the sample reported independent use of public transport at each of the follow-up time points. However, there was a small decline in independence in use of public transport and in driving, which was confined to participants older than 50 at time of injury.

Figure 5 shows that only about half of the sample had returned to all or most of their previous leisure interests at two years post-injury, although this percentage increased at five years post-injury. There was some decrease in participation in leisure activities by 10 years post-injury, evident in both the younger and older age groups with moderate to very severe injuries. By 10 years post-injury, none of the participants with mild TBI reported this as a problem.

#### Relationship issues

Of the participants with TBI who were married or in a de facto relationship prior to injury, 13.6% were separated, divorced, or widowed at two years post-injury, 22.4% at five years, and 20.4% at 10 years. Of those who were single prior to injury, 10.9% were married or in a de facto relationship two years post-injury, 22.2% at five years, and 29.2% at 10 years post-injury. The marital status of participants at each time point following TBI is shown in Figure 6.

The proportion of participants who reported difficulty in personal relationships and getting on with friends increased over time (see Fig. 7). Between 41% and 47% reported having lost friends or becoming more socially isolated since the injury. Approximately 40% of participants reported requiring more support than before the injury, with the proportion not decreasing greatly over time. Those age 50 or younger were more likely to report requiring more support than prior to injury than those older than 50. However, as is evident from Figure 7, the increase in reporting of difficulties in relationships, as well as with friends, was largely evident in those with severe and very severe injury severity. Similarly, individuals with mild TBI ceased to report need for additional support by 10 years post-injury. However, participants with moderate-to-very-severe TBI continued to reported need for additional support up to 10 years post-injury.

#### Employment and study

Prior to the injury, 66% of the sample indicated that they had been employed. Although a minority of participants reported having returned to their pre-injury employment on a full-time basis (28.4% at two years, 17.6% at five years, and 11.8% at 10 years), others were employed in alternative duties with the same or different employer (7.4% at two years, 18.6% at five years, and 11.8% at 10 years) and an increased proportion were working part-time (12.8% at two years, 11.1% at five years, and 19.0% at 10 years). Overall, 40% of participants returned to open employment in some capacity and this percentage did not change significantly over time. A significantly lower proportion of participants older than 50 were employed after injury. The proportion of participants by employment status is given in Figure 8. Rates of being non-vocational and unemployed decreased over time, with a concomitant increase in individuals reporting they were no longer in the labor force. These individuals generally had moderate to very severe TBI.

Of those studying or employed prior to injury, 53.2% were studying or employed at two years, 50.1% at five years, and 49.9% at 10 years. Of those studying or employed at two years ( $n=60$ ), 71.67% were studying or employed at five years and 68.33% at 10 years. Fewer participants were studying at five and 10 years, with only those with very severe injuries studying at the 10 year time point. A proportion of these appear to have dropped out of the workforce—either to retire or engage in home-making activities. These individuals were predominantly those older than 50 at time of injury. Conversely, of those not studying or employed at two years ( $n=76$ ), 18.42% were studying or employed at five years and 25.0% at 10 years.

#### GOSE at 10 years

Figure 9 displays overall GOSE scores at 10 years post-injury. There was a wide range of outcomes. Individuals with severe and very severe injury largely represent the group of individuals with vegetative, lower severe disability, or upper severe disability. Younger participants were overrepresented in the vegetative or lower severe disability categories, compared with older individuals.

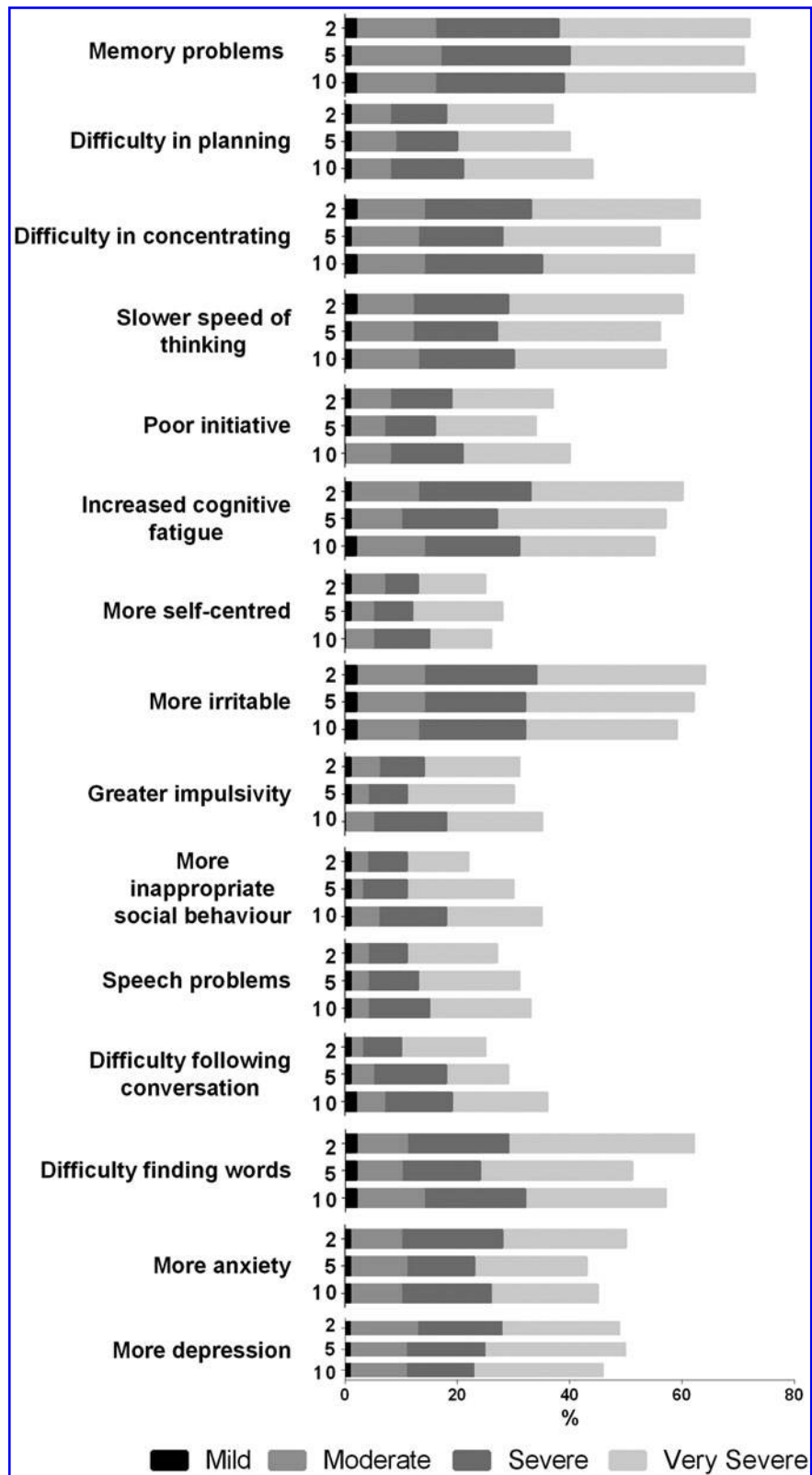


FIG. 3. Cognitive, behavioral, emotional, and communication changes that were present for participants at each time point post-injury.



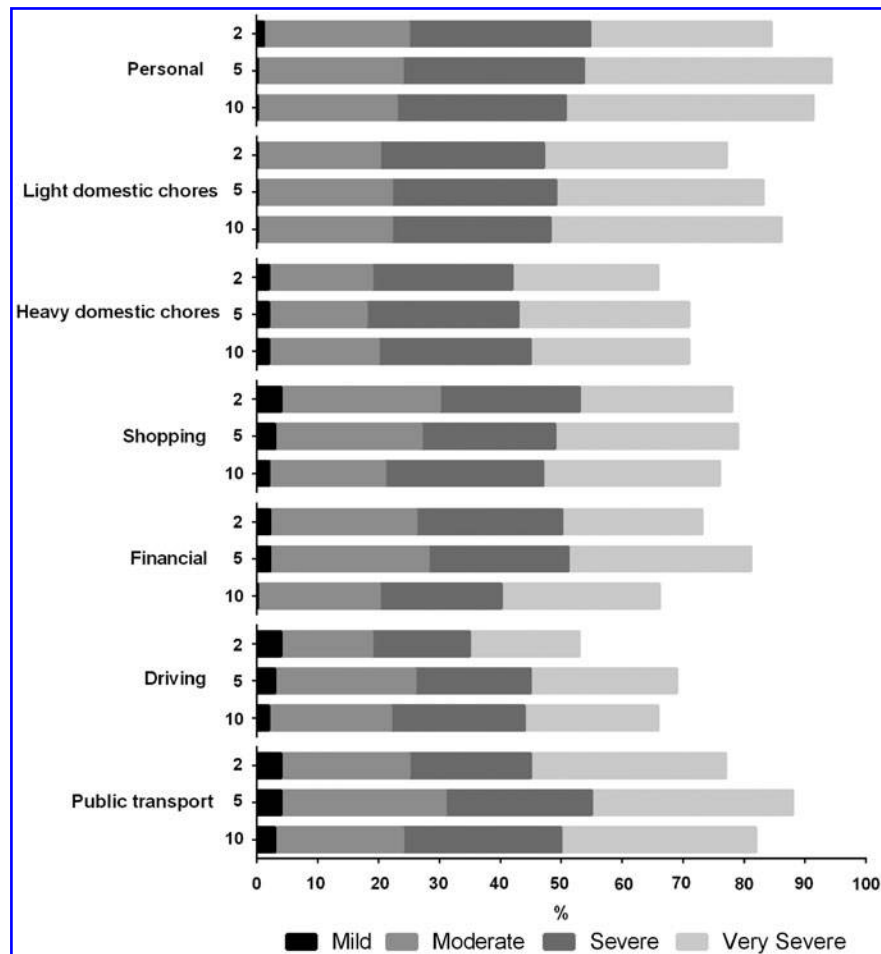


FIG. 4. Independence in activities of daily living at each time point post-injury.

Conversely, 61.8% of older individuals showed lower or upper good recovery, compared with 40.2% of younger individuals.

## Discussion

This is one of the first reports of longitudinal comparisons of functional outcome over 10 years in a sample across the spectrum of moderate-to-very-severe TBI. It has highlighted a number of the

key problems associated with these injuries that persist over many years.

Problems with fatigue and balance were the most common neurological symptoms reported by these participants with predominantly moderate-to-very-severe injuries, although they diminished to a small degree over the 10 years. Fewer individuals with mild TBI tended to reported neurological symptoms over the 10 years following TBI. Balance problems likely contributed to the

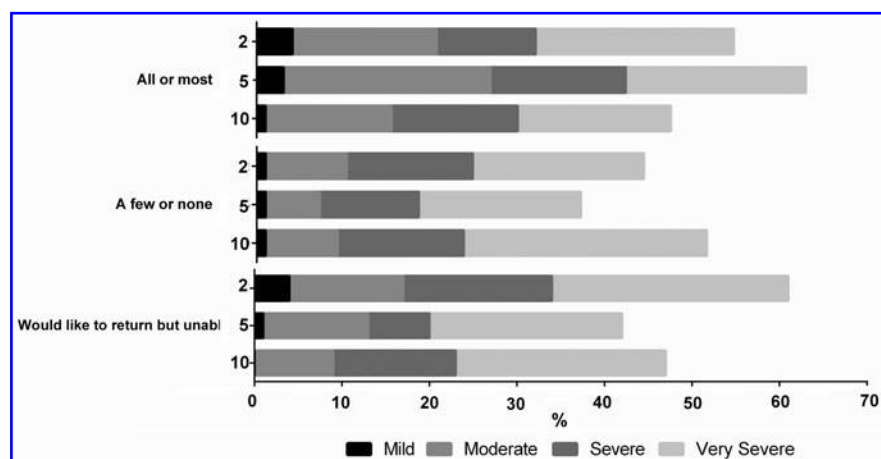


FIG. 5. The proportion of participants returning to leisure activities following their TBI (% of sample who responded Yes).

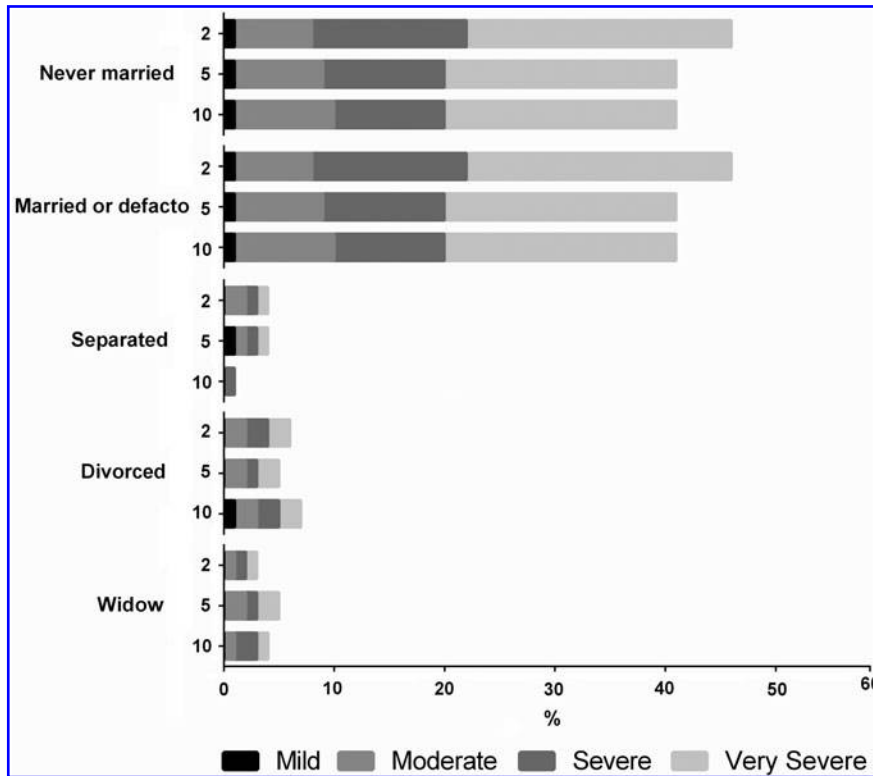


FIG. 6. The proportion of participants in each marital status category.

high level mobility problems persisting in a quarter of the sample. Overall, mobility outcomes were good, with only a few from both younger and older age-groups becoming more dependent over time. However, those reporting low mobility were individuals with moderate-to-very-severe TBI. Sensory changes, re-

ported by about a third of the sample, were quite persistent over time.

Changes in a broad range of cognitive functions, particularly in the domains of memory, attention, and cognitive fatigue, as well as word-finding difficulties, were far more common than physical

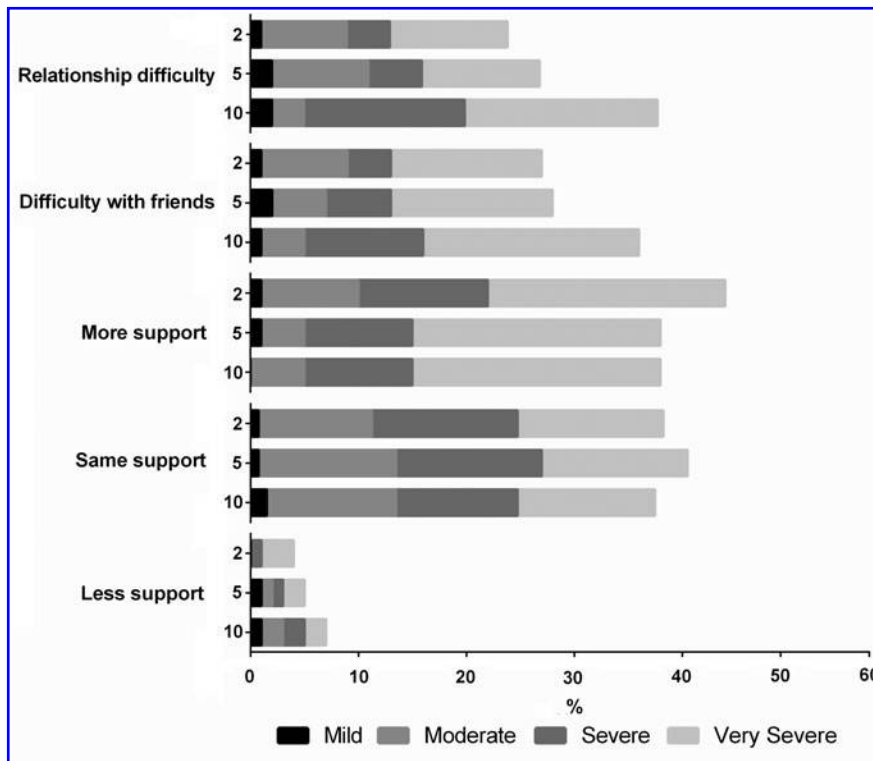


FIG. 7. Relationship and personal difficulties and level of support required (% of sample who responded Yes).

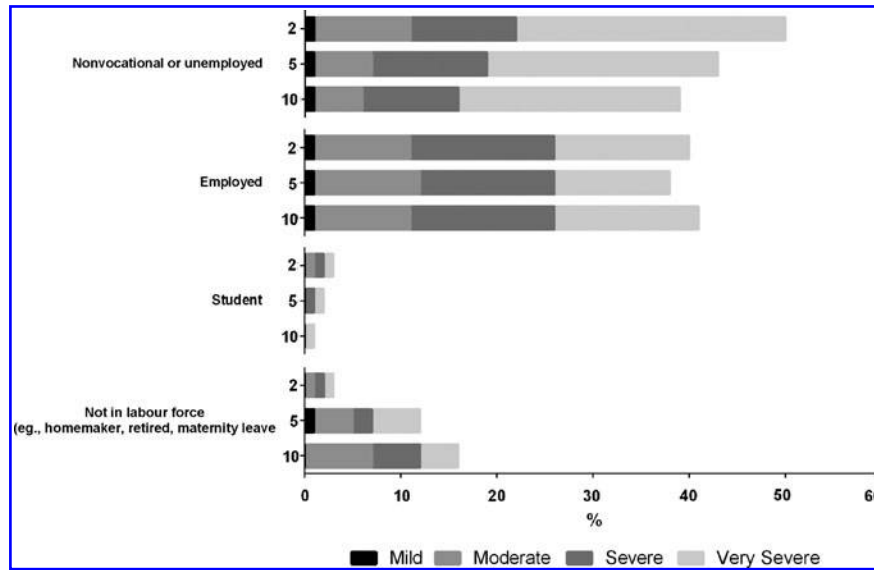


FIG. 8. Employment status at each time post-injury.

changes and did not diminish in frequency over time. The increased reporting of executive and behavioral changes in the domains of planning, initiative, self-centeredness and impulsivity, and inappropriate social behavior, suggested a growth in awareness of executive difficulties and behavioral changes, which individuals with severe TBI are commonly lacking in the early stages after injury.<sup>35</sup> There also appeared to be a growing awareness of the impact of these changes on social interactions over the 10 years, with increased reporting of difficulties in personal relationships and making friends and of social isolation. Irritability was a common and persistent problem for more than two thirds of the sample. Almost half the sample still felt more anxious and/or depressed 10 years post-injury. Although a rather crude measure, this frequency is consistent with rates of anxiety and depression reported over the long-term on the basis of symptom rating scales or diagnostic interviews in other studies.<sup>36-39</sup> There was no evidence of greater reporting of cognitive or emotional problems over time in the older age groups relative to the younger age group.

While consistent with the figures reported by Olver and colleagues<sup>19</sup> in an overlapping sample, the rates of symptom reporting were generally much higher in this study relative to those by

Dikmen and colleagues<sup>17,18</sup> and van der Naalt and colleagues,<sup>23</sup> presumably reflecting the far higher proportion of participants with moderate-to-severe TBI in this study, which was more similar to those of Dikmen and colleagues<sup>17</sup> and Brooks and colleagues.<sup>16</sup> All of these studies have revealed fatigue and memory problems to be the most common and persistent cognitive symptoms, along with irritability. What this study has shown is that these symptoms continue to be prominent over 10 years after injury. A higher proportion of participants with mild TBI likely also accounted for higher rates of return to employment in studies by Sigurdottir and colleagues<sup>39</sup> and van der Naalt and colleagues.<sup>20</sup> The rates of return to employment are similar to those reported by Grauwmeijer and colleagues<sup>2</sup> in their three-year follow-up study of a sample of similar injury severity and age. However, it was positive to see relatively high levels of employment being maintained up to 10 years post-injury, especially for those aged 50 or younger at injury.

Although high levels of independence were achieved in personal activities of daily living and significant and continuing improvement in independence in light domestic chores, about a third of the sample required assistance with heavy domestic activities and 20% of the sample required some assistance with shopping and financial

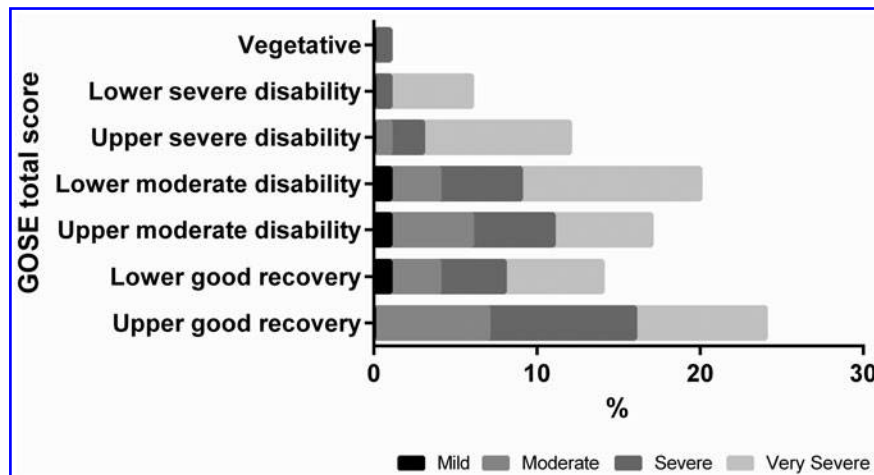


FIG. 9. Overall Glasgow Outcome Scale-Extended scores at 10 years post-injury.

management. A high proportion of patients were driving 10 years post-injury. The increase in proportion of the sample driving between two and five years post-injury suggests the need to provide services for assessment of return to driving over extended periods of time after injury.

Fewer than half the sample could participate in previous leisure activities and participation in these activities did not increase over the 10 years of the study for those with moderate to very severe injuries. Although more than 50% of those studying or employed prior to injury returned to employment, there was considerable movement into and out of employment. This suggests the need for continuing support and follow-up of those who return to work following TBI to ensure that if they lose their job they are supported in finding another one.

Approximately 40% of patients required more support after injury than prior to injury. Although individuals with mild or moderate TBI reported less need for support over the 10 years, rates for those with severe or very severe TBI stayed fairly consistent. Marital relationships remained remarkably stable, far more so than in studies by Thomsen<sup>22,30</sup> and Tate and colleagues.<sup>21,31</sup> This most likely reflected the fact that participants did not have such catastrophic injuries, but also possibly the fact that these injured individuals and their families had access to funded attendant care and other support services, which reduced the burden on caregiving spouses. Despite this, there was, however, a growing awareness of problems in personal relationships and friendships for almost 40% of the sample, predominantly in those with severe or very severe injuries.

Given that 28 participants had reached the age of 60 or older by the 10-year follow-up, of whom 16 had reached age 70, we examined whether some changes might have been age related. There were surprisingly few differences between those age 50 or younger and those older than 50 at time of injury. It needs to be acknowledged that the older subgroup had less severe injuries overall, as was reflected in the GOSE results at 10 years, and this may have contributed to the increased reporting of some changes by younger participants, as was evident, for example, in requiring more support and the reporting of some cognitive and behavioral changes. It may also have led to minimization of aged-related differences in the long-term effects of TBI. However, this comparison did allow for examination as to whether any decline evident in this cohort was associated with age per se, rather than the injury. The older group did show a significantly lower rate of return to employment and a higher proportion of participants leaving the workforce at five and 10 years post-injury. They were also less likely to return to driving and became less likely to be driving and independent in the use of public transport over time.

Overall, it would appear that, consistent with the findings of Brooks and colleagues,<sup>16</sup> Dikmen and colleagues,<sup>17</sup> and Tate and colleagues,<sup>21</sup> these injured individuals are developing and maintaining quite high levels of independence in mobility and activities of daily living, but there is growing awareness of cognitive and behavioral changes that impact increasingly on personal and social relationships and cause growing social isolation over time. There is significantly reduced participation in leisure activities. There are also significant ongoing emotional problems. Although these persisting, long-term, problems have been documented in previous studies, this study has shown that they did not diminish in the same group of individuals with moderate-to-very-severe injuries over 10 years after injury, in either the younger or older age groups. By and large, problems that were present at two years post-injury were still present at 10 years post-injury. The frequency of problems was

generally proportionate to the severity of injury, as measured by PTA duration. This highlights the usefulness of PTA duration as a measure of injury severity. Although aggregated findings should not be used to make specific predictions in individual cases, this is valuable information for these individuals themselves, their families, employers, and those funding and providing health care and social services.

This finding contrasts with the results reported by Sbordone and colleagues.<sup>5</sup> In their retrospective study based on reports by significant others, there was a gradual improvement in most dimensions of recovery over time. However, as previously stated, these findings are likely to have been affected by recall bias; the accuracy of retrospectively recalling an injured relative's functioning at time periods up to 10 years previously is questionable. Moreover, the manner of recruitment of the very small sample was unclear. The findings are generally consistent with the pattern of findings of Tate and colleagues,<sup>21</sup> who followed up a very severely injured group more than 23 years after injury. They did find a far greater decline in employability, which may have reflected both the greater injury severity and the older age at follow-up, with some participants having reached retirement age.

Although the physical and vocational rehabilitation of these individuals were reasonably successful, it would appear that there is a need for greater emphasis on providing rehabilitation for cognitive, behavioral, psychological and social issues that limit community participation in individuals with TBI. Even in this comprehensive rehabilitation setting, it is still the case that patients receive many more hours of physical and occupational therapy focused on independence in and return to activities of daily living than they do rehabilitation for cognitive, behavioral, and social problems. Many rehabilitation centers have limited staff with the expertise to treat these problems. Although the evidence base underpinning interventions is growing, it remains limited. Arguably, these interventions need to be carried out and certainly their effectiveness evaluated in the context of the community in ways discussed by Sloan and Ponsford.<sup>40</sup>

This study has a number of limitations, the most significant of which is that the group followed up represented a small proportion of the total group of patients treated in the center during the course of the study. Although not differing from the rest of the group in gender, education, or duration of PTA, the group was older than the group who did not attend follow-up at all time points and had lower GCS scores. This may have meant that the rates of reported problems were higher than in those who did not return to the follow-up clinic at all time points and in the total population of people with TBI. The older subgroup in the present study had less severe injuries than the younger subgroup, thus limiting conclusions regarding the impact of age on long-term outcome. The study findings cannot be generalized to individuals with uncomplicated mild injuries, of whom there were none in the sample. Nor can they necessarily be generalized to TBI groups who have not received inpatient rehabilitation. Findings were based on self-report by those who were injured, who may have been somewhat lacking in awareness of their limitations. However, it has been suggested that individuals with TBI are at least as accurate as their close others in reporting injury-related changes at such long periods after injury.<sup>35,41</sup>

Despite these potential limitations, the study has provided a comprehensive body of information documenting the long-term issues faced by a large group of individuals with moderate-to-severe TBI. This information may be used for education of health professionals, those injured and their families, and in the planning

and development of services for TBI. In particular, the study has also highlighted important directions for rehabilitation programs if they are to improve long-term outcome in individuals with TBI, namely the need for a greater focus on the cognitive, behavioral, psychological, and social problems that impede their community participation.

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Address correspondence to:

*Jennie L. Ponsford, PhD*

*Department of Psychology*

*Monash University*

*Clayton, Victoria, 3800, Australia*

*E-mail: jennie.ponsford@monash.edu*

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